

**THE IMPACT OF STROKE ON THE PRIMARY  
CAREGIVER**

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**ASSIGNMENT SUBMITTED IN PARTIAL FULFILLMENT  
OF THE REQUIREMENTS OF THE DEGREE MPhil  
(REHABILITATION) AT STELLENBOSCH UNIVERSITY**



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**AUGUST 2009**

## **DECLARATION**

I, the undersigned, hereby declare that the work contained in this assignment is my original work, that it had not been submitted in its entirety or in part to any other university for a degree, and that all the sources used or quoted had been acknowledged by references.

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## **ABSTRACT**

A stroke comes suddenly and has a devastating effect on the lives of the patient and the caregiver. It is disabling and often leaves the patient dependent on care. Providing this care can put tremendous physical, emotional, social and financial demands on the caregiver.

The purpose of the study is to determine the impact of caregiving on the primary caregivers of patients who suffered a stroke and were admitted to the Western Cape Rehabilitation Centre (WCRC), for intensive rehabilitation during 2006.

This is a descriptive study that utilised both quantitative and qualitative methods of data collection. Quantitative data were collected through two data coding forms, one for caregivers and one for patients, the Bartel Index, the Caregiver Strain Index (CSI) and the Satisfaction With Life Scale (SWLS). Qualitative data were collected through indepth interviews with caregivers. Fifty-seven caregivers participated in the study.

According to CSI findings 58% of caregivers were under levels of strain high enough to require support and intervention. The SWLS indicated that the life areas most adversely affected were employment and self and social life. Loss of employment by the caregiver ( $p = 0.04$ ) and financial difficulties ( $p = 0.06$ ), cognitive and perceptual problems ( $p = 0.01$ ), personality changes ( $p = 0.01$ ), level of physical dependency of patient (0.0012) and nervous strain experienced by the caregiver (0.01) were found to significantly impact on caregiver strain.

Caregivers perceived their caregiving duties as overwhelming and a great strain. This was aggravated in some instances by poor health care service delivery at the time of the stroke, no or inadequate explanations on stroke, poor or no training of caregivers, no home visits and a lack of follow-up services in the community. They experienced the period just after discharge as especially challenging and required support, assistance and guidance at that time.

Caregivers identified a need for community rehabilitation facilities, adult day care centres, outpatient rehabilitation services, home-based nursing care and caregiver support groups in the community.

### **KEY TERMS**

Burden; Care; Caregiver; Stroke; Support

## ABSTRAK

'n Beroerte gebeur skielik en sonder enige waarskuwing met 'n vernietigende uitwerking op die lewens van die pasiënt asook die versorger. Dit veroorsaak gestremdheid en laat dikwels die pasiënt afhanklik van sorg. Die voorsiening van hierdie sorg kan erge fisiese, emosionele, sosiale en finansiële eise aan die versorger stel.

Die doel van die navorsing is om die impak van versorging op die primêre versorger van beroerte pasiënte, wat gedurende 2006 intensiewe rehabilitasie by WKRS ontvang het, te ondersoek.

Dit is 'n beskrywende studie wat gebruik gemaak het van beide kwantitatiewe en kwalitatiewe metodes om data in te samel. Kwantitatiewe data was verkry deur twee datakoderingsvorme, een vir pasiente en een vir versorgers, die Bartel Index, die Caregiver Strain Index (CSI) en die Satisfaction With Life Scale (SWLS). In diepte onderhoude was gevoer met versorgers om kwalitatiewe data te verkry. Sewe en vyftig versorgers het aan die studie deelgeneem.

Bevindinge van die CSI dui daarop dat 58% van versorgers hoë vlakke van spanning ervaar en ondersteuning sowel as intervensie benodig. Volgens die SWLS was die areas wat die ernstigste beïnvloed was werk en eie en sosiale lewe. Die volgende areas het volgens resultate 'n statisties beduidende impak op die spanning wat versorgers ervaar het gehad: finansiële spanning en verlies van werk ( $p = 0.04$ ), in gevalle waar pasiente persoonlikheidsveranderinge ondergaan het ( $p = 0.01$ ) of kognitiewe en perseptuele skade oorgehou het ( $p = 0.01$ ) na die beroerte en die emosionele impak van versorging ( $p = 0.01$ ).

Versorgers het hulle versorgings take as oorweldigend en as 'n bron van groot spanning gesien. Dit is in sommige gevalle vererger deur swak ondersteuning van gesondheidsorgdienste direk na die beroerte, geen of swak verduidelikings oor wat 'n beroerte is, geen of swak opleiding aan versorgers, geen tuisbesoeke en 'n tekort aan opvolg dienste in die

gemeenskap. Die tydperk direk na ontslag uit die rehabilitasie sentrum was besonder uitdagend en hulle het ondersteuning, hulp en leiding nodig in daardie tyd.

Swak ondersteuning en 'n tekort aan of afwesigheid van hulpbronne in die gemeenskap het die situasie vererger. Versorgers het 'n behoefte aan gemeenskapsrehabilitasie fasiliteite, volwasse dagsorg sentrums, buite pasiënte rehabilitasie dienste, tuis verpleegsorg en ondersteuningsgroepe uitgespreek.

## **ACKNOWLEDGEMENTS**

I would like to dedicate this thesis to my late mother, Mariam Hassan, who suffered a stroke and was the inspiration for this study.

Then I would love to thank all who had been instrumental and who stood by my side throughout my studies:

My beloved father, Achmat Hassan, who had been a great support and had made things easier for me by taking on many responsibilities. For his love, dedication and care to our mother.

My sisters (Rashida, Farida, Gabeba, Ashieyah), brothers (Goolam, Ragieb, Muhdni, Hashir), family, colleagues and ALL my dear friends (you are too many to name personally) who selflessly supported, encouraged, inspired me and who were always there throughout the trying times. Thank you for understanding my absence at many occasions.

The director of WCRC, Jenny Hendry, who started this study with me, for her support, encouragement and guidance throughout my study.

To my supervisor, Gubela Mji, who had walked the long and winding road with me and had been an absolute inspiration with her enthusiasm and excitement for this study.

To my supervisor, Surona Visagie, who had been thrown in at the deep end and had been brilliant with her unselfish guidance, support, encouragement and for being an inspiration during the dark moments.

To my supervisor, Tertia McKee, for support, encouragement, sharing her computer skills and always being so accommodating.

To my research assistant, Kholeka Talakuneni, for assisting with the translations of the data coding forms to Xhosa, interviews with caregivers and for your passion and dedication towards the study.

To the librarians, Steven Fredericks and Wilhelmine Poole, who had been of great assistance during my study.

To the statistician, Professor Daan Nel, at the Centre for Statistical Consultation, for his assistance and guidance with the statistical calculations.

To the Almighty God for the perseverance, patience and ability bestowed upon me to do this study.

## **GLOSSARY OF TERMS**

### **Burden**

Burden is defined as the extent to which caregivers perceive their emotional or physical health, social life and financial status to be suffering as a result of caring for their relative (Zarit, Todd and Zarit 1986).

### **Care**

Care is provision for people's physical, psychological and material needs where they are unable to provide these for themselves (Terminology Committee for Social Work 1995).

### **Caregiver**

The caregiver is the person who is primarily involved in helping the person who had suffered the stroke to live independently at home. Usually it is the spouse or a family member. A caregiver is a person responsible for providing care to another person (Terminology Committee of Social Work 1995).

### **Depression**

Depression is intense despondency that goes hand in hand with feelings of helplessness, inadequacy, insecurity and pessimism regarding the future and is characterised by social withdrawal and decreased psychomotor activities (Terminology Committee for Social Work 1995).

### **Disability**

Disability is an umbrella term used to cover impairments, activity limitations and participation restrictions that hampers a person's function (World Health Organisation 2000).

### **Family**

Family refers to persons related by blood or marriage. The smallest social unit in society consisting of a man and his wife; a man and his wife and child; a

woman and her child; or a man and his child, usually under one roof (Terminology Committee for Social Work 1995).

### **Hemiplegia**

Hemiplegia refers to paralysis on one side of the body caused by a lesion in the contralateral hemisphere of the brain (McGlynn and Schacter 1989).

### **Outcome levels**

Outcome levels represent the basic domains human beings include in their lives, such as health, personal maintenance, home management, community activities and productivity. With catastrophic illness or injury, an individual typically becomes disabled to a varying degree relative to each of these domains (Landrum, Schmidt and McLean 1995).

### **Rehabilitation**

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation includes not only the training of disabled individuals, but also interventions in the general systems of society, adaptations in the environment (elimination of architectural and attitudinal barriers), equalisation of opportunities as well as the promotion and protection of human rights. Equalisation of opportunities includes access to health and social services, educational and work opportunities, the physical environment, housing, transportation, information, cultural and social life, including sport and recreational activities, with representation and full political involvement of persons with disabilities in matters of concern to them (Helander 1993).

### **Stroke**

A stroke happens when arteries supplying blood to the brain either gets blocked (thrombosis) or burst (causing bleeding or haemorrhaging). Blockage cuts off the blood supply to part of the brain, and, without the oxygen and nutrients carried by the blood, brain cells stop working. If brain cells lose their blood supply for more than four to eight minutes, they die and cease working

permanently. If a stroke is caused by a burst blood vessel, blood goes into the brain tissue, causing damage to brain cells (Coyne and Mares 1995).

### **Stroke rehabilitation**

Stroke rehabilitation is a restorative learning process which seeks to hasten and maximise recovery from a stroke by treating the disabilities caused by stroke and to prepare the stroke survivor to reintegrate as fully as possible into community life. Desired functional outcomes include a return to the least restrictive residential setting (home versus institutional care), decreasing the burden of care on the primary caregivers, and allowing the individual to engage in some productive activity, whether social or vocational (Goldbeck 2000).

### **Support**

Support means to assist a client through, for example, encouragement, generalisation and acceptance in order to reduce tension and promote self-confidence (Terminology Committee for Social Work 1995).

# CONTENTS

	<i>PAGE</i>
<b>DECLARATION</b>	ii
<b>ABSTRACT</b>	iii
<b>KEY TERMS</b>	iv
<b>ABSTRAK</b>	v
<b>ACKNOWLEDGEMENTS</b>	vii
<b>GLOSSARY OF TERMS</b>	ix
<b>CONTENTS</b>	xii
<b>LIST OF ACRONYMS</b>	xxvi
<b>CHAPTER 1 INTRODUCTION</b>	
1.1 STUDY OUTLINE	1
1.2 EVOLUTION OF THE STUDY	1
1.3 STUDY PROBLEM – THE CAREGIVER AS THE ‘HIDDEN PATIENT’	2
1.4 THE STUDY AIM	4
1.5 THE STUDY OBJECTIVES	4
1.6 THEORETICAL FRAMEWORK AND CONTRIBUTION OF THE STUDY	5
1.7 SUMMARY OF CHAPTER 1	8
<b>CHAPTER 2 LITERATURE REVIEW</b>	
2.1 INTRODUCTION	10
2.2 STROKE	10
2.3 REHABILITATION	15
2.3.1 Definitions and underscoring policies	15
2.3.2 Intensity of rehabilitation services	18
2.3.3 Rehabilitation outcome levels	19
2.3.3.1 Level 0: Physiologic instability	19

2.3.3.2 Level 1: Physiologic stability	20
2.3.3.3 Level 2: Physiologic maintenance (basic rehabilitation outcome)	20
2.3.3.4 Level 3: Home and/or residential integration	21
2.3.3.5 Level 4: Community reintegration	21
2.3.3.6 Level 5: Productive activity	22
2.4 STROKE REHABILITATION	23
2.4.1 Community-based versus institution-based stroke rehabilitation	26
2.5 REHABILITATION SERVICES IN THE WESTERN CAPE PROVINCE	27
2.5.1 Primary level rehabilitation services	28
2.5.1.1 Community health centres/clinics	28
2.5.1.2 Adult day care centres	28
2.5.1.3 Community-based rehabilitation (CBR)	29
2.5.2 Secondary level rehabilitation services	29
2.5.2.1 Regional hospitals	29
2.5.2.2 Step-down facilities	30
2.5.2.3 GF Jooste Stroke Unit	30
2.5.3 Tertiary level rehabilitation services	31
2.5.3.1 Groote Schuur Hospital (GSH) Stroke Unit	31
2.5.4 Specialist rehabilitation services	31
2.5.5 Private rehabilitation services	32

2.5.6 Adequacy of services	32
2.5.7 Adherence of services to standards set by National Rehabilitation Policy	33
2.5.7.1 Intersectoral collaboration with the Department of Social Development	34
2.5.7.2 Collaboration with the Department of Labour	34
2.5.7.3 The Red Door Project	34
2.6 THE CAREGIVER	35
2.6.1 The 'typical' caregiver	36
2.6.2 Burden of care	36
2.7 CAREGIVER RELIEF OPTIONS IN THE WESTERN CAPE PROVINCE	39
2.7.1 Relief/respice care	39
2.7.2 Home-based care	40
2.7.3 Adult day care centres	40
2.8 SUMMARY OF CHAPTER 2	41
<b>CHAPTER 3 METHODOLOGY</b>	43
3.1 INTRODUCTION	43
3.2 STUDY DESIGN	43
3.3 STUDY SETTING	44
3.4 STUDY POPULATION	47

3.4.1 Inclusion criteria	47
3.4.2 Exclusion criteria	47
3.4.3 Determining the participants	48
3.5 INSTRUMENTATION	49
3.5.1 Measuring instruments utilised to collect patient data	50
3.5.1.1 Data Coding Form A – Patient information (Appendix 5)	50
3.5.1.2 The Barthel Index (Appendix 6)	50
3.5.2 Measuring instruments utilised to collect caregiver data	52
3.5.2.1 Data Coding Form B – Caregiver information (Appendix 7)	52
3.5.2.2 Caregiver Strain Index (CSI) (Appendix 8)	52
3.5.2.3 Satisfaction With Life Scale (SWLS) (Appendix 9)	53
3.5.2.4 Interview Schedule (Appendix 10)	53
3.5.3 Instrument design and translation	54
3.6 PILOT STUDIES	54
3.6.1 Initial pilot study	54
3.6.2 Final pilot study	56
3.7 DATA COLLECTION	57
3.8 DATA ANALYSIS	58
3.8.1 Quantitative data	58

3.8.2 Qualitative data	58
3.9 ETHICAL CONSIDERATIONS	59
3.10 SUMMARY OF CHAPTER 3	60
<b>CHAPTER 4 RESULTS AND DISCUSSION</b>	61
4.1 INTRODUCTION	61
<b><i>SECTION 1 RESULTS PERTAINING TO PATIENT HEALTH AND DEMOGRAPHIC DETAILS</i></b>	62
4.2 INTRODUCTION TO SECTION 1	62
4.3 DEMOGRAPHIC PROFILE OF PATIENTS	62
4.3.1 Age and gender	62
4.3.2 Marital status	63
4.3.3 Population group and language	64
4.4 DEMOGRAPHIC DETAILS RELATED TO PATIENT AND CAREGIVER	65
4.4.1 Family relationship between patient and caregiver	65
4.4.2 Type of accommodation and basic amenities	67
4.4.3 Employment status of the caregiver and patient	69
4.4.4 Source of income and financial status	71
4.5 REHABILITATION OUTCOME LEVELS	77
4.6 HEALTH STATUS OF PATIENTS	80
4.6.1 Number of strokes	80
4.6.2 Presence of risk factors/other conditions	81

4.6.3 Unresolved effects of the stroke	82
4.6.4 Cognitive/perceptual deficits and personality changes after stroke	83
4.6.5 Degree of physical dependence of patients according to Bartel Index (BI) scores	86
4.7 PATIENTS DISCHARGED TO OLD AGE HOMES	88
4.8 SUMMARY OF CHAPTER 4, SECTION 1	90
<b>SECTION 2 CAREGIVER INFORMATION AND STATUS</b>	91
4.9 INTRODUCTION TO SECTION 2	91
4.10 DEMOGRAPHIC DETAILS OF THE PRIMARY CAREGIVER	91
4.10.1 Age and gender	91
4.10.2 Marital status of caregivers	92
4.10.3 Educational level of caregivers	93
4.11 HEALTH STATUS OF CAREGIVERS	93
4.12 RESPONSIBILITIES OF THE CAREGIVER	95
4.12.1 Caregiving duties	95
4.12.1.1 Time spent on caring per day	95
4.12.1.2 Intensity of care needed	96
4.12.1.3 Remuneration for caregiving	97
4.12.1.4 Time off	97
4.12.1.5 Assistance with caregiving duties	101

4.12.2 Other responsibilities of caregivers	101
4.12.2.1 Minor or dependent children	101
4.12.2.2 Household and other duties	103
4.12.3 Socialising and recreation	103
4.13 EXPERIENCES OF THE CAREGIVERS AT THE TIME OF THE STROKE	104
4.13.1 Feelings at the time of the stroke	104
4.13.2 Experience of caregivers regarding initial medical services	106
4.13.3 Aspects related to the period between discharge from the acute hospital and admission to WCRC	108
4.14 CAREGIVER KNOWLEDGE AND EDUCATION ON STROKE	110
4.15 EXPERIENCES OF CAREGIVERS WITH REGARDS TO REHABILITATION AT WCRC	113
4.15.1 Length of stay at WCRC	113
4.15.2 Contact on admission	113
4.15.3 Supportiveness of the rehabilitation team	114
4.15.4 Caregiver inclusion in rehabilitation team at WCRC	114
4.15.5 Caregiver training	116
4.16 NEEDS OF THE CAREGIVERS AT THE TIME OF DISCHARGE FROM WCRC	118
4.17 COMMUNITY SUPPORT SERVICES	120
4.17.1 Support groups	124
4.17.2 Peer counselling and support	125

4.17.3 Fear of violence	126
4.18 SUMMARY OF CHAPTER 4, SECTION 2	127
<b>SECTION 3 CAREGIVER STRAIN AND SATISFACTION WITH LIFE</b>	129
4.19 INTRODUCTION TO SECTION 3	129
4.20 STRAIN EXPERIENCED BY THE CAREGIVER	129
4.21 IMPACT OF DIFFERENT DEMOGRAPHICAL AND OTHER VARIABLES ON CAREGIVER STRAIN	133
4.21.1 Demographic details of the patient	133
4.21.2 Demographic details relating to the patient and the caregiver	133
4.21.3 Health status of the patients	137
4.21.4 Patients residual impairments	137
4.21.5 Understanding of diagnosis	140
4.21.6 Outcome levels at discharge	141
4.21.7 Demographic details of the caregiver	143
4.21.8 Health status of the caregiver	143
4.21.9 Caregiver duties	144
4.21.10 Management at WCRC	145
4.21.11 Community support services	146
4.22 SATISFACTION WITH LIFE OF THE PRIMARY CAREGIVER	147
4.23 SUMMARY OF SECTION 3, CHAPTER 4	149

<b>CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS</b>	150
5.1 INTRODUCTION	150
5.2 DEMOGRAPHIICS, HEALTH STATUS, RESIDUAL IMPAIRMENTS AND OUTCOME LEVELS	150
5.3 HEALTH STATUS OF THE PRIMARY CAREGIVER	152
5.4 EXPERIENCES OF CAREGIVERS DURING THE ACUTE PHASE	153
5.5 INFORMATION, EDUCATION AND TRAINING ON STROKE AND STROKE CARE	153
5.6 SUPPORT AND INCLUSION OF PRIMARY CAREGIVERS BY THE REHABILITATION TEAM AT WCRC	154
5.7 FOLLOW-UP SERVICES	155
5.8 RECOMMENDATIONS	156
5.8.1 Recommendations with regards to primary health care	156
5.8.2 Recommendations to WCRC	156
5.8.2.1 Caregiver education and training	156
5.8.2.2 Need for home visits	157
5.8.2.3 Follow-up support on discharge	158
5.8.2.4 Community liaison	159
5.9 RECOMMENDATIONS ON COMMUNITY SUPPORT RESOURCES	159
5.9.1 Community rehabilitation programmes	159
5.9.2 Adult day care centres	160
5.9.3 Stroke support groups	160

5.9.4 Respite care	160
5.9.5 Home-based care	161
5.9.6 Peer counselling and support	161
5.9.7 Psychological support	162
5.10 RECOMMENDATIONS TO PROVINCIAL AND LOCAL AUTHORITIES	162
5.10.1 Need for adequate housing	162
5.10.2 Financial aspects	163
5.10.3 Transport	163
5.11 FURTHER RESEARCH	164
5.12 LIMITATIONS	164
5.12.1 Missing clinical data	164
5.12.2 Inter rater bias	164
5.12.3 Verification of qualitative data	164
5.12.4 Simultaneous collection of qualitative and quantitative data	165
5.12.5 Additional data	165
5.13 SUMMARY	165
<b>REFERENCES</b>	167

## **APPENDICES**

Appendix 1 Letter of request to the Head of WCRC to access folders

Appendix 2 Permission from the Head of WCRC to access folders

Appendix 3 Letter to caregivers who could not be contacted telephonically

Appendix 4 Participant information and consent form

Appendix 5 Data coding form A – Patient information

Appendix 6 Bartel Index

Appendix 7 Data coding form B – Caregiver information

Appendix 8 Caregiver Strain Index

Appendix 9 Satisfaction with Life Scales

Appendix 10 Interview Schedule

## LIST OF FIGURES

**Page**

Figure 3.1: Determining the study participants	49
Figure 4.1: Age and gender distribution of patients	62
Figure 4.2: Marital status of the patients	63
Figure 4.3: Population group and language preference of patients	64
Figure 4.4: The relationship between the caregiver and the patient	65
Figure 4.5: Type of accommodation	67
Figure 4.6: Employment status of the caregiver and patient prior to the stroke	70
Figure 4.7: Rehabilitation outcome level on discharge and at time of interview	78
Figure 4.8: Number of assistants needed to access the community	79
Figure 4.9: Unresolved effects after the stroke	82
Figure 4.10: Presence of cognitive/perceptual deficits and personality changes	84
Figure 4.11: Physical dependence of patients according to the Bartel Index	86
Figure 4.12: Age and gender distribution of primary caregivers	91
Figure 4.13: Educational levels of the caregivers	93
Figure 4.14: Medical conditions prevalent amongst the caregivers	94
Figure 4.15: Hours spent on caregiving per day	95
Figure 4.16: Intensity of care	96
Figure 4.17: Presentation of the amount of time off for the caregiver	97

Figure 4.18: Caregivers able to attend appointments and someone responsible for patient during their absence	99
Figure 4.19: Presentation of who assists with caregiving duties	101
Figure 4.20: Presentation of the hours spent on household duties	103
Figure 4.21: Presentation of whether caregivers could socialise/were involved in recreation	104
Figure 4.22: Presentation of caregivers understanding of stroke	110
Figure 4. 23: Illustration of which team members were involved in goal setting	115
Figure 4.24: Community support services requested by caregivers	121
Figure 4.25: Scores for caregiver strain index	129
Figure 4.26: Presentation of 'Yes' scores in each CSI category	130
Figure 4.27: Impact of patient-caregiver relationship on caregiver strain	134
Figure 4.28: Impact of availability of running water in the house on caregiver strain	135
Figure 4.29: Impact of resignation from employment on caregiver strain	136
Figure 4.30: Impact of current income on caregiver strain	136
Figure 4.31: Scatter plot on the impact of cognitive and perceptual problems on caregiver strain	137
Figure 4.32: Scatter plot on impact of personality changes on caregiver strain	138
Figure 4.33: Scatter plot on the impact of BI scores on caregiver strain	138
Figure 4.34: The impact of level of care needed by patient on caregiver strain	139
Figure 4.35: The impact of swallowing problems on caregiver strain	140
Figure 4.36: Comparison of caregiver strain on caregivers who did and did not understand the diagnosis	141
Figure 4.37: Comparison of caregiver strain and discharge outcome levels	142

Figure 4.38: Impact of marital status on the caregiver strain	143
Figure 4.39: Impact of nervous condition on caregiver strain	144
Figure 4.40: Impact of inclusion in the rehabilitation team on caregiver strain	146
Figure 4.41: Presentation of scores in the four domains of the SWLS	147
Figure 4.42: Presentation of mean scores in the four domains of the SWLS	148

## LIST OF ACRONYMS

<b>BI</b>	Bartel Index
<b>CBR</b>	Community Based Rehabilitation
<b>CCRD</b>	Karl Bremer Centre for Care and Rehabilitation for the Disabled
<b>CSI</b>	Caregiver Strain Index
<b>DG</b>	Disability Grant
<b>GSH</b>	Groote Schuur Hospital
<b>ICF</b>	International Classification of Functioning, Disability and Health
<b>NGO</b>	Non-governmental Organisation
<b>NRP</b>	National Rehabilitation Policy
<b>OSDP</b>	Office on the Status of Disabled Persons
<b>RDP</b>	Reconstruction and Development Programme
<b>SASSA</b>	South African Social Security Agency
<b>SWLS</b>	Satisfaction With Life Scale
<b>USA</b>	United States of America
<b>WCRC</b>	Western Cape Rehabilitation Centre
<b>WHO</b>	World Health Organisation

# **CHAPTER 1**

## **INTRODUCTION**

### **1.1 STUDY OUTLINE**

It is the aim of the study to explore the impact that caring for a stroke survivor has on the physical, emotional, financial and social aspects of the caregiver's life. Furthermore, the impact of different variables on caregiver strain and caregiver satisfaction with life are investigated, that is, the demographic and health status of the patient, the health status of the caregiver, the extent of caregiving and other duties, health care services, rehabilitation at Western Cape Rehabilitation Centres (WCRC) and community support.

Chapter 1 explains why the researcher embarked upon this study and provides background information on caregivers and the challenges they face. The aim and objectives of the study are presented to the reader and finally the contribution that the study can make to the existing body of knowledge is discussed.

Chapter 2 discusses the available literature on stroke, rehabilitation in general and stroke rehabilitation as well as caregivers and their needs. The research design and the study methodology are explained in Chapter 3. Chapter 4 presents and discusses the study results. In Chapter 5 the conclusions drawn from the study are summarised and recommendations are made to the relevant authorities and service providers.

### **1.2 EVOLUTION OF THE STUDY**

The primary motivation for the study was a personal experience that the researcher had. Her mother suffered a stroke more than ten years ago. She and other family members perceived health professionals as being unsympathetic towards the family while they were experiencing a state of incomprehensible

shock, disbelief, uncertainty and trauma. The sympathies of health professionals seemed to be mostly directed towards her mother, the patient.

The suddenness and unexpectedness of the event were devastating for the researcher's mother and the family. Professionals took it for granted that they, the family, should cope with the care of their mother, the patient, without giving a thought to the trauma and the uncertainty they were experiencing. There was the fear that their mother was vulnerable and they wondered what the chances would be of their mother suffering another stroke. It was difficult to accept that their mother, who was a proud and fiercely independent person, had to be confined to a wheelchair after her stroke. The experience was life changing for the whole family, besides being both physically and emotionally draining.

Although the researcher had been working as a social worker in a Rehabilitation and Care Unit for patients with physical impairments for several years prior to her mother's stroke, she found herself lacking the inner strength and resources to cope with the experience. This experience, however, caused the researcher to reflect on the situation and she became interested to know whether other families/primary caregivers have similar experiences. Thus the study evolved.

### **1.3 STUDY PROBLEM – THE CAREGIVER AS THE ‘HIDDEN PATIENT’**

Stroke concerns the entire family and its impact on the family is tremendous (Wade, Leigh-Smith and Hewer 1986). The family's equilibrium and functioning are threatened and disrupted in the same way as that of the patient. Stroke impacts on all levels of their being, that is, physical, emotional, psychological, economic and social (Gorman and Anderson 1982). However, the primary caregiver, often a member of the core family, has been forgotten to such an extent that they are named the 'hidden patient' (Thompson, Bundek and Sololew-Shabin 1990).

More likely than not the care burden is not acknowledged and caregiver needs are not exposed. Hence, the need for the burden experienced by the caregiver to be investigated acknowledged and addressed. While initiatives to investigate this have been taken (Bresick and Harvey 1997; White, Mayo, Hanley and Wood-Dauphinee 2003; Visser-Meiley, Post, Schepers and Lindeman 2005), there is a

need for a full exploration of the situation, especially in South Africa, since rehabilitation services and community support services in this country are often inadequate, thus adding to the responsibilities of the primary caregiver (Office of the Deputy President TM Mbeki (ODP) 1997). Areas relating to caregivers and their experiences in South Africa, and more specifically the Western Cape Metropole, and the current study population that need to be explored include:

- The magnitude and type of lifestyle sacrifices and adjustments that caregivers make in order to take up caregiving duties;
- The financial implications and economic impact of caregiving, as taking up the care responsibility might cause a decrease in or complete loss of income, while adaptations could well incur extra expenses;
- The extent to which the social lives of caregivers are restricted;
- The emotional and psychological impact of caregiving;
- The effect of caregiving duties on the health of the caregiver;
- The type and amount of social support that the caregivers need; and
- Whether caregivers are adequately included, supported, educated and trained by the professional team at WCRC.

Thus while many studies (Anderson, Linto and Steward-Wynne 1995; Dennis, O'Rourke, Lewis, Sharpe and Warlow 1998) focus on the emotional status of the person who suffered the stroke, few examine the caregivers and their needs. With the current study the researcher aims to determine the impact of stroke on the primary caregiver and thus to highlight the important role the caregiver plays in the life of the patient as well as that of the community and the state. The study seeks to expose the burden that the caregiver carries and the negative consequences entailed for both the caregiver's well-being and that of the patient.

## **1.4 THE STUDY AIM**

The aim of the study was to determine the strain experienced by the primary caregivers of patients who suffered a stroke and received inpatient rehabilitation during the period 1 January 2006 to 31 December 2006 at the Western Cape Rehabilitation Centre (WCRC), and who had subsequently been discharged home into the care of a caregiver.

## **1.5 THE STUDY OBJECTIVES**

In order to reach the aim of the study 16 objectives grouped into three sections were addressed.

### **Section 1: Objectives related to the patients' demographic status, health and functional abilities**

1. Determine the demographic profile of patients.
2. Determine demographic information pertaining to patient and caregiver jointly.
3. Determine the health status, residual impairments and degree of physical dependence of patients.
4. Compare the current rehabilitation outcome level of patients with their rehabilitation outcome level on discharge.
5. Determine why patients who were discharged to old age homes were not discharged home.

### **Section 2: Objectives related to the caregivers**

6. Determine the demographic profile of the primary caregivers.
7. Determine the health status of the primary caregivers.
8. Determine the extent of caregiving and other duties.
9. Determine the caregiver's experience at the time of the stroke.

10. Determine the caregiver's knowledge and education at the time of the stroke.
11. Determine the caregiver's experiences with regards to rehabilitation at WCRC.
12. Determine the extent of discharge support that the caregiver needed and received.
13. Determine the type and adequacy of community support services.

### **Section 3: Caregiver strain and satisfaction with life**

14. Determine the strain experienced by the caregiver.
15. Determine which variables impact significantly on caregiver strain.
16. Determine the caregiver's satisfaction with life.

## **1.6 THEORETICAL FRAMEWORK AND CONTRIBUTION OF THE STUDY**

Stroke is a major cause of disability in most societies. One hundred thousand people suffer a stroke in Britain annually (Coyne and Mares 1995). South African society is no exception. Stroke is amongst the most common chronic diseases of lifestyle as well as one of the highest causes of disability in South Africa (Puoane, Tsolekile, Sanders, and Parker 2008). About 70% of stroke victims survive and start to rebuild their lives. In doing so they will depend heavily on the support and assistance of their family and closest friends.

The impact of stroke on the patient and family is compared with that of a death since it comes suddenly, without warning and is devastating and traumatic. The family unit is disrupted and thrown out of balance because of the unpredictable and uncontrollable nature of a stroke. The patient and family might experience multiple losses after a stroke, including loss of function, loss of income, loss of social life, loss of the ability to communicate, loss of the ability to return to work, loss of friendships and loss of living an independent, self-sufficient and private lifestyle (Fengler and Goodrich 1979; Bresick and Harvey 1997; Birkhead and Graham 2005; McCullagh, Brigstocke, Donaldson and Kalra 2005).

The recovery process after a stroke is lengthy and the possibility that the patient may not recover much and, therefore, remain dependent on care or supervision from a caregiver, is real. An incomplete recovery and care dependency dramatically changes the lives of those family members who are involved with the patient, and especially that of the primary caregiver (Schulz, Tompkins and Rau 1988; Coyne and Mares 1995; Wade, Hewer, Skilbeck and David 1996; Forsberg-Warleby, Möller and Blomstrand 2001). Changes that the caregiver might experience include resigning from employment, financial strain, discontinuing extramural activities, relocating to a different home and physical alterations to the home or car (Coyne and Mares 1995; Clark and Smith 1999a).

The caregiver can become isolated, lonely and feel unappreciated and this could lead to burn-out and depression. Caregivers need social support and the physical and mental capacity to cope with the situation if they are to provide adequate care (Coyne and Mares 1995; Bresick and Harvey 1997). The burden of care is higher for the caregiver if her/his own health and/or functional ability is poor. Caregivers often display symptoms and complaints related to their caregiving obligations, such as increased anxiety, depression, decreased feelings of life satisfaction and self-esteem, worry, frustration and sadness, besides being restricted in terms of attending social and recreational events (Thompson et al 1990; Bresick and Harvey 1997; Mayo and Wood-Dauphinee 2004; Teasell and Kalra 2005).

According to Forsberg-Warleby et al (2001) each caregiver is affected differently by and responds in different ways to the stress of caregiving duties. They emphasise that it is important to investigate variables that affect the well-being of the caregiver such as the caregiver's own health, experience of previous critical life events as well as internal and external strengths and resources as possible benchmarks of the caregiver's coping capacity.

Currently the rehabilitation team at WCRC has no information on the extent of these changes in the lives of the caregivers of patients who received treatment at WCRC. The amount of strain experienced by them and their satisfaction with life are unknown. Furthermore, both the number of caregivers of stroke patients who experience high levels of strain and are in need of intervention as well as the variables which cause these high levels of strain is unknown. This study explores these questions and through findings makes recommendations on how caregivers

in this setting can be assisted to reduce the levels of strain that they experience and increase their satisfaction of life.

At WCRC information and training are often imparted during a single family conference or on discharge. Furthermore, family conferences as well as the entire rehabilitation process focus on the patient's needs. The team that is present at the family conference/meeting is made up of the team members who are directly involved in the rehabilitation programme of the patient. Little effort is made to determine the caregiver's state of mind and requirements and whether he/she has the resources to provide the complete care that is expected. In addition, the interdisciplinary team often becomes impatient when the patient has completed the rehabilitation programme and can be discharged, but the primary caregiver is not yet ready to accept the patient into their care. As part of this study the researcher aims to identify, from the caregiver's point of view, to what extent the professional team at the Western Cape Rehabilitation Centre offers support and addresses the needs of the caregivers as well as whether caregivers feel that they have been integrated into the rehabilitation team. Results will therefore provide the professional team at WCRC with background information against which they can start to understand and address the individual needs of every caregiver that they work with and will suggest what kind of follow-up support caregivers need from the WCRC.

Caregivers' experiences with regards to health care services from the time of the stroke through rehabilitation and up to their current functioning in the community will be assessed. Therefore, results from this study will provide rehabilitation professionals with information on how to assist/support the caregiver in an attempt to lessen the care burden. If the needs of the caregiver are addressed, the caregiver would be better equipped to offer comprehensive care to the patient. This in turn can lead to improved prevention of secondary complications, for example, pressure sores or painful shoulders and help prevent recurrent strokes, thereby preventing repeated admissions or the repeated need for therapy by the patient or burn-out of the caregiver.

The South African government is committed to bringing health services closer to the people by adopting the Primary Health Care approach, of which rehabilitation is an integral component (Department of Health 2000; Schaay and Sanders 2008).

Despite this approach, the researcher in her experience as a social worker found that community rehabilitation resources/support services, respite care, day care facilities and home-based care services are greatly lacking, absent or have long waiting lists. Consequently, caregivers are not adequately supported, guided, encouraged, advised or intermittently relieved of their care responsibilities. Therefore, it is important to take cognisance of the level of care required, of the well-being of the caregiver as well as the various aspects regarding the coping capacity of the caregiver as enough knowledge and insight into the caregiver's situation could assist in determining the amount and type of community support that the caregiver requires. This study seeks to determine, from the caregivers' point of view, what type of resources and support they expect in the community. Adequate resources would in turn assist with integrating patients into the community and allow family members to continue their lives especially in terms of their employment status and thus lessen the care and financial burden on the family. This would also lessen the financial burden on the community and the state.

The information gathered in this study will assist professionals to paint a clear picture of caregivers of patients who suffered a stroke and who were rehabilitated at WCRC and who live in the Western Cape Metropole. The study will throw light on their health and demographic profile, the strain they experience, their satisfaction with life as well as their community support needs. This information could be used to assist service developers and providers to tailor services to the needs of the consumers, in this case, the caregivers.

## **1.7 SUMMARY OF CHAPTER 1**

The study aims to determine the impact of stroke on the primary caregiver. A stroke comes suddenly and without warning, with a devastating effect on the lives of the patient and the caregiver. It results in feelings of confusion and fear about the future. Furthermore, a stroke is disabling and often leaves the patient dependent on care. While the needs of the patient are mostly attended to, the impact on the caregiver is not as well known and often ignored. The caregiver seems to suffer in silence and has been aptly named the 'hidden patient'

(Thompson et al 1990). It is essential that the needs of the caregiver be acknowledged and addressed in order to prevent the caregiver from suffering burn-out, becoming exhausted and depressed and thereby being unable to offer adequate care to the patient. The caregivers are delivering an invaluable service to the patient, the families, the communities and the state and should be recognised, acknowledged, appreciated and especially taken care of.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This study investigates the impact of caring for a patient who has suffered a stroke and who has received inpatient rehabilitation at the Western Cape Rehabilitation Centre (WCRC). Therefore, the literature reviewed focused on information related to stroke and stroke rehabilitation, post-stroke care, factors predicting the amount of care needed, the impact of various impairments and activity limitations on care, as well as issues surrounding the caregiver. Finally, the current caregiver relief options in the Western Cape Metropole will be identified and discussed.

#### **2.2 STROKE**

Stroke is a major cause of death and disability worldwide. The incidence of stroke is highest in the developed world where it is said to be the third most important cause of death and disability. However, perceptions that stroke affects only high income Westernised countries are being challenged (Farham 2004).

South Africa is in a process of transition from the epidemiological profile of a developing country, where communicable diseases are the most significant, to one where chronic diseases of lifestyle are becoming more prevalent. In 2006 non-communicable diseases accounted for more than 50% of all deaths in the Western Cape Metropole. Studies in South Africa indicate that stroke accounts for 8–10% of total deaths and are amongst the top ten diseases and conditions that contribute to mortality. These figures are high and do not reflect those stroke survivors who have been disabled by the event. It is also expected that the number of stroke survivors needing rehabilitation will increase as acute stroke care improves and the mortality rate drops. The prevalence of stroke-related disability in South Africa is unknown but it is considered by many researchers to be high (Hale and Eales 2001;

Bradshaw, Schneider, Dorrington, Bourne and Laubscher 2002; Connor, Thorogood, Casserly, Dobson and Warlow 2004).

Some of the impairments that stroke survivors frequently present with are (National Stroke Association 2008):

- Problems with memory, thinking or problem solving;
- Poor vision and/or changes in vision;
- Problems with speech and language;
- Problems with bladder and/or bowel control;
- Trouble swallowing;
- Weakness or paralysis on one side of the body;
- Poor balance and/or clumsy movement;
- Not knowing what happens on one side of the body;
- Numbness; and
- Problems getting around and caring for themselves.

The various impairments experienced by stroke survivors all have a different impact on the ultimate burden of care. Literature on this topic has found the following impairments to have the most serious adverse effect on burden of care: Memory loss, decreased attention span, poor problem solving ability, problems with vision, communication problems, swallowing problems as well as decreased perception, attention, planning and spatial orientation (Bresick and Harvey 1997; Birkhead and Graham 2005; Rombough, Howse and Bartfay 2006; National Stroke Association 2008).

Rombough et al (2006) did a critical review of the available literature on the burden and strain experienced by caregivers of stroke patients and the relationship between aphasia and caregiver burden and strain. A comprehensive review of three electronic databases (Cumulative Index to Nursing and Allied Health Literature, Medical Literature Online and Psychological Information) was conducted

to identify all published peer-reviewed literature which examined the association between primary caregiver's burden of strain and caring for stroke patients with or without aphasia. One hundred and fifty-eight articles were originally retrieved, and fourteen met the inclusion criteria. These authors concluded that research on caregiver burden caused by stroke is limited and suggested further research on this aspect including the development of an instrument with psychometric properties appropriate for assessing the burden and strain on caregivers of stroke patients. However, on the issue of communication the authors concluded from the literature that loss or limitation of the ability to communicate was devastating and frustrating to both the patient and the caregiver and could result in fear, feelings of hopelessness and depression. In fact according to them communication is considered the impairment with the greatest adverse effect on the social functioning of the stroke patient. The ability to communicate is vitally important to the rehabilitation process and reintegration of stroke survivors into their home environment and the community. Where communication problems exist the caregiver often assumes an added responsibility for interpreting non-verbal cues and communication on behalf of the patient. This can affect the caregiver's response to and relationship with the patient adversely. It could limit conversation between the patient and the caregiver which is important for communicating needs, desires and just expressing and sharing ideas and thoughts which are important aspects in relationship building (Rombough et al 2006).

According to Bresick and Harvey (1997), who wrote an article on the subject, but did not perform any research to support their opinions, impairments as a result of stroke affects the patient's self-image and interpersonal skills but while these are disabling for the patient, they also have a direct and disabling effect on family relationships. These authors state that roles may become blurred after stroke and in their desire to care for their loved ones the caregiver's overcompensate and unintentionally encourage dependency by performing tasks which the patient can relearn. The caregivers thus overextend themselves and can experience strain and burn-out.

Birkhead and Graham (2005) conducted a study to ascertain the needs of caregivers of stroke patients for the purpose of developing a guideline for occupational therapists. A descriptive, quantitative-qualitative study design was

utilised with a study population of n=30. The patients of these caregivers were discharged home from two public hospitals and a private hospital in the greater Johannesburg area after involvement in a rehabilitation programme.

Two questionnaires were compiled based on a review of literature pertaining to the assessment of caregiver needs. They found that if caregivers' needs were met, both the caregiver and the patients have improved quality of life and the patients showed better recovery. The greatest needs of the caregivers according to this study are related to educational, emotional, social and physical aspects. According to them impairments can result in the caregiver having to take responsibility for the patient's care without letting the patient try to regain his/her independence. For instance after changes in vision the patient might want to regain his/her independence but the caregiver might be concerned about the patient's safety and therefore perform tasks for the patient (Birkhead and Graham 2005).

Stroke survivors who have trouble swallowing may also place a great burden on the caregiver. Firstly, there is always uncertainty about whether they have eaten enough to satisfy the body's nutritional needs; and secondly, they must be observed while eating to ensure that they do not choke on their food. The same is true for those with memory loss who may forget to chew or swallow (National Stroke Association 2008).

Sometimes patients are unaware of these deficits and this may have serious implications for the caregiver because they may want to undertake activities that they can no longer perform safely such as wanting to drive the car. This situation can become very draining on the caregiver and increases the burden of care. The caregiver may experience the effects of memory and problem solving challenges adversely as the patient has difficulties relearning movement patterns or absorbing information that has been lost because of the stroke. These often invisible impairments, like cognition, perception, neglect of affected side, personality changes, behaviour changes, mood swings and speech impairments can be misleading to outsiders who thus do not realise the immense burden on the caregiver. Such changes can be so subtle that even the family may not notice them at first. The caregiver may, however, feel misunderstood, frustrated, experience feelings of guilt and may become depressed (Ross and Morris 1988; Bresick and Harvey 1997; Birkhead and Graham 2005).

According to the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2000), impairments can lead to various activity limitations and participation restrictions. However, the ultimate impact of the impairment is determined not only by the type, number and severity of impairments, but also by the person's social roles and how the impairment affects these as well as the impact of various contextual factors on the situation.

The impact is further intensified by contextual barriers like inadequate social support, housing, transport and poverty (Geyh, Kurt, Ceiza, Ewert, Omar and Resch 2004; Ostwald, Bernal, Cron and Godwin 2009).

Family caregivers are seriously in need of social support as they often report physical and psychological distress as a result of caregiving which could lead to social isolation and burnout. (Birkhead and Graham 2005; Schure, van den Heuvel, Stewart, Sanderman, de Witte and Meyboom- de Jong 2006; Ostwald et al 2009)

According to Whitelaw, Meyer, Bawa and Jennings (1994), rehabilitation in South Africa is unsatisfactory, to a large extent because of the lack of appropriate transport. This lack of appropriate transport is also reflected in the Western Cape Province. Despite the fact that the Dial-a-ride transport service was introduced for persons with disabilities in the Western Cape Province, it is restricted to certain areas only, mostly in the Cape Metropole. Furthermore, it is limited in capacity and cannot cope with demands for the service to persons with disabilities (City of Cape Town 2008). The Office of the Deputy President, T Mbeki (ODP) (1997) has identified a need for rapid progress in developing a public transport system which is accessible to people with disabilities. The ODP (1997) states that the absence of such a transport system is a serious barrier to the full integration into the communities and societies of persons with disabilities. This is supported by Howell, Chalken and Alberts (2006) who further states that safe public transport is one of the barriers that continue to exclude persons with disabilities from opportunities, including employment and equal participation in society. According to these authors the pressure from disabled groups has made certain municipalities in the Johannesburg area aware of their responsibilities towards persons with disabilities including the provision of accessible transport, but despite substantial gains in various areas, extensive barriers still exists in the communities thus leaving persons with disabilities excluded from full participation.

Housing is a national problem in South Africa (Human Right's Unit 2006). However, the lack of adequate housing has an even bigger impact on the family if a family member is disabled. Inadequate space, no running water and electricity as well as outside toilets all place an extra burden on the caregiver (Bresick and Harvey 1997). The Reconstruction and Development Programme (RDP) on housing is poorly planned, poorly built and families live under crowded conditions (Wikipedia 2009).

Overcrowding creates a lack of privacy because the rooms are often not partitioned and toilet facilities are still built outside depending on the income of the family. Families are expected to upgrade their own homes but they do not have the finances and so this may not materialise. Accessibility is not considered when the houses are built and often families do not know who to approach about this before their houses are built. Families often have to cover costs for ramps or other adjustments that are required at a later stage. On the other hand, if accessibility issues were addressed in the conceptual stage accessibility could have been assured with little or no increase in cost (Coulson, Napier, Matsheba 2006).

Poverty has a major impact on disability and often families become impoverished because of the needs of the disabled. Poor people face a greater risk of impairment or disability as the birth of a disabled child, or the occurrence of disability in a family can place heavy demands on the family morale and place them into deeper poverty. This implies that there is a higher proportion of disabled people amongst the very poor, but also that there is an increase in families living in poverty as a result of disability (ODP 1997; Emmet 2006).

Rehabilitation can play a huge role in diminishing the effects of various impairments, activity limitations and contextual barriers and thus facilitate participation. It is an essential part of stroke management (Kwakkel, Kollen and Lindeman 2004).

## **2.3 REHABILITATION**

### **2.3.1 Definitions and underscoring policies**

Rehabilitation is a goal orientated and time limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functional level,

thus providing the individual with tools to change his/her life when and where necessary. It is the combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of functional activity. Rehabilitation can be achieved through modification of the impairment by way of medical and surgical methods, compensation for loss of function with assistive devices and techniques as well as the facilitation of social adjustment and acceptance through modification of the community. Therefore, rehabilitation includes all measures aimed at reducing the impact of the disability at an individual and societal level, prevent recurrent stroke and complications and should provide emotional support to the patient and family. It should enable the person to achieve independence, social integration, a better quality of life and self-actualisation, besides addressing broader issues like the equalisation of opportunities, adaptations of the environment and the promotion and protection of human rights (Helander 1993; World Health Organisation 1995; Duncan, Zorowitz, Bate, Choi, Glasberg, Graham, Katz and Lamberty 2005; Department of Health 2008).

The need for rehabilitation to intervene not only at a personal level, but also at a societal level is underscored by Community-Based Rehabilitation (CBR) policy (World Health Organisation (WHO) 2004) which states as one of its objectives that communities must be activated to promote and protect the human rights of persons with disabilities through changes in the community. Einar Helander (1993) states that Community-based Rehabilitation is a strategy within the community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. It advocates the full participation and integration of persons with disabilities into their home and community environments. CBR is implemented through the combined efforts of people with disabilities themselves, the families and communities, and the appropriate health, education, vocational and social services.

These definitions and policy statements as mentioned above are in agreement with the social model of disability which was developed by persons with disabilities themselves in response to the unsatisfactory medical model. In the medical model disability is seen as a state of disease and a deviation from the norm which medical professionals should cure in order for the person to become as 'normal' as possible

and fit into society. Disability is seen as a personal tragedy that happens to individuals on a random basis and the assumption is made that disabled people are biologically and psychologically inferior and are therefore not competent to take control over their lives and play a full role in society. Thus patients and families play a limited role in rehabilitation decision making and health issues are frequently treated in isolation. On the other hand, the social model sees disability as a human rights issue and locates the problem of disability within society, which is structured in such a way that persons with disabilities are prevented from exercising their rights as citizens (for example, inaccessible buildings, transport and technology as well as prejudice and hostile attitudes) (World Health Organisation 2000). Thus, disability is the direct result of society's failure to provide adequate and appropriate services and of discrimination and oppression. According to the social model, disabled people must have control over how they live and as such determine policies related to them and drive the rehabilitation process. No one aspect such as health, income or mobility should be treated in isolation (Lang 1998). As described above the social model underpins CBR policy; it also underpins the South African National Rehabilitation Policy (NRP) (Department of Health 2000). The NRP is committed to allowing persons with disabilities the opportunities to reach their optimum potential as productive members of society. The NRP states that CBR principles of service delivery should be incorporated in all levels of service delivery from primary through to tertiary health care (Department of Health 2000).

In order to be in line with above policies and with the social model rehabilitation services should adhere to the following principles (Department of Health 2000):

- Be people centred and people driven.
- Address equalisation of opportunities for persons with disabilities.
- Allow for self-representation of persons with disabilities.
- Be multi-sectoral.
- Be accessible to all.
- Focus on social integration/participation for persons with disabilities.

- Embody the principles of dignity and respect and as such address issues of social justice.
- Facilitate appropriate distribution of resources and encourage optimal utilisation thereof.
- Develop human resources.
- Be monitored and evaluated.
- Promote research.

Currently rehabilitation services in the Western Cape often fall short of these principles (Department of Health, Western Cape Province 2007) and these problems will be expanded on in the discussion of rehabilitation services in the Western Cape.

According to the South African National Rehabilitation Policy (Department of Health 2000) and Department of Health, Western Cape Province (2007), rehabilitation services should be provided at all levels of health care and at different levels of intensity according to the needs of the individual patient.

### **2.3.2 Intensity of rehabilitation services**

Rehabilitation services vary in intensity from low to high. The intensity of rehabilitation services is determined by the frequency and duration of patient-therapist contact per day. Low intensity rehabilitation services are usually rendered by only one or two professionals for less than an hour per day and usually only once or twice a week. The patient lives at home with the family and is taken to a facility for treatment or receives treatment at home. Medium intensity services involve more therapists and are usually provided on a daily basis for 1–2 hours per day. Patients are usually living at home and are treated on an outpatient basis.

High intensity services typically involve the full complement of therapists and are provided for three or more hours on a daily basis. Patients are most often treated while being admitted as inpatients to a rehabilitation unit. Ideally the intensity of services that patients receive should be determined by the patient's condition and ability to physically, mentally and emotionally cope with a certain amount of input.

Unfortunately, in practice, it is often the reality of a lack of resources that determines the rehabilitation intensity level that a patient receives rather than the patient's requirements and coping abilities (Department of Health, Western Cape Province 2007).

### **2.3.3 Rehabilitation outcome levels**

In 1995 Landrum, Schmidt and McClean published a work on outcomes oriented rehabilitation. One of the core concepts introduced in this work is rehabilitation outcome levels. These outcome levels constitute six chronological levels that the authors suggest the patient should progress through during the rehabilitation process. The first level is physiologic instability where the person is medically unstable and usually in need of some acute type of treatment. From there the patient progresses through physiologic stability, physiologic maintenance, residential integration and community integration to the highest level which is productive activity. The authors go on to suggest what outcome level should be achieved through what type of service delivery. These suggestions are incorporated in the guidelines of the Department Of Health, Western Cape Province (2007). Levels 1 and 2 are usually achieved in an acute care setting like an acute hospital, clinic or community health care centre. Levels 3 to 5 should be achieved through inpatient and outpatient rehabilitation services and community-based rehabilitation (CBR) programmes. A specialist rehabilitation centre should mostly focus on achieving level 3 while CBR programmes should focus on levels 4 and 5. A detailed discussion of each level is given below.

#### **2.3.3.1 Level 0: Physiologic instability**

This is usually at the onset of illness or injury when the patient's physiological and medical conditions have not been assessed, diagnosed and managed/treated. The patient is usually treated in an acute hospital setting. Intensive medical and nursing management are required at this stage.

In the case of a stroke patient this would be when the patient has just suffered the stroke and is still medically unstable, that is, the blood pressure has not been stabilised, or the level of consciousness might be reduced. The patient usually needs medical interventions such as stabilising the blood pressure and investigations to determine the cause of the stroke.

It is essential that professionals offer the patient and family the necessary emotional support at this stage as they are still in a state of shock and uncertain of whether the patient will survive the incident or what the consequences/effects of the stroke would be.

### **2.3.3.2 Level 1: Physiologic stability**

Physiological stability is seen as the first and most basic clinical outcome level. At this stage the patient's physiologic and medical conditions have been assessed, diagnosed and managed; or management strategies are in place. The patient is, therefore, considered to be medically stable and can be discharged from the acute care setting. At completion of this phase the patient should enter comprehensive rehabilitation. Therefore, a very important part of this phase is planning for long-term management, rehabilitation and care as well as family education, empowerment and training. While family support and empowerment is an ongoing process, this is the stage during which the patient and family should be given the bulk of information on stroke and offered an opportunity to ask questions about the diagnosis and prognosis. The information will empower them to make the necessary decisions on long-term management strategies and will lessen the anxiety experienced and thereby the burden of care.

For stroke patients this phase would be when the cause of the stroke has been determined and the appropriate treatment has commenced. Ideally at the end of this phase patients become involved in an intensive rehabilitation programme, are admitted to a step-down facility for involvement in a low impact rehabilitation programme or are discharged home. The option that is chosen depends on many factors like the severity of the stroke, availability of services and support.

### **2.3.3.3 Level 2: Physiologic maintenance (basic rehabilitation outcome)**

At this stage the emphasis is on maintaining and preserving the immediate and long-term physiologic health of the patient. The physiologic maintenance outcome level may be achieved within an acute hospital-based setting or a specialised rehabilitation centre, but can also be achieved in other settings, which may include step-down care, sub-acute care, post-acute inpatient rehabilitation, or community-based settings such as outpatient rehabilitation services or rehabilitation in the home environment.

Essentially this phase involves the instigation of practices that will prevent secondary complications. This includes ensuring that the patient's nutritional needs are met, the prevention of aspiration, skin preservation, joint maintenance and bowel and bladder management. These strategies must be successfully completed before the patient can be discharged safely to a long-term residential (home or other) setting. The patient and the caregiver should be trained or appropriately referred to manage these protocols efficiently to ensure safety and prevent the development of secondary complications.

#### **2.3.3.4 Level 3: Home and/or residential integration**

At this level the patient may be discharged to a long-term residential setting, be it his/her home or an old age home or a care facility. The patient should have reached a moderate level of independence in self-care, mobility, safety, communication and basic home management appropriate to the patient's capacity and environmental conditions. Moderate levels of assistance and supervision may still be required by the patient. Reinforcement of the training and skills transference to the patient and the caregiver is essential in order to maintain the physiological stability of the patient and to prevent the development of secondary complications and a relapse following discharge to the home environment.

For stroke patients this usually means discharge to the home environment with the support of the appropriate community resources, like home-based care, community-based rehabilitation and adult day care if needed and if available or possible discharged to an old age home which would usually be considered as the last resort.

#### **2.3.3.5 Level 4: Community reintegration**

At this outcome level the focus is on achieving advanced rehabilitation outcomes that would allow functioning within the patient's community. The goals of this rehabilitation level place the emphasis on self-management, social competencies, community mobility, financial management self-directed health monitoring, participation in sport, recreation and other community activities. The person may utilise assistance but the assistance must be directed by the person. The actual availability of assistance and the environmental resources and barriers are

important factors in determining the client's ultimate degree of community integration.

Successful reintegration into the community is influenced by factors like attitudinal barriers, a lack of social/family support systems, a lack of finances, structural barriers in the community and a lack of community support services. These barriers should be assessed and where possible addressed during rehabilitation. The continued training of the caregiver/family is important so that they may feel confident in their caregiving tasks in order to achieve and maintain this advanced outcome.

This might mean that the patient is integrated into his/her community despite not being functionally independent. Thus the patient relays his/her desires or needs to the caregiver who assists and ensures integration. As a result the impact on the caregiver could be huge. It should be noted that the degree of assistance is irrelevant as long as the assistance enables the person to integrate into the community and the person drives the process him/herself.

#### **2.3.3.6 Level 5: Productive activity**

This stage focuses on reintegration into productive activities suitable for the person's stage of life and interests. For example, a retired person could return to activities like volunteer work that he/she was involved in before the incident. Typical components of this outcome level include vocational education, job site evaluation and employer education. For stroke patients it would be when the patient returns to work/school after the necessary adaptations and adjustments have been made to accommodate the needs of the patient. It could also mean that the patient returns in an alternative capacity. The necessary adaptations and alterations should also be suggested and considered in the work/school's physical environment for the patient to have accessibility, full reintegration and participation in this environment. This would include public transport and removal of structural barriers, like pavements that need to be lowered, ramps and lifts that need to be installed if needed.

As shown through the above examples, rehabilitation of a person who suffered a stroke can be structured according to these outcome levels.

## **2.4 STROKE REHABILITATION**

Stroke rehabilitation is a very important part of recovery for many people who have suffered a stroke. It builds the stroke victim's strength, co-ordination, endurance and confidence and the person relearns to move, talk, think and care for him/herself. Stroke rehabilitation addresses the effects of stroke in order to decrease the participation restriction that the person experiences and thus lessens the burden on the caregiver. The overall aim of stroke rehabilitation is to get the person back or as close as possible to his/her previous level of function in the home, work environment and the community. The primary goal of rehabilitation is thus to enable the patient to reintegrate into the home and community environment with the highest possible level of functional independence and a good quality of life. At the same time the burden of care on the family and caregiver must be reduced significantly (Department of Health, Western Cape Province 2007).

Rehabilitation begins in the early stages post stroke, as soon as the patient is medically stable, and it involves evaluation and intervention by the rehabilitation team which includes a doctor, nursing staff, physiotherapists, occupational therapists, social workers and speech and language therapists. Early intervention and greater intensity of treatment are associated with better outcomes (Teasell and Kalra 2005).

Education of the patient and the family on the management of the stroke, as well as prevention of further strokes and secondary complications is a vitally important part of rehabilitation. The more information the patient and the family have on stroke and the prevention of further strokes, the more they become empowered and confident in dealing with their current situation (Clark and Smith 1999b; Clark, Raubenach and Winsor 2003; Mackenzie, Perry, Lockhart, Cottee, Cloud and Mann 2007). The information should, however, be user friendly and appropriate. According to Smith, Forster, House, Knapp, Wright and Young (2009) information should be provided in a way that actively involve the caregiver and patient and where a comfortable atmosphere is created which offers repeated opportunities to ask questions. If the patient and family are equipped with all the relevant information and knowledge on stroke, intelligent and informed choices can be made. However, families who have an inadequate understanding of stroke may have ill-informed and unrealistic

expectations of the rehabilitation process (Clark and Smith 1999b; Mackenzie et al 2007).

Mackenzie et al (2007) conducted a study to determine the support required by caregivers who were caring for a patient who suffered a stroke. They recruited 42 caregivers and perform a survey of needs, knowledge, satisfaction and competencies in caring before and four to six weeks after discharge from an acute stroke unit. The following instruments were administered in this study:

- 1) The Carer Assessment Scale, an 18-item Likert-type scale that assesses the physical, practical, psychological, and social needs of the caregivers, was administered to identify anticipated needs one week before discharge and to report problems that caregivers experienced four to six weeks after discharge.
- 2) The Knowledge of Stroke Scale, a 30-item scale was administered four to six weeks after discharge to identify their level of stroke knowledge.
- 3) The Sense of Competence Questionnaire, a 27-item Likert type scale was administered to caregivers four to six weeks after discharge to assess perceived burden under three subscales: i.e. satisfaction with dependent person as recipient of care, satisfaction with own performance as caregiver, consequences of caring for personal life.
- 4) The Satisfaction with Stroke Services Scale, a twelve question Likert-type scale was amended to better reflect the caregiver's perspective and was administered four to six weeks after discharge.
- 5) The Bartel Index to determine the level of physical dependence of the patient. These scores were exacted from professional notes.

Results showed that caregivers need information on stroke, planning, inclusion in decision making and professional support (Mackenzie et al 2007).

The patient, which in stroke rehabilitation includes not only the patient but also the family and the caregivers, needs as much appropriate information as possible. Furthermore, they should be actively involved in every step of the decision making process regarding rehabilitation and future planning. According to Clark et al (2003), there is evidence to suggest that patients make a better recovery when they have

adequate knowledge on stroke. They maintain that patients and families may become frustrated by a lack of information on stroke and this in turn may interfere with the family functioning. Clark et al (2003) conducted a study of stroke patients who were admitted to hospital. Demographic details and baseline functional status, depression, anxiety and mastery were recorded on admission for rehabilitation. Family functioning (patient and spouse) and social functioning were measured on admission for rehabilitation. Except for social functioning, these measures were repeated on discharge and then six months after discharge. The authors designed a two-group randomised control trial including sixty-two patients and their spouses, 32 in the intervention group and 30 in the control group. On discharge and at the end of the rehabilitation programme, patients and their spouses were randomly allocated either to an intervention group who received information and counseling, or a control group who did not. The package issued to the intervention group included information about stroke and its consequences, highlighted measures for reducing the risk of further stroke, provided practical coping suggestions and included information about community services and support structures. This was followed up with three visits (three weeks, two months and five months after discharge) from an independent social worker who discussed and reinforced the information and counselling was offered on stroke related issues. This study found that education and counselling intervention not only lead to the maintenance of family functioning, but also to improved functional and social outcomes for the patient.

Two further aspects that enhance caregiver coping and that should be part of stroke rehabilitation is phased discharge and home visits (Bresick and Harvey 1997). Phased discharge describes a process where the amount of time that the patient spends at home is gradually increased from a weekend to a week and longer periods before final discharge. This process enables rehabilitation personnel to identify future problem areas at home and address them before final discharge. Spending weekends at home is not enough and should not be seen as a substitute for phased discharge. Home visits encourage family and caregivers to take more responsibility for the rehabilitation process as they are more relaxed in their home situation (Bresick and Harvey 1997).

According to the Department of Health, Western Cape (2007), stroke rehabilitation can be provided both on an inpatient or outpatient basis; in an institution and as part

of a community-based rehabilitation programme depending on the needs of the individual client.

#### **2.4.1 Community-based versus institution-based stroke rehabilitation**

Stroke rehabilitation can be community-based or institution-based. With the present emphasis on primary health care in South Africa it is conceivable that the rehabilitation of persons with stroke will become progressively more community-based, with less emphasis on inpatient/facility-based rehabilitation.

The South African National Rehabilitation Policy (Department of Health 2000) states that strategies for the prevention of disabilities should include sufficient hospital stays to achieve rehabilitation goals, the prioritisation of family involvement and educational and support programmes to ensure community follow-up after discharge. However, in September 2001, not even a year later, a set of norms and standards was drawn up which stated that rehabilitation services should provide all patients with a comprehensive assessment, followed by an appropriate treatment programme in consultation with the family, as the latter may have to be the implementers of the programme (Birkhead and Graham 2005). This paper suggests that the major part of the rehabilitation programme is expected to be done at home. It implies an earlier discharge home from the acute hospital and places a greater burden on the family and caregiver. Early discharge of stroke patients allows for increased patient turnover and decreased financial expenses to the hospitals but this has been found to impair the mental health of the caregivers as it often puts a heavy burden on caregivers who are generally not equipped to look after the patient (Bresick and Harvey 1997; Mann 1997; Clark et al 2003). Bresick and Harvey (1997) state that on discharge from hospital family opinion might differ as to whether the patient should go home or to a convalescent facility. These conflicts may be an additional source of stress for the caregiver.

According to Isaacs (1982), families often eagerly support early discharge from the hospital setting as they are deceived by the sudden onset of the illness into believing that it will suddenly improve once the patient returns to the normal, familiar environment.

A study done by Anderson et al (1995) compared early discharge (plus home-based care) to inpatient rehabilitation (with follow-up care) of stroke patients, and found the

recovery in the patients was the same in both situations. However, the caregiver's mental health was found to be more adversely affected where there was an early discharge home of patients. This finding is confirmed in a study by Hale (2004) who in this paper reviewed literature on stroke rehabilitation in the community and debated the issue as to whether it is truly community-based or just merely an extension of institutional care. The author found evidence that stroke rehabilitation in the community significantly improves personal and extended activities of daily living, and does not result in functional deterioration. However, this model of service delivery does result in greater caregiver stress. Hale (2004) continues that community-based stroke rehabilitation can be confusing, as interventions and services are not well defined.

According to the Department of Health, Western Cape Province (2007), community-based rehabilitation programmes should provide the bulk of primary level rehabilitation in the Western Cape Province. However, rehabilitation services are limited to low intensity therapy at certain community health centres.

A major concern is thus that the primary health care systems and other support services in the community are not fully functional in many areas, and therefore the caregiver burden becomes more severe (Office of the Premier Western Cape 2002)

## **2.5 REHABILITATION SERVICES IN THE WESTERN CAPE PROVINCE**

The Department of Health, Western Cape Province's (2007) policy document creates an opportunity for the development of rehabilitation services across all levels of health care services. It envisions rehabilitation as both a facility and community-based service. The aim of rehabilitation is for the patient to reach his/her optimum level of independence and to facilitate the smooth reintegration of the patient into the home and community environment. This should also lessen the burden of care on the caregiver. According to this document, a patient who suffered a stroke should commence with rehabilitation at the point of entry into the health care system.

Thereafter, rehabilitation should continue along a continuum of care until the patient is reintegrated back into the home and community environment (Department of Health, Western Cape Province 2007).

Rehabilitation services available along the continuum of care include services at primary, secondary and tertiary level.

### **2.5.1 Primary level rehabilitation services**

Primary level rehabilitation services for stroke survivors include both facility-based and community-based services, and are offered in a variety of formats such as step-down care, community-based care, adult day care centres and the outpatient or ambulatory services offered by community health care centres (Department of Health: Provincial Government Western Cape (PGWC) 2006).

At primary level low intensity rehabilitation services are rendered. The advantage of this type of service is that the patient stays in a familiar environment amongst loving and caring family members. On the negative side transport might become costly and transport and caring responsibilities might add to the burden on the family. Rehabilitation at primary level is provided at any one of the following settings: community health centres/clinics, adult day care centres, or community-based rehabilitation.

#### **2.5.1.1 Community health centres/clinics**

Community health centres or clinics should ideally be the level of entry into the formal health sector. They provide basic health care that includes primary, secondary and tertiary prevention strategies. These facilities are mostly nurse-driven with, in some instances, a therapist on staff that provides low intensity outpatient rehabilitation.

#### **2.5.1.2 Adult day care centres**

The primary purpose of adult day care centres is to provide care to people who need care during the day while family members attend to their daily responsibilities. As such these facilities will be discussed fully under the caregiver relief options. However, these centres do employ therapists and do provide a medium intensity rehabilitation service when needed.

### **2.5.1.3 Community-based rehabilitation (CBR)**

Community-based rehabilitation services aim at providing a holistic service which involves all sectors of the community. They aim to address the needs of persons with disabilities in the communities where they live. Community-based rehabilitation promotes the active involvement of persons with disabilities, the families, the community and all the appropriate sectors in the rehabilitation process. CBR serves to complement and enhance facility-based services by providing services in a community setting and also by creating mechanisms through which communities can become aware of their health needs. It is a way of empowering the community in terms of knowledge and the needs of persons with disabilities. It is a process that creates the equalisation of opportunities and the social integration of all persons with disabilities into the community, workplace or school (World Health Organisation 2004; Department of Health, Western Cape Province 2007). However, currently CBR programmes in the Western Cape Province are still in their infancy and do not provide much rehabilitation services at all (Office of the Premier Western Cape 2002).

### **2.5.2 Secondary level rehabilitation services**

Secondary level rehabilitation services include regional hospitals, step-down facilities and stroke units at different hospitals.

#### **2.5.2.1 Regional hospitals**

Secondary level health care and rehabilitation services provides a more specialised level of care and are usually based at the larger regional hospitals such as New Somerset, Paarl, Worcester and George regional hospitals. The rehabilitation services provided at these regional hospitals are largely outpatient-based and of a low intensity. They are typically rendered by one or two rehabilitation professionals and are usually not a daily service. Patients can only access these services if they have the necessary transport and if the facility is close to home.

In terms of the Comprehensive Service Plan these clients should be ideally accessing these rehabilitation services at a primary level, but due to the very slow development of services at primary level, stroke clients continue to access

rehabilitation services at a secondary level (Department of Health, Western Cape Province 2007).

Accessing rehabilitation at secondary hospitals can have a negative impact on caregivers as they often have to take time off work and arrange transport to get the patient to the facility and also bear with the incumbent cost implications. In addition, they have to deal with the physical demands of caring for the patient, often without adequate training (Bresick and Harvey 1997).

### **2.5.2.2 Step-down facilities**

Rehabilitation is also provided at step-down rehabilitation facilities that offer low intensity inpatient rehabilitation programmes to patients. Examples of such facilities in the Western Cape Metropole are the Booth Memorial Hospital, Life Care, Maitland Cottage Home and Sarah Fox. Typically patients who are not able to manage an intensive rehabilitation programme because of complications like confusion, perceptual problems and pressure sores that must improve or heal before the patient can become involved in an intensive rehabilitation programme and who need a more intense level of nursing care than what families can provide at home are admitted to these facilities.

### **2.5.2.3 GF Jooste Stroke Unit**

GF Jooste Stroke Unit gets all its referrals from primary level health care facilities within its drainage areas. There is a resident physiotherapist and the speech therapist of Grootte Schuur Hospital who visits this stroke unit twice a week. Patients and families are referred to the social worker. The families are encouraged to attend the ward rounds where the team explains the diagnosis and prognosis. The staff nurse in the team liaises with the families and makes the necessary arrangements for the appropriate referrals for rehabilitation where indicated.

The aim, however, is to get the patient medically stable, to have all necessary investigations completed and then to have the patient discharged home or to a rehabilitation facility. (Dr de Villiers, senior consultant at GF Jooste Hospital),

### **2.5.3 Tertiary level rehabilitation services**

Tertiary level health care and stroke rehabilitation services are provided at specialist tertiary hospitals such as Groote Schuur and Tygerberg. Even though they are specialist units with technologically advanced diagnostic and treatment options these facilities usually only render an outpatient, low impact rehabilitation service which has the same impact on the caregiver as rehabilitation at secondary hospitals.

#### **2.5.3.1 Groote Schuur Hospital (GSH) Stroke Unit**

Patients are referred to Groote Schuur Hospital's stroke unit from secondary level hospitals in the GSH drainage area and tertiary level hospitals from anywhere in the Western Cape Province. The GSH stroke unit team consists of an occupational therapist, a physiotherapist, speech therapist, social worker, University of Cape Town neuropsychology masters students and a liaison sister. The team also includes medical professionals that is, a senior house officer, registrar and stroke consultant. The team has ward rounds twice a week to assess the progress of the patients and to decide whether the patients should get in or outpatient rehabilitation. The referrals for outpatient rehabilitation services are sent to the community health centres or GSH depending on what the patient requires. There are no occupational therapy or speech therapy services at the community health services facilities while GSH offers these. The patients are all assessed and get some rehabilitation while they are in the stroke unit but the aim is to discharge them appropriately, either home or to a rehabilitation facility, as soon as they are medically stable and all the investigations have been completed. Dr. Kalula, Department of Medicine and Geriatrics at GSH,

### **2.5.4 Specialist rehabilitation services**

There is one rehabilitation facility, namely, the Western Cape Rehabilitation Centre (WCRC) in the Western Cape Province that provides specialised, high intensity, outcome-based rehabilitation programmes within a safe and supportive environment on both an in and outpatient basis. Rehabilitation at WCRC focuses on community reintegration programmes for people who have a permanent disability following disease or injury.

WCRC is the only specialist service run by the state and it services the entire Western Cape Province as well as the neighbouring provinces (Western Cape Rehabilitation Centre 2007).

The WCRC has no specified admission criteria as all clients are individually assessed to determine if they will benefit from receiving rehabilitation at WCRC. The patient must, however, be medically stable and must be able to participate in a high intensity rehabilitation programme. The bed management team at the WCRC strives to admit the acute stroke patients within seven days of approval of the application for admission as it is considered ideal to admit these applicants as soon as possible after the stroke event. Unfortunately, the demand for WCRC services is so great that there is a waiting list for the non-acute applicants who often have to wait several weeks for a bed vacancy to occur. Mrs. McKee, Assistant Social Work Manager at WCRC.

### **2.5.5 Private rehabilitation services**

South Africa has a two-tiered system of health provision and while the public system discussed in this chapter does provide health care to the majority of the country's population (80%+) a small minority access private health care services and private rehabilitation services (Schaay and Sanders 2008). These are mainly provided on an individual basis by private therapists and to a small extent at private rehabilitation hospitals. Services provided by therapists in private practice tend to be of high to medium to low intensity while those provided in rehabilitation hospitals are mostly of high intensity. Services are costly and the patients or family must have the finances or adequate medical insurance coverage in order to be able to afford them (Office of the Premier Western Cape 2002).

### **2.5.6 Adequacy of services**

Although the government sector in the Western Cape Province offers rehabilitation services at all health care levels the vast majority of these provide only low intensity rehabilitation. The only medium and high intensity rehabilitation is provided by a few day care centres and WCRC; not nearly enough as waiting lists at WCRC indicate. Services in rural areas are limited and where patients from rural areas are admitted to WCRC, they find themselves far from their families, who often have limited access to the team because of constraints like transport and finances. This is not

conducive to effective rehabilitation. The inaccessibility of rehabilitation services in the rural areas places much strain and a greater burden on the caregiver.

The lack of appropriate and adequate assistive devices to the patient makes the care burden on the caregiver even more difficult. In the rural areas the services of the orthopaedic after care sisters and home-based carers have thus become invaluable (Office of the Premier Western Cape 2002).

### **2.5.7 Adherence of services to standards set by National Rehabilitation Policy**

In the discussion on rehabilitation definitions and policies a number of principles that rehabilitation services should adhere to were mentioned. When comparing the different services discussed above to these principles it becomes clear that services still fall short to a large extent. In fact it can be said that despite the NRP being eight years old little has changed at the actual point of service delivery.

The medical model is still largely in operation with the focus on curative services and very little self-representation, intersectoral collaboration, poor accessibility, little equalisation of opportunities and integration of persons with disabilities; there is less than optimal adherence to principles of dignity and respect and inequities in resource distribution (Department of Health (NRP) 2000).

Primary health care services that should provide both the point of entry into the health care system as well as ongoing support to caregivers are especially under strain as indicated by Kautzky and Tollman (2008). Specific areas of concern include a shortage of personnel due to factors such as a high rate of immigration and inequities in the distribution of health care workers, low morale, the complex, protracted health transition process, the fact that the focus is still on curative services and a lack of managerial capacity and leadership. According to Kautzky and Tollman (2008), there is a need for many more mid level workers, integration of community health workers, curriculum audits and changes in order to prepare health care workers for primary health care service provision and integrated primary health care teams.

WCRC, which is seen as a model for rehabilitation services and a leader in the field (Western Cape Rehabilitation Centre 2007), has made progress towards integrating these principles in rehabilitation services. Examples include intersectoral

collaboration with the Department of Social Development, collaboration with the Department of Labour and the Red Door Project.

#### **2.5.7.1 Intersectoral collaboration with the Department of Social Development**

Intersectoral collaboration with the Department of Social Development where an agreement was negotiated between WCRC social workers and the local South African Social Security Agency (SASSA) office to visit WCRC weekly to complete the patients' disability grant applications. This facilitates the patients' financial independence and eases reintegration into the home and community. It takes some of the financial strain off the caregivers. A local financial institution also visits WCRC to assist patients in opening banking accounts as this is a requirement of SASSA for the patient to apply for a disability grant.

#### **2.5.7.2 Collaboration with the Department of Labour**

There is collaboration with the Department of Labour whose officials visit WCRC fortnightly to assist patients with possible work opportunities and appropriate work placements, answer enquiries regarding benefits and provide career counselling sessions.

#### **2.5.7.3 The Red Door Project**

The Red Door Project, which is an initiative of the Enterprise Development sub-directorate within the Department of Economic Development and Tourism, has an agreement with the rehabilitation teams at WCRC and provide an invaluable service to patients who wish to enter or re-enter the productive world. This project was initiated by the occupational therapists. Red Door offers a three day course to in and outpatients with their spouses/partners on starting small businesses (including 'house shops') and how to access financial assistance. Arrangements can be made for outpatients and their spouses/partners to overnight at the Lodge when attending these courses. However, on the whole even the services at WCRC fall short of adhering to the gold standard set by the NRP. Specific areas that prove challenging are full involvement of patients and families in the rehabilitation process (or even more so by creating a situation where patients and families drive the rehabilitation process). Unfortunately families may be absent or unable to be involved because of work commitments, transport problems, financial difficulties, or because they live

out of the area or the patient has distanced and isolated him/herself from the family and/or the whereabouts of family members may be unknown. Liaison with other sectors, such as the Departments of Transport, Education and Labour, local authorities and other community organisations, with regards to addressing structural and attitudinal barriers which hamper reintegration of the patient into the home and community environment need to be more formalised. While this does happen on an ad hoc basis there are no structures or protocols in place to inform the process and ensure that it happens on a continuous basis.

While WCRC is rather well staffed when compared to other health care institutions a lack of manpower and the limitations of the current curricula that are being taught to the various professional groups at the universities still hampers the ability of staff to fully adhere to and work according to CBR principles as set out by the NRP. These challenges must all be addressed before it can be said that state rehabilitation services in the Western Cape Metropole adhere to the principles of the NRP. On the whole the inadequacy of rehabilitation services can lead to a situation where patients are discharged home into the care of a caregiver without either patient or caregiver having received the benefit of participating in a comprehensive rehabilitation programme and this increases the burden of care.

## **2.6 THE CAREGIVER**

She is not trained for her job, a priori. She may have little choice about doing the job. She belongs to no union or guild, works no fixed maximum hours.

She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her job situation, she bears a heavy emotional load, but has no colleagues or supervisor or education to help her handle this. Her own life and its needs compete constantly with her work requirement. She may be limited in her performance by her own ailments (Golodetz, Evans, Heinritz and Gibson 1969:390).

This quote by Golodetz et al (1969), of so many years ago, still applies to the situation regarding caregivers in our present day. It displays the plight of the caregiver that seems to go unaddressed. While many health professionals express their concerns about the plight of caregivers very little had been done to assist and support them. The burden of care is thus not addressed and the caregiver is so aptly called the 'hidden' patient (Fengler and Goodrich 1979). The 'hidden' patient is

as much a victim as the disabled person whom he/she is caring for. The caregiver frequently experiences problems of isolation, loneliness, economic hardships and role overload (Fengler and Goodrich 1979; Kilonzo 2004).

### **2.6.1 The 'typical' caregiver**

A caregiver provides the daily care necessary to enable a frail or physically challenged person to live at home despite illness or disability (American Heart Foundation 2008). As such Bugge, Alexander and Hagen (1999) describe informal caregivers as the backbone of the service provided to surviving stroke patients.

Anderson et al (1995) describe caregivers as a heterogeneous group and there is no typical caregiver. It is often the daughter, spouse or mother who assumes caregiving duties. In terms of characteristics caregivers vary with regards to age, gender, experience, physical health and strength and emotional endurance, the relationship to the patient, frequency of contact with the patient, coping mechanisms, personality, living arrangements with respect to the patient, and the quality of the interpersonal relationship with the patient. However, informal caregivers are most frequently members of the immediate family and usually women who must often balance the role of caregiver with other responsibilities both in and outside the home. All of these characteristics are related in a positive or negative way to the potential for experiencing emotional distress and impact on the ultimate burden of care.

### **2.6.2 Burden of care**

Zarit, Todd and Zarit (1986) defined burden as the extent to which caregivers perceived their emotional or physical health, social life, and financial status to be suffering as a result of caring for their relative. Caregiving is complex in nature with both an activity and an emotional component. Therefore, it requires both labour and love from the caregiver. Consequently the burden experienced by caregivers is usually considered to have both objective (actual tasks performed) and subjective (personal feelings in response to providing care) components. The actual tasks performed by the caregiver (objective component) are dependent on the physical dependency as well as the mental and emotional health of the patient and the extent of these tasks can be determined through measuring these aspects.

The caregiver's personal feelings in response to providing care (subjective component) which can increase the caregiving burden include negative feelings with regard to lack of time for oneself, lack of privacy, lack of social life, one's health status, feelings of stress, embarrassment and inability to manage the care responsibility. These feelings must also be explored if the caregiver burden is to be determined accurately. Research found that where a combination of the subjective and objective components led to high levels of caregiver strain there was a significantly higher probability that patients would be institutionalised at some stage (Brown, Potter and Foster 1990).

A study by Greveson, Gray, French and James (1991) found that 30% of caregivers were under considerable strain three years after stroke while a study by Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell and Beech (1997) found that 21% were under strain five years after the stroke. Greveson et al (1991) conducted a prospective study which included patients who had been admitted to hospital after an acute stroke between February 1985 and September 1986. In 1988 these patients who lived at home were traced, various functional outcomes were assessed using the Bartel Index, the Wakefield Depression Inventory, Nottingham Health Profile (measuring emotional outcome and subjective health status), social activities were assessed with the Frenchay Activities Index and the cognitive function was assessed using the 37-point Mental Test Score and picture drawings (patients were asked to copy a house, draw a man and a clock from memory). Patients and caregivers were interviewed on their subjective health status. Caregiver's level of strain was measure with the Caregiver Strain Index.

Caregivers experience strain from the early post stroke phase, and that strain further increases with time. In the first six months after stroke the actual amount of time spent on assisting and being with the patient increased strain. This suggests that the caregivers under greatest strain are those who had to set aside specific time to provide care, that is, those who have to fit caring into an already busy schedule. Interestingly these authors found that the location of the patient was not a predictor of strain. So whether the patient resides with the caregiver or not, within the first six months there will be caregivers under strain (Wilkenson et al 1997; Bugge et al 1999).

Furthermore, family caregivers play an essential role in the recovery process after stroke, particularly because the length of stay in the hospitals and rehabilitation settings continues to decrease for reasons like budget cuts, waiting lists and shortage of staff. Gray-Davidson (2002), Han and Haley (1999), Anderson et al (1995) confirm that patients are often discharged home as soon as, if not before, they are medically stabilised after they have suffered a stroke. The result is increased pressure on families to take responsibility for the patient's care. The caregiver may not be ready to undertake this responsibility and might not have had adequate training in caring for the stroke patient. It can be very stressful and frustrating to be suddenly thrust into a position of caregiving with little or no warning.

In most instances caregivers are quite willing to take on the care responsibility despite the physical, emotional, financial and social demands that caregiving puts on them. However, some caregivers may feel duty bound to care for the patient irrespective of the consequences because this is what society or their culture expects of them. Sometimes this is even demanded by the patient. The caregiver might thus be expected to accept the care responsibility and does not have the courage to decline. Furthermore, caregivers might be unaware or uninformed of the implications of taking responsibility for the patient who suffered a stroke. It is only once the caregiver has taken on the care responsibility that he/she realises the implications.

While family care can be a mutually rewarding experience the adverse effects often outweigh the positives as the demands of caregiving can be strenuous and a great burden. Stress tends to increase over time if the caregiver's needs are not met. Caregiver needs include a need for information (especially better understanding of the emotional and behavioural changes after stroke) and the need for skills to cope with the physical aspects of care. In terms of emotional reactions, caregivers often feel one or more of the following: anxiety, guilt, depression, frustration, resentment, impatience and fear. They may fear that the stroke may recur, that the stroke patient may be unable to accept the disability or may have to go to a nursing home; they also fear making mistakes and isolation and abandonment from friends. The caregivers must be supported and their needs must be addressed because coping with these reactions is paramount for a healthier caregiver and thus ultimately for a healthier patient (Edwards 2008).

Caregivers in poorer health were found to be under greater strain. So too were those caregivers who spend much time helping the patient and those caring for patients who were more dependent on care (Bugge et al 1999).

According to Korpelainen, Nieminen and Myllylä (1999) stroke also impacts on the sexual relationship of the patient and the spouse. The spouse who is also the caregiver may have an increased burden in having to meet this need or having to cope with the lack of libido. There is also the fear that something may happen to the patient during the actual sexual act. Korpelainen et al (1999) found that patients and spouses reported an interest in sexual counselling and regarded it as an essential part of stroke rehabilitation, but only few of them received it. They suggested that a need clearly exists for sexual counselling after stroke (Korpelainen et al 1999).

According to Drummond (1988), the most common reasons for not resuming a sexual relationship after stroke appears to be repulsion, fear of another stroke, impotence due to medication, general marital breakdown and lack of interest due to depression.

From all of the above it is clear that stroke cannot be assessed simply by its effect on the patient since it is associated with a high risk of disrupting the integrity of the family and the quality of life of the caregiver. Therefore, this situation should be assessed holistically. Strategies should be implemented to support and maintain the well-being of the caregiver. Assessment of the caregiver's own medical, social and emotional needs must be done as part of routine follow-up stroke services (Anderson et al 1995) and ongoing provision of support and relief services to caregivers is essential if they are to continue their duties year in and year out.

## **2.7 Caregiver relief options in the Western Cape Province**

### **2.7.1 Relief/respice care**

Respite care provides inpatient care to the patient for a period of at least a month at a time in order to relieve the caregiver from the care responsibility. It allows the caregiver to regain his/her strength and to rejuvenate.

The caregiver can rest without undue worries about the patient who is being cared for in a safe and caring environment. These services are offered by Booth Memorial Hospital, Life care, state subsidised and private old age homes as well as Cheshire Homes in the Western Cape Metropole.

The researcher considers respite care an essential service to the caregiver and would even suggest that during this period of hospitalisation the patients should be fully reassessed for any further rehabilitation potential and treated accordingly. Should further rehabilitation be warranted and the patient's independence improves it would mean that the burden would be lessened for the caregiver.

### **2.7.2 Home-based care**

Home-based care services are co-ordinated from the primary care level. They provide basic nursing care by formal or informal caregivers to patients in their homes. They aim to promote, restore and maintain the person's maximum level of function, comfort and health including care towards a dignified death. Home-based care services can be classified as preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care. Home-based care is an integral part of community-based care (Department of Health 2001).

Amongst people who qualify for this care are those who have had strokes, who are living with HIV and Aids, who are physically or mentally challenged, frail older persons or those who are terminally ill. The purpose of home-based care is not to provide a 24-hour service and so it does not replace the family as primary caregiver. It is a complementary and supportive service designed to assist caregivers (Uys 2005).

### **2.7.3 Adult day care centres**

The researcher is a strong supporter and advocate of adult day care centres and finds that they offer an invaluable service to the caregivers as well as the patient. In 1991 the researcher spent four months as an exchange student at an adult day care centre in San Diego, USA. This experience was most valuable and taught the researcher that caregivers can continue with their lives while the patient is being cared for in an adult day care facility. Caregivers can continue to earn a living and

be self-reliant/sufficient while they have peace of mind that their family member is being cared for in a safe environment.

An adult day care centre offers a day service to the patient. The patient is taken to the facility by the family or collected at home by the facility in the morning if the patient lives within a certain radius of the centre and if transport is available at the centre.

The patients are cared for and exercised by various professionals and trained caregivers during the day. An example is the Rehoboth Centre in Hanover Park. These centres run an excellent day care service for the client and in the process relieve the burden on the caregiver.

The adult day care centre provides an organised day programme. It offers care and companionship to elderly persons and other adults with physical or mental impairments to restore and maintain to the fullest extent possible their capacity for self-care. The centres also offer relief to family members or caregivers, allowing them the freedom to work, handle personal business or just relax, knowing that their relative is being well cared for. Being part of a group also helps elderly people and adults with disabilities who are isolated by illness or loss, to maintain a positive orientation to life as they can socialise. These services ensure that the client can live in the family home as long as possible and prevent institutionalisation.

The adult day care centre has medical and nursing staff, physiotherapists, occupational therapists, speech therapists, social workers, dieticians and could include psychiatric services when required. Unfortunately these adult day care services are very limited in our Western Cape communities.

## **2.8 SUMMARY OF CHAPTER 2**

It is clear from the literature review that stroke is a serious condition that can result in multiple impairments and activity limitations and that leaves the person in need of daily care and dependent on a caregiver. In order to diminish the effects of these impairments, rehabilitation is considered an essential part of stroke management. According to the South African National Rehabilitation Policy (Department of Health

2000), rehabilitation in South Africa must focus on social integration and equalisation of opportunities for persons with disabilities. While rehabilitation is offered through various institutions at various levels of care in the Western Cape, these services are still mostly based on the medical model and they are too few in number. Caregivers form the backbone of community support services for persons who have suffered a stroke. However, their burden is seldom exposed, acknowledged and addressed. Caregiver relief options are also too few in number to provide adequate periods of rest (so essential to their functioning) to caregivers. It is essential to determine and acknowledge the needs of the caregiver and to take care of the caregiver by providing the necessary support services as mentioned above to lessen their care burden and in turn ensure that the patient will be better cared for.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

The following aspects pertaining to the methodology of the study will be discussed in this chapter study design, study setting, study population (including inclusion and exclusion criteria as well as sampling), instrumentation, pilot studies, data collection, data analysis, ethical implications and limitations and possible bias.

#### **3.2 STUDY DESIGN**

A descriptive study that utilised a concurrent mixed methods design as described by Kroll, Neri and Muller (2005) was done. Qualitative and quantitative data were collected and analysed simultaneously. The quantitative component included demographic details of the patient and the caregiver, the discharge destination of the patient, the outcome levels and caregiver strain as well as caregiver satisfaction with living scores. The qualitative component of the study focused on the perceptions, attitudes and beliefs of the caregivers, with regards to stroke rehabilitation and their caregiving duties.

There are many good reasons for combining quantitative and qualitative methods in research design. Firstly, combining the quantitative and qualitative methods has several advantages as any one of the following three scenarios can occur when integrating and interpreting data. Secondly, by combining the two methods richness is added to findings where the two methods found complementary information. It can confirm findings where both methods lead to the same conclusion and thus validate the conclusion. Thirdly, data can be divergent or contradictory as different views can be expressed by respondents in the qualitative part of the study than collected through more rigid quantitative methods. This gives new insights that can be addressed and explored (Rossman and Wilson 1985; Kroll et al 2005).

In a descriptive study the aim is to describe the problem through answering the questions who, how, when, and where (Katzenellenbogen, Joubert and Abdool Karim 1997). In the current study these questions were answered in order to develop a profile of the patient and the caregiver and to determine the dependency of the patient as well as the care burden; in brief the impact of caring for a patient who suffered a stroke, the level of support that caregivers have experienced and the needs of the caregivers. Therefore, the study utilised a variety of instruments in order to fully answer the questions being asked.

### **3.3 STUDY SETTING**

The study was conducted at the Western Cape Rehabilitation Centre (WCRC). This centre came into existence in October 2004 when the old Conradie Hospital and Karl Bremer Centre for Care and Rehabilitation of the Disabled (CCRD) amalgamated and relocated to Lentegeur Hospital in Mitchell's Plain. These two institutions had different approaches and methods of work. Conradie Hospital was a big institution with an intensive care section, acute care wards, rehabilitation wards and wards for admitting patients with secondary complications. This required a much bigger staff complement, which lead to a departmental structure. This structure as well as rotation of staff members through different areas made multi-disciplinary team work more feasible than interdisciplinary teamwork. In contrast CCRD was a small rehabilitation unit which only admitted patients for intensive rehabilitation, the staff complement was small and an interdisciplinary teamwork approach could be followed.

Since the amalgamation the teams have been striving towards implementing client managing methods that are in compliance with national policies like the National Rehabilitation Policy (Department of Health 2000), for example, by working within the social model of disability and following an interdisciplinary teamwork approach, where the patient and family are included in the decision-making process from the time of admission while simultaneously addressing societal barriers through multi-sectoral collaboration. This is a continuous process and while rehabilitation services offered at WCRC have made progress towards realising this objective they still have some way to go in the quest of a full realisation as discussed in Chapter 2.

Staff members are designated to one of three functional service units and not to discipline-specific departments. Each of these functional units services two 26-bed wards. An interdisciplinary teamwork approach should be followed in each of the functional units. Each team consists of the following professionals: medical doctor, physiotherapists, occupational therapists, social workers and nursing staff. Support staff includes administrative personnel, radiographers, pharmacists, wheelchair repair workshop staff, a clinical psychologist, dietician, auxiliary services workers, technical staff and volunteers. The three units share the services of two speech therapists.

There are three wards at WCRC that accommodate patients who have suffered a stroke (together with patients with other diagnoses, like amputations, head injuries and other neurological deficits). A further three wards are dedicated to patients who have suffered spinal cord injuries.

Each member of the interdisciplinary team should assess newly admitted patients within 48 hours after admission. The social worker establishes contact with the patient and family/significant others in order to determine and verify background information discuss future care plans as well as work through the loss/trauma experienced by the patient and the family (WCRC Strategic Planning Task Team 2007) The ward doctor should assess the patient on the day of admission and should spend time with the patient explaining the diagnosis, prognosis and medication. The doctor answers any questions that the patient or family may have. The family is encouraged to be present in order to include them on the team. The rest of the team should reinforce the information on stroke and explain the rehabilitation programme in order for the patient and family to develop insight into the rehabilitation process. The nursing staff should assess the patient on the day of admission and explain the functioning of the ward, the rehabilitation process, what the professional team expects of the patient and family and determine what the patient and family expect of the professional team (WCRC Strategic Planning Task Team 2007).

During the first consultation with the patient the therapists should find out what the patient's goals and expectations are. After the assessment and at the first team meeting these are discussed and compared. These goals set by the patient; the outcome level on admission as well as the proposed rehabilitation outcome level on discharge and the proposed date of discharge are agreed upon by the professional

team and recorded (WCRC Strategic Planning Task Team 2007). Family conferences, which include the team members working with the patient, the family/caregiver and any significant others, may be held once, twice, or more often depending on the needs of the patient and family. The first family conference should take place as soon as the team has assessed the patient. It is arranged and chaired by the case co-coordinator. The aim of the family conference is for the family to meet the team working with the patient, to determine the family's expectations of rehabilitation, to make them understand that they are part of the team and that all are working towards a common goal. It also provides an opportunity for the professional team to answer questions and clarify uncertainties experienced by the patient or the family (WCRC Strategic Planning Task Team 2006).

Every member in the team should have an opportunity to contribute and participate in the goal-setting process. Goals can be altered and changed depending on the progress of the patient. This is done through consultation by the team which includes the patient and family. It creates a positive working relationship between the rehabilitation team, the patient and the family (WCRC Strategic Planning Task Team 2006).

The case co-ordinator should maintain contact with the family and encourages the family to maintain contact and report any difficulties, fears or major progress experienced, for example, during weekend leave. Therapists should then attend to these issues. During regular team meetings/discussions the therapist should update the team on the patient's progress. This information should then be relayed to the family by the case co-ordinator (WCRC Strategic Planning Task Team 2007).

The families should also be involved in family training sessions. They should be trained to physically care for the patient by the therapists and nursing staff before the patient can spend his/her first weekend at home. Weekend leave to the family home is encouraged as soon as the patient and the family are ready. After the weekend the patient and family may consult with the rehabilitation team or any member of the team if they are experiencing any difficulties. This is then assessed and attended to by the team (WCRC Strategic Planning Task Team 2006; WCRC Strategic Planning Task Team 2007). Home visits are arranged only when the team has determined this is necessary, (either from information gained from the patient or the family) to train the family within the home environment and to advise them on any adaptations or

changes in the home that will make the environment more accessible and safe for the patient (WCRC Strategic Planning Task Team 2006; WCRC Strategic Planning Task Team 2007).

### **3.4 STUDY POPULATION**

The study population consisted of all caregivers of patients who suffered a stroke and were admitted to the Western Cape Rehabilitation Centre for inpatient rehabilitation between 1 January 2006 and 31 December 2006. Some information on the patients whom these caregivers cared for was collected and the patients could be seen as a secondary study population. However, caregivers could still consent to participate in the study even if the patient they were caring for refused to participate. However, that situation did not arise in the study as none of the patients refused.

#### **3.4.1 Inclusion criteria**

Inclusion criteria were refined as follows:

- Caregivers of patients who suffered a stroke and were admitted to WCRC in 2006
- Only caregivers who live in the Western Cape Metropole region were included for convenience of data collection. The Western Cape Rehabilitation Centre serves the whole of the Western Cape Province, as well as patients from other Provinces, but the bulk of patients are from the Western Cape Metropole.
- Caregivers who were willing to participate in the research project.

#### **3.4.2 Exclusion criteria**

The following exclusion criteria were chosen:

- Caregivers of patients who could not be located;
- Patients who recovered enough from their stroke not to require a caregiver at the time of discharge;
- Caregivers who lived outside the Western Cape Metropole region;

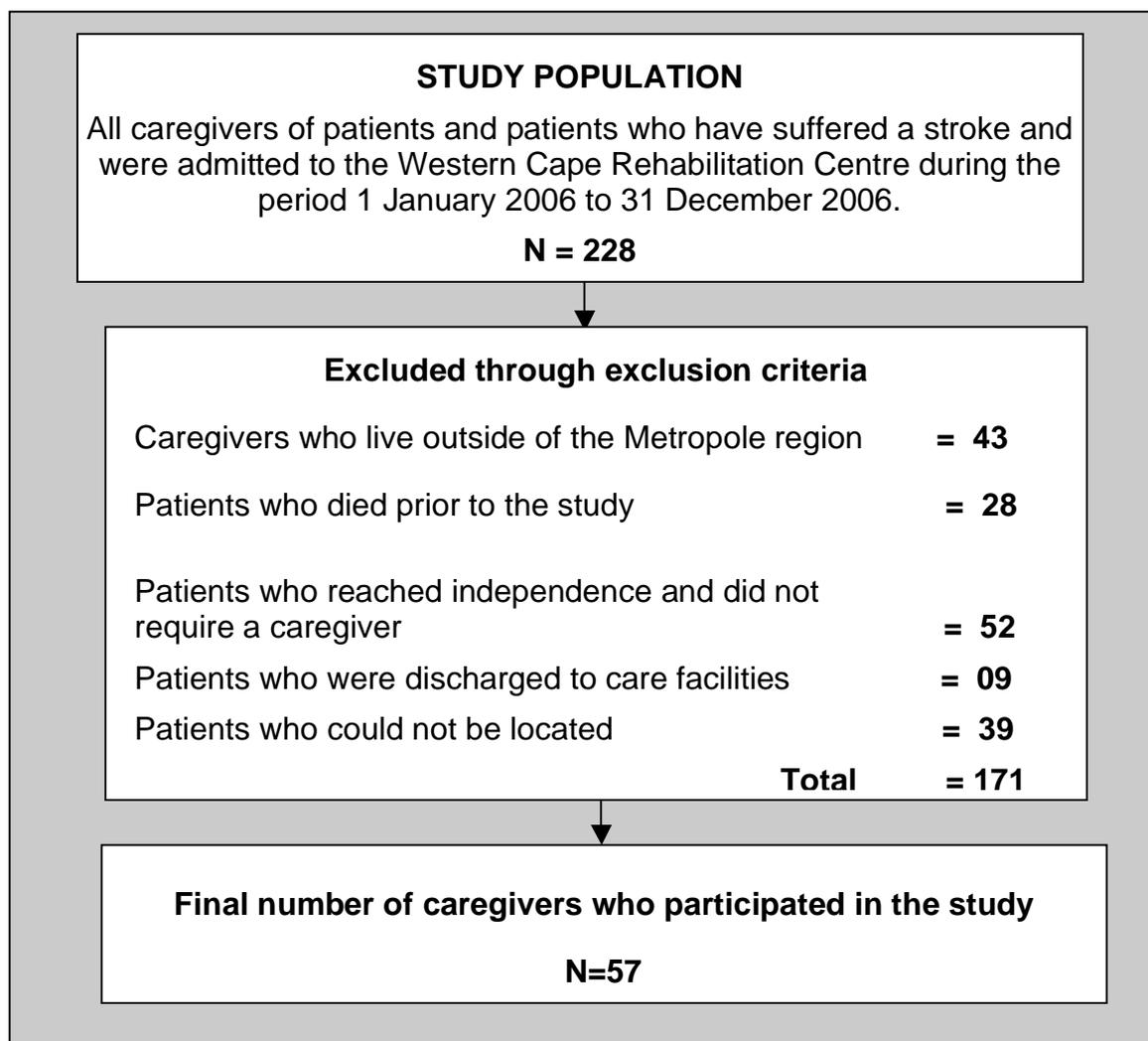
- Caregivers who were not willing to participate in the study;
- Patients who were discharged to a long-term care facility (although some data was collected from this group they did not form part of the main study, that is, to determine caregiver strain; and
- Patients who died.

### **3.4.3 Determining the participants**

The process for determining who would participate in the study was as follows:

- A complete list of patients who suffered a stroke and were admitted for rehabilitation at WCRC during the study period (1 January 2006 to 31 December 2006) was compiled from the wards' admission registers as well as the social workers' admission books. The list contained 228 names.
- The names of patients who had to be excluded from the study according to the exclusion criteria were removed. These factors are presented in detail in figure 3.1. A total of 96 patients were left. The 96 caregivers of these patients were contacted telephonically and provisional consent was obtained from those who could be located.
- During this process caregivers who could not be located telephonically were sent letters informing them on the study and requesting them to contact the researcher (Appendix 3). The process was repeated and letters were resent to those who had not responded to the first letter.
- Several weeks later a third letter was sent to those who had not responded by then. In the end 39 caregivers could not be located.
- Thus from the initial 96 a total of 57 caregivers could be contacted and were willing to participate in the study. These 57 caregivers formed the study population. No further sampling was done. The researcher had initially planned to perform the quantitative part of the research first and then do purposive sampling for the qualitative phase of the study through identifying caregivers with a need to share indepth information about the caregiving duties, those who had unique insights to share and those identified as at risk by the Caregiver Strain Index (CSI). However, it became obvious during the

pilot studies that all caregivers had a great need to share their experiences and the researcher decided that it would be unethical to deprive them of this opportunity. Thus an indepth interview was conducted with every participant at the same time that quantitative data were collected instead of doing sampling first and performing indepth interviews with selected individuals at a later stage.



**Figure 3.1 Determining the study participants**

### **3.5 INSTRUMENTATION**

Separate measuring instruments were used to collect patient and caregiver data and can be found in Appendices 5, 6, 7, 8, 9 and 10.

### **3.5.1 Measuring instruments utilised to collect patient data**

The Data Coding Form A (Appendix 5) and the Barthel Index (Appendix 6) were used to collect patient information.

#### **3.5.1.1 Data Coding Form A – Patient information (Appendix 5)**

The Data Coding Form A was an instrument designed by the researcher. It contains questions about the demographic data and medical information of the patient. Demographic details include age, gender, ethnicity, level of education, employment, finances and number of children. These details served to indicate the social roles of the patient within the family and how the stroke impacted on the patient and the family in respect of finances, living arrangements, family support and responsibilities towards minor/dependent children.

The medical history and the level of recovery of the patient at the time of discharge were also recorded on Data Coding Form A. These details indicated the patient's risk factors and residual impairments.

The Rehabilitation Outcome Level at the time of discharge was recorded as was the current outcome level, to determine whether the patient's outcome level had improved or deteriorated after discharge from WCRC.

#### **3.5.1.2 The Barthel Index (Appendix 6)**

There is a variety of instruments that measure physical dependence either on its own, in all physical areas or only some physical components, or in conjunction with cognitive and other aspects. Examples include the Functional Independence Measure, the Stroke Interview Schedule, the timed walking test, the Rivermead Activities of Daily Living Scales, the Functional Ambulation Category, the Canadian Neurological Scale, the Chedoke McMaster, the Frenchay Activity Index and the Motor Assessment Scale (Wade 1994; Dittmar and Gresham 1997; Duncan, Wallace, Lai, Johnson, Emberstson and Laster 1999). Since the researcher was looking for a simple tool that would be easy to administer during an interview and would provide a single numerical value that can be used to compare physical dependence with strain experienced and satisfaction with life she chose the Barthel Index (BI). The Barthel Index is a ten category, weighted index that measures

physical dependency (Uyttenboogaart, Stewart, Vroomen, De Keyser and Luijckx 2005).

The Bartel Index scored different steps to recovery, for example, bathing and grooming are scored 0 or 5; feeding, dressing, bladder control, bowel control, getting onto and off the toilet and ascending and descending stairs are scored 0, 5 or 10. Items regarding moving from wheelchair to bed and walking on level surfaces are scored 0, 5, 10 or 15 (Uyttenboogaart et al 2005). The main aim of the Bartel Index is to establish the degree of independence from any help, physical or verbal. Supervision does not render the patient independent but the use of aids to be independent is allowed (Uyttenboogaart et al 2005).

The total Bartel Index is a cumulative score of ten items, with a maximum score of 100 indicating complete independence, and a minimum score of 0 indicating total dependence on care. For various reasons a Barthel Index score of 100 does not necessarily mean that the patient is able to live alone, but it does indicate that he or she does not need attendant care. The researcher implemented the basic version of the Barthel Index and not the modified version because she considered it adequate for the purpose of this study. Similarly the researcher was of the opinion that the limitations of the Bartel Index according to Horgan and Finn (1997) i.e. a lack of sensitivity to reflect small changes as well as change in high functioning patients, that it does not attempt to measure improvement in quality of movement and that it does not distinguish between gains in function as a result of motor recovery, and those that result from compensation would not impact negatively on the results of this study. The focus of this study was on the caregivers. Therefore, the Barthel Index was only applied to determine an estimate of the patient's level of physical dependence, in order to determine if that influenced the situation of the caregiver. The Barthel Index can be completed by asking the patient, friends/relatives and nurses for information or through observation. Physical testing is therefore not needed (Wade 1994). The Barthel Index is recommended as the disability measurement of choice for its established reliability and validity (Wade 1994; Sulter, Steen and De Keyser 1999; Uyttenboogaart et al 2005).

### **3.5.2 Measuring instruments utilised to collect caregiver data**

Caregiver data were collected using Data Coding Form B (Appendix 7), the Caregiver Strain Index (CSI) (Appendix 8), the Satisfaction With Life Scale (Appendix 9) and an Interview Schedule (Appendix 10).

#### **3.5.2.1 Data Coding Form B – Caregiver information (Appendix 7)**

This form was used to collect and record the demographic data as well as information on the health and physical status of the primary caregiver. The instrument was designed by the researcher. Questions include areas like the age, gender, ethnicity, marital status, finances, employment, support systems, the relationship of the caregiver to the patient, the caregiver's financial situation, employment, responsibility towards dependent children, medical situation and support in the community.

#### **3.5.2.2 Caregiver Strain Index (CSI) (Appendix 8)**

The Caregiver Strain Index (CSI) is a simple, concise, standardised, validated and reliable measure for early detection of families with potential caregiving concerns in clinical practice and research. It is a brief instrument that is easy to administer and can be used for all ages of caregivers and over a variety of diagnosis/impairments. It consists of 13 questions with Yes/No answers that measure strain related to caregiving. All affirmative responses are added to arrive at a total numerical score. The higher the score, the higher the burden. Positive responses to seven or more items on the index indicate a greater level of strain and possible coping problems (Robinson 1983; Wade 1994; Scherbring 2002; Sullivan 2002; Van Exel, Scholte, Reimer, Brouwer, van den Berg, Koopmanschap and van den Bos 2004; Post, Festen, van de Port and Visser-Meily 2007). It shows high internal consistent reliability ( $\alpha = 0.86$ ). Its construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the caregiving situation (Sullivan 2002). There is at least one item on each of the following major life domains: Employment, Financial, Physical, Social and Time. The CSI is limited by its lack of corresponding subjective rating of caregiving impact. However, this instrument has been found to effectively identify families who may benefit from more indepth assessment and follow-up (Scherbring 2002).

Other measurement tools on caregiver strain include the Caregiver Reaction Assessment and the Sense of Competence Questionnaire. However, research found the CSI more feasible and valid than these two instruments and thus the CSI was chosen for use in the current study (Van Exel et al 2004).

### **3.5.2.3 Satisfaction With Life Scale (SWLS) (Appendix 9)**

The Satisfaction with Life Scale (SWLS) was used to measure caregiver satisfaction with life. The SWLS was developed to assess satisfaction with the respondent's life as a whole. The SWLS measures an individual's satisfaction with life in four domains: Living Situation (items 1–4); Social Relationships (items 5–10); Employment/Work (items 12–13); and Self and Present Life (items 11 and items 14–18). The respondent's mean score for each of the four domains is calculated. A domain score for Work should not be calculated if responses to any of the items are missing. For each of the other three domains, no more than one item should be missing.

Finally, it is neither psychometrically nor theoretically appropriate to simply use the sum of all 18 items to gain a measure of 'overall' satisfaction (Diener and Diener 1995; Test, Greenberg, Long, Brekke and Burke 2005).

The scale does not assess satisfaction with life domains such as health or finances but allows subjects to integrate and weigh these domains in whatever way they choose. Normative data are presented for the scale, which show good convergent validity with other scales and with other types of assessments of subjective well-being (Diener and Diener 1995).

The SWLS can be administered during a face-to-face interview of fully informed and consenting participants or participants can complete the questionnaire on their own.

The 18 items of the SWL are each followed by a five-point scale, a Likert-type response option. Scores vary from 0 to 4 for each item, with 0 representing the least degree of satisfaction (that is, Not at all) and 4 representing the greatest satisfaction (that is, Very much).

### **3.5.2.4 Interview Schedule (Appendix 10)**

The interview schedule was developed to use as a guide during semi-structured interviews in order to gain qualitative information on the experience of the caregiver

at the time of the stroke, during the rehabilitation process, at the time of discharge as well as to obtain information about how the stroke and caregiving duties have impacted on their personal, social, employment, financial, physical, emotional and recreational well-being. During the interview the researcher created an opportunity for the caregiver to share the experiences on caring in their own words.

### **3.5.3 Instrument design and translation**

All three of the above self-designed instruments were created through consulting the literature reviewed (Terre Blanche and Durrheim 1999; De Vos 2002), through input from experts in the field of stroke rehabilitation and with the help of a statistician.

All six data collection instruments were translated into Afrikaans and Xhosa in order to perform data collection in the participants' home languages. The initial documents were developed or sourced from the literature in English. They were then translated into Afrikaans and Xhosa respectively and these translations were translated back into English by another person to ensure correctness of translations. Where participants preferred English or Afrikaans the researcher did all the data collection herself as she is fluent in both these languages.

The researcher appointed an assistant (one of the persons involved in the translation of the forms into Xhosa) to assist with data collection from Xhosa-speaking caregivers. The translator is fluent in all three languages dominant in the Western Cape Metropole that is, English, Afrikaans and Xhosa.

## **3.6 PILOT STUDIES**

### **3.6.1 Initial pilot study**

In August 2002 the researcher conducted her first pilot study with three caregivers. The aim of the pilot study was to: Improve the methodology of the study.

- Test the workability and appropriateness of what was then data coding forms A, B and C as well as the interview schedule.
- Get feedback from the caregivers on whether the questions were clear and understandable.

- Evaluate whether the sequence of the questions was correct and whether it answered the research aim and objectives.
- Determine whether any other information and/or measuring instruments should be included in the study.

The researcher randomly selected caregivers of patients who were admitted to the then Conradie Hospital between 1 June 2001 and 31 May 2002. The caregivers were informed about the study and consented to participate in the pilot study. The researcher interviewed them in their home environment.

Findings show a lack of information about the patient's physical dependence and the strain and stress that the caregiver is experiencing in caring for the patient. The actual burden on the caregiver was not determined.

For this reason additional measuring instruments were introduced to ensure a more comprehensive picture, namely:

- The Caregiver Strain Index (CSI) in order to quantify the strain that the caregiver experience;
- The Barthel Index to quantify the patient's level of physical dependence;
- The Satisfaction With Living Status (SWLS) to quantify the caregiver's satisfaction with living; and
- The Data Coding Forms A and B that were combined into a new Data Coding Form A because both gathered information on the patient.

After the pilot study had been completed, Conradie Hospital (where the researcher was employed) and Karl Bremer Centre for Care and Rehabilitation of the Disabled (CCRD) relocated to Lenteguur in Mitchell's Plain and became as mentioned the Western Cape Rehabilitation Centre. In order to accommodate these developments the researcher postponed the study to 2007 and drew upon the study population of 2006. By then WCRC had established its working philosophy and staff from the two institutions had found common ground in their approach.

### **3.6.2 Final pilot study**

The aim of the second pilot study was to:

- Further improve the methodology of the study.
- Test the workability and the appropriateness of the revised data coding forms regarding the patient.
- Administer the standardised forms, that is, the Bartel Index, the Caregiver Strain Index and the Satisfaction with Living Status to determine suitability for this study and its participants.

The researcher randomly selected seven caregivers from those patients who were admitted to WCRC during 2006 who suffered a stroke and received inpatient rehabilitation. The caregivers were approached and agreed to participate in the second pilot study.

Data Coding Form A, in respect of the patient, was completed with the assistance of the caregiver and those patients who were able to participate. The administration was easier as this form had been changed to include the demographic and medical details of the patient. No further changes were necessary.

Data Coding Form B and the interview schedule were piloted during an interview with the caregivers. The researcher found during the pilot study that after Data Coding Form B was completed the caregivers had a great need to communicate and share their caregiving burden. Therefore, it was decided to allow caregivers the opportunity to narrate their story in their own words through implementing the interview schedule directly upon completion of Data Coding Form B during the main study. The researcher took notes while implementing Data Coding Form B and switched the tape recorder on when she commenced with the indepth interview. The caregivers were in agreement with this. The CSI and SWLS were also piloted, but no changes were made to these two instruments.

The instruments were compiled in two packages to facilitate easier administration. Data Coding Form A and the Bartel Index which gathered data from the patients and Data Coding Form B, the Caregiver Strain Index, the Satisfaction with Living Scale and the Interview Schedule which were used to gather data from the caregiver.

### 3.7 DATA COLLECTION

Data collection occurred according to the following processes:

- The researcher obtained written permission from the Director of WCRC to conduct the study and to be allowed to access the relevant patient folders (Appendices 1 and 2).
- Initial patient information was collected from the medical and social work folders and used to partially complete Data Coding Form A.
- Initial caregiver information was collected from the social work folders and used to partially complete Data Coding Form B.
- Caregivers were contacted reminded of the research and asked whether they were still willing to participate. If they agreed, the date and venue were determined with the caregiver for the researcher to administer the measuring instruments. Some interviews were performed with the patient present in the patient's home, while other caregivers felt freer to talk about their experiences without the patient present. They expressed feelings of guilt and therefore preferred to be alone. Interviews with these caregivers were conducted in the privacy of the researcher's office.
- This session was initiated by asking the caregiver to sign the Informed Consent Form (Appendix 4).
- Following that, all data collected from the folders were verified.
- Then Data Coding Forms A and the BI were completed.
- Following this Data Coding Form B, the CSI and SWLS were completed.
- Then caregivers were asked to express their experiences in a narrative story and thus the indepth interview was automatically conducted. The interview was recorded on tape with the caregivers' permission.
- Initially the research assistant (who was also one of the translators of the instruments) accompanied the researcher when conducting interviews so that she could observe the researcher. Thereafter, the researcher accompanied the research assistant when she initially interviewed the Xhosa-speaking caregivers. After the research assistant had gained some experience and was

comfortable she conducted the rest of the interviews with Xhosa-speaking caregivers on her own.

- The data collected on the data coding forms and the standardised forms, namely, the Bartel Index, the Caregiver Strain Index and the Satisfaction With Life Scale were recorded immediately after the interview onto a data spreadsheet that was compiled in consultation with a statistician.

### **3.8 DATA ANALYSIS**

The study generated both the quantitative and qualitative data. Quantitative data were analysed statistically and qualitative data were analysed thematically.

#### **3.8.1 Quantitative data**

First of all, numerical scores were obtained and then the graphs were drawn up. Numerical scores that were obtained from the CSI, the SWLS and the BI as well as data from the two data coding forms represent the quantitative data for this study. According to the literature reviewed, data is needed from 30 or more participants in order to do meaningful statistical analysis (Domholt 2005). Therefore, data from the 57 participants in this study could be analysed for statistical significant relationships between variables. Correlations between variables were made with various statistical tests like the ANOVA, the Mann Whitney and the Chi Square test to determine if there were any statistical significant relationships between them. A p value of less than 0.05 was deemed statistically significant. Furthermore means, medians and distribution of data were calculated and data presented through graphs and tables as applicable.

#### **3.8.2 Qualitative data**

Thematic analysis of qualitative data was done. The qualitative data were collapsed into emerging themes so that the main aspects could be identified. The researcher went through the following steps in the process:

- She initially familiarised herself with the data by reading and rereading her notes as well as listening to the tape recordings to develop a thorough

understanding of the data. Data from tapes were transcribed and verified by an assistant to improve trustworthiness.

- Thereafter, the researcher identified themes from the data and organised data according to emerging themes.
- Where themes corresponded with quantitative aspects which were studied the results were integrated and presented as well as discussed together to indicate where findings converge, where they were complementary to each other or where they diverged from each other. Narrative information was used to enhance the discussion.
- Where new themes were identified they were described and discussed as well as highlighted through narrative information.

### **3.9 ETHICAL CONSIDERATIONS**

Due consideration was taken to ensure that the study complied with academic best practice in terms of ethics.

- The researcher completed a proposal of her study and submitted this to the Committee for Human Research at the University of Stellenbosch for their scrutiny and acceptance. The Ethics Committee accepted the proposal and the researcher was given permission to carry out her research study (Research Number: 2003/079/N).
- Written permission was obtained from the Head of the Western Cape Rehabilitation Centre to conduct this study and to peruse patient folders.
- Written informed consent was obtained from the caregivers who participated in the study (Appendix 4). They were also informed that they could withdraw from the study at any stage and would not be coerced to remain in the study.
- Consent was obtained from the caregivers to use a tape recorder during the interview. Confidentiality was respected and adhered to and the identities of the caregivers were not disclosed in any way.

- The researcher acted professionally and with respect, consideration and courtesy towards participating caregivers, patients and other family members.
- The interpreter was fully trained regarding the study as well as the ethical considerations.
- The completed forms were stored in a sealed box to which only the researcher had access. Data on computer were password protected.
- The researcher formally arranged for the reassessment for inpatient or outpatient treatment at WCRC, for those patients who might benefit from further therapy and whose caregivers were experiencing strain. Furthermore, the researcher referred caregivers who experienced strain appropriately to the local home-based care services and daycare centres for assistance with patient care and relief as well as where relevant to the local SASSA offices for assistance with applications for disability grants since the means test of spouse's income had been reviewed.
- The outcome of the study will be reported to the primary caregivers and the management team at the Western Cape Rehabilitation Centre.

### **3.10 SUMMARY OF CHAPTER 3**

This study aimed to determine the impact of stroke on the caregiver by implementing two self-designed data coding forms and three standardised forms (the BI, CSI and SWLS) in respect of the patient and the caregiver as well as an indepth interview with the caregiver. The caregivers were given the opportunity to express their caregiving experiences in their own words and in the language they were most comfortable with. Quantitative information was statistically analysed and qualitative information was thematically analysed. Chapter 4 presents the data in an integrated way through graphs, tables and in narrative form.

## **CHAPTER 4**

### **RESULTS AND DISCUSSION**

#### **4.1 INTRODUCTION**

The results of the study are presented and discussed in Chapter 4 in three sections according to the objectives of the study.

The qualitative data presented in this study are themes that were identified from the in-depth interviews which the researchers conducted with the caregivers.

In Section 1 demographic and other data pertinent to the 57 patients who suffered a stroke will be presented and discussed. Included in this section is a discussion on the demographic data of the patient, demographic details pertaining both to the patient and the caregiver, the health status and residual impairments of the patient, a discussion on rehabilitation outcome levels of the patient at the time of discharge and at the time of the visit and a discussion on why some of the patients were discharged to an old age home and not into the care of a caregiver.

Section 2 deals with the demographic details of the caregivers, their health status and responsibilities, their knowledge on stroke, their experiences regarding the stroke, the role the caregivers played in the rehabilitation team at WCRC and the support the caregivers received at WCRC, the needs of caregivers at the time of the patients' discharge from WCRC and the current needs of caregivers.

In Section 3 the results of the Caregiver Strain Index (CSI) and the impact of variables on caregiver strain, as well as results from the Satisfaction with Life Scale (SWLS) are presented and discussed.

## SECTION 1

### RESULTS PERTAINING TO PATIENT HEALTH AND DEMOGRAPHIC DETAILS

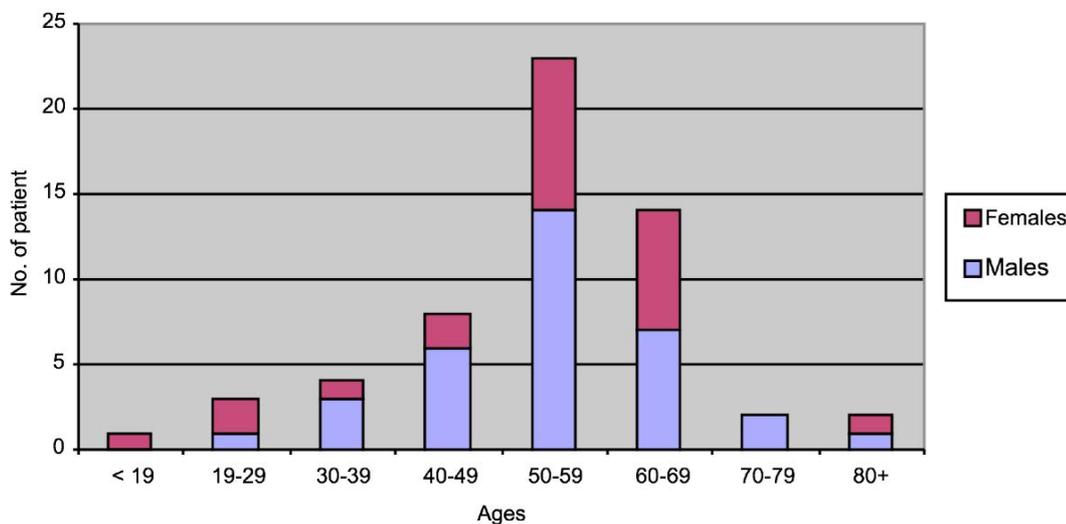
#### 4.2 INTRODUCTION TO SECTION 1

This section contains the results and discussions on patient demographic data, joint demographic data of the patient and the caregiver, the current health status and residual impairments of the patient as well as the rehabilitation outcome levels of the patient and reasons why some patients were discharged to old age homes.

#### 4.3 DEMOGRAPHIC PROFILE OF PATIENTS

##### 4.3.1 Age and gender

The ages of the patients ranged from 18 to 83 years. The majority of patients (23; 40%) fell in the 50–59 age bracket. The mean age of patients in this study was 53. Figure 4.1 shows that female patients who suffered a stroke were generally younger than the males in this study.



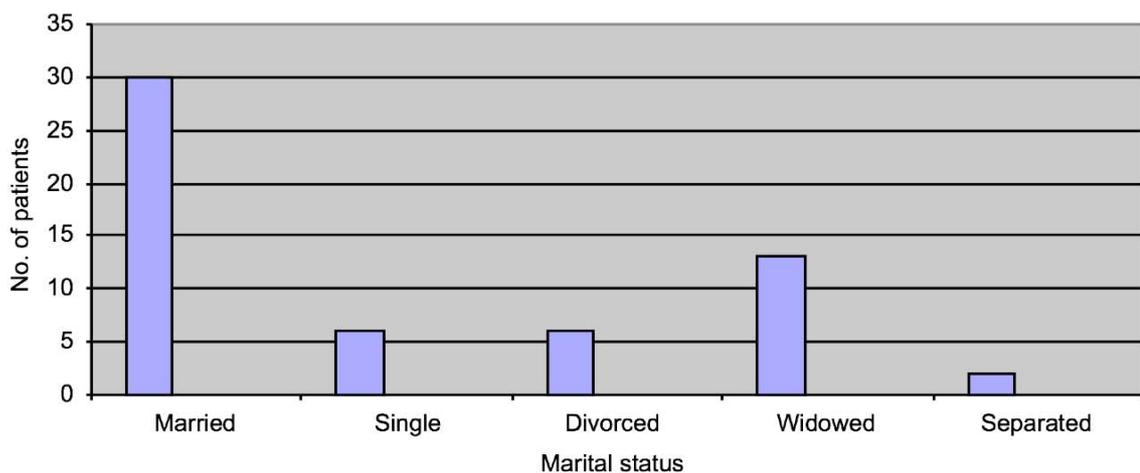
**Figure 4.1: Age and gender distribution of patients**

However, the mean ages did not show much difference as the mean for females was 52 and the mean for males 54. These findings are similar to those of other South African studies. Rhoda and Hendry (2003) found the mean age of a group

of stroke survivors in Bishop Lavis, Western Cape, to be 59 years, with ages ranging from 33 to 83 years. While in a recent study done in Gauteng Province, South Africa, Mamabolo, Mudzi, Stewart, Mbambo and Olorunju (2008) found that the ages of stroke patients ranged between 18 and 75 with the highest incidence of stroke in the 45–64 age bracket.

According to figure 4.1 there were 33 (58%) male and 24 (42%) female patients who suffered a stroke in this study; nine more males than females. The literature differs on this issue. Korpelainen et al (1998) found there were significantly more males (117; 61%) who suffered a stroke than females (75; 39%); while in the Bishop Lavis study of Rhoda and Hendry (2003) found more females (54%) suffered a stroke than males (46%). The study by Mamabolo et al (2008) had a gender distribution of 60% for females compared to 40% for males. The differences in the results of these studies seem to indicate that gender does not influence stroke incidence or survival. The male to female ratio in the community from which study participants come should be considered as it could be an influencing factor. No statistical difference could be found between age and gender ( $p = 0.17$ ).

#### 4.3.2 Marital status

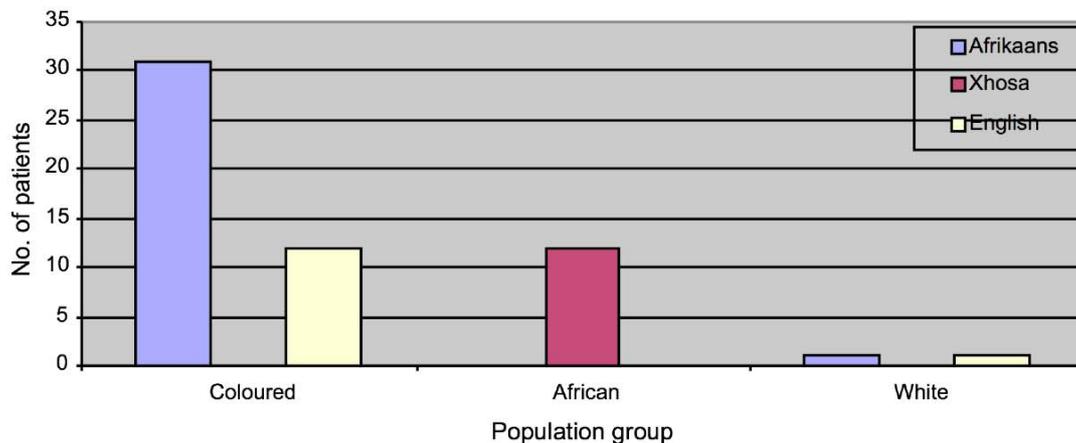


**Figure 4.2: Marital status of the patients**

Twenty-nine patients (51%) included in this study were married. The marital status of the rest were relatively evenly distributed amongst single, divorced and

separated people, with a slightly higher number of patients being widowed as is shown in figure 4.2. Again these findings are similar to those of Rhoda and Hendry (2003) who found that 56% of study participants were married. The findings from Mamabolo et al (2008) differ slightly with only 38% of participants being married and a higher percentage (44%) being single.

### 4.3.3 Population group and language



**Figure 4.3: Population group and language preference of patients**

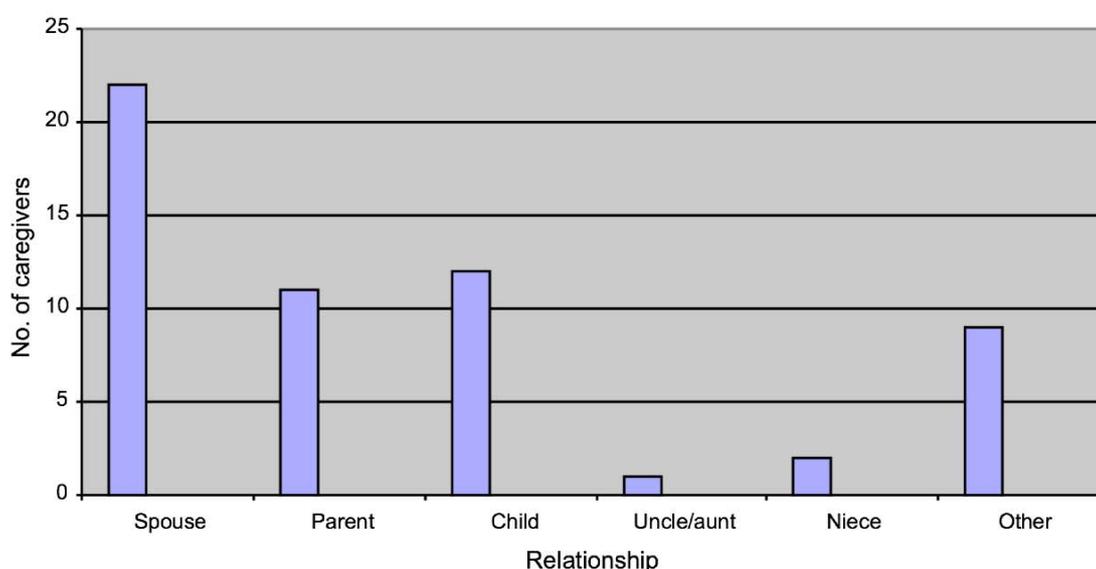
The majority of patients (43; 75%) who participated in the study were Coloureds, while the African and White groupings were represented to a lesser extent (see figure 4.3).

The Western Cape Province is historically known to be the Coloured preferential area and this seems to be reflected in this study population. According to Gaffney (2007) Coloureds at 53.9% form the majority of the Western Province’s population. A further reason for the high number of Coloureds in the population might be that the WCRC is situated in Mitchell’s Plain, a historically Coloured area. Afrikaans was the mother tongue of 32 patient participants (56%), English of 13 (23%) and Xhosa of 12 (21%).

## 4.4 DEMOGRAPHIC DETAILS RELATED TO PATIENT AND CAREGIVER

### 4.4.1 Family relationship between patient and caregiver

Figure 4.4 show that 22 (38%) caregivers were spouses of the patients whom they were taking care of. According to Cheung and Hocking (2004) spousal caregivers face many challenges especially when the partner's ability to perform the activities of daily living deteriorates. They found in their study that spousal caregivers experienced confinement to the home as well as physical and financial strain.



**Figure 4.4: The relationship between the caregiver and the patient**

While spousal caregivers were committed to their caregiving tasks they experienced a tremendous sense of worry. Through their caregiving roles, they are challenged to face their own vulnerability and experience conditions that limit their caregiving ability. They worry about their future, their own health and institutional care as well as the lack of community support (Cheung and Hocking 2004).

These opinions were confirmed in the current study. While the spouses of the patients were shocked at the time of the stroke most considered it their duty to take responsibility for the patient as the following quotes show:

*My husband was a good provider and took good care of us for all the years. We lived in comfort and never lacked anything. It is my duty to take*

*care of him and I am doing it with much love and from deep down in my heart.*

*My wife never worked outside the house but she was the best caretaker. She took good care of me and took most of the responsibility of raising our children. She was the best wife and mother one could have asked for! Now I will look after my wife as best I can.*

However, the concerns mentioned by Cheung and Hocking (2004) are also found in the qualitative data:

*My husband was hard working and he was a good provider. He earned a good salary, now he is getting a grant and we are struggling. We never lacked anything and I think this frustrates him. He then becomes abusive towards me. Financially we are not coping!*

*I worry about my husband's health and how long I'll be able to manage his care. I am exhausted but I don't have the heart to even think of placing him in a home.*

*If only WCRC would admit my husband for a short period for some exercises while I can get a rest. I need to have a good break from looking after my husband so I get some of my energy back.*

While most spouses were willing to take responsibility for the patient whether they felt duty bound or not, one caregiver was very distressed and shared the following:

*When she (my sister) had the stroke her husband just disappeared. He just simply ran away and we do not know his whereabouts. How much did he as a husband really care about her?*

Non-spousal caregivers expressed more reservations about caregiving duties as expressed by a sister-in-law:

*My brother-in-law became my responsibility after his stroke. It is a major adjustment in my life but I'm only doing [it] for my husband's sake.*

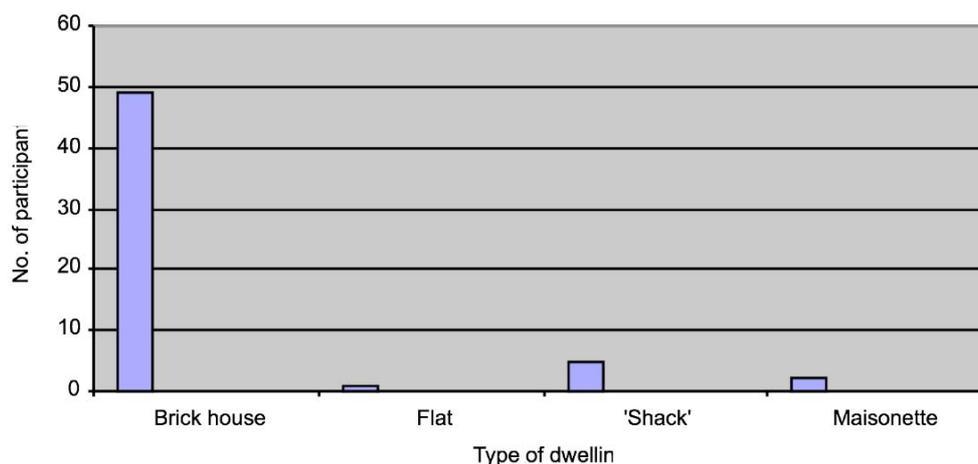
A man expressed his feelings when the responsibility of his male cousin who suffered a stroke became his responsibility:

*Suddenly my cousin became my responsibility and this was the biggest shock to me. I was thrown into the deep end.*

Of further concern are the 11 (19%) parents who are caregivers. With time and age they might lose the strength necessary for caretaking duties; and without anyone realising it, both the standard of care, and thus the health of the patient, as well as their own health might be jeopardised.

The nine caregivers categorised as 'other' were five sisters of the patients and respectively a sister-in-law, a girlfriend, a son's girlfriend and a neighbour.

#### 4.4.2 Type of accommodation and basic amenities



**Figure 4.5: Type of accommodation**

Figure 4.5 indicates the type of dwellings that the caregivers and patients were occupying. The majority (49; 86%) lived in brick houses. These patients had running water inside the house and electricity except for one person who had no electricity at the time of the visit because of a lack of finances. The family living in a flat occupied a downstairs flat which made accessibility easy.

Of concern are the five (9%) families who lived in a shack without any running water in close proximity to the shack. Two families also had no electricity in the

shack. Three of these patients used wheelchairs and although two of them walked indoors with sticks they needed a wheelchair for long distances. A third patient was dependent on a wheelchair and he could not move around, because the shack was not wheelchair accessible. He was thus confined to one area in the shack. There is a lack of space for the wheelchairs and although it does seem inconvenient the families managed. These families use communal toilets that are some distance from the shack and the toilets are not wheelchair accessible. Two families had no toilets and had to relieve themselves in the bushes. The problem was solved for one family to whom the occupational therapist issued a commode.

The other family built a home-made commode using a bucket and an old chair. Families have been very creative in building things to make life easier for them and the patient.

Both patients living in maisonettes only use the downstairs area. One was washed in her room and used a commode. The other had a shower and toilet downstairs, but the toilet was not accessible for her wheelchair. Her caregiver was advised by a friend to buy a commode prior to the patient's admission to WCRC. Families are anxious at the time of the stroke and sometimes seem to take advice that may or may not be appropriate for the patient.

Before the stroke 41 caregivers were living in the same household as the patient and they continued to live there afterwards, while 16 caregivers lived elsewhere and had to either move in with the patient or accept the patient into their homes whichever caused the least disruption to their families.

Caregivers express their experiences of discomfort, stress, inconvenience and sacrifice to accommodate the patient:

A daughter, who experienced her mother's stroke with great shock, was physically and emotionally exhausted with the care responsibility. She had to deal with the move to her mother's home and said:

*I lived between two homes when my mum had a stroke. My husband wasn't happy about the big trek (move) every day and we decided to move into my mother's home. It was a big decision especially because of the*

*children's schooling but they are living with my sister during the week until we made other arrangements.*

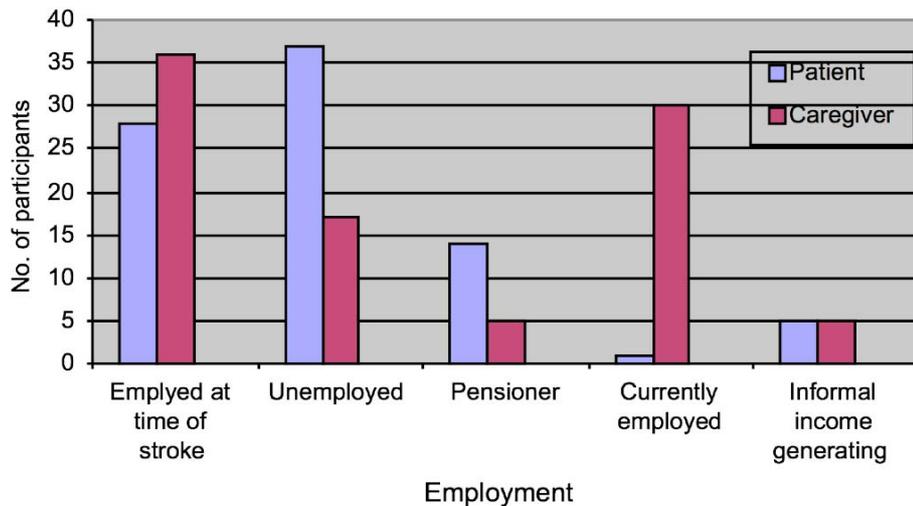
Another said:

*My father came to live with us. My daughter had to give up her bedroom. She wasn't too happy at first but now she's settled into the room with her younger sister. I think my father feels that he is disrupting the household but I assure him it is not so.*

#### **4.4.3 Employment status of the caregiver and patient**

Figure 4.6 shows that 36 (63%) caregivers were employed at the time of the patients' stroke while 27 (47%) patients were employed. It is worrying that 11 (30%) caregivers were compelled to resign from employment to take up the care responsibility of the patients.

Only one of the 44 patients who fell within the economically active group (that is, females younger than 60 and males younger than 65) are employed again after the stroke. Rhoda and Hendry (2003) found that six patients (N = 168; 3.5%) returned to work after the stroke. In the current study five patients created some way of generating an income for themselves, either by assisting the caregiver with selling goods at the 'house shop' or by making crafts and selling them to supplement their disability grant and/or the family income. Thus in total six (10.5%) of the patients in the current study performed some activity to decrease the financial burden on the family/caregiver.



**Figure 4.6: Employment status of the caregiver and patient prior to the stroke**

The importance of employment and the negative impact of the loss of employment are demonstrated by the fact that the caregiver's employment status at the time of the interview is the only demographic detail of both patients and caregivers that showed a statistically significant impact on caregiver strain ( $p < 0.04$ ). In addition to having an income and financial independence employment creates a sense of worth and dignity. It can also engender a sense of importance as being a provider and being needed especially if the person is the breadwinner.

Some caregivers (at least five of them mentioned this) started 'house shops' selling chips, sweets and other foodstuff to supplement the family income. A caregiver had to find employment to support the family. He leaves his wife alone at home; while he expressed that this forces her to become independent since she would otherwise just lie in bed all day and want everything to be done for her, he also expressed feelings of extreme guilt and worry about her being at home alone. Another caregiver said that she had to continue working to support the family. Her husband was the breadwinner and now he has no income. He does not qualify for a state disability grant because of her income. She feels uneasy at work and guilty because she worries all the time and cannot deliver her best at work. Her spouse is also aware that she is not delivering her best at work and worried that her employer might confront her and that she might lose her job.

#### 4.4.4 Source of income and financial status

WCRC is a state health care facility and serves mostly persons from the lower socio-economic groups. However, it also serves a minority of private patients with medical insurance, road accident claims or workman's compensation claims.

Accordingly, at the time of the research 45 (79%) patients were in receipt of state financial assistance, that is, either in the form of a state disability grant (DG) or an old age pension, while two (3,5%) patients were in the process of re-applying for their state disability grants. Of the rest, five (9%) patients were in receipt of work pensions which are considerably higher than the state financial assistance but lower than what their income was before the stroke; a further five (9%) patients had no income of their own as they had no work benefits since they were self-employed or unemployed prior to the stroke and did not qualify for state financial assistance because the spouse's income was higher than the means test applied by the South African Social Security Agency (SASSA). At the time that these patients applied for a grant they were not eligible if their spouses earned more than R2 700 per month (Government Gazette 2004). SASSA had recently reviewed its policy in terms of the means test and since 1 October 2008 the income threshold has been increased and a spouse may not earn more than R4 800 per month. Therefore, many more patients whose spouses are employed can now apply for state financial assistance. This could ease the financial burden for many families. The SASSA offices arranged community meetings and handed out information pamphlets to inform people on the new developments.

The loss of income after the stroke severely affected most families, especially if the patient was the only provider or the caregiver had to resign from employment to take on caregiving duties. Families sometimes found themselves facing insurmountable debt. One caregiver had to take a bank loan to lessen the financial impact felt at the time of her husband's stroke and is now experiencing pressure as she is unable to make regular payments towards the loan. This was a pressing issue during the interview and she expressed her absolute worry as follows:

*I am in such a fix financially that I feel sick with worry and have sleepless nights. I made a loan and cannot afford the repayments. I am thinking of*

*approaching my husband's workplace to find out whether they can pay out his pension now. He is only 51 years old and has to wait until he is 63 years old. If I can get that right all my problems are solved.*

Further statements by caregivers that reflect their financial predicament included:

*My husband's family provides us with foodstuff when they can; otherwise we would have had to go hungry at times. My husband has no income and does not qualify for a grant because of my salary. I feel as if I'm working and I cannot see what I'm working for. It makes me so despondent.*

*My husband was a good provider and took good care of us. He becomes frustrated because he can no longer support us. I think he feels inadequate because he is now dependent on others and he becomes so moody that we have to stay out of his way. It really hurts me and affects the children badly.*

*We are dependent on my sister's grant. Her husband is also not working. Sometimes we have no money for paraffin and sometimes we have no food at all.*

*My daughter told me, 'Jy vriet my geld op'. ('You eat up my money'). I could not believe it! I worked and earned R850 per week and I supported the household. I had to give up my work to look after her and she gets a disability grant of R940 per month. What does she think she lives from? I was really hurt because I sacrificed my work, my independence and all for her. How can I misuse her money?*

These quotes paint a picture of despair and destitution. Although the disability grant plays a very important role in at least alleviating the situation somewhat, there are aspects around the issuing and management of DGs that cause unnecessary added strain in an already stressful situation that need to be pointed out.

While the social workers at WCRC have an agreement with the local SASSA office that they will complete the patient's disability grant applications close to the

patient's date of discharge, everybody is not lucky enough to have this type of invaluable assistance as this quote shows:

*We waited almost two years before he (brother-in-law) got a disability grant. First, we had to wait for the sick benefits to be paid by the Department of Labour and thereafter I had to take off work so many times to get to the SASSA offices. It was a nightmare and I wanted to give up but I can't afford to support him.*

This caregiver had a great struggle because she first had to apply for the patient's sick benefits at the Department of Labour. Once the caregiver managed to finalise the sick benefit payments with the Department of Labour she had to wait until these payments were completed before the disability grant could be applied for. This long process made the caregiver despondent and months went by before she gained enough courage to approach the task and call at the SASSA offices.

At WCRC the social workers prepare all the documentation necessary for the completion of the disability grant application and the SASSA officials call at the centre to process the application. This eliminates the inconvenience experienced of calling at the SASSA offices as illustrated by another caregiver.

*It is difficult because we had no income. I had to go up and down in the taxi with my brother and his wheelchair to the SASSA offices to have his grant completed. No one understands how awkward it is and how much I worry about our finances. It gives me sleepless nights.*

Caregivers often have to return to the SASSA offices with the patient for the completion of a disability grant application. This causes great inconvenience and costs especially if they need to use public transport or have to pay for private transport. While SASSA officials can do home visits to patients who are bed bound and unable to call at their offices, families become impatient when officials cannot call at their homes timeously. Furthermore, the requirements are unrealistic at times, especially when documents like proof from the Supreme Court must be attained to state that the deceased spouse of the applicant had not left a will. Families then have to travel to these offices to obtain the documents at great cost in terms of time and finances.

Even when the application was done through WCRC the family would still have to wait from six weeks to three months for the application to be processed and to receive the first payment. According to the Government Gazette (2004) a person is not eligible for state financial assistance while being cared for in a state institution. The state operates from the premise that it is already taking care of the patients' needs while they are hospitalised and cannot at the same time provide financial assistance. Therefore, the DG can only be applied for shortly before discharge and this causes financial strain on the caregiver who must provide food and other basic necessities during the waiting period. This becomes an even greater financial burden for the caregivers when the patient has special needs like diabetic meals as 21 of the patients in this study had.

Since most patients are only at level 3 of the rehabilitation outcome levels (Landrum, Schmidt and McClean (1995)] at the time of discharge from inpatient rehabilitation (see figure 4.10) and further progress is still to be expected, it is understandable that temporary DGs are issued. However, the re-assessment process does not take the patient's needs into account. Currently, two patients have no income because their grants are being reviewed and the same trial awaits others with a temporary disability grant. Temporary disability grants are issued for six months or one year and are thus re-assessed after this period. The patient cannot apply for this re-assessment before the date of expiry of his/her current disability grant.

The process of re-application follows the same procedure as a new application and can be as lengthy as a first application. During this time the patient, and sometimes by extension, the family has no income. This causes unnecessary hardship, stress and anxiety.

A medical doctor, not necessarily the one that has been treating the patient, decides whether the patient qualifies for a temporary, permanent or no disability grant. The decision is made purely on the basis of impairments and no common assessment tool is utilised. The researcher is of the opinion that this assessment should be done in consultation with the rehabilitation team, especially when taking into account the invisible impairments caused by stroke. The patient may look physically competent to return to work but once placed in the work situation the

cognitive, perceptual, executive and insight difficulties may be discovered. If the medical doctor is unaware of this the patient might be discriminated against and denied the financial assistance that would lessen the financial burden on the patient and caregiver. While assessment panels were briefly utilised in some South African provinces the Western Cape Province has never made use of this practice and the practice has since been discontinued in all other provinces because of fears that it led to too many successful applications (Nattrass 2006).

Hence, the researcher is of the opinion that the comprehensive International Classification of Functioning, disability and health (ICF) (World Health Organisation 2000) based assessment tool that has been developed by the Department of Social Development and that is currently being assessed in the field is a huge step forward (Department of Social Development 2005).

Also patients should be allowed to start the review of their grants at least two months before the grant expires and earlier in the hospitalisation period for new grants to ensure that there is no period where they receive no financial assistance especially after discharge home to the care of the caregiver.

Another problem related to DG applications is the means test. As previously mentioned five people were not eligible for a DG because of the spouse's earnings. Since then the criteria for the means test have been made less stringent and these people can now re-apply for a DG.

However, should the applications still be unsuccessful these families would have to cover the added medical expenses as well since not receiving a disability grant means that the patient will also not receive the free health care which policy promises persons with disabilities. In addition to the DG further financial support to patients who are in receipt of a state disability grant or old age pension is provided through free health care in government institutions. This implies that they do not pay for any services, medication or assistive devices that they receive through state health care services.

However, these free services are not available during the rehabilitation period in hospital and for those whose applications are refused since they are dependent on receiving a disability grant. This period of hospitalisation might be one of

exceptional financial strain as the caregiver/family has to travel to and from the hospital for visits at a cost and also buy all the necessities like toiletries and pay for transport or fuel when taking patients home for weekends. WCRC is not easily accessible by public transport and caregivers have to walk a distance of at least 1 kilometre from the entrance gate to visit patients. There is a wheelchair accessible railway station close by but families feel unsafe using it, especially when travelling out of peak hours. Sometimes caregivers do not visit the patient because of the financial constraints and transport costs but then they have to deal with the responses of patients who feel neglected. Any casual income that the caregiver might have earned is lost or decreases because she/he has less time to work. Finally a minimum fee must be paid for hospital services and any necessary assistive devices. Despite the fact that the fees are very low in terms of the actual costs of the services they are still unmanageable to these patients who have no income and if not paid they are handed over to the debt collectors who must retrieve the outstanding monies.

Further financial assistance comes in the form of a state grant-in-aid for caregivers who care for patients that are fully dependent on care. This amount is added to the disability grant or pension but the amount is minimal (presently R230). Of the caregivers in the current study only two received this grant in spite of the fact that seven patients required maximum care and the act states that the person must require regular attendance by another person (Government Gazette 2004).

In instances where the patient has to retire from work for medical reasons caregivers also have to consult with the patient's employer regarding his/her benefits. This may sometimes be stressful for the caregiver especially if the employer is not co-operative. The caregiver has to move between the patient's workplace, the hospital and the Department of Labour to get the necessary documents in order for the patient's benefits to be paid out. The caregiver can be under great pressure as it could mean having to take hours off work for these matters to be finalised.

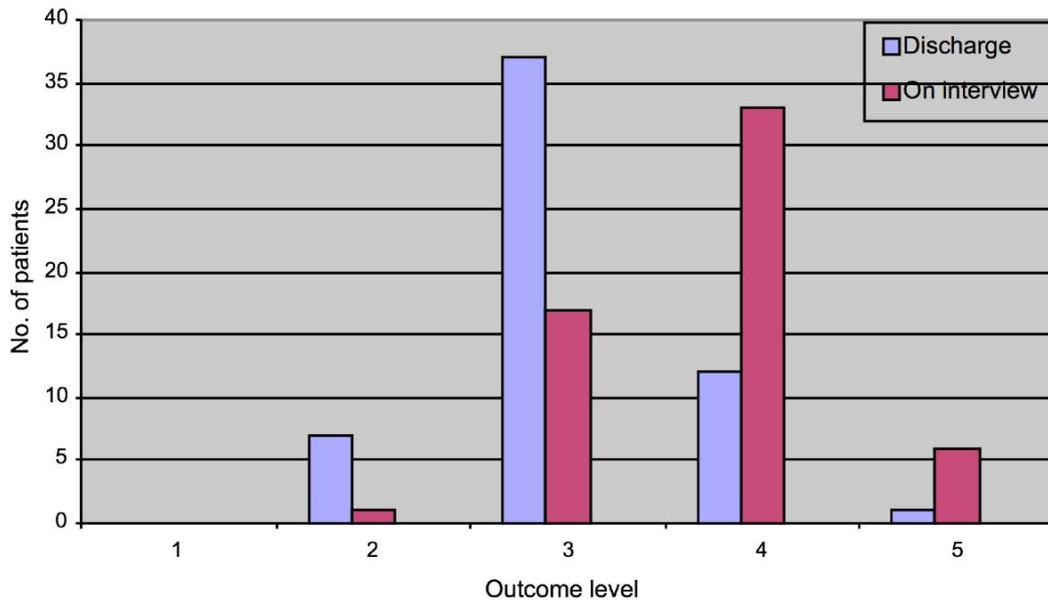
#### **4.5 REHABILITATION OUTCOME LEVELS**

The patient's outcome level on discharge was obtained from the completed Data Coding forms in the patient's folder. The case co-ordinator is responsible to complete this form as accurately as possible with consultation of the other team members at the time of discharge.

According to the information collected from the Data Coding forms most patients (37; 65%) were discharged once they had reached rehabilitation outcome level 3 (home and/or residential reintegration). Discharge from inpatient rehabilitation at this level is in accordance with the Department of Health, Western Cape (2007) which states that levels 4 and 5 should ideally be achieved while the person is already integrated back into the home through community-based rehabilitation (CBR) in conjunction with the primary health care system. Rehabilitation services should be provided through a continuum of care from the time of entry into the health care system, ideally at primary level, through acute care and inpatient rehabilitation, where this is warranted, back into the primary health care system and community-based rehabilitation. Unfortunately a lack of resources at all levels, but especially the primary level, impacts negatively on the continuum of care. Furthermore, communication and referral between health care professionals from the various levels are poor and patients may be discharged home to the family without being referred for follow-up or further rehabilitation services. This places a great responsibility on the caregiver.

At level 3 training and skills transference to the patient and the caregiver should have been done in order to maintain the physiological stability of the patient and prevent the development of secondary complications and a relapse following discharge to the home environment.

The caregiver has a great responsibility during the period of adjustment after the patient is discharged home to provide a positive, supportive environment in which further improvement can occur where the lesion allows for this.



**Figure 4.7: Rehabilitation outcome level on discharge and at time of interview**

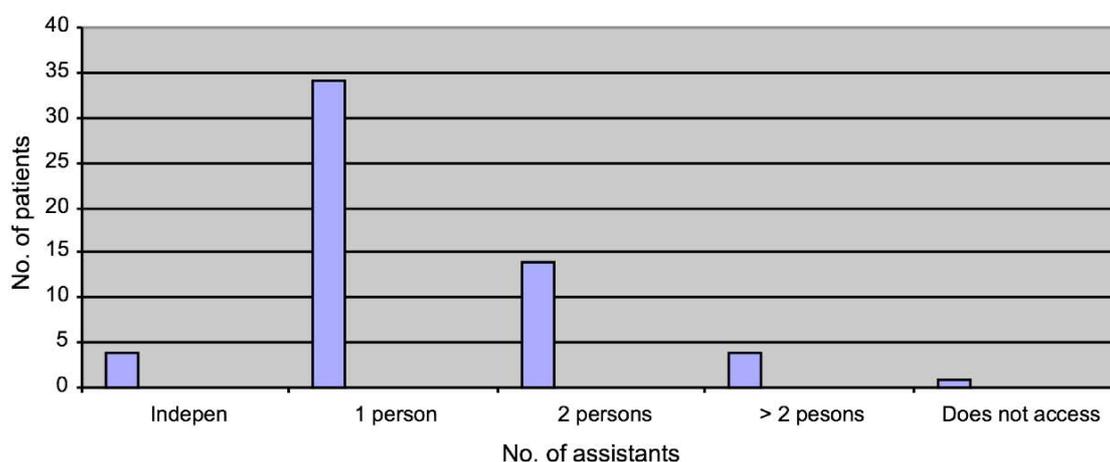
During the visit at the time of the study the patient's rehabilitation outcome levels were reviewed and a general improvement was observed as shown in figure 4.7. This is especially noticeable in the advancement from level 3 to 4.

There were 12 patients (21%) on level 4 at the time of discharge and 32 (56%) at the time of the visit. This improvement from level 3 to level 4 after discharge is in accordance with the Department of Health, Western Cape (2007). However, 36 (63%) of the patients received no follow-up services after they were discharged home. While 21 (37%) patients received some intervention from community-based services after their discharge, eight (38%) of these patients and their caregivers said that these services were inadequate. Therefore, it is feasible that the improvement might be attributed to a large extent to the caregiver's efforts and not to CBR as proposed by Department of Health, Western Cape (2007). Again this places a major burden on the caregiver.

As discussed in the literature review (Chapter 2) the outcomes necessary to achieve level 4 revolve around self-management, social competencies, community mobility, financial management, self-directed health monitoring as well as participation in sport, recreation and other community activities. A person may

utilise assistance but the assistance must be directed by the person personally (Landrum et al 1995). Therefore, the caregiver may still have to assist the patient to reach and maintain this rehabilitation outcome level and caregiving tasks might even increase as community outings are included in daily life.

In fact, this is true for the current study as is illustrated by figure 4.8 which shows the number of people that patients needed to assist them to access the community. The majority of patients (52; 91%) needed one or even two or more people to assist them in order that they may access the community. The one patient who did not access the community at all did not get out because of his attitude. This attitudinal barrier isolated him and his wife from the community. Only four patients could access the community independently.



**Figure 4.8: Number of assistants needed to access the community**

Furthermore, figure 4.7 shows that six (9%) patients moved from level 2 to level 3 and five patients moved from level 4 to level 5. In total 39 (68%) patients showed improvement according to the outcome levels, 14 (25%) stayed at the same level and four (7%) patients dropped a level.

It is worrying that only six (10%) patients reached level 5, since 39 (68%) study participants fell in the economically active group (see figure 4.1) and 27 (47%) of them were employed before the stroke (see figure 4.6). Furthermore, five of these six patients could not find employment in the open labour market after their stroke.

They were very creative and generated an income by running a 'house shop' or making crafts to sell in order to supplement the family income. However, this yielded but a small income. In the researcher's opinion this points towards the lack of CBR and primary health care resources. Community integration can to a large extent be facilitated by resourceful caregivers, family members and friends. However, re-entering employment often needs the special skills of a therapist to support patient and employer alike in the successful return to the patients' workplace. This opinion is substantiated by the fact that the one person who was employed in the open labour market spent eight days in WCRC during which period therapists assisted with his reintegration to work. If community rehabilitation services were adequate this admission would not have been necessary and the person could have been reintegrated to work while in the community.

## **4.6 HEALTH STATUS OF PATIENTS**

### **4.6.1 Number of strokes**

The majority of patients in this study (41, 72%) experienced their first stroke. Similarly the majority of participants (77%) in the study by Rhoda and Hendry (2003) suffered a first stroke. Caregivers of the 15 (26%) patients who had suffered a second stroke reported that the majority of these patients recovered fully after their first stroke and they expected the same level of recovery after this one. One person suffered multiple strokes during the process of admission to the acute hospital.

A great fear that the caregivers expressed is that the patient is vulnerable to have another stroke. This is evident in what this caregiver shared:

*I have this constant fear that my husband will get another stroke. I wake up during the night just to see if he is alright. It is very disturbing and I always try to stay close to him.*

This uncertainty about the patient's prognosis and the risk for further strokes caused much anxiety and fear and is also described in the literature (Isaacs 1982).

Initially patients and caregivers alike are in a state of shock and often do not fully comprehend what is explained to them. Therefore, it is important that the professionals reinforce information through repeated sessions and that the information is shared in a caring and supportive manner.

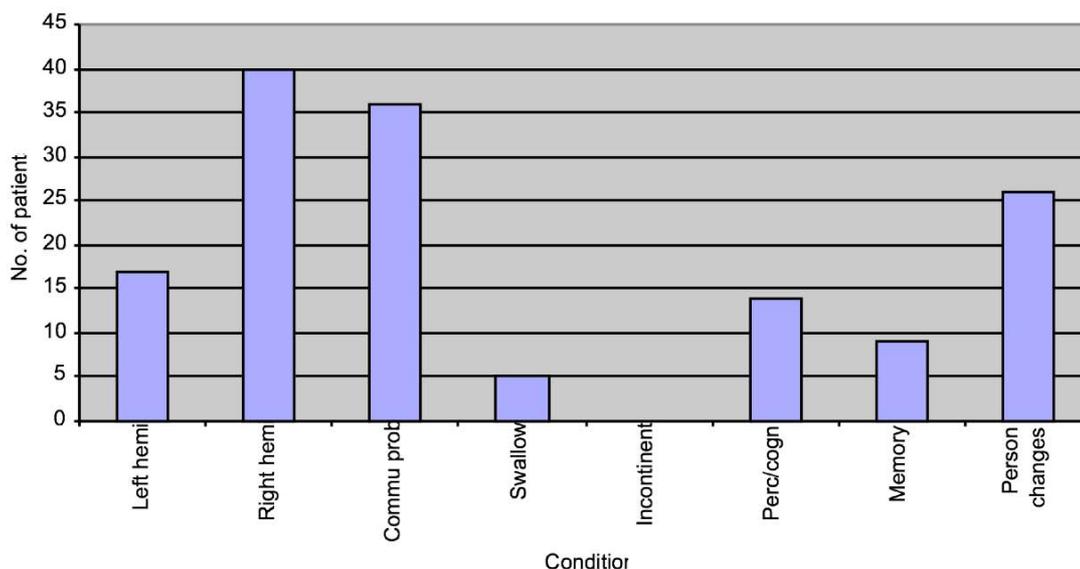
Information can be imparted to the patients and caregivers individually and in groups. It can be reinforced through stroke pamphlets and booklets, by using video or audio material as well as having regular talks on various aspects of stroke, but it is important that the first information sessions are provided in person and on a one-on-one basis as circumstances differ from patient to patient and pamphlets, booklets, talks or videos only provide generalised information (Gorman and Anderson 1982).

#### **4.6.2 Presence of risk factors/other conditions**

Again in accordance with the findings of Rhoda and Hendry (2003) hypertension was the most frequently mentioned risk factor. In this study 43 (75%) patients suffered from hypertension and in the study by Rhoda and Hendry (2003) 73% of patients suffered from hypertension. Similarly, in accordance with a study conducted by Thorogood, Connor, Lewando-Hundt, Tollman and Ngoma (2004) 71% of the participants in their study suffered from hypertension. A positive finding when compared to figures of Rhoda and Hendry (2003) is that only 12% of the patients in the current study smoked while Rhoda and Hendry (2003) found that 29% of participants in their study smoked. Interestingly, in the study conducted by Thorogood, et al, (2004) smoking was an uncommon practice and only .09% of the participants in the study were smoking. In the current study diabetes at 37% (21) was the second biggest risk factor as opposed to smoking in the study by Rhoda and Hendry (2003). Most patients (21; 37%) suffered from one condition or risk factor only while 14 patients had two and another 14 three risk factors. This finding differs from that of Rhoda and Hendry (2003) who found that a combination of risk factors was present in the majority of their study population. Only eight patients in the current study had more than three conditions or risk factors.

### 4.6.3 Unresolved effects of the stroke

According to figure 4.9 many more patients suffered from paralysis of the right side of the body (70%) than from the left side (30%). This finding is not supported by the literature, since Rhoda and Hendry (2003) for instance found a difference of only 4% between left and right sided hemiplegia.



**Figure 4.9: Unresolved effects after the stroke**

Figure 4.9 shows that more than half of the patients (30, 63%) experienced communication problems, but unfortunately data does not indicate the degree of the problem and whether the patient can be understood or can get the message across.

While only five (0.09%) patients suffered from swallowing problems, qualitative data served to enhance the severity of the impact of swallowing problems on caregivers where they were present as the following statement shows:

*My daughter has swallowing problems ... the feeding is a nightmare to me. She eats so slowly it takes more than an hour to feed her. She forgets to swallow and I have to remind her but the greatest nightmare is the fear that she will choke.*

No patients experienced incontinence. However, the Bartel Index score reflected that 12 (21%) were completely dependent when using the toilet and ten (17%) needed assistance to use the toilet. During an interview one caregiver explained that her husband needed assistance with toileting but when they went out she had to put on a nappy for him because she feared that there might not be a toilet for persons with disabilities and therefore she found it more convenient. However, the patient finds it humiliating to wear a nappy and the caregiver finds the entire situation stressful.

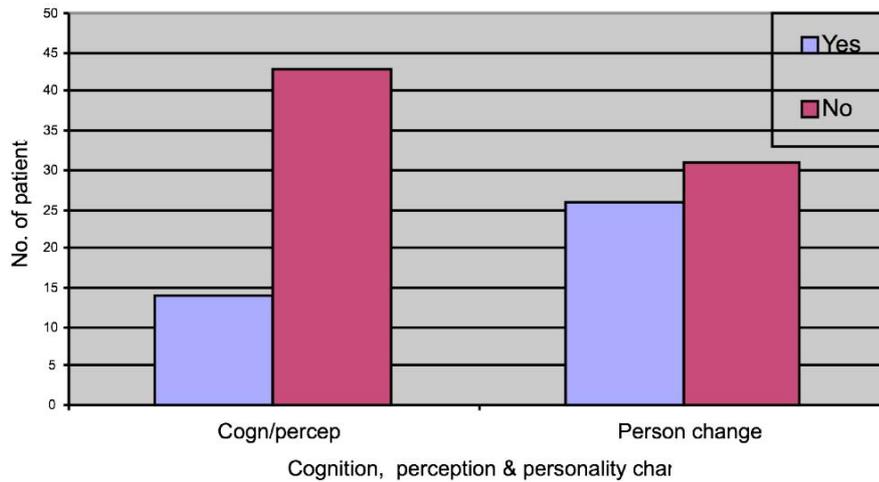
While one patient experienced premorbid memory problems nine indicated that they had unresolved memory problems post stroke. The following statement highlights the frustration that memory problems caused the caregiver:

*My husband sometimes forgets where he put things and then would blame me for taking the things. This makes life difficult in this house.*

The effects and the impact of physical dependency and the cognitive/perceptual and the personality changes on the patient and the caregiver are discussed in detail under 4.6.4 Cognitive/perceptual deficits and personality changes after stroke; and 4.6.5 Degree of physical dependence of patients according to Bartel Index scores.

#### **4.6.4 Cognitive/perceptual deficits and personality changes after stroke**

As shown in figure 4.10 caregivers indicated (as perceived and experienced by the caregivers) that 14 (24%) of the 57 patients had cognitive and perceptual deficits and that 26 (46%) of the patients experienced personality changes. Personality changes were especially difficult for caregivers to accept because they felt the person was not the spouse or child they knew before the stroke.



**Figure 4.10: Presence of cognitive/perceptual deficits and personality changes**

Cognitive and perceptual deficits are considered invisible impairments. However, according to the literature reviewed these deficits can aggravate the strain experienced by caregivers to a large extent (Ross and Morris 1988; Bresick and Harvey 1997; Birkhead and Graham 2005). Furthermore, personality changes are more stressful and threatening than physical changes since they can be equated to the loss of a loved one while the person is still alive.

In the present study both quantitative and qualitative data indicate the severity of the impact of problems related to perception and cognition as well as personality changes on caregiver strain. Quantitatively both had a p value of 0.01 which indicates that these changes had a statistically significant impact on caregiver strain. During the interviews caregivers expressed great frustration and some were at the end of their tether with the effects of the cognitive, perceptual and personality changes of the patients. They felt that friends and family did not seem to believe them nor did they have any insight into how much this affected the caregiving situation. In one instance the patient acted aggressively and abusively towards other family members and friends and he could not see that they wanted to be of assistance. The wife explained:

*My husband has chased away family and friends with his aggressive and abusive ways. He was never like this before and he doesn't understand*

*that they just want to assist and support us. He even scolded the neighbour the other day. I feel really embarrassed.*

These family members and friends just stayed away after a while and the caregiver felt isolated as she actually needed their support. Caregivers also expressed being emotionally exhausted and being on edge all the time because of the patients' demanding, unappreciative and unpredictable manner. This is how they describe the effect of these impairments in their own words:

*The children have drifted away because of their father's behaviour; so it is just the two of us.*

*My daughter drives me mad. She is so demanding, impatient and will nag all the time because she wants something to be done NOW! She provokes me and I get frustrated. The other day she pushed me too far that I slapped her through her face. I know she cannot help it. She changed since her stroke and I felt so guilty but I cannot take it. She's worse than the children.*

*My husband makes life impossible for me. He sometimes refuses to take his medication and on other days he refuses to eat and I stress. In the middle of the night he wants me to bath him and he demands to drive the car. He cannot drive and I have to hide the keys. His actions just don't make sense to me or the children.*

*My husband doesn't trust me. He times me when I go to the shop and accuses me of being unfaithful. I don't know how to handle this because he believes it and becomes abusive. We were very close before his stroke and how could he ever think this of me?*

*My husband is a stranger and I do not know him as my husband. It is painful for me to look at him and think that you are not the man I married. The children are devastated as they do not know him as a father either.*

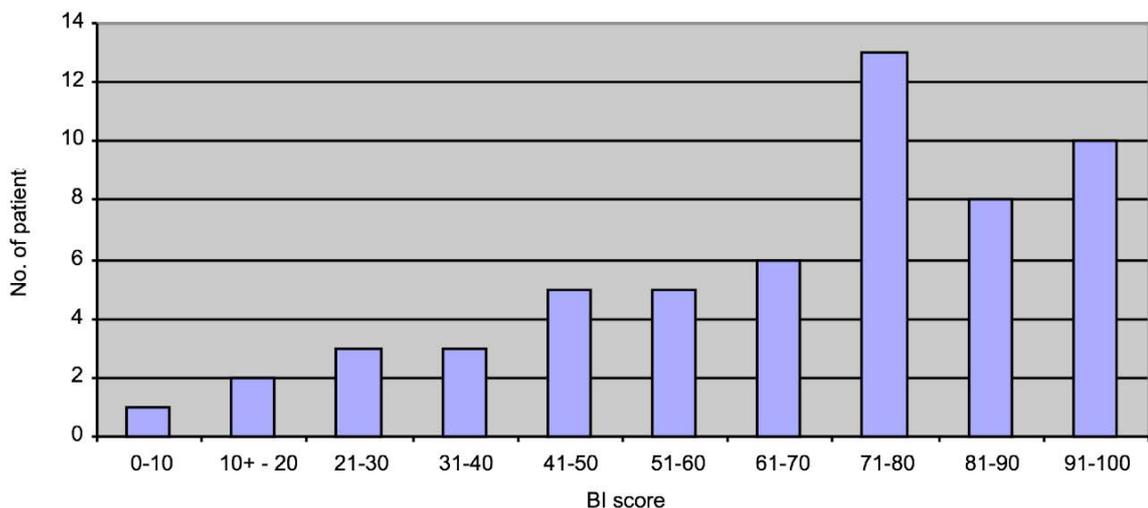
The occupational therapist should explain these conditions to the caregivers during rehabilitation, the findings of the various tests done and how to deal with

these issues. This knowledge will assist them to better understand why the patient acts as she/he does and also how to deal with this behaviour.

#### 4.6.5 Degree of physical dependence of patients according to Bartel Index (BI) scores

According to Granger, Albrecht, Hamilton (1979), a score of 60 or less on the Bartel Index indicates that the patient is physically severely affected and will thus be more dependent on physical care.

As shown in figure 4.11 in the current study 37 patients (65%) scored above 60 on the Bartel Index (BI) thereby implying a high level of physical independence. The study by Mamabolo et al (2008) paints a different picture with only 47% of participants scoring above 60 on the BI. This difference might be due to various reasons. For instance, the participants of the Mamabolo et al (2008) study have not yet completed rehabilitation while those in the current study did complete their rehabilitation. Also participants in the study by Mamabolo et al (2008) are being treated at various outpatient facilities while participants in the current study received high intensity inpatient therapy.



**Figure 4.11: Physical dependence of patients according to the Bartel Index**

This level of physical independence, however, does not imply that these patients could live on their own. They may be independent with their activities of daily living but they might be unable to observe household duties and responsibilities, like paying bills, managing the household finances and managing the maintenance of the house. The 20 patients (35%) who scored below 60 would need added physical assistance in addition to assistance with the above mentioned tasks. Premorbidly these patients were all physically independent.

A higher level of dependence as quantified by the BI caused statistically significantly more strain on caregivers than lower levels of physical dependency ( $p = 0.0012$ ). Qualitative data verified this and indicated that paralysis of the arm and hand added strain, because most of these patients needed some degree of assistance. Caregivers tended to do things for the patients when they were struggling with one arm or hand or because the patient was taking much longer to complete an activity. This caused more strain on the caregiver (Hunt and Smith 2004). Caregivers and patients alike expressed the following wish: *'If only the arm would work!'*

However, there are also positive stories which bring inspiration. One determined young female patient who suffered a dense right hemiplegia has started to do beading. During the interview her husband commented:

*She is a perfectionist and wants me to keep up with her standards. She made me buy a sewing machine but she is doing well, she needs a little assistance sometimes. She doesn't let her arm get her down and I'm so proud of her!*

Granger, et al (1979) state that one of the goals of rehabilitation should be to reduce the number of individuals in the more severe Bartel Index ranges of 0–60 and increase the number of individuals in the less severe ranges of 61–100. The researcher is in agreement with this stance because when patients become physically more independent it would give them a sense of achievement and confidence. This sense of achievement and confidence would give them the will to push themselves to reach further independence while it decreases frustration and the care burden.

#### **4.7 PATIENTS DISCHARGED TO OLD AGE HOMES**

Only nine patients were transferred to old age homes because they were care dependent. This very low figure (5%) can be the result of various factors some of which are related to government policy and institutional issues, while others are related to societal norms or personal factors. These factors often combine and force people to consider placement in an old age home as a last resort. Government policy calls for the integration of all members of society into communities, including the elderly and disabled persons, and accordingly subsidies to old age homes have been cut severely. However, in spite of this it is still difficult to access old age homes because of long waiting lists. The need for placement in spite of the policies is in part caused by inadequate community resources to support policy. Home-based care, community rehabilitation facilities and primary health care services are all insufficient in one or more of the four areas (accessibility, availability, acceptability and quality), which according to the United Nations Committee on Economic, Social and Cultural Rights (United Nations 2000) can be used to determine the standard of health care services.

Society expects family members to take care of their own and some families resist placing their loved ones into an old age home because of the stigma that they are abandoning the person. These expectations are stronger in some cultures/religions than others and might place undue pressure especially on persons who have an African or Muslim background (Rispler-Chaim 2007).

Often financial realities dictate the decision. On the one hand, government subsidies to old age homes were drastically reduced and families were expected to cover the shortfall; on the other hand, many families are dependent on the patient's disability grant for their survival and would rather struggle at home with caregiving duties than forfeit the disability grant.

Accordingly in the current study it was found that old age home placements were used only as a last resort as demonstrated in the discussion that follows. Of the three married patients, two of the spouses were females who could not cope with the care responsibility and one male held a full-time job as a long distance truck driver and could not give up his work because he had to maintain himself and the

household. These partners expressed guilt because of their decision to place their spouses in an old age home. On top of that, some were criticised by family and friends who made them feel even worse about their decision.

Another patient was admitted from an institution and was discharged back there. She was widowed and became dependent on care at the time of her stroke. Since the family could not cope with caregiving duties they placed her in an old age home. She was later referred for comprehensive rehabilitation with the view that should she become independent she could return to the family home. Unfortunately, the patient remained dependent on care and was discharged back to the old age home.

Then there were three patients who were living independently before the stroke. They had no spouses or children. Family members were unable to cope with the care responsibility for various reasons and they had to vacate their homes and move to old age homes. These patients initially experienced great difficulty in relinquishing their independence which caused feelings of guilt in the families because they could not care for these patients or support them to maintain their independence.

In one instance, a patient whose adult son was living with her was placed in an institution because she was dependent on care and his social habits made him irresponsible with regards to care.

Another patient's only daughter died suddenly and she could not return home to independent living. She had no family who could take responsibility for her care and the only option was placement in an old age home. She had extreme difficulty dealing with her daughter's death, the loss of her independence as well as moving from her home. Thus, even while it is frowned upon to place your loved ones in an old age home by government, society and the family, old age homes are in some instances an unavoidable necessity. They serve to care for those who are unable to care for themselves and have no one who is able to manage the care responsibilities.

#### **4.8 SUMMARY OF CHAPTER 4, SECTION 1**

The results in this section highlight a number of findings. Patients came from both genders and ages ranged from 18 to 83 years with a peak in the 50–59 age group. The majority of patients were Afrikaans-speaking, Coloured South Africans.

Caregivers were mainly members of the core family, that is, spouses, parents and children. Spousal caregivers seemed more willing to accept responsibility for the patient than other family members. The fact that the caregivers had to rearrange their lives to accommodate the patients created great stress.

The changes in employment status of both the patient and the caregiver had a major financial impact on families. Obtaining financial benefits for the patient and applying for state financial assistance proved to be difficult and the financial circumstances of some participants were dire.

The physical dependency of the patient caused great strain, but the invisible impairments like the cognitive, perceptual and personality changes were an even greater cause of strain. Families were often misled by this invisible impairment and did not realise the strain the caregiver was experiencing. Therefore, they did not offer the caregiver the necessary support.

The majority of patients showed improvement according to the outcome levels since they were discharged home. This is despite the lack of community resources to facilitate the continued rehabilitation in the community. Caregivers were thus mainly responsible to assist the patient to achieve community integration and in some instances even productive activity.

In accordance with government policy, families consider placement in an old age home as a last resort and even then may experience criticism from friends and family which causes guilt. However, the necessary resources to support caregivers in the communities are not in place. This places an extra burden on the caregivers who have to take responsibility for the patient without the necessary support.

## SECTION 2

### CAREGIVER INFORMATION AND STATUS

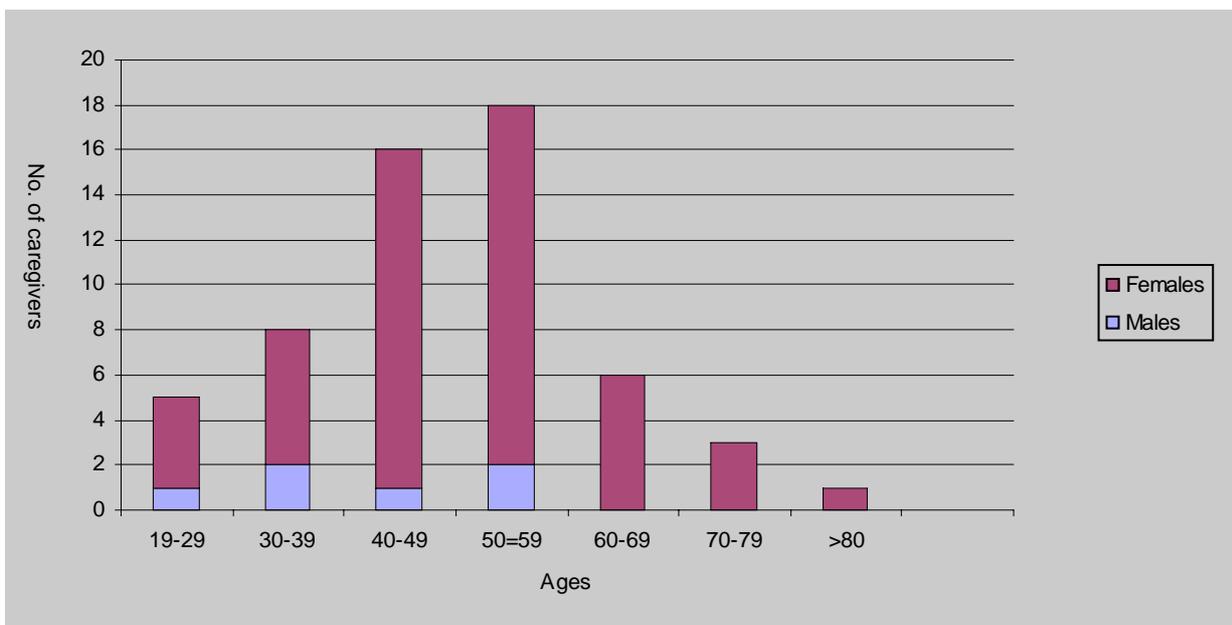
#### 4.9 INTRODUCTION TO SECTION 2

Section 2 provides an overview of the demographic details of the caregivers, their health status, their caregiving and other responsibilities, their knowledge on stroke, and what they experienced when the person suffered the stroke. Aspects of how involved the caregivers were in the planning process during the rehabilitation programme at WCRC and how supportive they found the rehabilitation team will also be discussed, as well as the needs of the caregivers at the time of the patients' discharge from WCRC and their current needs in the community.

#### 4.10 DEMOGRAPHIC DETAILS OF THE PRIMARY CAREGIVER

Demographic details of the primary caregiver included age and gender, marital status and the educational level of caregivers.

##### 4.10.1 Age and gender



**Figure 4.12: Age and gender distribution of primary caregivers**

Figure 4.12 shows that the majority of caregivers (51; 89%) in this study were female. According to the literature reviewed women are the major providers of informal caregiving and although men also provide assistance, female caregivers spend as much as 50% more time providing care than male caregivers (Family Caregiving Alliance 2008). This is supported by Robinson (1983) who found that women are not only portrayed as primary caregivers but also as providing more extensive care than men who would possibly experience more strain. These societal expectations of women as caregivers and nurturers place an added burden on women and might make it even more difficult for them to refuse the caregiving duties when they are expected of them.

The ages of caregivers in this population ranged from 20 to 81 with a mean age of 48. The majority of caregivers (34) were between 40 and 59 years of age. Figure 4.12 shows that ten (17%) caregivers were older than 60 years of age. This is worrying, because the effort involved in caretaking might be too taxing at their age.

While five (83%) out of the six caregivers in the 60–69 age group scored seven or more on the CSI (an indication that the person is under great strain) none of the four caregivers older than 69 scored seven or more on the CSI. All the patients being cared for by these older caregivers scored between 75 and 85 on the Bartel Index, indicating high levels of physical independency, and two had some assistance with care from family. In the 50–59 age group 14 caregivers (78%) scored seven or higher and in the 40–59 age group eight (50%) caregivers scored seven or more. Of those caregivers who were younger than 40, 60% had a score of seven or more. It appears as if age does not have an influence on the strain experienced by the caregivers and in accordance no statistical significance could be found between age and caregiver strain ( $p = 0.5$ ).

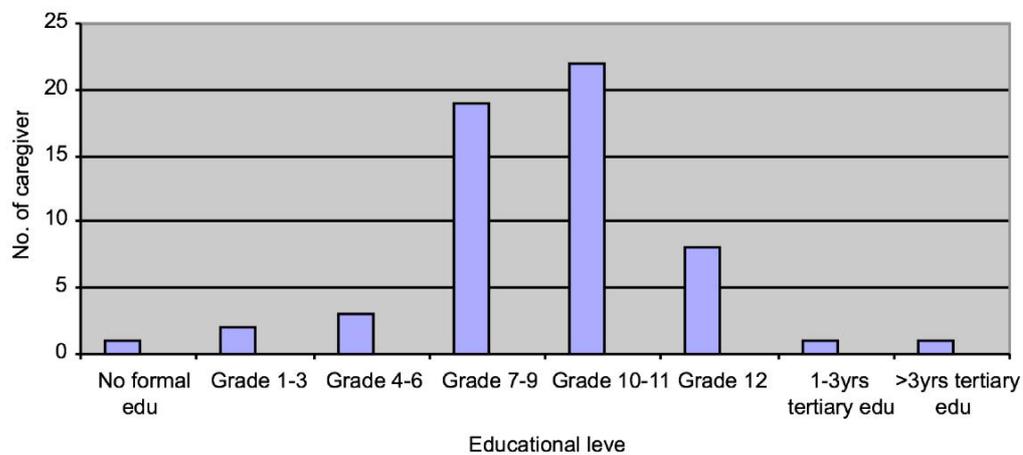
#### **4.10.2 Marital status of caregivers**

Just over half (32; 56%) of the caregivers were married. Of these 22 were spouses of the patients whom they were caring for. The impact of this was discussed in detail under 4.4.1, Family relationship between patient and caregiver.

### 4.10.3 Educational level of caregivers

Figure 4.13 shows a group of well-educated caregivers with the majority (41; 72%) having some high school education and ten (17%) having completed grade 12 or having higher education. Of the caregivers with high school or tertiary education 51% were employed at the time when the patient suffered a stroke and 17% had to terminate their employment in order to take responsibility for the patient.

These caregivers had to relinquish their financial independence and became a financial burden on the family.



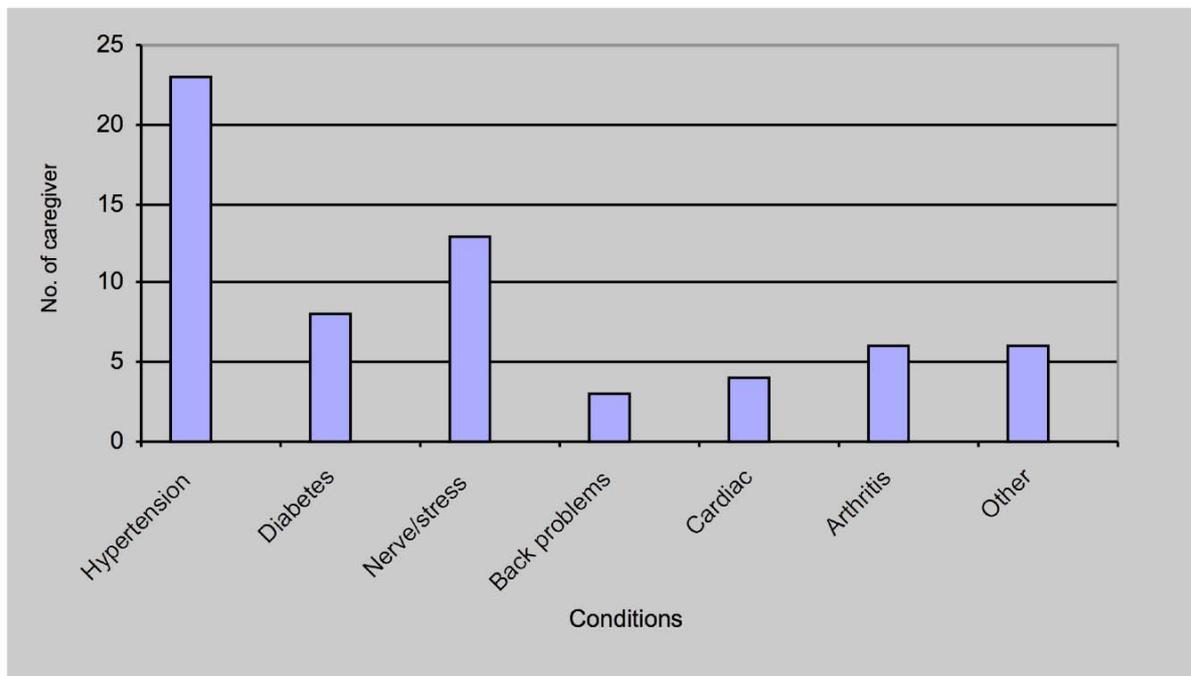
**Figure 4.13: Educational levels of the caregivers**

### 4.11 Health status of caregivers

Only 21 (37%) caregivers had no health complaints. As shown in figure 4.14 the most commonly encountered medical condition was hypertension from which 23 (40%) caregivers suffered. The condition was controlled through medication. A further eight (14%) caregivers had diabetes mellitus and 13 (23%) had nervous/stress conditions. Back problems were present in three caregivers, of whom one complained that she had hurt her back while lifting the patient. She was experiencing severe discomfort and back pain and was being treated by a physiotherapist. The four caregivers who suffered from cardiac problems found their condition limiting because they tired

easily. The six caregivers who suffered from arthritis mentioned that hot and cold weather affected the efficacy of their caregiving because of pain.

The 'other' conditions included asthma, thyroidism, gout and severe migraine.



**Figure 4.14: Medical conditions prevalent amongst the caregivers**

The above findings are in accordance with those of Medalie (1997) with regards to hypertension and migraine. The other two conditions mentioned by Medalie (1997), namely, bleeding duodenal ulcers and depression were not present amongst the caregivers who participated in the current research, although ulcers and depression can be seen as stress-related conditions and stress was found to be present in 13 (23%) of caregivers. According to Medalie (1997) the family system is a sensitive structure and if one member of the family is affected by an illness then the rest of the family is affected. He states further that the caregiving responsibility within the family is often delegated mainly to one person. Further more he informs that the caregiver should be directly asked about her health, encouraged to express her feelings and should be encouraged to have intervals of respite care. He feels strongly that the caregiver should receive sufficient emotional and practical support as overwhelmed caregivers may develop hypertension, migraine, bleeding duodenal ulcers, depression and may become the "hidden patient." This was echoed by Thompson et

al (1990), Coyne et al (1995), Bressick et al (1997), Mayo et al (2004) and Teasel et al (2006) in chapter 2.

Nervous strain was the only condition to show a statistically significant ( $P = 0.01$ ) impact on the strain that caregivers experienced. Nervous strain can affect the well-being of the caregiver and the quality of care that is delivered and can cause or negatively influence physical symptoms such as hypertension, asthma and migraine. This finding shows a need for the emotional support of caregivers in the community and the need was echoed by the caregivers themselves when they suggested support groups in the indepth interview. Psychological support services are severely lacking in the primary health care system.

### 4.12 RESPONSIBILITIES OF THE CAREGIVER

This section of the study describes caregiving duties, other responsibilities of caregivers and time spent socialising and on recreation.

#### 4.12.1 Caregiving duties

The study examined the time spent on caring per day, the intensity of care needed by the patients, remuneration for caregiving, time off and any assistance with the caregiving duties.

##### 4.12.1.1 Time spent on caring per day

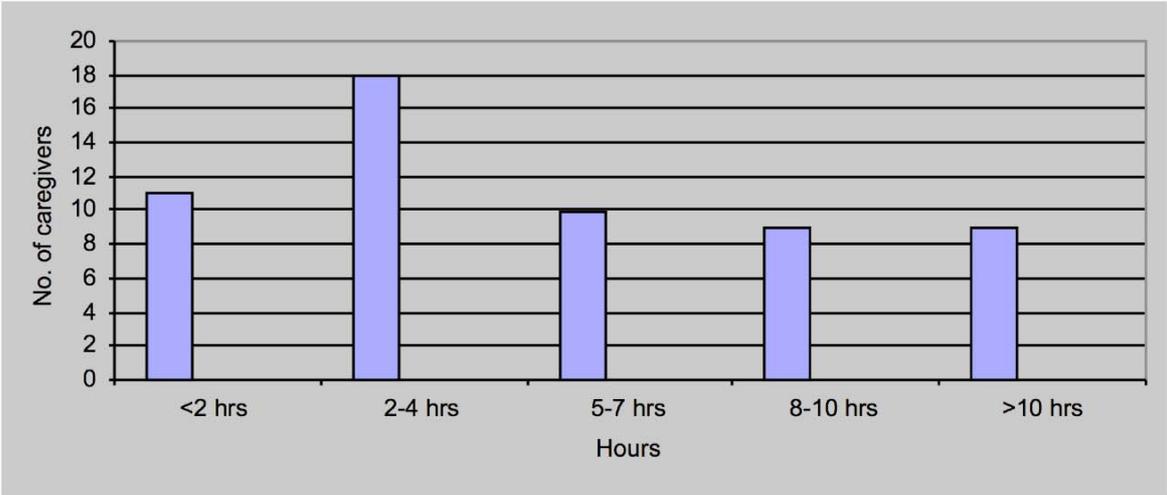


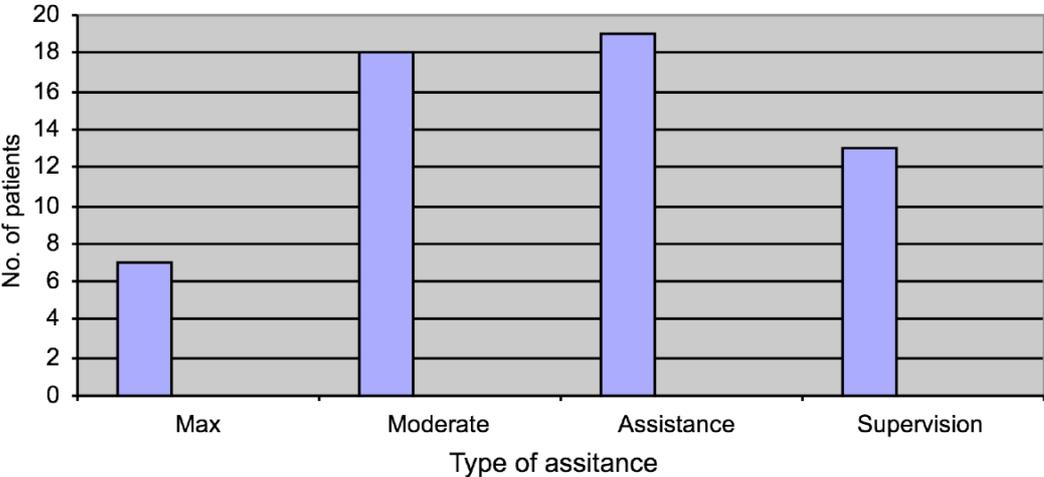
Figure 4.15: Hours spent on caregiving per day

The majority of caregivers (18; 31%) said they spent between 2 and 4 hours per day on caregiving, while ten (17%) spent between 5 and 7 hours per day on caregiving. As figure 4.15 shows 18 (31%) caregivers spent more than 8 hours per day on caregiving duties. This meant a full day's work and more delivered by these caregivers. Although not statistically significant at  $p = 0.07$  the analysis does indicate that the effect of long hours of caring on caregiver strain should be kept in mind. These long hours are physically as well as emotionally exhausting because caregivers tend to worry all the time and have difficulty unwinding. One caregiver said:

*My husband's stroke was the biggest shock ever. I am so scared that he will get another stroke. I think he is vulnerable and I am never relaxed, I worry all the time.*

**4.12.1.2 Intensity of care needed**

Figure 4.16 shows that 25 (44%) patients needed maximum or moderate care, indicating that they were either fully dependent for all the activities of daily living or needed help with at least some activities. Patients who need assistance are able to carry out most activities of daily living by themselves and only need a little assistance, for example, with the cutting of meat at meal times. Supervision entails, for example, administering medication or assuring that medical appointments are kept.



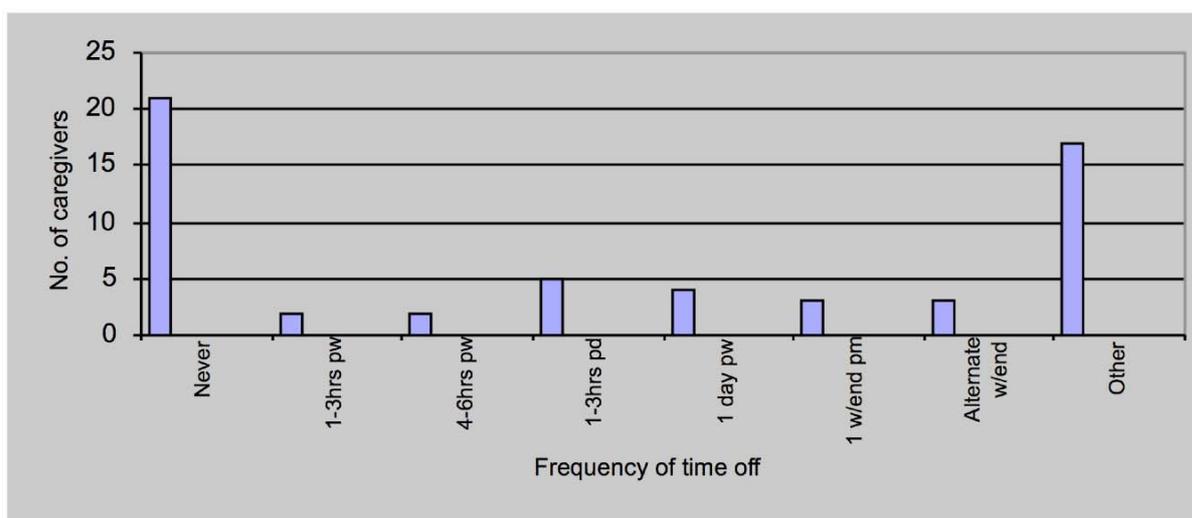
**Figure 4.16: Intensity of care**

#### 4.12.1.3 Remuneration for caregiving

The vast majority of caregivers (46; 81%) were not being remunerated for their caregiving duties, while 11 (19%) were remunerated. Of these two received the grant-in-aid (R230 per month) paid by the state. The accommodation, food and provision for other basic requirements that caregivers received were seen as a form of remuneration. One caregiver who is single and lives with her sister said that besides caring for her brother she had to take care of the household responsibilities in return for accommodation, food and toiletries. She expressed extreme frustration at her loss of independence but felt that she had no choice. Her family expected her to be responsible for her brother's care since she is single and has no family responsibility of her own.

#### 4.12.1.4 Time off

Figure 4.17 shows that 21 (37%) caregivers had no regular time off and could not arrange for time off to take care of themselves or to regain some strength and rejuvenate. Surprisingly only five (24%) of these caregivers scored seven and above on the CSI which indicates that these caregivers experience high levels of caregiver strain. It is in the interest of both the caregiver and the patient that the caregiver has some time off from the care responsibility to re-energise themselves and thus to maintain a good quality of care to the patient.



**Figure 4.17: Presentation of the amount of time off for the caregiver**

Those 17 (30%) caregivers listed under 'other' in figure 4.17 could arrange time off when they needed it.

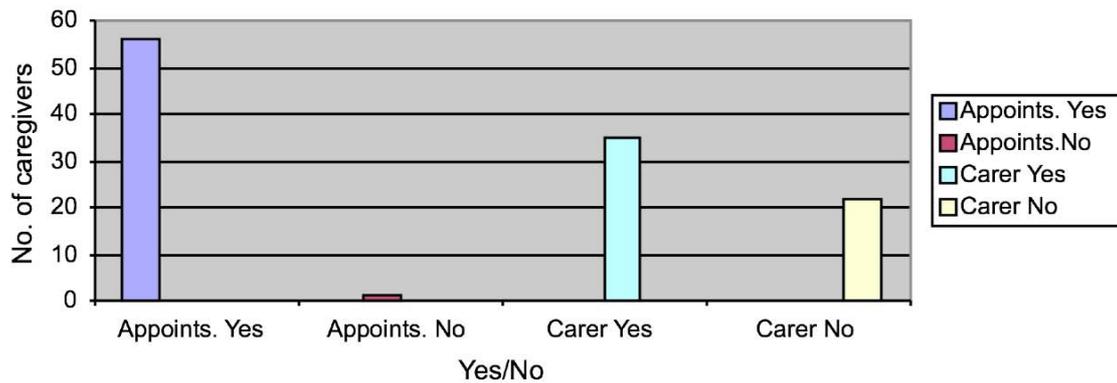
One caregiver shared how she takes time out:

*I simply love being in a mall, so on a Saturday morning I get up early and spend some time at the mall. It gives me such pleasure walking around, having a coffee and just watching the people. It sounds simple but I love it and find it so relaxing to be away from home and all the responsibilities.*

Another caregiver said:

*I took my husband to his sister for a few days so that I could rest. I was so exhausted and I wasn't in a good space with him, so it was best for both of us. It was good to have him back again.*

These two examples clearly illustrate the importance and positive effects of taking time off. The time needed depends on the needs of the caregiver. It may be short periods of relief in the home where a friend or relative takes responsibility for the patient for several hours while the caregiver can take care of him or herself. It may be at an adult day care centre that the patient attends on one or several days per week while the caregiver has time off. Respite care may be offered at an institution where the patient is admitted for a period of two to four weeks while the caregiver can recover and restore his/her energy and rejuvenate before resuming the care responsibility. Allowance should also be made for emergency respite especially when unforeseen events may warrant this. Respite care has been shown to have a positive effect on the health of the caregivers. Respite care has been shown to help sustain family caregiver health and wellbeing, avoid or delay out-of-home placements, and reduce the likelihood of abuse and neglect (Wikipedia 2008). Without respite care families may suffer economically and emotionally and may face serious health and social risks as a result of stress associated with continuous caregiving. Respite care may help to sustain family health and well-being, may help to avoid premature institutionalisation and may reduce the likelihood of abuse or neglect. It is most important to take care of the caregivers because they provide an invaluable service. The United States has the Lifespan Respite Care Act of 2006 to ensure that this service is provided and that the caregiver is taken care of (Wikipedia 2008)).



**Figure 4.18: Caregivers able to attend appointments and someone responsible for patient during their absence**

The majority of caregivers (98%) could attend appointments when they needed to. However, some caregivers did not feel at ease because their spouses would be unpleasant and make all kinds of accusations when they get back home, as the following examples illustrate:

*I tell myself I don't care and will not worry about any accusations but deep down it really hurts me. I feel so uneasy that I want to rush to get back home to avoid his abusiveness. He accuses me of have other men and that I am having affairs.*

*My husband watches what I wear and tells me I want to keep me young for other men. He wants to dictate what I must wear and how long I must take at the shops otherwise I've been with a lover. It is so absurd! I feel anxious while I'm away from home.*

One caregiver said that she did not need to attend appointments. She said:

*I am healthy and do not have to see a doctor regularly.*

However, the caregiver said that she is able to do her shopping and socialise with her friends when she arranges with her sister to take responsibility for her daughter during her absence. The caregiver and her sister can make arrangements with their niece to care for the patient when they want to spend some quality time together.

Some caregivers could leave the patient on their own while they went out. One caregiver said:

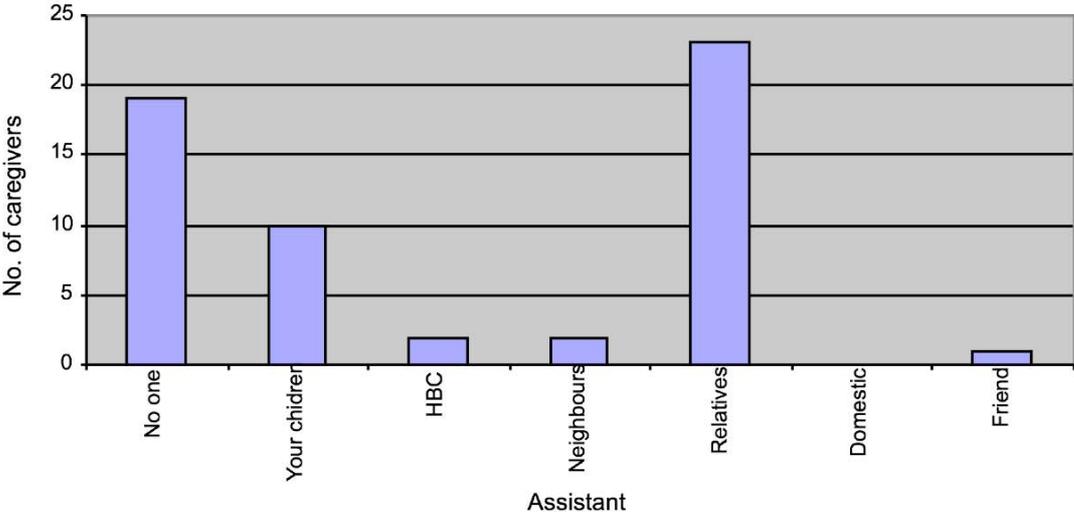
*I close all the blinds and I tell my brother that if anyone knocks he must not open the door. It is not a problem to leave him alone if I have to do an errand and he is quite content watching the TV. There is no one who can stay here while I'm out.*

This is a potentially dangerous situation for the patient as he might fall or should anything else happen like a fire he would be trapped inside. The high crime rate in the communities is also a concern as the patients are vulnerable and represent easy targets. A far safer situation could have been created if there were community resources available to step in and provide care while the caregiver needs to step out.

Only 35 caregivers could arrange for a responsible person to be with the patient while they were out. Some caregivers said that they had to make arrangements well ahead of time with someone to take responsibility for the patient and some people expect to be compensated. A caregiver who had been very agitated by her sister said:

*I seldom ask her (sister) to take care of our mother, I actually expect that she should offer. She had the nerve to ask me for petrol money when she came to fetch my mother for the day so that I could get my things sorted out. I almost swore at her! It is her mother too!*

**4.12.1.5 Assistance with caregiving duties**



**Figure 4.19: Presentation of who assists with caregiving duties**

Figure 4.19 show that 19 (33%) caregivers had no assistance with the caregiving tasks. These caregivers experienced high levels of stress, as is shown by the fact that 63% of them scored between 7 and 12 on the CSI, because the burden is not lessened through sharing the care responsibilities. According to figure 4.19 relatives, who included sisters, brothers, aunts and cousins provide assistance to 23 (40%) caregivers. In the case of ten (17%) the children of caregivers assisted them with the care of the patient. These children were living in the house and were mostly available to help. Some caregivers said that their children had their own lives to live and they could not always be depended upon to assist with the caregiving duties.

**4.12.2 Other responsibilities of caregivers**

Other responsibilities of caregivers included minor or dependent children, as well as household and other duties.

**4.12.2.1 Minor or dependent children**

In addition to caregiving duties 35 (61%) caregivers had minor or dependent children for whom they were responsible for as well. While 30 (53%) took care of one or two children, five (9%) took care of between three and six children each.

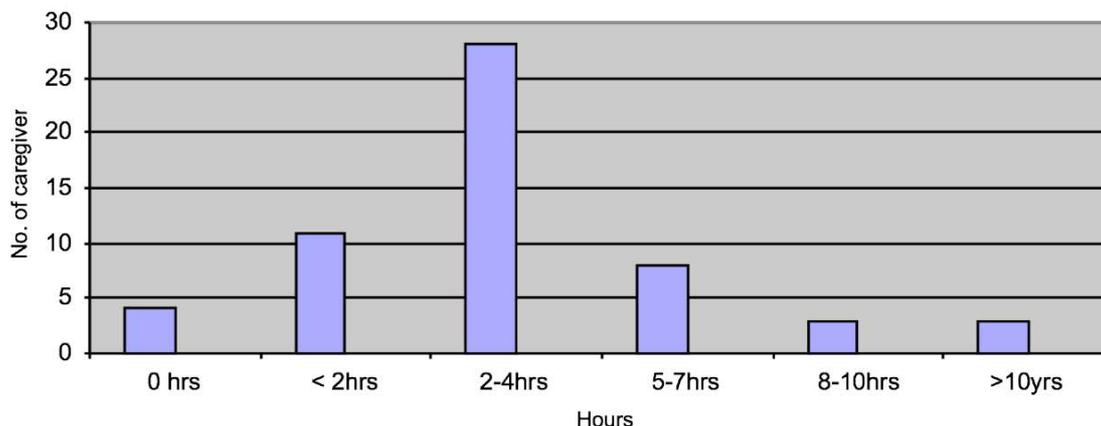
These caregivers had to juggle responsibilities towards the children with those of the patient. One caregiver had an adult dependent child who was severely disabled and needed maximum care. She said that there was often tension between her and her husband because of her care responsibility towards her daughter. She shared:

*I am at my busiest with ... then my husband demands that I attend to his needs first. It doesn't matter whether I'm busy putting on a nappy for her I have to leave her otherwise he becomes so rude and abusive. It's almost as if he cannot understand.*

Juggling the care responsibilities caused major strain for caregivers. Caregivers were torn between demands and expectations from the patient and the dependent children. The caregiver may feel that she is neglecting the one because of the demands of the other and may have feelings of guilt and inadequacy.

However true or imagined these feelings might be, they still cause the same amount of strain in the caregiver. One caregiver said that she neglected assisting her children with their school work and she only discovered how the children felt because they started acting out to gain her attention. She had to work out a programme so that her mother's needs were all met prior to the children arriving home from school so that she could offer them the necessary attention. As seen in this example the caregivers often had to make all the practical arrangements and respond to everyone's demands and needs with no consideration for their own needs and coping capacity.

#### 4.12.2.2 Household and other duties



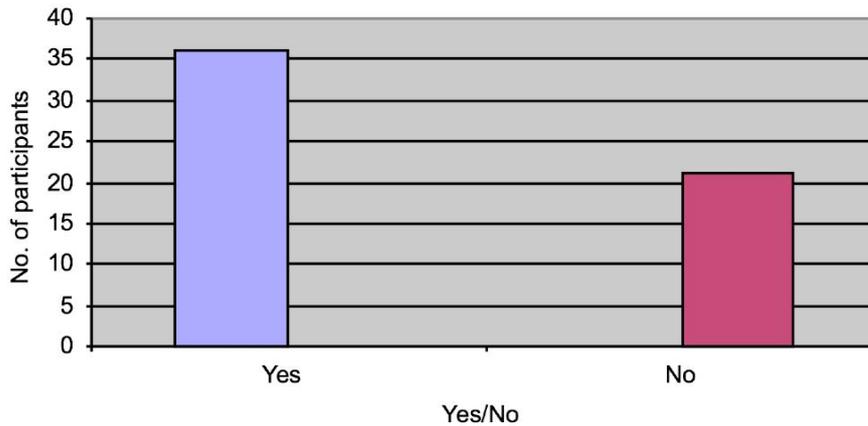
**Figure 4.20: Presentation of the hours spent on household duties**

Figure 4.20 indicates that the majority (28; 49%) of the caregivers spent between 2 and 4 hours on other household duties. The 13 (18%) caregivers who spent more than 5 hours per day on household duties on top of their care duties basically hold down two full time jobs. When these figures were correlated with the number of hours spent on caretaking duties it was found that six caregivers spent a minimum of 13 hours per day on these two duties together. When taking into account that this is done seven days a week and 52 weeks a year it becomes a mammoth task.

The caregivers who spent more than 5 hours daily on household duties spent long hours on cleaning, cooking, washing and ironing. This takes up the bulk of the day and then caregivers still have their responsibilities towards the patient. Some of these caregivers are unable to employ domestic help because of a lack of finances.

#### 4.12.3 Socialising and recreation

Figure 4.21 shows that 36 (63%) caregivers could make time to socialise or get involved in some recreational activities. Some caregivers could arrange with family, relatives or friends of the patient to take responsibility in their absence. Caregivers could also leave some patients on their own for a reasonable amount of time while they were out. The 21 (37%) caregivers who answered no to this question could not socialise unless it was at home, nor were they involved in any recreational activities.



**Figure 4.21: Presentation of whether caregivers could socialise/were involved in recreation**

One caregiver said:

*I cannot visit friends or family because it is difficult to travel with my husband, so they always come over to 'braai' and my husband enjoys their company too.*

These findings on the roles and duties of caregivers are very similar to those of a study done on caregivers of children with disabilities in Botswana. Like the study by Kilonzo (2004) this study also found that caregivers experience severe difficulties in fulfilling all their roles, that they are overwhelmed by their role as caregiver and that this impacted negatively on their health and social life.

#### **4.13 EXPERIENCES OF THE CAREGIVERS AT THE TIME OF THE STROKE**

The study looked at the feelings of the caregivers at the time of the stroke, their experience regarding initial medical services, and other aspects related to the period between discharge from the acute hospital and admission to WCRC.

##### **4.13.1 Feelings at the time of the stroke**

During the unstructured interview the researcher asked the caregivers how they felt at the time of the stroke. The majority of caregivers expressed feelings of shock and devastation, especially those who were living with the patient at the time. Caregivers

felt helpless and hopeless and some expressed feelings of panic, uncertainty, desperation and being alone. The following statements by caregivers highlight these feelings of shock and uncertainty:

*I felt so shocked that I could not even think straight but I had to pull myself together and be strong.*

*It was a shock to see my husband who is such a strong and independent person, in such a hopeless state. He looked so vulnerable and this was so painful!*

*I felt so devastated and shocked at the time of the stroke. My husband was so strong and independent and it is painful for me to see him in this state and in a wheelchair! I could not look at him without breaking down. I wasn't sure what to expect.*

*I was very shocked and felt lame when my wife had a stroke. I couldn't understand why this had happened to my wife. She can't even hold our baby because her arm is not working. I feel sorry for our son.*

*I did not know what to do or what to expect. No one prepares you for this and the shock debilitates one.*

Furthermore, in some instances the initial trauma and uncertainty are still present as two caregivers explain:

*I still feel so traumatised because I fear that it will happen again and I never feel at ease ... I always worry!*

*It was a big shock then but I still feel so traumatised about my husband's stroke.*

A mother who is the caregiver of her young daughter who had a stroke shared these continued feelings of fear:

*"I felt paralysed when my daughter had a stroke. She is so young. Sometimes I lie awake at night worrying about her future. I never relax and this is affecting my health.*

These feelings are confirmed by the literature reviewed. Dowswell, Lawler, Dowswell, Young, Forster and Hearn (2000) explain that experiencing a stroke and its aftermath can be devastating for patients and caregivers alike. They state that the experience of stroke is one of disruption and that the lives of the patients and caregivers are turned upside down. According to Anderson et al (1995), the spouse or closest relative is affected by the stroke from the onset. They found that these caregivers must overcome the initial shock and readjust their own lives and those of their families in order to provide what is often an extraordinary level of care.

#### **4.13.2 Experience of caregivers regarding initial medical services**

In conjunction with these feelings of shock and fear the system failed some caregivers at this crucial initial phase. One wife shares the following experience:

*I rushed from work when I heard my husband got sick. My sister-in-law had already called the ambulance. I was so desperate to get my husband to hospital for treatment, the ambulance had not arrived so I arranged for transport. When we got to the hospital in the area we were turned back and told we must have a referral letter or we must go the nearest day hospital. My sister-in-law decided that we take him to a private hospital and they paid the costs. We were desperate and horrified that we were turned back at the local hospital. It made me really angry and I feared what would happen as time was passing by.*

This initial failure was compounded by a further lack of essential support by the medical services as is described by another wife:

*At the time of the stroke I had to keep myself strong for my children's sake. I was too busy getting my husband to hospital to think of what I was feeling. I am generally a strong person and have been through several traumas with family and friends. But I was in a state of extreme shock when after eight days, the hospital said my husband is being discharged. I did not know what to do, how to look after him as he is a big man and he did not even have any balance. I was in such a panic stricken state, I was so fearful of what lies ahead for me.*

Another caretaker shared the following experience:

*I was in such a shock, didn't know what was happening to my husband but I knew I had to get him to hospital. No ambulances were available and in my panic I phoned his employer who sent a car to take us to hospital. I didn't know what the procedure was but was sent from one hospital to another and then we had to wait for hours to be attended to. The hospital staff walked past us all the time not asking whether we were okay while I was bleeding inside with pain. I was too scared to ask anything because they really didn't look interested.*

Another patient was turned away from a state medical facility because there was no referral letter.

These experiences are a long way off the gold standard for rehabilitation as set out by the South African National Rehabilitation Policy (Department of Health 2000) and discussed in Chapter 2. According to the Department of Health, Western Cape Province (2007), the level of primary health care should ideally be the point of entry into the health care system. However, as discussed in Chapter 2, the primary health care system and other support services in the community are not fully functional in many areas. These systems, that should have provided initial care and support, failed patients and caregivers dismally in some instances and created more stress and anxiety as shared by the caregivers above. Unfortunately this lack of empathy is more widespread than one would like and the (Lehmann 2008) indicates that 9% of persons who access health care in the Western Cape Metropole found staff to be rude or uncaring or they were turned away, while 32% cited long waiting times as a problem. Similar challenges were identified by a group of caregivers of disabled children in Botswana who complained about the lack of attention and the quality of care they received from formal health care services (Kilonzo 2004).

One caregiver was unhappy with the standard of care her husband received at an institution and took him home. She was made to understand that if she took her husband from the institution the doors of that institution would be closed to them in the future. This is contrary to the Batho Pele principles (Department of Public Service and Administration 1997) where the patient and the caregiver may consult with the

service provider about the standard of service delivered as well the Patients Rights Charter (van der Walt 2008) and the South African Constitution (Government Gazette 1996) that state there should be no discrimination against a person on any grounds. Patients may not be refused admission at a later stage or judged/discriminated against because of an earlier action or decision (Government Gazette 1996).

A caregiver remarked:

*I was very unhappy with the care my husband was receiving. The matron was so angry with me because I wanted to take my husband home. She told me if I take my husband home I could never bring him back again. I didn't know how to look after him and was not trained at all. I struggled with my husband, he was weak and I had no help. I was so depressed and felt alone but God helped me because my friend told me about WCRC.*

#### **4.13.3 Aspects related to the period between discharge from the acute hospital and admission to WCRC**

The majority (38; 67%) of patients in this study were transferred directly from the referring hospital to WCRC for rehabilitation. Of the 19 (33%) patients who were discharged home to await placement at the WCRC, nine (16%) waited for more than four weeks before they were admitted to WCRC. None of these nine caregivers had received any training before the patient was discharged home and eight of them said they could not cope with the care responsibility during this period. They expanded on this aspect in the interviews:

*It was extremely difficult to manage and I had to get some help, it was a terrifying experience.*

*No one trained me when my husband was discharged from hospital. I didn't know how to handle him. I dragged him on my back to the bathroom. He had no balance and my day was spent looking after him and giving him exercises the way I thought was right. I was emotionally drained after my husband's discharge home but I saw improvement and that gave me strength to go on.*

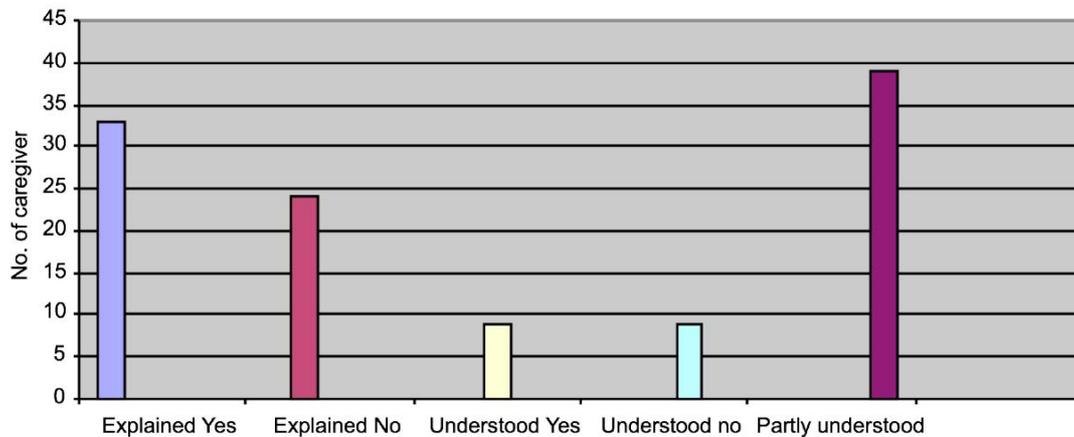
Of the other patients who waited shorter periods two caregivers were not trained and could not cope.

Another four patients (7%) waited at home for less than a week before admission to WCRC. None of the four caregivers had been trained prior to the patient's discharge. However, three caregivers still felt that even with training they could not cope with the care responsibility. Caregiver training is essential. If the caregiver is not adequately trained the risk of injury to either the patient or the caregiver or both is high. Caregivers may hurt their backs if they are not trained in the correct lifting techniques while patients are at high risk to develop a painful shoulder which is a known and very debilitating secondary complication of stroke often caused by incorrect handling of the affected arm (Scheffler and Visagie 2007).

The risk of injury and the emotional strain experienced by the caregivers is extremely high in this initial period just after the stroke since the condition is new to them and they have not had time to come to terms with the situation emotionally as well as physically. Furthermore, very often the patient does not have any assistive devices like a wheelchair or commode during this period to ease the physical management of the patient. The optimal situation is for a patient to be admitted directly from the acute care hospital to a rehabilitation facility where inpatient rehabilitation is indicated. This is even more important in the South African situation where community-based and primary health care services are not adequate enough to provide an interim service. However, waiting lists at rehabilitation centres and the pressing need for beds in the acute care hospitals often force a discharge home to await rehabilitation. Therefore, it is of utmost importance that caregivers are adequately trained to deal with the care responsibility during this period and that the caregiver should get professional support if needed. This support should be available and the caregiver should know how to go about accessing it.

There were 15 (26%) caregivers in the current study who had previous experience of caring for someone who had suffered a stroke or who were dependent on care. These caregivers were more comfortable and confident with accepting the care responsibility.

#### 4.14 CAREGIVER KNOWLEDGE AND EDUCATION ON STROKE



**Figure 4.22: Presentation of caregivers understanding of stroke**

Caregivers were asked whether stroke were explained to them. If stroke was explained the caregivers indicated which disciplines explained stroke and whether it was reinforced during the rehabilitation process. Thereafter the caregivers were requested to explain stroke in their own words. This indicated whether the caregiver understood basic information on stroke, like, the stroke occurred in the brain, why the paralysis, the risk factors and therefore the prevention of further strokes.

Figure 4.22 shows that the diagnosis was explained to just more than half of the caregivers (33, 58%) by a health care worker. Of these 22 (39%) received the explanation from the doctor who attended to the patient at the time of the stroke. Other health care workers who provided explanations were the nurse, the physiotherapist and ward doctor at WCRC. The questionnaire was not clear with regards to whether this question only refers to an initial explanation or to further explanations as well. If further explanations were included in this data a clear omission on the side of health care providers is exposed here. Two very important team members, namely, the social worker and occupational therapist never explained the diagnosis according to these findings while the nurse and the physiotherapist only explained it to respectively three and four caregivers. Similarly the ward doctor at WCRC is only mentioned twice as having explained the diagnosis. It is of utmost importance that these professionals repeat and reinforce the explanation and expand on it in areas that are relevant to their specific fields, for

example, cognitive function for the occupational therapist and mobility for the physiotherapist.

Even while caregivers stated that the information on diagnosis was reinforced by the team at WCRC, data indicate that 48 (84%) caregivers only partially understood or did not understand the explanation at all (see figure 4.22). Thus even while it was done it was not done clearly enough or not reinforced enough. The need for repeated explanations is well known and again exposed through these findings. Patients and family may initially be in such a state of shock that even though the professionals may have explained the diagnosis and prognosis, caregivers may not have absorbed what was being said or explained. It is important for the different disciplines to take responsibility to explain and convey the information to the patients and caregivers on a continuous basis. Furthermore, patients and families must feel free to approach the professionals if they want to further discuss any information.

The 13 (23%) caregivers who indicated 'other' as their source of information on stroke said that family members, neighbours, friends and the home-based carer provided information. The problem with this is that information received through these sources are not specific for that particular patient and as stroke varies widely in its severity and areas and consequently functions affected, generalised information is not sufficient. This became clear from the following statement by a caregiver:

*I depended on my children to look for information on stroke on the Internet but the information was too much and scary and we abandoned this because we needed information relevant to my husband's stroke. I think it is of utmost importance that this knowledge be imparted by the professionals because the more we know and the more we understand what stroke is about the more confidence we will have in helping the patient.*

The insights shown by this caregiver are confirmed by the literature reviewed. According to Clark, Rubenach and Winsor (2003), there is evidence to show that patients recover better when they have been well informed and have good knowledge on stroke. This also reduces the anxiety experienced by the caregiver and the patient. According to these authors, patients and families may become frustrated

with the lack of knowledge and this may interfere with the family functioning. The rehabilitation team should provide the appropriate information so that the patients and the caregivers are equipped and confident. Clark and Smith (1999b) found that families have a poor basic knowledge on stroke and that this must be addressed by the rehabilitation team in order to reduce the anxiety experienced by the patients and the caregivers and to prevent them from having unrealistic expectations of the rehabilitation process and outcome.

Lincoln, Francis, Lilley, Sharma and Summerfield (2003) suggest that a combined (caregivers and patients) counselling and education programme significantly improved caregiver knowledge and stabilised some aspects of family function. The patient and caregiver could assist each other with the information received and could share what they understood. Should information not yet be clear, they should consult with the professionals for clarity.

Further comments on the lack of information and the stressfulness of this as well as suggestions by caregivers included the following;

*I knew nothing about stroke and nobody explained it to me!*

*I knew nothing about strokes or how to care for my husband. I needed someone who has knowledge to explain it and to show me. A booklet on stroke and how to care for the stroke patient would be helpful and beneficial even to those who have not been through this experience.*

*We should all get a booklet with information on stroke and then we must have some individual and group lessons and training because the more information one has the more confident we will feel to take on this responsibility. We can also watch videos on stroke. That will be very helpful.*

A booklet like this has been developed and tested in a joint effort by WCRC and the Centre for Rehabilitation Studies at Stellenbosch University (Botha 2007). This booklet is still in the final stages of being refined before it will be distributed to caregivers and patients as a guideline. It is recommended that this guideline become available to caregivers and patients as soon as possible as there is a dire need for it.

It would be an excellent source of information and reference to both the patient and the caregiver and will alleviate much of the uncertainty and anxiety experienced. However, booklets contain generalised information and although this one was found to be of exceptional value to patients and caregivers alike it is still only an aid to enhance personal explanations by team members.

#### **4.15 EXPERIENCES OF CAREGIVERS WITH REGARDS TO REHABILITATION AT WCRC**

In this section the experiences of caregivers are described in terms of the length of stay at WCRC, contact on admission, the supportiveness of the rehabilitation team, caregiver inclusion in rehabilitation team at WCRC and caregiver training.

##### **4.15.1 Length of stay at WCRC**

Both the average and median length of stay for patients in this study were 58 days. The shortest length of stay at WCRC was eight days and the longest was 101 days. The patient who was hospitalised for only eight days had recovered well prior to his admission and only needed a short admission to assist with the preparation to return to work. Usually the average length of stay for stroke patients at WCRC can be from two weeks to three months but can be extended should the patient benefit from continued inpatient rehabilitation. Some patients remained longer than the average length of stay because they suddenly showed some improvement and further rehabilitation would be in their and the caregiver's interest. It meant that they would have improved independence which implied that the caregiver burden in respect of care would be lessened.

##### **4.15.2 Contact on admission**

The caregivers were mostly very positive about the way they were welcomed to the ward. Quantitative data indicted that 55 (96%) caretakers were made to feel welcome when the patient was admitted. This was expanded on and confirmed through the qualitative data in the following remarks:

*The staff in the ward was very friendly and they made us feel most welcome. It made me feel at ease and I had peace of mind to leave my mother behind.*

*I am impressed with the services at the rehabilitation centre. This is a world class team! I have no complaints except that the food was monotonous but then it was wholesome.*

*This rehabilitation centre and the services is a cut above any other facility. It is of world class standard and the staff was very friendly and helpful. It was a great experience for my husband and me and people should know about this facility.*

This is a positive finding and one that staff at WCRC should proudly build on as a warm welcome and the knowledge that the patient is left in good care can ease the mind of caregivers, as well as lessen anxiety and consequently strain.

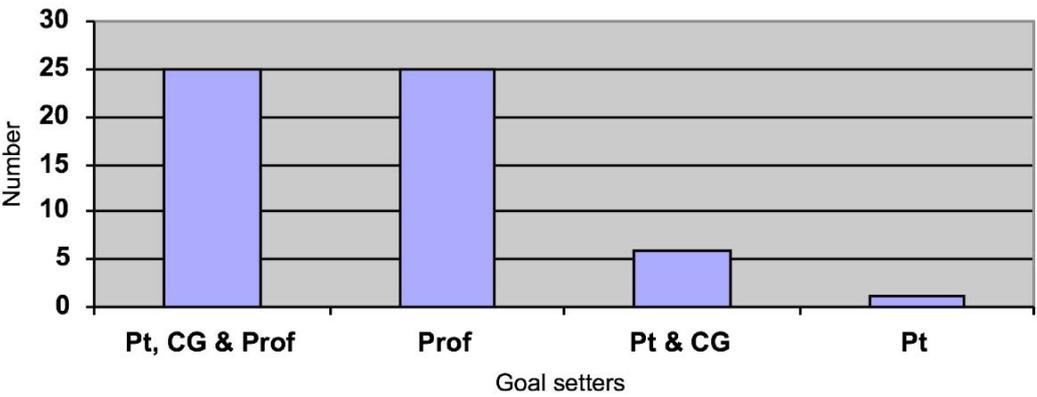
#### **4.15.3 Supportiveness of the rehabilitation team**

It is disappointing that only 33 (58%) caregivers were of the opinion that they received support from the team and 24 (42%) caregivers indicated that their needs were met during the rehabilitation programme. These figures showed that the team still focussed on the patient and that the caregiver is still not included optimally; the same neglect that the researcher experienced so many years ago and that in part served as motivation for this study. In this area the staff at WCRC should identify ways to improve their service. The finding also shows that the teams at WCRC are still struggling to fully implement an interdisciplinary teamwork approach.

#### **4.15.4 Caregiver inclusion in rehabilitation team at WCRC**

The rehabilitation programme was explained to 43 (75%) caregivers, while 14 (25%) felt left out of this process. However, a smaller number of 25 (61%) understood their role in the team and 32 (56%) caregivers felt included and part of the team. On the other hand, 22 (39%) caregivers indicated that they did not understand their role in the team and 25 (44%) caregivers did not feel part of the team.

Figure 4.23 illustrates that 25 (44%) caregivers indicated that the rehabilitation goals were determined by the patient, the caregiver and the professionals. A further 25 (44%) indicated that only the professionals determined the goals, while six (10%) indicated that the goals were determined by the patient and the family; one (2%) indicated that the goals were set by the patient. Thus in total, as is shown in figure 4.23, 32 (56%) caregivers and patients were part of the goal setting process. This is a positive finding in South Africa where the medical model and paternalistic ways of rehabilitation with professionals setting goals on behalf of patients and families are still very much in practice. However, WCRC is a specialised rehabilitation unit and serves as model for the province, if not the country, and in that capacity it would have been good to see much higher patient and family involvement in the determination of rehabilitation goals.



**Figure 4. 23: Illustration of which team members were involved in goal setting**

In an interdisciplinary teamwork approach as is followed by WCRC both the patient and the caregivers must be part of the team and should feel at liberty not only to participate in the rehabilitation planning process, but actually to drive the process. When the caregivers and the patients feel part of the team and fully understand their role in the team they can fully contribute and guide the team on their needs. They should drive the goal setting process and not allow the professionals to make decisions on their behalf.

Furthermore, if patients and caregivers are empowered on these fundamental rights during rehabilitation they would continue to exercise them in the primary health care

setting once the patient is discharged. On the other hand, where caregivers are not informed and included in the rehabilitation process further anxiety and uncertainty are caused. They remain disempowered and cannot take up their rightful role as consumers who drive the rehabilitation as well as the entire health care process (Department of Public Service and Administration 1997; Malaysian Medical Association 2007).

#### **4.15.5 Caregiver training**

A limitation of this study was that it did not determine how many caregivers were trained for their caregiving duties during the rehabilitation period. It was however determined how many caregivers were trained before the patient's first weekend home and 31 (54%) caregivers said that they were trained before the weekend while 26 (46%) did not receive training before the first weekend home. Again while the high number who had been trained is encouraging, the figures are not acceptable as it is policy at WCRC for caregivers to be trained before the patient goes home for the first weekend (this explains the oversight of not asking about training at other stages during the rehabilitation programme since the researcher assumed that training would have been done at this stage according to policy). This first weekend home is very important as it paves the way towards the future. The caregiver's experiences during this period can create a positive or negative mindset towards caregiving and everything possible should be done to try and make this experience a positive one. Furthermore, the risk of injury to one or both parties is again higher if no training was offered.

Kalra, Evans, Perez, Melbourn, Patel, Knapp and Donaldson (2004) suggest that training caregivers in the basic skills of moving and handling, facilitation of activities of daily living, as well as simple nursing tasks reduces the burden of care and improves the quality of life in patients and caregivers. It allows the caregivers to perform the activities with confidence and pride over weekends and when the patient is discharged.

Only 38 (67%) caregivers felt at ease enough to share their experiences and fears regarding this first weekend home with the professionals. The other 19 (33%) said that they were not comfortable to share their fears and experiences nor were they

asked questions about it. Thus if any of these 19 should have had a bad experience no opportunity presented itself to discuss the situation, to debrief them and to learn from the experience for the future.

In general 35 (61%) caregivers indicated that they felt comfortable to approach the professionals at WCRC regarding issues of concern and 14 (25%) said that they did not feel comfortable to approach the professionals.

Sometimes caregivers form a bond with a certain team member and thus feel comfortable to share pressing issues with that person who in turn could discuss it with the team if it must be followed up or addressed. This is encouraged so that caregivers should feel free to share their feelings. One caregiver shared the following:

*The physio was really good. It is because of her that ..... is now able to walk. She took her time to explain everything to me and showed me how to lift and care for ..... I could talk to her and she would understand me.*

This situation is optimal if the person with whom the bond is formed is also the case co-ordinator whose role it is to be the primary liaison between family and team. The team at WCRC should try to encourage this. Admittedly this is not always possible since the case co-ordinator has to be appointed in the first week after admission. However, in situations where a bond with one of the team members is already evident that team member should be appointed as case co-ordinator for the patient.

It is essential for the rehabilitation team to create an environment where the caregivers feel free to talk about their fears and concerns regarding the stroke and caregiving. The caregivers should feel free to speak to any of the members of the rehabilitation team and should be involved in some debriefing process possibly by the social workers or the psychologist. The caregiver should be given an opportunity to relay her experience in a step-by-step manner to create some order out of the chaotic experience. It would allow the caregiver to vent traumatic experiences and to prevent any experiences of post traumatic stress at a later stage. This would affect the quality of care towards the patient.

Of the current caregivers eight (14%) were not involved with the patient's care at the time that the patient was an inpatient at WCRC. They only took responsibility for the patients after the patient was discharged home. Most of these caregivers were thus not trained by a rehabilitation team member because the patient was discharged home before the caregiver took responsibility. The interim caregiver was trained and it was expected that this person should carry over the training. Patients and other family members should know that they are welcome to make an appointment for training of a new caregiver at WCRC. Home visits and follow-up assessments to determine if the patient and caregiver have adjusted after discharge should be considered. One advantage of such activities is that these caregivers could be identified and trained.

#### **4.16 NEEDS OF THE CAREGIVERS AT THE TIME OF DISCHARGE FROM WCRC**

Caregivers expressed a sense of loneliness and uncertainty on discharge of the patient as the following quotes show:

*It [the home visit] should have happened ... when she was discharged.*

*... We felt so alone when my brother was discharged home.*

It is important to provide a follow-up service in order to ensure a smooth transition from the rehabilitation facility to the home environment. The patient, after all, receives a high level of support from the rehabilitation professionals during the inpatient treatment and experiences a major adjustment after discharge home where a minimal level of assistance/support may be available.

Support given to patients and their caregivers during this transition period may impact positively on their levels of anxiety, depression and caregiver strain. Follow-up especially through home visits is a way to ensure that all environmental barriers have been addressed and that training given in the hospital environment is applicable to the home situation where beds, basins and toilets to name but three things, are different. With this knowledge and within the home situation training can be optimised. This provides an opportunity to identify any changes in function.

Unfortunately this study did not determine how many patients received home visits either during rehabilitation or after discharge, but from the responses of caregivers this seems to be an area where services at WCRC can be improved on.

Caregivers expressed their feelings of gratitude for the telephone calls and home visits done by the researcher. There is a great need for some caregivers to share and vent their caregiving experiences and for follow-up and support after the patient is discharged from the rehabilitation centre. Caregivers felt that they were being acknowledged and appreciated in this way. Some responses from the caregivers included:

*It feels good that you can do this home visit. It should have happened while my daughter was in hospital and also especially when she was discharged. It makes me feel important to share my experiences and frustrations. I feel so good since I spoke to you!*

*It is wonderful that you are phoning to come and see us. I think the rehab centre is wonderful and to show an interest now is just amazing because we felt so alone when my brother was discharged home.*

*Do you know that it is the first time that I am able to sit like this without being interrupted and just chat? I am always kept busy in this house. I feel so relieved that I could share my feelings with someone who understands me.*

According to Drummond (1988), professional services should be well co-ordinated and domiciliary services should commence immediately after discharge. Grant, Elliot, Weaver, Bartolucci and Giger (2002) found in their study that telephonic interventions and problem solving for caregivers of stroke patients at critical points in the caregiving period, such as after the patient is discharged home improved the well-being of the caregiver. There is a lack of continuity once the patient is discharged from the rehabilitation centre since the resources are lacking or are non-existent in the communities.

This lack is clearly shown by the following data from the study: It was found that at the time of discharge from WCRC 36 (63%) patients were not referred for follow-up

services in the community because there were no appropriate services in their immediate vicinity and no transport was available to access services in adjacent communities. Furthermore, 13 (23%) patients were referred to the local home-based care services in the community, one (2%) patient was referred to an adult day care facility, one (2%) for respite care, three (5%) went to 'other' follow-up services and three (5%) patients attended outpatient follow-up at the local community health centre. Of these 21 people, 13 (62%) caregivers indicated that the services were adequate while eight (38%) found the services to be inadequate. Thus in total 44 (77%) caregivers and patients did not receive adequate support once discharged into the community because of a lack of services or an inadequacy of services.

#### **4.17 COMMUNITY SUPPORT SERVICES**

It became clear during the interviews that there is a severe lack of support services in the community as illustrated by these quotes:

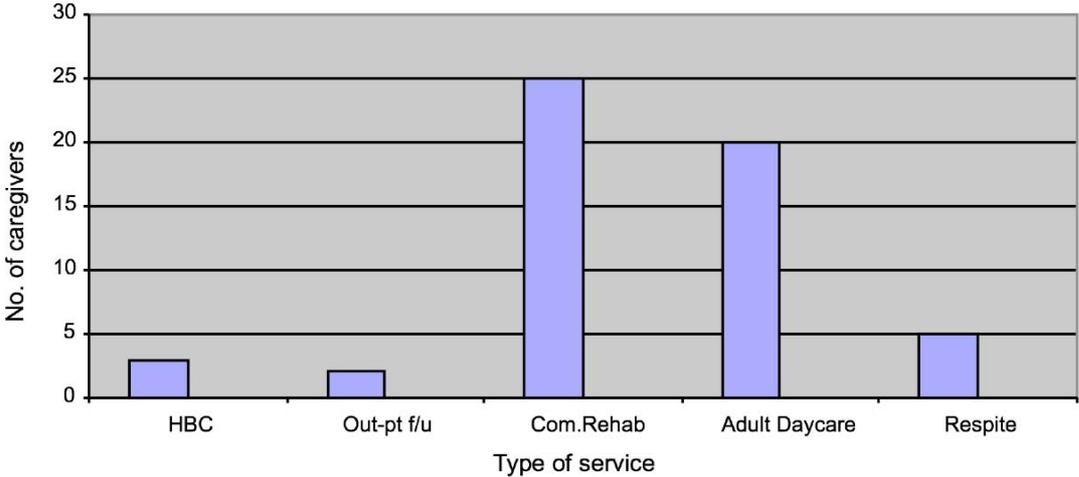
*My husband loves to be with people. He is a very social person and now he sits at home and we get on each other's nerves. There are no groups or clubs for people like him that he can attend. It will be good for him but I will also get a break.*

*My daughter is young and gets frustrated being at home all the time. There is nowhere in the community that she could go for exercises so that she can improve. She will get better if she has more therapy.*

*Sometimes I need a break or I have to do some business and I can't leave my husband alone. If there were only a place that he could go certain days where he is looked after but also gets therapy it will solve many of our problems.*

This lack of social and health support services in the community was also identified by Kilonzo (2004) in a study on caregivers of children with disabilities in Botswana who indicated a need for the development of caregiver support services like counselling, provision of financial and material assistance, support groups and respite care.

Caregivers had some suggestions on how to address these needs. The majority (25; 44%) suggested a Community Rehabilitation Centre as a resource in order for the patient to continue with therapy after discharge home. According to them this would ensure that the patient could improve and become more independent. This is in accordance with the Department of Health, Western Cape Province (2007) which states that outcome levels 4 and 5 should be achieved through CBR programmes. Patients could improve over time once they are at home with the necessary support structures in the community. According to the Department of Health, Western Cape Province (2007) patients should have reached rehabilitation outcome level 3 when they are discharged from inpatient rehabilitation. The results of this study indicate that WCRC accordingly discharged the majority of patients at rehabilitation level 3. However, at this point a breakdown in services occurs as the services in the community are not in place and often patients receive no further rehabilitation. Another aspect that falls outside the scope of this study, but that needs exploration is the type of rehabilitation currently being offered through primary health care services in the community. Does it adhere to CBR principles and provide rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities and does it focus on addressing community integration and productive activity (World Health Organisation 2004)?



**Figure 4.24: Community support services requested by caregivers**

Patients and families/caregivers were eager to get the patient involved in more therapy because they felt the patients would improve:

*If only she can go back to the rehab centre and improve her swallowing and this drooling. See her lips are broken with all that wiping.*

*I phoned the rehab centre to ask for an appointment as my husband wants to go back to learn to walk. He keeps falling and he had now been assessed at outpatients so we have to wait until a bed is available. He becomes too frustrated with himself and I become his punching bag.*

At the time of discharge the patients and their caregivers are informed about WCRC's open door policy and that they are welcome to make contact should they experience any difficulties or when they see more improvement and want the patient to be assessed to further inpatient therapy. It is unknown how many patients make use of this opportunity.

WCRC, however, has a long waiting list and patients may wait long to re-access the programme. Transport is a problem for families and it is difficult to physically attend an outpatient appointment and there is no guarantee that the patient would be considered suitable for admission for an inpatient programme.

Another question that arises is related to education. WCRC will discharge a patient when the team feels that the person has progressed optimally and little further progress in terms of the impairments is expected. Rehabilitation is a time limited programme with a definite end at this point. However, it seems that families think ongoing rehabilitation will result in ongoing improvement; this is not necessarily so and this point needs to be clearly explained to patients and families. However, patients who suffered a stroke can still improve after many years. There is a common belief that the most improvement happens within 6 months after a stroke but significant improvement can occur after the first 6 months and several years post stroke. These improvements are highly likely with the necessary support for both the patient and the caregiver but also with the appropriate community resources and support. (Clark, Rubenach and Winsor 2003).

Patients are sometimes discharged home when they have reached a plateau and a follow-up is arranged for the patient to be assessed with the view of further inpatient treatment if this is warranted. Patients often do well when they are home in their

familiar circumstances and with the love and care of their families and may need a short readmission for further rehabilitation to improve their independence.

Furthermore, 20 caregivers felt that an adult day care centre would be ideal as the patient would be able to socialise with other persons in a similar situation. They may get minimum therapy but it would get the patient out of the house and involved in some activities. It would also mean that the caregiver would have some time off and that the care burden is lessened. Caregivers can breakaway from the caregiving responsibility during this time and could take care of their own wellbeing by getting involved with their own activities and what is meaningful to them. Of these caregivers 42 said that transport should be provided otherwise it would be difficult to get the patient to the facility.

The role of home-based carers and the support derived from their services were positively commented on:

*I am so grateful to the home-based carers who come to wash my husband three mornings a week. They are caring, dedicated and so passionate about helping their patients. My husband has a good relationship with the home-based carers and one hears how they chat and laugh. They are such a blessing and such a help.*

This positive experience is unfortunately only reserved for a minority as most caregivers felt that the home-based carer services were inadequate or non-existent in their communities. One caregiver said:

*The home-based carers came for the first two weeks and then they just stayed away without even a reason or any replacements.*

Another caregiver informed on her experience and fear of having the home-based carers:

*I struggle on my own because the home-based carers who came to help me talk out of one's home. They come here and talk about other patients then they go and gossip about things they see in my house. I do not want them talking out of my house.*

The lack of support and the need for some respite care is expressed by this mother who does not seem to have high expectations:

*I feel like running away. Nobody relieves me from this responsibility. She (daughter) is so demanding and blatantly rude and unappreciative. I will be so grateful if the rehab centre can keep her just for a weekend so that I can rest.*

If respite care were available to caregivers the caregiver could rest and regenerate and then resume the caregiving tasks refreshed in body and mind. This will also ensure that the patient remains in the community for longer in accordance with national policy instead of being prematurely institutionalised.

Another issue that was highlighted through the qualitative data was the frustrations of long hours spent waiting at the community health centres:

*I have to spend the day at the day hospital when my husband has to see the doctor. We get there before 6 a.m. and there are lots of people already.*

*My mother is not taking any medication because she doesn't want to sit at the day hospital all day. I panic about this but my mother doesn't care.*

This situation at community health centres is of great concern because patients feel that the waiting times and sometimes even the attitude of the staff are unacceptable and they risk having further strokes and secondary complications if they do not attend appointments and receive chronic medication regularly (Department of Public Service and Administration 1997).

During the indepth interviews caregivers suggested two further solutions that can provide assistance in the community: support groups and peer counselling.

#### **4.17.1 Support groups**

It is essential for caregivers to share their fears and experiences on caregiving with those who are in the same situation and they expressed this need in the following ways:

*I want to suggest that a support group be available for the patients and for us carers because we need each other. We can share our experiences or fears and we can surely learn from each other. We can be there for each other.*

*There must be a group that we can attend otherwise you feel so lonely. I want to know how others cope with the duty of looking after your family member. Sometimes I feel I'm the only one that struggles.*

*We need to have some support group so that we as caregivers can connect and share our experiences, fears and anxieties. It is good to know there are others in the same boat. It just lightens the burden when we can share with one another. There was a stroke group at the day hospital but that no longer exists.*

Kalra et al (2004) state that interventions to attend to emotional experiences in caregivers and the provision of support programmes benefit both the caregiver and the patient. Schulz, Tompkins and Rau (1988) maintain that caregivers need to know that their well-being could be at stake with the care responsibility and that they should be encouraged not to ignore it or to feel guilty about feelings of stress and burden. They suggest that attending a caregiver support group may be beneficial because support groups provide the opportunity for reciprocal confiding, information exchange and emotional support. Family and friends should be made aware of their responsibility in offering support to the caregiver who must go well beyond the initial crisis period.

#### **4.17.2 Peer counselling and support**

Peer counselling assumes an approach where individuals who have a disability assist patients who have recently experienced the same or similar disability in an atmosphere of mutual respect, privacy and confidentiality. Peer counselling is based on the assumption that individuals who have experienced a disability can better understand and relate to individuals trying to deal with their disability. Furthermore, the person who is newly disabled is encouraged by the peer counsellor's achievements and the understanding that the peer counsellor has experienced the same fears, frustrations and feelings of hopelessness. This input from a peer

counsellor can have a major positive effect on the patient's mood, feelings of depression and hopelessness about the disability and in turn lessen the burden on the caregiver (Independent Living Research Utilization 2008).

The ward setting itself can be therapeutic as patients tend to support each other and their emotional condition may improve markedly with this support.

The social workers at WCRC are running groups and have a peer counsellor involved in a session with the group. This has a positive impact on the patients. The social workers are also planning a database to create a buddy system so that patients who are discharged are linked with a buddy. It is a very challenging period for patients once they are discharged and the buddies would be a great support for them as they would have been through all the challenges and emotions of being reintegrated into the home and community environment already. The researcher is of the opinion that these buddies should be trained and supervised to avoid any situation where a buddy could create secondary trauma.

#### **4.17.3 Fear of violence**

A caregiver expressed her feelings of fear, insecurity and feeling unsafe that seems to reflect the violence we are experiencing in our communities:

*I am so on my nerves when we collect my brother's disability grant because people get robbed and they don't care whether you are disabled or old. They don't just take your money, they hurt you too.*

SASSA have implemented a system where they transfer the beneficiary's money directly into a banking account. It prevents the beneficiaries from having to go to the pay point on days that they do not feel well or are unable to attend on that specific day. The banks have also introduced Mzansi banking accounts that charge less than half the interest rate than a normal savings account and where no bank charges are charged for these clients. The WCRC social workers have an agreement with Standard Bank who sends an official to call at the wards to open banking accounts for patients. No deposit is required to open a Mzansi account with Standard Bank. This makes it very convenient for the patient and relieves the caregiver of this burden.

#### **4.18 SUMMARY OF CHAPTER 4, SECTION 2**

This section dealt with the caregivers' demographic details, health and caregiving duties as well as rehabilitation and support services. The majority of caregivers were female. Pressures and societal expectations of women as caregivers and nurturers place an added burden on women and they may feel obliged to accept the care responsibility.

Nervous strain was the only health condition to show a significant impact on caregiver strain. Caregivers work long hours – some as many as 13 or more per day – attending to caregiving duties, household chores and children. Taking time off is not easy for caregivers as there are few formal support structures in the community. Sometimes patients are left at home unattended and exposed to many risks.

In some instances the caregiver's initial contact with health care services left much to be desired, because Batho Pele principles, the Department of Health, Western Cape Province (2007), the Constitution of the Republic of South Africa, and health care policies promising the right to health services have been poorly adhered to. The caregivers experienced high levels of physical and emotional strain in the initial period after the stroke. They worried about the health of the patient, whether the patient would suffer another stroke and whether they would manage the care responsibility. The work situation was also stressful as the caregiver had to take time off to attend to matters concerning the patient's hospitalisation, work benefits or family meetings.

The experiences of the caregivers at WCRC were explored and while some positive trends have been found like caregiver and patient involvement in goal setting and support of caregivers these areas can all still be improved on by the WCRC team. Caregivers expressed a great need for information on stroke, training and support during the acute and rehabilitation phase as well as at the time of discharge which is especially challenging for both the patient and the caregiver.

Follow-up services are lacking in the communities and once the patient is discharged home the caregivers/families feel isolated and without the necessary support. WCRC can offer support after discharge by extending a telephone call and possibly a home visit to address the problems that caregivers may be experiencing. Community

resources were found to be lacking and caregivers have suggested a community rehabilitation centre, adult day care centres, home-based carers, support groups and peer counsellors.

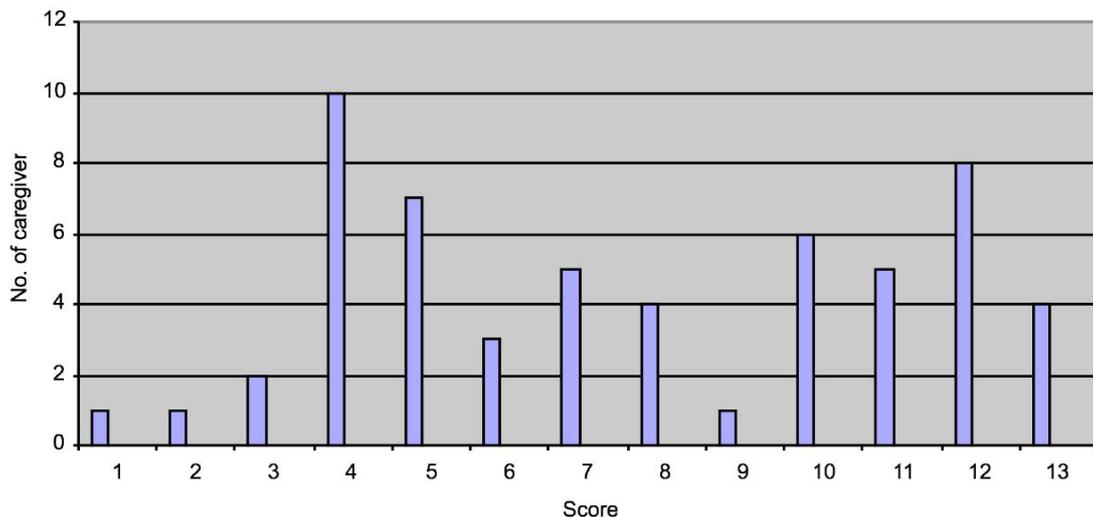
## SECTION 3

### CAREGIVER STRAIN AND SATISFACTION WITH LIFE

#### 4.19 INTRODUCTION TO SECTION 3

In this the final section results, the results from the Caregiver Strain Index (CSI) as well as the Satisfaction With Life Scale (SWLS) will be presented and discussed. Furthermore, the impact of different variables on caregiver strain will be analysed and presented.

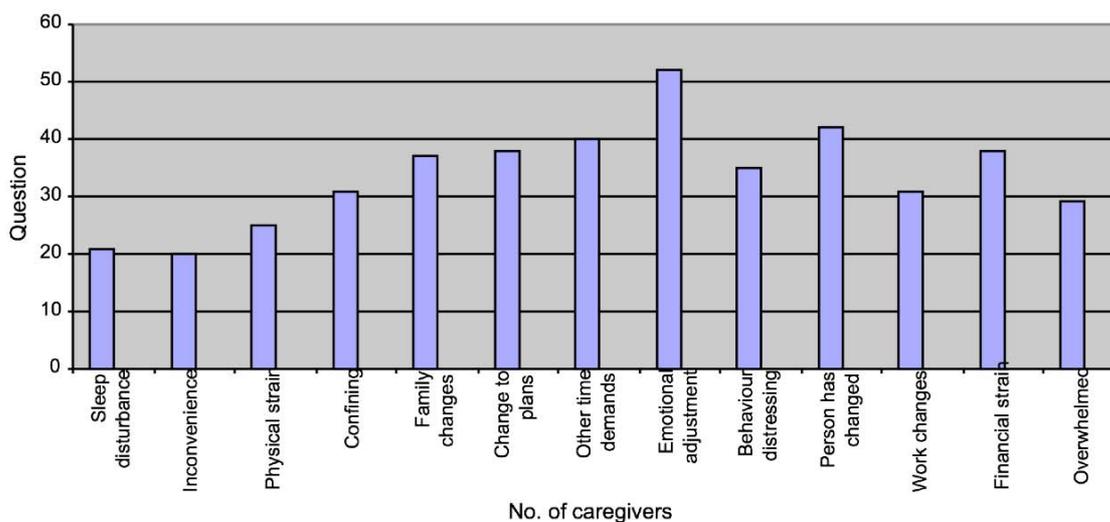
#### 4.20 STRAIN EXPERIENCED BY THE CAREGIVER



**Figure 4.25: Scores for Caregiver Strain Index (CSI)**

According to the literature reviewed a positive score on 7 or more items on the Caregiver Strain Index (CSI) indicates that the person might be at risk and in need of support or intervention (Sullivan 2002). In the current study 33 (58%) caregivers scored 7 or more on the CSI (see figure 4.25), while four caregivers scored the maximum of 13.0

This is of great concern and indicates that although patients are progressing well according to the outcome levels, caregivers are under strain and in need of support.



**Figure 4.26: Presentation of 'Yes' scores in each CSI category**

The Caregiver Strain Index (CSI) comprises 13 distinct categories (Appendix 18). In figure 4.26 the number of 'Yes' responses in each of the 13 categories are presented. Category 8 had the highest number of 'Yes' responses and indicated that 52 caregivers (91%) experienced emotional adjustment after taking on the caregiving duties. They expanded on emotional adjustment during the indepth interviews:

*After my sister's stroke she came to live with me. I was worried about her health and it was a great adjustment to have her in our 'hokkie' because it leaks, the floor is wet and even the clothing is wet from the recent rains. I am scared that this would make her sick again.*

*I was emotionally drained after my husband's discharge home but I saw improvement and that gave me strength to go on.*

The caregiver had to adjust to the 'new' husband who had been independent, her partner, her lover, her friend and the provider but who now had to be cared for. These caregivers need support and counselling as this adjustment could be difficult and emotionally exhausting.

The category that caused strain to the second highest number of caregivers was personality changes. On the CSI 42 caregivers (74%) indicated that the patient had undergone some kind of personality change and that it caused strain to the

caregivers. This is higher than the 46% that was indicated on the patient's data coding form. An explanation for this difference in findings might be the different way the two questions were structured. In the patient's data coding form it is mentioned as part of other unresolved effects of the stroke while in the CSI it is an individual question and structured in a way that refers to the impact on the caregiver.

Caregivers found this experience painful as the following reflects:

*My husband is a stranger and I do not know him as my husband. It is painful for me to look at him and think that you are not the man I married. The children are devastated as they do not know him as a father either.*

*My husband has changed since the stroke. He was an extrovert, out going and had many friends, now he has become very quiet and prefers to stay at home all the time. I have to stay home too, and I miss those outings we use to enjoy together.*

*My mother doesn't give me space, she follows me all over the house and has become so demanding. She was a very independent person before the stroke and used to travel and enjoyed her life. I can't even spend quality time with my children.*

The caregivers had difficulty understanding the patients who experienced personality changes after the stroke. It was a new person, often a stranger, whom they had to adjust to, get to know and try to understand. It was a devastating experience for the caregivers/families to get to know this person over time and to adjust to the person they had known differently before the stroke. This caused major emotional strain for the caregivers/families.

The CSI scores also indicated that the high demands on the caregiver's time caused strain in 70% (40) of caregivers as is expressed by this mother:

*I had to give up my work to look after my daughter and she takes me for granted. I spend all day looking after her and her children. They all demand my attention and don't realise that I get tired too. I don't have time for myself and have no friends since I'm caring for her. I have so many responsibilities. My body sometimes aches, so tired I get.*

Changes in personal plans (65%), the confining nature of caregiving (67%) and the financial strain (67%) experienced by caregivers scored high on the CSI. A study by Bugge et al (1999) verifies this and they report that the CSI identified that caregivers reported changes to family life, changes to personal plans and the confining nature of caregiving as three common factors that increased caregiver strain.

Caregiver strain is further highlighted by the following:

*I had to give up my work to look after my mom. It caused friction between me and my husband but I have no option, who else would have looked after my mom? My mom gives me the R210 per month she receives for the grant-in-aid.*

*My brother-in-law became my responsibility after he had a stroke. Financially it crushed us. It took a long time before his disability grant was finalised. We had to support him in every way and it was difficult.*

One caregiver expressed her feelings of being overwhelmed by her caregiving duties towards her brother and the expectations from other family members:

*I feel so overwhelmed with my caregiving duties towards my brother. I am confined to this house day and night and on top of that I have to take responsibility for the household duties because my sister is working. I feel I am being taken for granted and not being appreciated. I feel like just running away to I don't know where. I feel finished!*

She seemed visibly exhausted at the time of the interview.

The lack of resources to offer the necessary support (physical, emotional and financial) in the community is aggravating strain and caregivers mostly have to manage on their own. Sometimes community referrals must be followed up several times before the support services make contact with the patient and the caregiver because of the shortage of staff and other resources in the community.

## **4.21 Impact of different demographical and other variables on caregiver strain**

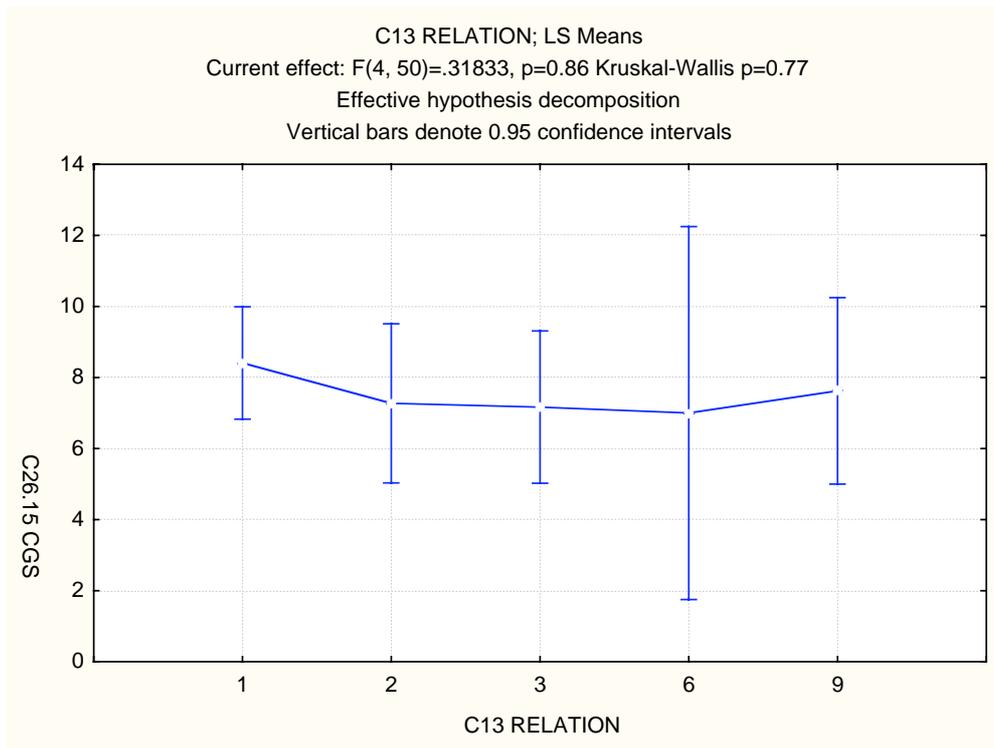
Different demographical and other details affect caregiver strain. These include the demographic relating to the patient and the caregiver, the health status of the patient and residual impairments. Other variables that affect caregiver strain are understanding the diagnosis, the outcome level of the patient at discharge, the health status of the caregiver, the duties of the caregiver, management at WCRC and community support services

### **4.21.1 Demographic details of the patient**

The patient's demographic status did not show any statistically significant impact on caregiver strain. P values were as follows: Gender ( $p = 0.37$ ), age ( $p = 0.14$ ), educational level ( $p = 0.9$ ) and marital status ( $p = 0.15$ ).

### **4.21.2 Demographic details relating to the patient and the caregiver**

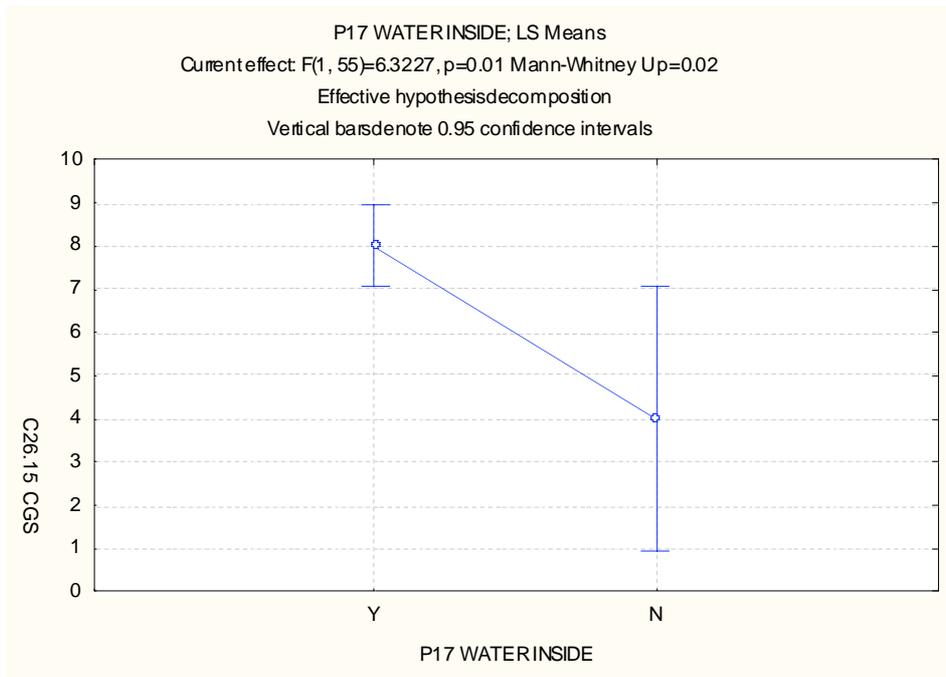
The relationship between the patient and caregiver had no statistical significance on caregiver strain ( $p = 0.77$ ). However, figure 4.27 shows a slightly higher mean caregiver strain score for spouses than for other groups of caregivers. This increased strain that spousal caregivers experience concurs with the literature (Cheung and Hocking 2004) and was verified through qualitative data from this study.



**Figure 4.27: Impact of patient-caregiver relationship on caregiver strain**

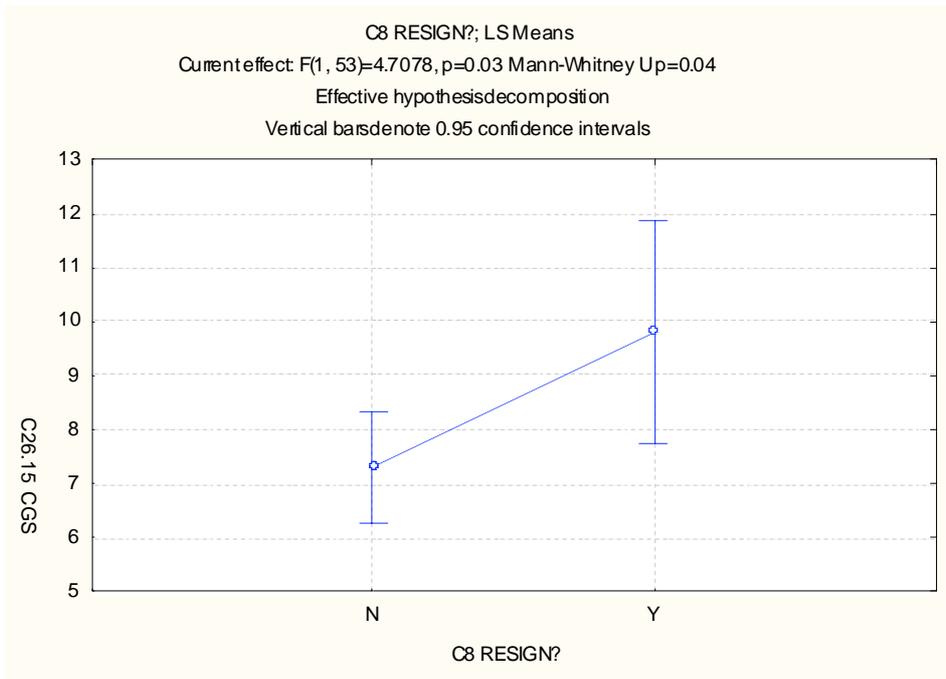
**Key:** 1 = Spouse; 2 = Parent; 3 = Child; 4 = Grandchild; 5 = Aunt/uncle; 6 = Niece/nephew; 7 = Friend; 8 = Paid caregiver; 9 = Other

The type of housing that patients and caregivers shared had no statistically significant impact on caregiver strain ( $p = 0.22$ ). With regards to basic amenities it was found that electricity in the house had no impact on caregiver strain ( $P = 0.2$ ). However, an interesting finding was made when the impact of water inside the house on caregiver strain was analysed. No running water was found to have a significantly positive impact on caregiver strain ( $p = 0.02$ ) (see figure 4.28). This might be because of the very small number of caretakers (5) who did not have running water inside the house, but further investigation is needed to determine the cause of this finding.

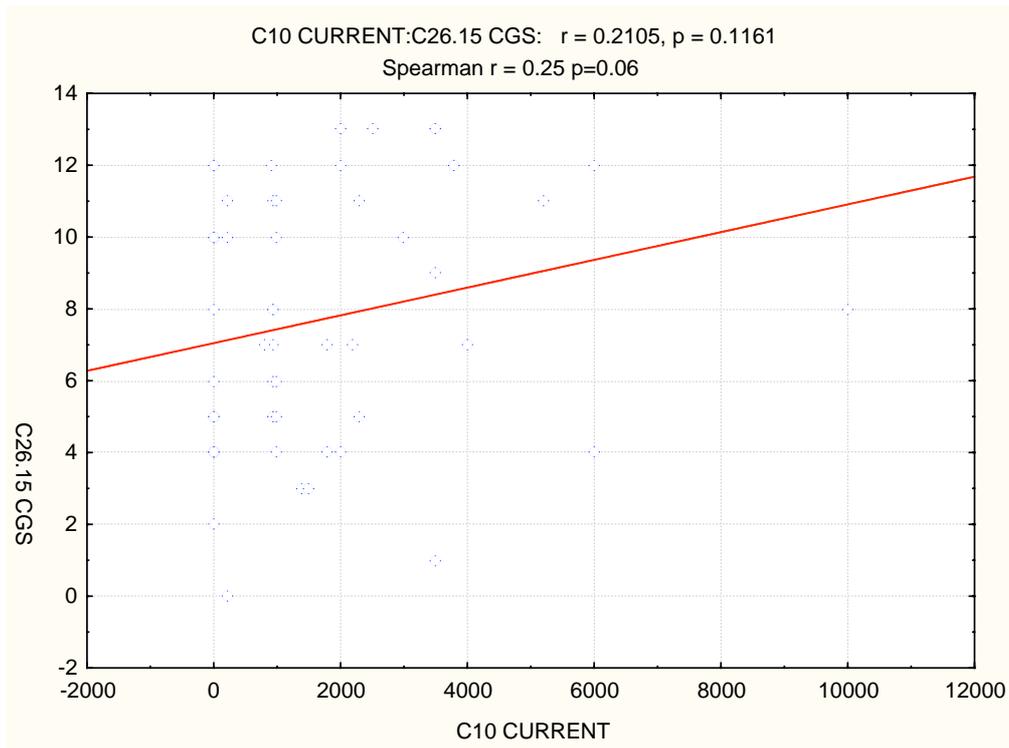


**Figure 4.28: Impact of availability of running water in the house on caregiver strain**

Figure 4.29 shows that resignation from employment by caregivers in order to take responsibility for the patient had a statistically significant impact on caregiver strain ( $p = 0.04$ ). Clinically the difference in mean strain scores are also notable, with those caregivers who resigned from employment having a mean score of 9.8 versus a mean score of 7.3 for those who did not have to resign employment. This had an impact on the financial independence of the caregiver as is indicated by the fact that the current income of the caregivers, although not statistically significant, does at  $p = 0.06$  have some impact on strain. The general low income levels of the study population are also exposed in figure 4.30. The huge strain that financial problems caused was verified through the qualitative findings of this study as discussed under 4.4.4 Type of accommodation and basic amenities.



**Figure 4.29: Impact of resignation from employment on caregiver strain**



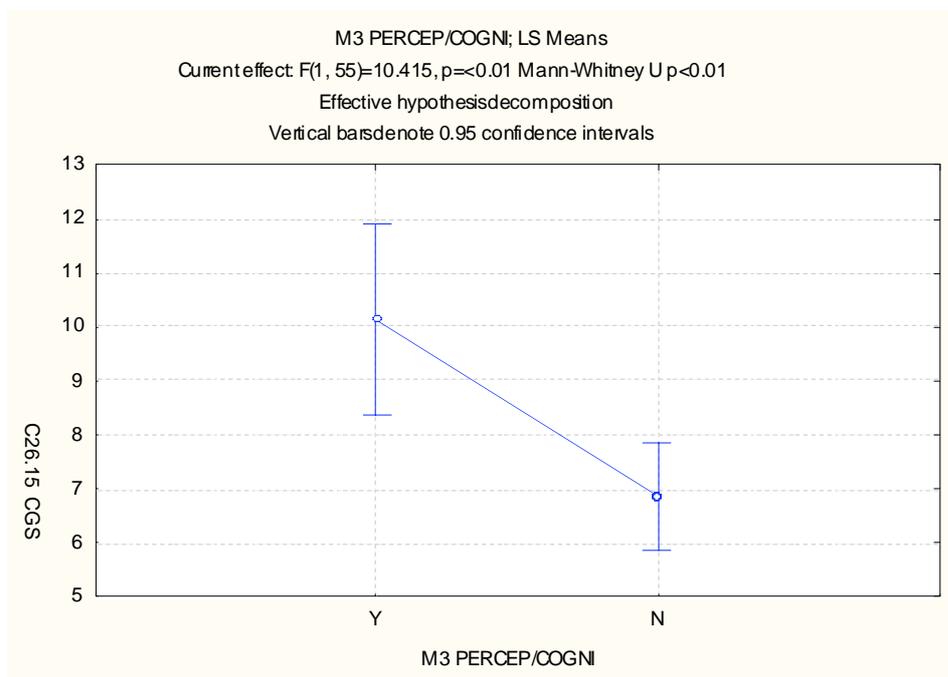
**Figure 4.30: Impact of current income on caregiver strain**

### 4.21.3 Health status of the patients

None of the health conditions/risk factors from which patients suffered had any statistically significant impact on caregiver strain as the following p values indicate: Hypertension  $p = 0.56$ , diabetes mellitus  $p = 0.24$ , cholesterol  $p = 0.34$ , cardiac problems  $p = 0.69$ , obesity  $p = 0.66$ , smoking  $p = 0.20$ , nervous conditions  $p = 0.96$ , arthritis  $p = 0.20$ , cancer  $p = 0.70$  and other conditions  $p = 0.17$ . The presence of more than one of these risk factors/health conditions in the same patient also did not show a significant impact on caregiver strain ( $p = 0.30$ ). Neurological conditions, lung conditions and tuberculosis could not be statistically compared with caregiver strain because one of the categories for these variables had too few cases for comparison with the ANOVA or with the Mann Whitney Test.

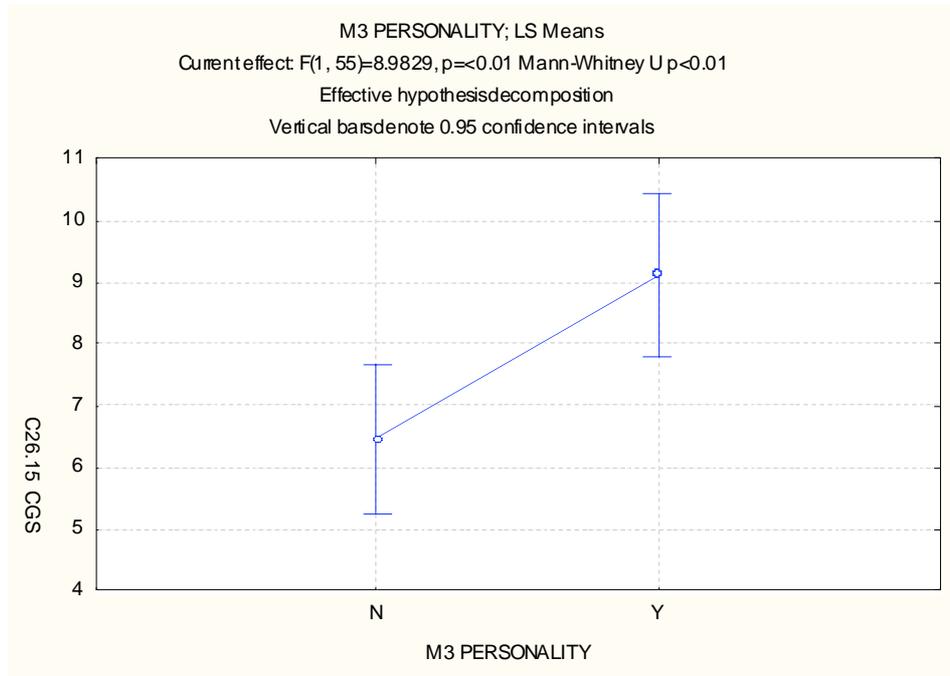
### 4.21.4 Patients residual impairments

Problems related to perception and cognition as well as personality changes showed a statistically significant impact on caregiver strain. Both had a p value of 0.01 as figures 4.31 and 4.32 indicates.

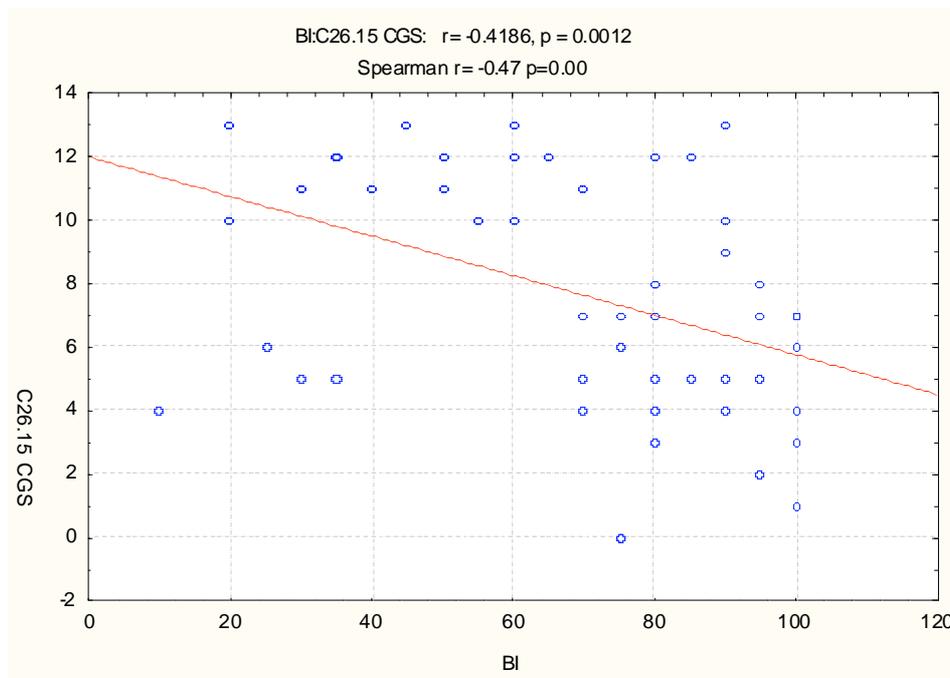


**Figure 4.31: Scatter plot on the impact of cognitive and perceptual problems on caregiver strain**

Furthermore, both showed quite a difference in mean scores (3.2 and 2.6) and score ranges between strain experienced by caregivers of patients with these problems and caregivers of patients without these problems. The findings are verified by qualitative data as discussed at the beginning of this chapter.

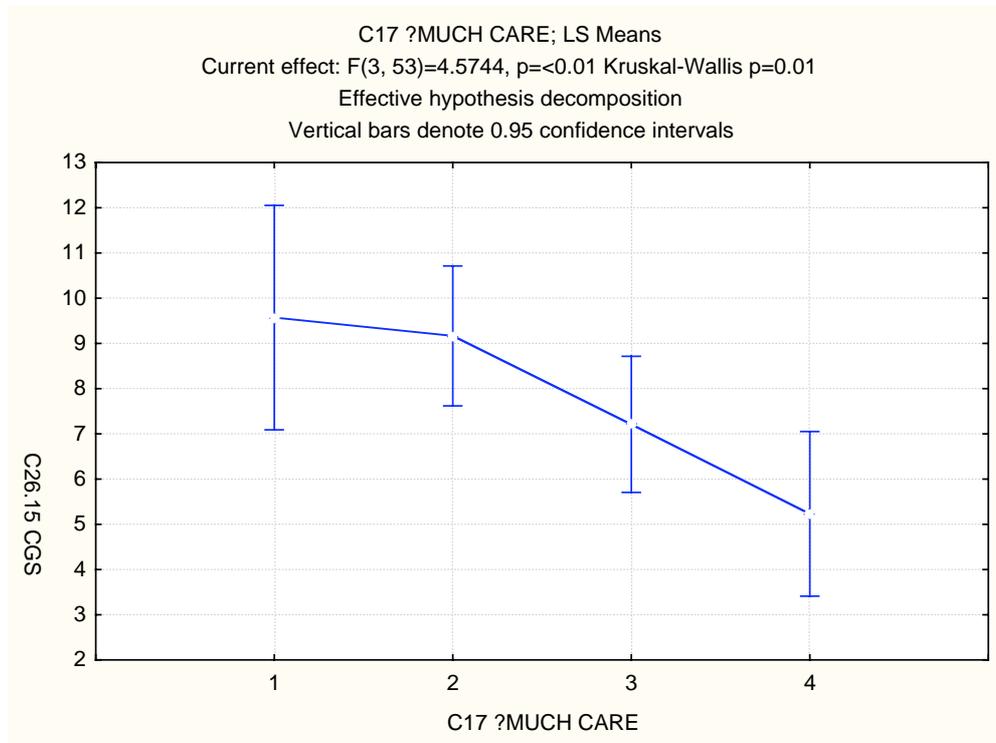


**Figure 4.32: Scatter plot on impact of personality changes on caregiver strain**



**Figure 4.33: Scatter plot on the impact of BI scores on caregiver strain**

As can be expected and as shown in figure 4.33 lower BI scores that indicate higher levels of physical dependence caused statistically significantly more strain on caregivers than higher BI scores ( $p = 0.0012$ ).

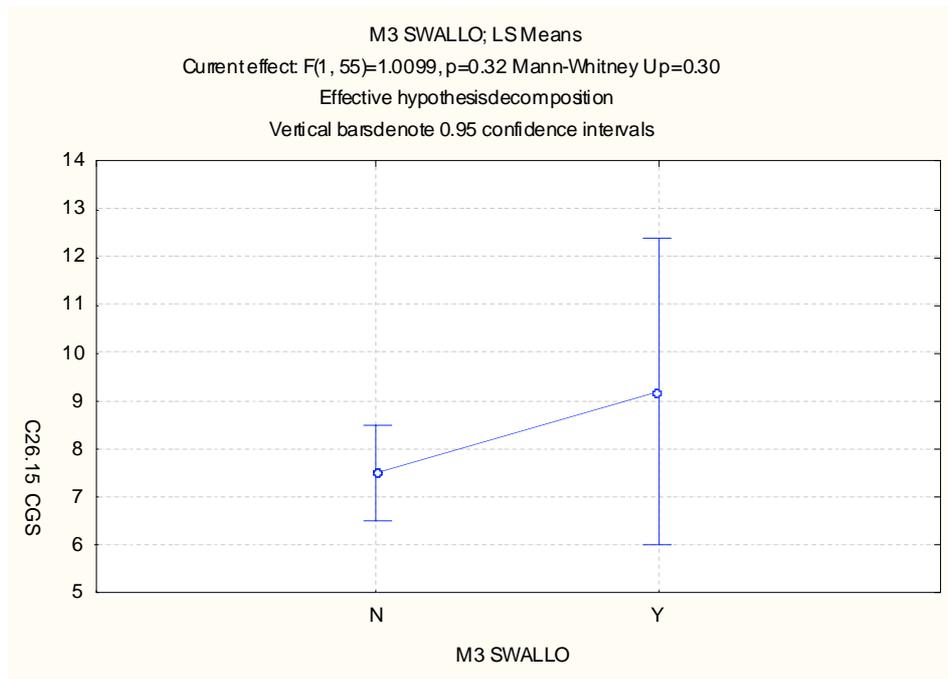


**Figure 4.34: The impact of level of care needed by patient on caregiver strain**

**Key:** 1 = Maximum care; 2 = Moderate care; 3 = Assistance; 4 = Supervision

This is also confirmed by the fact that caregivers who provide maximum or moderate levels of care experienced higher mean levels of caregiver strain than those who gave only assistance and supervision as shown in figure 4.34. The level of care also had a statistically significant impact on caregiver strain ( $p = 0.01$ ).

Contrary to literature findings communication problems did not show a statistically significant impact on caregiver strain ( $p = 0.6$ ) and neither did swallowing problems ( $p = 0.3$ ) (see figure 4.35).



**Figure 4.35: The impact of swallowing problems on caregiver strain**

The mean CSI scores for caregivers of patients with and without communication problems were virtually the same at 7.8 and 7.3. There is however some difference in mean swallowing scores. Figure 4.35 indicates that caregivers of patients who did have swallowing problems had a mean CSI score of 9.2 and caregivers of patients with no swallowing problems had a mean score of 7.5. Furthermore, the upper range of the scores for caregivers of patients with swallowing problems is much higher than for caregivers of patients without swallowing problems as figure 4.34 shows. This is in keeping with the frustration some participants expressed with regards to swallowing problems in the interview.

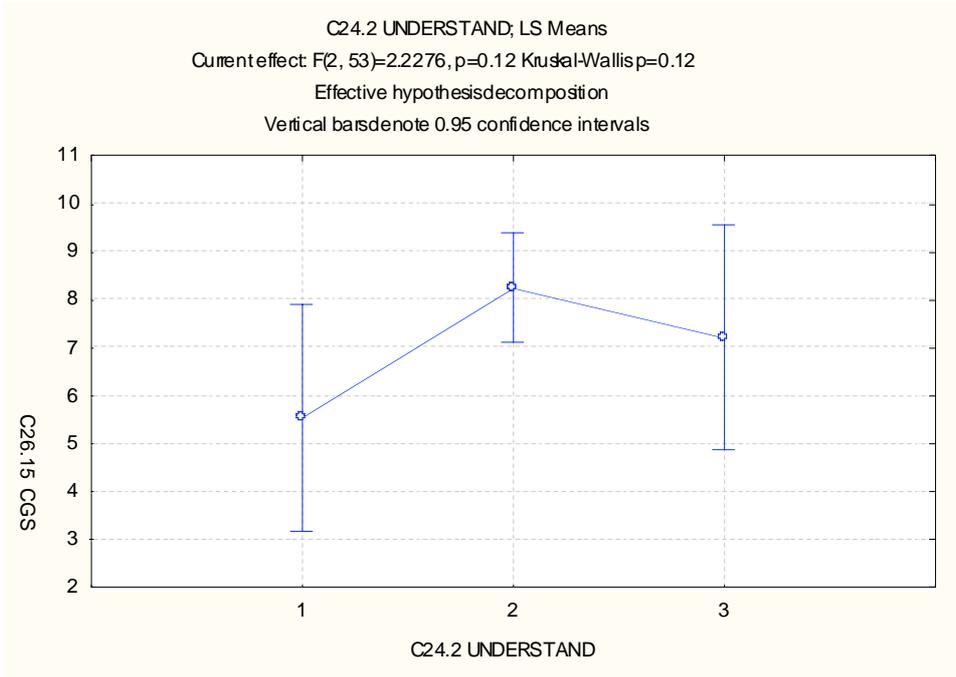
The impact of memory on caregiver strain showed no statistically significance ( $p = 0.78$ ). The mean scores for the two groups were virtually the same. The only difference is a much wider distribution of scores for the group of caretakers who took care of patients with memory problems than for the other group.

#### 4.21.5 Understanding of diagnosis

When a statistical analysis of the impact of understanding the diagnosis on caregiver strain was done no significance could be found ( $p = 0.12$ ). However, a closer look at figure 4.36 shows that the group who only partially understood as well as the group

that did not understand the diagnosis did experience clinically more strain. Their distribution is higher than that of the group who did understand the diagnosis and their combined means are also higher at 7.7 versus 5.5.

Caregivers were asked to explain what they understood a stroke was in their own words and the basic information on stroke was expected, like, does the carer understand that the stroke occurs in the brain, that the paralysis is a result of the injury to the brain and that it affects the opposite side of the body, the risk factors and the prevention of further strokes.



**Figure 4.36: Comparison of caregiver strain on caregivers who did and did not understand the diagnosis**

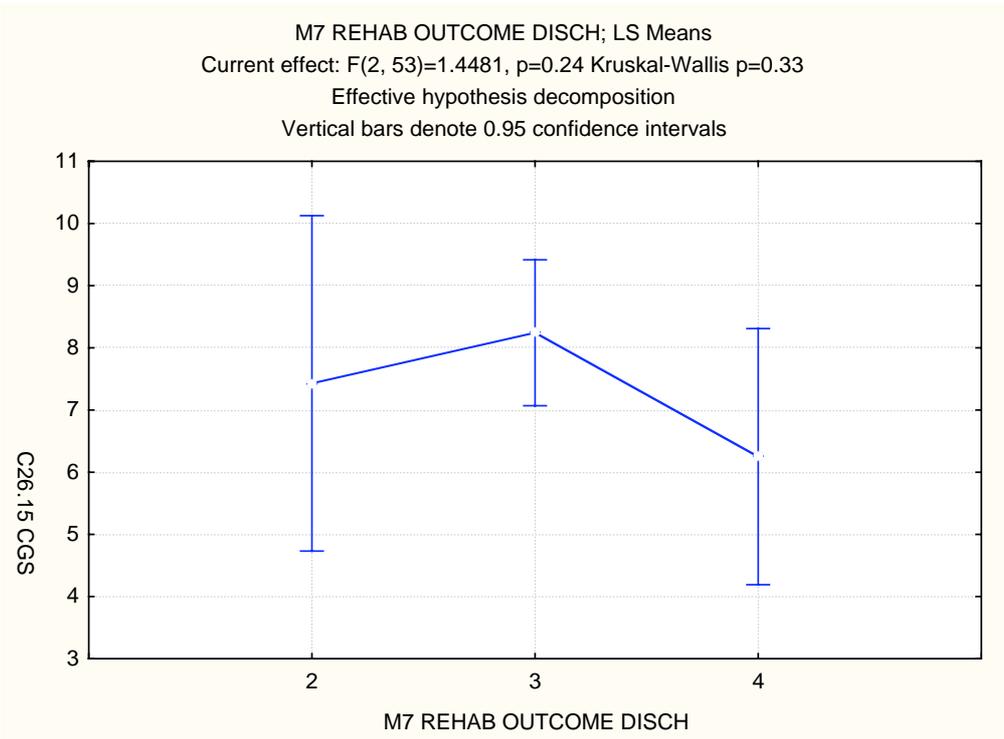
**Key:** 1 = Did not understand at all; 2 = Partly understood; 3 = Fully informed

**4.21.6 Outcome levels at discharge**

Discharge outcome levels showed no significant impact on strain (p = 0.33). However, those caregivers caring for patients on level 4 had a slightly lower mean score than the other two groups as seen in figure 4.37.

A study done by Anderson et al (1995) compared early discharge (plus home-based care) to inpatient rehabilitation (with follow-up care) of stroke patients, and found the

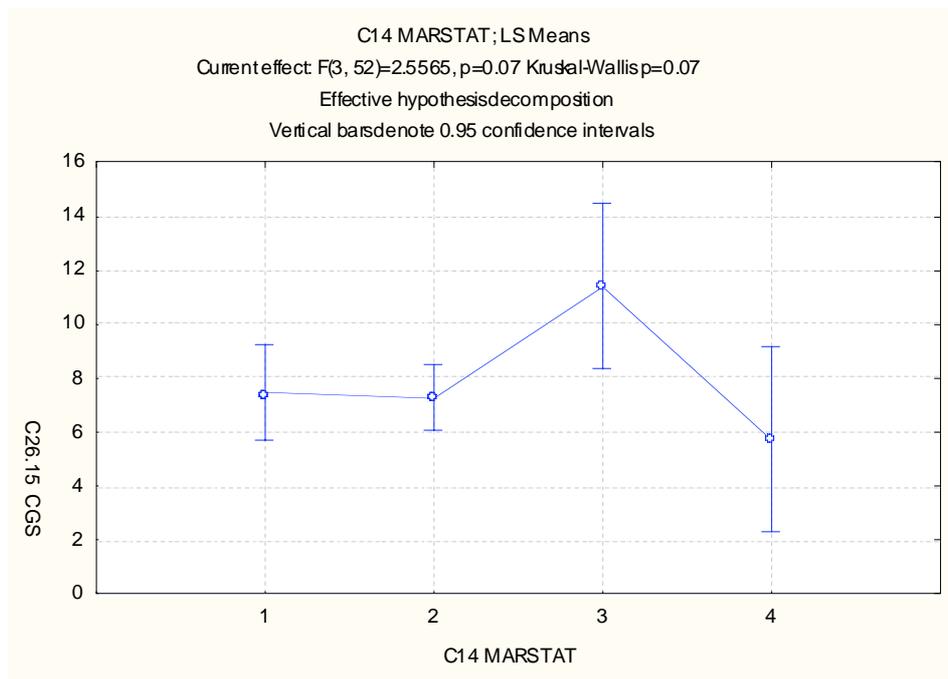
recovery in the patients was the same in both situations. However, the caregiver's mental health was found to be more adversely affected where there was an early discharge home of patients. This finding is confirmed in a study by Hale (2004) who found evidence that stroke rehabilitation in the community significantly improves personal and extended activities of daily living, and does not result in functional deterioration. However, this model of service delivery does result in greater caregiver stress. Hale (2004) continues that community-based stroke rehabilitation can be confusing, as interventions and services are not well defined.



**Figure 4.37: Comparison of caregiver strain and discharge outcome levels**

**Key:** 2 = Basic rehabilitation outcome; 3 = Intermediate rehabilitation outcome;  
 4 = Advanced rehabilitation outcome

#### 4.21.7 Demographic details of the caregiver



**Figure 4.38: Impact of marital status on the caregiver strain**

**Key:** 1 = Single; 2 = Married; 3 = Divorced; 4 = Widowed

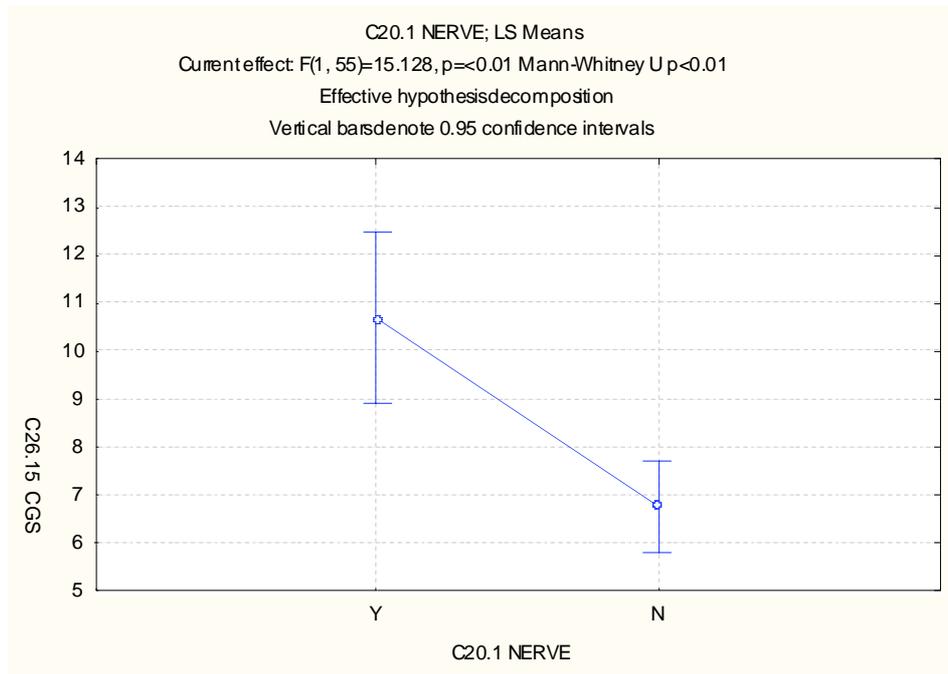
The age ( $p = 0.52$ ), gender ( $p = 0.78$ ), ethnicity (0.19) and educational levels ( $p = 0.67$ ) of the caregiver showed no statistically significant impact on caregiver strain. Figure 4.38 show that caregivers who were divorced experienced higher levels of strain with a mean score of 11.4 while means for the other groups are all below 8. Although not statistically significant at  $p = 0.07$  one should take cognisance of the fact that divorcees might experience higher levels of strain in their role as caretakers than persons who are married, single or widowed. It must also be taken into account that divorce in itself is a very traumatic experience and might cause higher general levels of strain in an individual.

#### 4.21.8 Health status of the caregivers

The only health condition to have a statistically significant impact on caregiver strain was nervous strain ( $p = 0.01$ ). Clinically the impact of nervous strain was also notable with a difference in mean scores of 3.9 as shown in figure 4.39.

Caregiver strain may imply much broader aspects than just nervous strain which may aggravate the situation. The caregiver may be anxious and worried about all her tasks she has to complete during the day. The caregiver may not have the necessary

support and a lack of time can cause nervous strain and places the caregiver under much pressure.



**Figure 4.39: Impact of nervous condition on caregiver strain**

P values for the other health conditions were as follows: Hypertension  $p = 0.86$ , diabetes mellitus  $p = 0.83$ , cardiac conditions  $p = 0.99$ , arthritis  $p = 0.52$  and back problems  $p = 0.44$ . Caregivers in poorer health were found to be under greater strain. So too were those caregivers who spend much time helping the patient and those caring for patients who were more dependent on care (Bugge et al 1999).

#### 4.21.9 Caregiver duties

Although not statistically significant at  $p = 0.07$  the analysis does indicate that one should keep in mind the effect of long hours that caregivers spend taking care of the patient. Whether caregivers were remunerated for their duties or not did not show an impact on strain ( $p = 0.35$ ). However, it could be argued that even those who did receive remuneration received so little that it did not really assist in alleviating the financial problems that caregivers experienced.

Longer hours spent on household duties had no significant impact on caregiver strain ( $p = 0.1$ ) and persons spending little or no time on household duties had similar mean caregiver strain scores than those spending 5 and more hours on household duties.

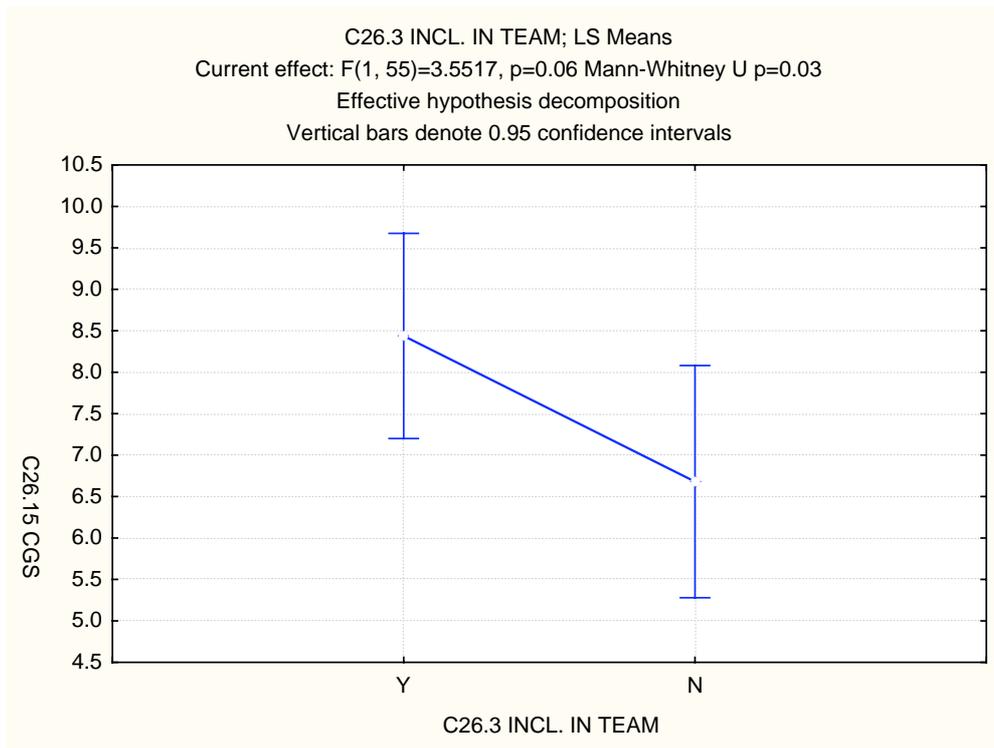
The number of dependent children did not have a statistically significant impact on caregiver strain ( $P = 0.10$ ). On the other hand, regular time off showed a positive statistical significance on caregiver strain ( $p = 0.03$ ). During this time off the caregiver is relieved of the caregiving duties and is able to relax, rejuvenate and be energised to resume the caregiving duties. However, some of the study participants were not able to enjoy time off or the luxury thereof since they did not have the necessary support systems and most importantly there is a lack of community support resources that consequently impacts largely on the well-being of caregivers.

#### **4.21.10 Management at WCRC**

Statistical analysis of variables indicates that no aspect of caregiver involvement in the rehabilitation process at WCRC had a statistically significant impact on caregiver strain. Whether caregivers were trained or not before the patient's first weekend home showed no statistical significance on caregiver strain ( $p = 0.87$ ). The support from the rehabilitation team and meeting the needs of the caregivers also showed no statistical significance on caregiver strain with  $p$  values of 0.69 and 0.22 respectively. Neither did any of these variables show any clinical impact on strain experienced by caregivers.

An explanation for these findings could be the time lapse since discharge and the time of the interview as well as the severe lack of support systems in the community, which could diminish or even nullify the expected benefits of training and support by the rehabilitation team. It could also be that even while caregivers were trained and felt supported that it was not enough to provide them with the knowledge and strength needed for long-term caring and that training, support and meeting their needs should be an ongoing process.

A surprising finding was that those caregivers who felt included by the rehabilitation team experienced statistically significantly more strain than those who did not feel included ( $p = 0.03$ ).



**Figure 4.40: Impact of inclusion in the rehabilitation team on caregiver strain**

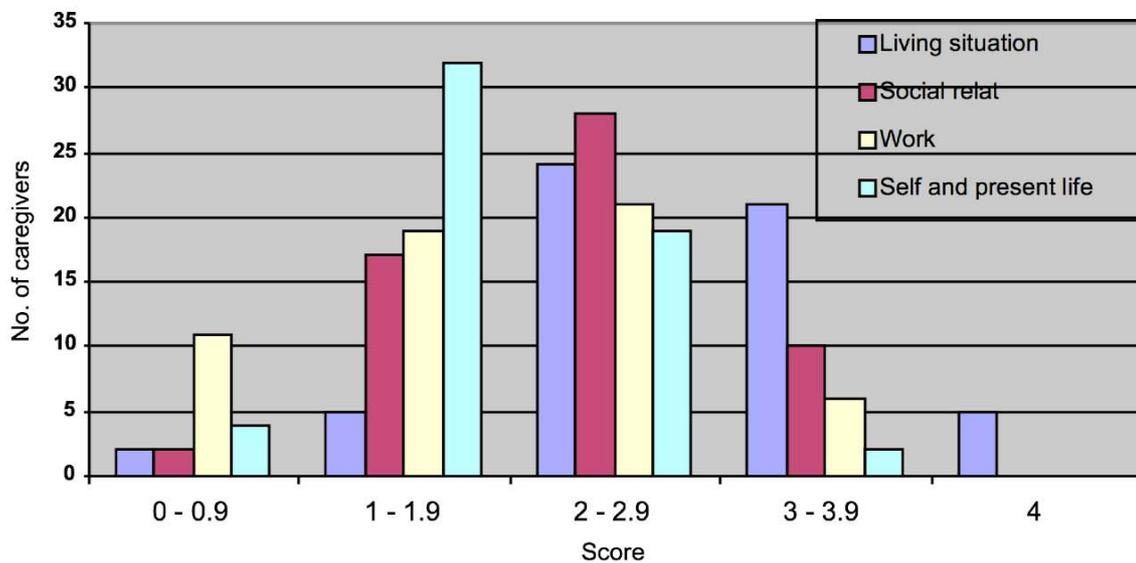
A possible reason for this finding might be that the caregivers who were included in the team placed greater pressure on themselves as they did not want to let the team down, while those caregivers who were not included in the team felt less pressure in performing their caregiver duties since they did not feel the need to prove themselves. Another reason could be that caregivers felt that the team expected them to perform their duties and as a result caregivers had difficulty expressing their anxieties or requesting help for fear that this would be seen as a sign of failure or inadequacy (Anderson et al 1995).

#### **4.21.11 Community support services**

The community support services that caregivers utilised after the patients were discharged home showed no statistical significance on the caregiver strain ( $p = 0.33$ ). This could be due to the fact that very few caregivers received any support services. Caregivers identified a great need for different services in the community as discussed under 4.17 Community support services.

## 4.22 SATISFACTION WITH LIFE OF THE PRIMARY CAREGIVER

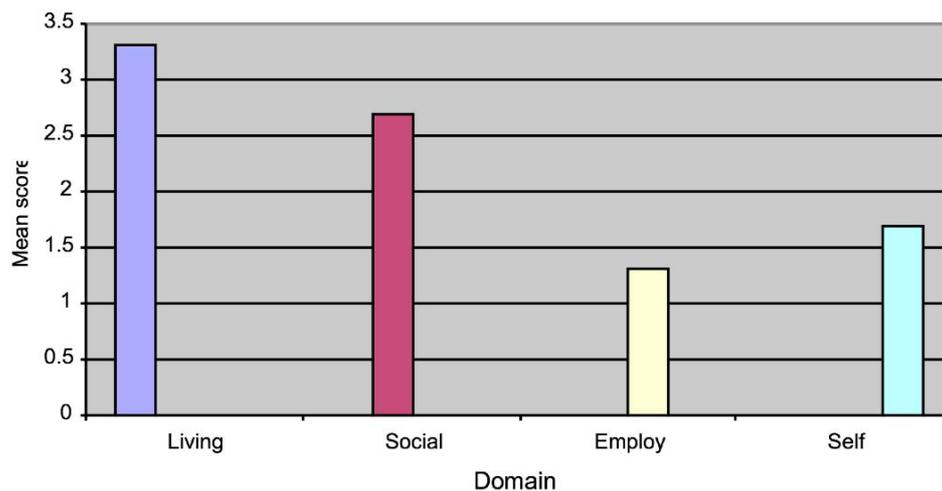
As discussed in the literature review, SWLS is measured in four domains, namely, living situation, social relationships, employment/work as well as self and present life. Figure 4.41 presents these scores in comparison to each other while the mean scores of caretakers in each of these domains are illustrated in figure 4.42. Caregivers show a medium level of satisfaction in most areas with scores of 1.0 to 2.9 being the most frequent. However, employment/work showed a very low level of satisfaction for 11 caregivers (19%), which is in accordance with the finding that 11 caregivers had to resign from their employment.



**Figure 4.41: Presentation of scores in the four domains of the SWLS**

According to figure 4.42, employment with a mean of 1.25 is the area with the lowest mean satisfaction score. This is followed by self and present life that represent areas like satisfaction with the way one's days are spent, one's psychological condition and oneself on the whole, as well as one's freedom and enjoyment of life, where 32 caregivers scored between 1 and 1.9, with a mean of 1.6. The lack of satisfaction that caregivers experienced in these areas and the sacrifices they had to make have been clearly demonstrated by both quantitative as well as qualitative findings as discussed in the previous two sections of Chapter 4, that is, the changes the caregivers had to make in their personal plans, the confining nature of their caregiving duties, the financial strained experienced and the demands on their time.

Only in one area, namely. living situation, which refers to issues like satisfaction with where one lives, physical space, privacy and food did some of the caregivers, albeit only five (9%) score the maximum of 4 as shown in figure 4.41. This area also shows the highest mean in figure 4.42. In the opinion of the researcher this can be attributed to the fact that most caregivers still live in their own homes in more or less the same physical circumstances as prior to their caregiving duties.



**Figure 4.42: Presentation of mean scores in the four domains of the SWLS**

Scores from different domains of the SWLS were statistically compared to BI scores to determine the impact of physical dependence of patients on caregiver SWL as well as with CSI scores to determine if higher caregiver strain indicates lower SWL.

Findings indicated that the physical dependence of patients as measured by the BI had a statistically significant impact on two of the four domains of satisfaction with living. These are social relationships ( $p = 0.03$ ), as well as self and present life ( $p = 0.0046$ ). Employment/work showed marginal significance with a  $p$  value of 0.06 and living situation was not significantly affected at all with a  $p$  value of 0.4. The patient's level of dependence on care and the intensity of the care responsibility mean that the caregiver has less time for him or herself. The physical strain becomes a burden on the caregiver as this responsibility becomes longer.

The caregiver may have difficulty getting time off to enjoy outside of the home environment or to take responsibility for his/her own well-being.

Higher CSI scores significantly impacted on most areas of SWL as p values of 0.0001 for social relationships, 0.01 for employment and 0.000 for self and present life shows. Again only living situation was not significantly affected ( $p = 0.36$ ).

#### **4.23 SUMMARY OF SECTION 3, CHAPTER 4**

The results of this section reflect the strain experienced by the caregiver, the significance that different variables had on strain and the impact of caregiving on the caregiver's satisfaction with life.

More than half of the caregivers experienced levels of strain to indicate that they are at risk and in need of intervention. Specific areas that caused strain were found to be the emotional adjustment to the caregiving duties, which is aggravated because the community support services were lacking; personality changes in the patient; high demands on the caregiver's time; the need to make adjustments like terminating employment; abandoning plans previously made; and adjusting to financial dependence.

The following variables had a statistically significant impact on caregiver strain: Resignation from work in order to take responsibility for the patient; nervous strain in the caregiver; the level of physical dependence of the patient; and the presence of perceptual and cognitive problems as well as personality changes after the stroke. Time off showed a positive statistically significant impact on caregiver strain.

The domains of employment and self actualisation showed the lowest satisfaction with life according to the SWLS.

## **CHAPTER 5**

### **CONCLUSION AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

The aim of the study was to determine the impact of stroke on the primary caregivers of patients who received comprehensive rehabilitation during the period of 1 January 2006 to 31 December 2006, at the Western Cape Rehabilitation Centre (WCRC), and who have subsequently been discharged home into the care of a caregiver. Findings indicated that caring for a stroke patient caused high levels of strain and decreased life satisfaction in caregivers. In total 58% of caregivers experienced levels of strain indicative of a need for support and intervention. The domains of employment and self actualisation were most adversely affected by caregiving duties. Areas that were found to cause the most strain were the emotional adjustment to the stroke and caregiving, personality changes in the patients, cognitive and perceptual problems with behaviour changes, other demands on the person's time, having to adapt one's own plans and changes in one's family life, loss of employment, financial problems and the confining nature of caregiving duties. Other factors that caused strain were a lack of knowledge, information and training on stroke and stroke care, a lack of community resources and a lack of support services once the patient is discharged home to the caregiver.

#### **5.2 DEMOGRAPHICS, HEALTH STATUS, RESIDUAL IMPAIRMENTS AND OUTCOME LEVELS**

The risk factors which were most prevalent amongst the patients were hypertension and diabetes. Qualitative findings suggest that in some instances patients did not take their medication for these chronic diseases regularly. While specific explanation of risk factors were not assessed in the study the findings on stroke education suggests that this might also be a neglected area. Risk factors should be explained to the patient and the caregiver and prevention of further strokes and healthy

lifestyles should be promoted. Information on the importance of why the patient needs to take medication and have regular medical check-ups must be emphasised. It must be determined whether this information is understood because patients often stop their medication when they feel better and then they may suffer a stroke without realising that the medication was actually making them feel better.

Physical dependence, cognitive and perceptual problems as well as personality changes were all found to have a significant impact on caregiver strain. Findings in terms of the patient's residual impairments and outcome levels at the time of the interview show a high level of correlation. An outcome level of four or five implies a high level of cognitive independence while physical assistance is allowed. It also implies the ability to communicate, in one way or another, with strangers. Findings indicate that 39 patients reached an outcome level of four or five, 37 patients did not need high levels of physical support according to the BI and 43 did not experience cognitive and perceptual problems in the opinion of the caregiver. Thus this is very much in accordance to what one would expect or one might even expect higher levels of community integration since an extra four patients should presumably have the ability to cognitively integrate. However the finding on cognitive and perceptual problems is open to some questioning since this aspect was not formally assessed, but rather based on the perceptions of caregivers. Cognitive and perceptual changes can often be very subtle and difficult to identify, therefore the number of patients suffering from these impairments might be higher especially since literature suggest that most stroke patients suffer from these impairments to some extent. In accordance with above findings 20 caregivers indicated a need for adult day care (18 patients did not reach outcome level four and 20 needed high levels of physical assistance according to the BI). The need for day care become even more apparent when one takes into account that according to the BI 22 patients needed assistance to use the toilet. Thus, even if these 22 people need no other assistance they cannot be left alone for more than a few hours at a time. This implies that none of their caregivers would be free to seek employment and so decreased the financial burden that many of the families experienced.

Another aspect that warrants mentioning is that the BI fails to measure the amount of physical support that a patient needs to integrate into the community. Findings show

that 52 patients in the current study needed physical assistance to enter the community. Thus many of those on level 4 and 5 needed someone to assist them with aspects like transferring to and from vehicles and they can therefore not access the community independently (assistance to access the community and employment is allowed within outcome level four and five as long as the patient directs the assistant). One wonders what benefits CBR programmes would have held for these patients and their caregivers. While 25 caregivers indicate a need for community rehabilitation services it is clear from the qualitative comments that they are thinking more about therapy than CBR. However, CBR is a new and relatively untried concept and it is conceivable that patients and families do not know about its purposed benefits. But the researcher is of the opinion that if these patients could have been integrated into CBR programmes where they are actively involved in some form of productive activity while therapeutic needs are attended to as necessary it would have been highly beneficial to them as well as their caregivers. It might even have assisted some patients to integrate back into the open labour market again.

The issue of communication raises some controversy since it was not found to have a statistically significant impact on caregiver strain while literature identifies it as one of the biggest causes of strain in caregivers. Furthermore, it is conceivable that some of the 36 patients with communication problems might also need a caregiver to act as interpreter during conversations necessary for community integration such as communicating with shop assistants.

### **5.3 HEALTH STATUS OF THE PRIMARY CAREGIVERS**

The most commonly encountered medical condition experienced by the caregivers was hypertension which they controlled through medication. The fact that 13 of the caregivers complained of nervous strain shows the psychological impact of caregiving on the individual and highlights the need for psychological support in the community in the form of support groups and professional counselling.

Community support services/resources are crucial to ensure caregiver well-being. The services could vary in input according to needs, for example, the home-based carers could visit and attend to the patient in the home for a couple of hours per day

or every second day, adult day care centres could provide care for 3 to 5 days a week, respite care could provide a holiday period of a minimum of two to four weeks to caregivers and CBR programmes could provide rehabilitation towards full integration.

#### **5.4 EXPERIENCES OF CAREGIVERS DURING THE ACUTE PHASE**

The majority of patients (72%) experienced a first ever stroke and both the patient and the caregiver were deeply traumatised by the event. Initially the patients and caregivers were in a state of shock and needed urgent access to medical services. As shown in the results section this access was delayed for some. A stroke is a medical emergency and should be treated as such instead of turning patients away from hospitals or letting them sit and wait for long periods. While one has sympathy with overburdened health care workers one would expect them to be able to identify when a patient has a serious condition like a stroke and to respond quickly and competently. It is the intention of the researcher to bring the information to the attention of the authorities at the institutions that were involved in unfortunate incidents where patients were not attended to promptly.

#### **5.5 INFORMATION, EDUCATION AND TRAINING ON STROKE AND STROKE CARE**

Caregivers expressed a lack of knowledge on stroke which professionals failed to adequately address. Knowledge breeds confidence and where there is a lack of knowledge caregivers will experience overwhelming strain, negativity and fear towards caregiving. Patients and caregivers gain confidence and are empowered when they are informed and understand the diagnosis, prognosis, treatment procedures and risk factors. This information must be shared and reinforced through various methods, but should also include personal sessions with health care professionals to ensure that information is relevant for the particular patient.

Similarly not all caregivers were trained in the physical aspects of stroke care. For instance, only half of the caregivers (54%) in this study indicated that they received

training on how to care for the patient before the patient spent his/her first weekend home. This is not acceptable as WCRC policy states that all caregivers must be trained before the patient spends the first weekend at home. While omission of training did not have a statistically significant impact on caregiver strain the researcher maintain in the light of literature emphasis on this aspect that training of caregivers are crucial to protect the patient and the caregiver against injuries and to decrease anxiety at this stressful time. This is supported by the fact that at least one caregiver hurt her back while performing caregiving duties.

## **5.6 SUPPORT AND INCLUSION OF PRIMARY CAREGIVERS BY THE REHABILITATION TEAM AT WCRC**

The caregivers and the patients generally felt welcome at the time of admission to WCRC and felt that the rehabilitation programme was explained to them. Caregivers said this made them feel at ease and they felt confident that the patient would be well taken care of.

Unfortunately, figures on the inclusion of caregivers in the team, on supporting caregivers and allowing caregivers and patients to become part of the team and goal setting process were less favourable. While these things were done in many instances it should have been done in most if not all instances as WCRC follows an interdisciplinary team approach, that bases patient management on the social model of disability and that is hailed as a model for the province. However, the lack of statistical significant impact of these actions on caregiver strain causes one to reflect on the purpose of such actions. It has at its core the empowerment of patients and families to take control over their lives and rehabilitation. Being in control however does not mean that one is exempted from experiencing strain in a situation. Therefore the comparison of these aspects of rehabilitation with caregiver strain might have been uncalled for.

## 5.7 FOLLOW-UP SERVICES

Caregivers felt unsupported and without the necessary assistance, guidance and relief from their caregiving tasks once patients were discharged. It is usually only after discharge that the full realisation dawns on the caregivers of the extent of the responsibility, their limitations and the loss of independence. Support from the WCRC as well as from community services at this point is crucial. Support includes home visits and telephonic follow-up by the WCRC team, CBR and ongoing rehabilitation as well as support groups, home-based care, day care centres and respite care.

Caregivers need support from various official bodies, for example, health services, social services, transport services, housing services, recreational services as well as, community resources, support groups and family/friends. These services must be coordinated in order to ensure efficiency, effectiveness and quality. Unfortunately these resources and support systems are lacking in the communities. It would be in the interest of the patients, the caregivers, the communities and society that the various government departments implement the services promised by the Department of Health: Western Cape Province (2007). These services should be regularly monitored and reviewed and staff should be adequately trained with the Batho Pele principles enforced throughout the various levels of health services.

There are a few resources available, but they cannot cope with the large numbers of patients and caregivers in need and patients and caregivers from adjacent communities need transport to access these services.

Furthermore, patients often have to deal with long hours of waiting at their local Community Health Centres to see the doctor or to collect their medication on follow-up appointments. On top of that they sometimes found the staff to be unfriendly and impatient which is contrary to the Batho Pele principles. The problem is so big that at least one patient decided to forgo medication.

## **5.8 RECOMMENDATIONS**

### **5.8.1 Recommendations with regards to primary health care**

While Primary Health Care are at the core of South Africa's health policy implementation of this philosophy in South Africa is under severe strain. Various reasons for this are discussed in depth by authors such as Kautzky & Tollman (2008) and Sanders & Chopra (2006) and include a shortage of health care workers, the impact of HIV/AIDS, managerial deficiencies and a lack of resources. These problems are deep seated and will not resolve themselves overnight. However in the interim there is a need to ensure that patients suffering from a serious condition like a stroke are identified immediately and that their needs are responded to quickly and competently. Performing a quick screening of every person who presents at clinics to identify those with serious conditions and then subsequent fast tracking of those patients might be an interim solution.

### **5.8.2 Recommendations to WCRC**

Certain areas of stroke management have not been addressed sufficiently by the team at WCRC. The most important of these is education and information on stroke and its effects as well as training caregivers to physically care for patients, and equipping caregivers with strategies on how to deal with difficult situations in respect of behaviour, cognitive, perceptual and memory problems that the patient might be experiencing after the stroke. Furthermore, the team must support the caregiver, address the needs of the caregiver, include the patient and caregiver and provide follow-up support on discharge. The following recommendations are made with regards to these issues:

#### **5.8.2.1 Caregiver education and training**

The omissions that this research uncovered in these areas are inexcusable and should be addressed as a matter of urgency.

Information sharing and education should occur throughout the rehabilitation process. All the professionals should take responsibility for this and it should not be taken for granted that if it was explained once the caregiver understands. Information sharing and education should be done through information sessions with the patient

and family/caregiver, group sessions, stroke information booklets and videos as often as the patient and caregiver require. The study population expressed a specific need for a booklet. Such a booklet had been developed and positively received. However, one year later this booklet is still in the process of being completed. This booklet should be completed by WCRC and US for distribution as a matter of urgency.

Information should be appropriate and should be provided in ways that are understandable and culturally acceptable to caregivers. Opportunities should be given to caregivers to clarify uncertainties and alleviate unfounded fears.

The training of caregivers would help to ensure that the patient is adequately cared for and would prevent injuries to both parties. Training should not be just a once off training session but should continue until the caregivers feel confident that they have mastered the caregiving tasks. The team, including all the disciplines, should take responsibility for this and all team members must reinforce information and training. The nursing staff should involve the family in training from admission and should train the caregivers throughout the rehabilitation programme. Furthermore, the significant impact that cognitive and perceptual problems as well as personality changes had on caregiver strain means that the occupational therapist and social worker should pay special attention to education on and management guidance of these aspects.

Goals with regards to training and education should be specific in terms of the length and frequency of sessions as well as the responsible parties and the desired outcomes in order to ensure that education and training are done optimally.

#### **5.8.2.2 Need for home visits**

Caregivers said that home visits by the WCRC team prior to the discharge of the patient were very valuable. They found the guidance by the team regarding accessibility in the home prior to the patients discharge invaluable.

It is recommended that home visits be done on a more regular basis. Caregivers also suggested a home visit after the patient had been discharged in order to discuss and address difficulties or problems they might be experiencing as well as to receive support and guidance from the team. In fact it might be this very further support and guidance that will build on the team's efforts during inpatient rehabilitation and create

team support, inclusion and the education of the caregiver to gain a significant impact on reducing strain as it should.

### **5.8.2.3 Follow-up support on discharge**

The rehabilitation team should provide a service to the patient and caregiver after discharge from WCRC until a community-based rehabilitation team can take over the responsibilities. Furthermore, there should be comprehensive referral of the patient to community-based rehabilitation professionals. While acknowledging the limitations of the WCRC team because of case loads, physical capacity, staff shortages and other commitments like training and education, the researcher strongly recommends that instead of severing contact on discharge some form of support to patient and caregiver alike be built into this crucial period. An open door policy and an invitation to contact the team if a need arises is not enough. Completion of the CSI on discharge together with a home visit or urgent referral to the orthopaedic after care sister where scores show that caregivers are at risk and telephonic contact with all others in the team over the initial period will not take up that much time and would go a long way towards decreasing strain on caregivers and ensuring that the time and effort spent on the rehabilitation of the patient bears fruit.

Caregiver training should be considered in the home environment before the patient is discharged as well as after discharge. Training can be more specific and effective in the familiar environment of the patient and caregiver. The rehabilitation team could make suggestions on rearranging or adapting and adjusting the home environment in order to make it more accessible and safer for the patient.

The researcher would also like to recommend another solution in the form of a phased discharge to ease the discharge process and to resolve problems experienced by the patient and the caregiver during this period.

It is recommended that while the above recommendations are initiated further research be conducted to determine how patients and caregivers can best be supported by the WCRC team after discharge into the community in order to improve rehabilitation outcomes with the most efficient use of resources.

#### **5.8.2.4 Community liaison**

There must be a close liaison between the WCRC team and community services to ensure a smooth transfer from the rehabilitation centre to community. This should extend beyond a referral letter to telephonic contact and joint home visits and training sessions if necessary are recommended. This would ensure a continuum in service delivery. Besides the benefits to patients and caregivers it can also serve as an opportunity for WCRC staff to train community service providers, which is one of their responsibilities as the specialist rehabilitation centre in the province.

Finally, the researcher wants to recommend the implementation of a stroke management protocol at WCRC. Those aspects already discussed in this chapter that were sometimes neglected should be included in such a protocol which will then serve as a reminder to address these issues.

In accordance with NRP which states that CBR principles should be practised in all rehabilitation facilities this protocol should adhere to NRP and CBR principles and include such aspects as multi-sectoral collaboration, the equalisation of opportunities for persons with disabilities and focus on social integration/participation of persons with disabilities (National Rehabilitation Policy 2000).

### **5.9 RECOMMENDATIONS ON COMMUNITY SUPPORT RESOURCES**

#### **5.9.1 Community rehabilitation programmes**

The caregivers considered this as one of the most important services because they felt a need for continued rehabilitation once the patient was discharged from the rehabilitation centre.

The Department of Health: Western Cape (2007) Healthcare 2010 should be implemented. Primary health care facilities should address the rehabilitation component urgently so that this service becomes available in all the communities. The Department of Health should appoint rehabilitation professionals at the community health centres and at all the different levels in the health system. CBR programmes with the aim of full integration of persons with disabilities must be

established in the communities. There must be an emphasis on assisting patients to enter the labour market again. This will enable patients to regain their self-worth, self-esteem, become self sufficient and once again to find meaning in their life situation.

This is such an urgent matter that the researcher wants to recommend a task team, that includes all role players that is co-coordinated from provincial level, to investigate, research and drive the implementation of this.

### **5.9.2 Adult day care centres**

It is recommended that adult day care facilities be established in all the communities. This will serve a dual purpose as the patient would be involved in activities and socialise while the caregiver could give attention to minor or dependent children or take up employment. The facilities must be situated within communities to facilitate easy access. Ideally transport should be provided for patients. It is recommended that research be conducted to identify the extent of the need, suitable sites and the resources needed as well as progress with development from that point.

### **5.9.3 Stroke support groups**

Stroke support groups are an invaluable service and although these groups are mostly for patients it is of vital importance that support groups for caregivers be initiated as well. These groups should be run at suitably accessible venues in the community like churches or community centres. While it is necessary that support groups be initiated by professionals they should be taken over and run by the caregivers themselves as soon as possible to give them a sense of ownership and belonging as well as to ensure sustainability. Caregivers could have a forum to share their experiences. They will also get the necessary support from other caregivers who have been through similar experiences, difficulties and problems encountered and how these could be resolved. Since WCRC has a development role to play it is recommended that the management team at WCRC co-ordinate the development of support groups in the communities.

### **5.9.4 Respite care**

Respite services can serve the dual purpose of providing caregivers with a short holiday as well as reassessing patients to determine if any changes in their condition

have occurred and whether further rehabilitation is warranted. Current respite care services in the Western Cape Metropole are insufficient to address the need. It is recommended that in future planning more respite beds be incorporated in hospitals and similar institutions. Respite care beds must be specifically designated for that purpose. The process must be managed from one central point and all caregivers as well as community health care centres should have information on how to access respite care. Further research on the extent of the need for respite care and other related issues is recommended.

#### **5.9.5 Home-based care**

The home-based carers fulfil a valuable service to the patients and the caregivers and they relieve the caregiver of some of the care burden, but again they are too few and some participants commented on the fact that their conduct is not always professional. This lack of professionalism should be addressed during their training and it is recommended that this aspect be included in the training programme. Furthermore, home-based carers need to be supported so that they can render an effective, efficient and excellent service. This is another area where a lot of further research is necessary and includes a needs analysis and an assessment programme effectiveness and client satisfaction.

#### **5.9.6 Peer counselling and support**

Peer counselling provides an effective method of reaching persons who are newly disabled. While peer counselling programmes have been initiated by WCRC social workers it is recommended that this become a more constant part of rehabilitation and especially that it be expanded to include peer support in the community. A register of names and contact details could be developed and maintained by a peer counsellor with a special interest in this under the guidance of a social worker if needed. This information could then be used to create a buddy system where people can find peer support and friendship as needed. Peer counseling and a buddy system would be equally important at the time of discharge when patients face many new challenges. The burden on the caregiver could be minimised to a great extent should such supportive services be in place.

Peer counsellors should have some training on how to relate their experiences in an effective, positive and encouraging manner.

### **5.9.7 Psychological support**

This area is severely neglected and nervous strain showed a significant impact on caregiver strain. While support groups and other facilities that decrease care responsibilities and provide periods of rest will alleviate this caregivers must have access to professional counselling services in the form of social workers and psychologists when needed. It would offer the caregivers/family including the patient an opportunity to a valuable service that takes care of their emotional, psychological and mental wellbeing.

## **5.10 RECOMMENDATIONS TO PROVINCIAL AND LOCAL AUTHORITIES**

### **5.10.1 Need for adequate housing**

The lack of adequate housing is a major national problem. Houses should be built according to the needs of the families and it is essential to accommodate the members with disabilities within their families. The accessibility of the houses for persons with disabilities should be considered and should be brought to the attention of the authorities. Housing projects have previously been approached on behalf of patients regarding accessibility and they have been very accommodating and have requested the input of the occupational therapist during the building period. In one instance a house was built taking into consideration the requirements as set out by the occupational therapist. This is however not enough. The researcher is of the opinion that all the stakeholders should be involved and that communities should be built instead of houses. The Department of Housing and other government departments, like the Department of Social Development and Poverty Alleviation, the Department of Transport, the Department of Parks and Recreation should be involved together with the NGOs, the disability sector, the Office for the Status of Disabled People (OSDP) and the private sector to address the housing issue. In this way the housing issue could be addressed holistically and not piecemeal as when a need is identified. It is important that the disability sector becomes involved so that

the accessibility of housing for persons with disabilities can be assessed and monitored. Persons with disabilities should be advised on appropriate housing requirements to suit their needs and any adjustments and adaptations that may be necessary. In this way they may be empowered to approach the housing authorities themselves.

### **5.10.2 Financial aspects**

At the time of the study the majority of patients were in receipt of some state financial assistance. This meant that the patients had but a minimum income and possibly much less to what they earned when they were working. Financial worries place a lot of stress on the caregiver and even greater financial stress if the caregiver had to terminate work.

The researcher is of the opinion that SASSA should be approached to reassess its policy regarding when an application for a recently disabled person can be submitted both on the first application as well as when re-applying after a temporary grant has expired to ensure that there is no period during which the patient does not receive money. Furthermore, the re-instatement of assessment panels and the finalising and roll out of the assessment tool currently under trial should be dealt with as a matter of urgency.

### **5.10.3 Transport**

A great disadvantage in our communities is the inaccessible and wheelchair unfriendly public transport services. They do not cater for the needs of persons with disabilities and therefore limit the mobility and accessibility of persons with disabilities. The Dial-a-ride transport service is excellent and invaluable to persons with disabilities but it is limited in its capacity to meet the needs of all those in need of its assistance and is thus restricted to certain areas which it serves.

Dial-a-ride services should be upgraded so that persons with disabilities can gain access to the community. The inaccessibility of public transport services must be addressed and every effort should be made to accommodate persons with disabilities and thus improve community reintegration. It is also essential that the

staff serving on these transport facilities for persons with disabilities should be educated and trained.

## **5.11 FURTHER RESEARCH**

While areas for further research have been mentioned amongst the recommendations made, the researcher wants to suggest a follow-up study within two or three years to see if recommendations have been implemented and to assess the difference that they have made in the lives of caregivers.

## **5.12 LIMITATIONS AND POSSIBLE BIAS**

### **5.12.1 Missing clinical data**

Several folders did not have all the details regarding the patient or the processes followed. Where this information was not available in the medical or social work folder, the therapists' notes (physiotherapists, occupational therapists, speech therapists) had to be consulted. Fortunately the information required was available in some of these notes.

### **5.12.2 Inter rater bias**

Having to use a research assistant for the Xhosa interviews unfortunately increased bias even though the assistant had been thoroughly trained.

### **5.12.3 Verification of qualitative data**

No methods to verify qualitative data such as member checking or data coding by more than one person were incorporated in the study methodology. However, quantitative data were utilised to verify qualitative data through triangulation as described by Kroll et al (2005).

#### **5.12.4 Simultaneous collection of qualitative and quantitative data**

During the analysis of quantitative data there were some unexpected findings, that is, the positive impact of no running water on caregiver strain and the lack of positive effect on strain that support and inclusion in the rehabilitation team showed. The reasons for these could have been explored during the interview if quantitative data were collected and analysed before qualitative data were collected, as planned in the original methodology. However, since the pilot study exposed the huge need that caregivers had to share their experiences the researcher felt under a moral obligation to allow caregivers to narrate their stories at the same time as quantitative data collection, instead of starting to probe the experience by completing quantitative data coding forms, and then leaving them with the emotions created by this and not providing them with an immediate opportunity to share everything felt.

#### **5.12.5 Additional data**

During the analysis of data certain aspects were identified where additional data would have enhanced study findings, for example, further exploration on the subject of whether caregivers were trained by WCRC professionals and whether the health conditions of some of the caregivers were pre-existing.

### **5.13 SUMMARY**

The most important issue that arose from the research is the need for all stakeholders to become involved in order to ensure the availability of resources and support structures for the patient and the caregivers in the communities. It stresses the importance of a continuous rehabilitation service to the patient and the caregiver from the primary health care level and throughout the different levels in the health system; and eventually full circle back to the primary health care level. The professionals and other stakeholders from the different health care levels should thus work in close liaison in order to deliver an effective and efficient service.

The caregivers felt very strongly about the lack of information on stroke and the lack of training which cause uncertainties, unfounded fears and which disempowered

them. The caregiver is an important member in the team who delivers an invaluable service and should be treated and respected as such.

Resources such as CBR, adult day care, respite services, home-based care, caregiver support groups as well as inclusion in the WCRC team, proper training and education, an information booklet, home visits and telephonic follow-up could go a long way to lessen caregiver strain.

Recommendations on these issues have been made and they should be implemented as a matter of urgency.

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**Personal communication:**

Dr Linda de Villiers. Senior consultant at GF Jooste and Groote Schuur Hospital. September 2008.

Dr Sebastiana Kalula. Department of Medicine and Geriatrics at Groote Schuur Hospital. September 2008.

Mrs. Tertia Mckee. Assistant social work manager at Western Cape Rehabilitation Centre. September 2008.

## APPENDIX 1



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY  
jou kennisvennoot • your knowledge partner

6 Liverpool Road  
Wynberg  
7800  
October 2005

Ms Jenny Hendry  
Deputy Director : Western Cape Rehabilitation Centre  
Highlands Drive  
Lentegeur  
Mitchells Plain  
7785

Dear Ms Hendry

**RE: PERMISSION TO ACCESS PATIENTS RECORDS  
RESEARCH PROJECT: "IMPACT OF STROKE ON THE PRIMARY CAREGIVER"  
PROJECT NUMBER: 2003/079/N**

I am presently conducting a research project in partial fulfillment of an MPhil in Rehabilitation at the University of Stellenbosch. I am interested in conducting a research project to determine the impact that stroke has on the primary caregiver.

I am therefore requesting your permission to access records / files of patients who suffered a stroke and were submitted to the General Rehabilitation Unit between Wards A, B, C from 1 January 2006 to 31 December 2006.

Once I have made my study sample I plan to conduct in-depth interviews with the primary caregivers who consented to participate in the study.

All information obtained will be kept strictly confidential and files will be kept safe.

Your approval of this request and support for this study will be highly appreciated.

Yours Faithfully

Soelaylah Hassan  
Supervisor: Gubela Mji  
Student number: 13481959



Fakulteit Gesondheidswetenskappe . Faculty of Health Sciences





Enquiries: Soelaylah Hassan

Telephone: 021-372443 wk / 021-7624544 hm / 0826495127cell

Facsimile: 021-3702434

Reference: Research

Date:

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The Family of A. Adams

13 Hampshire Street

Wynberg

7800

Dear Sir/Madam

**RESEARCH PROJECT ON THE IMPACT OF STROKE ON THE CAREGIVER**

I am conducting a study on the impact of caring for a person who suffered a stroke. These patients were admitted to the Western Cape Rehabilitation Centre during 2006 and were discharged home to a caregiver after involvement in a rehabilitation programme.

I would like to know whether you, as the caregiver of the abovementioned patient, would be willing to partake in this study. We, unfortunately, could not reach you by telephone.

If you are willing to partake in this study by answering some questions and a possible interview that would eventually help us to improve our services towards the caregivers, please contact me at the above telephone numbers. I will gladly refund your telephone costs.

Your co-operation regarding this request would be highly appreciated.

Yours faithfully

.....

Principal social worker

**APPENDIX 4**

**PARTICIPANT INFORMATION AND CONSENT FORM**

**TITLE OF THE RESEARCH:** THE IMPACT OF STROKE ON THE PRIMARY CAREGIVER

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR:** SOELAYLAH A.M HASSAN  
**ADDRESS:** WESTERN CAPE REHABILITATION CENTRE  
HIGHLANDS DRIVE, LENTEGEUR  
MITCHELLS PLAIN, 7785

**STATEMENT BY THE PARTICIPANTS**

We, the undersigned,.....(participants), confirm that:

1. We have been invited to participate in the abovementioned research project initiated through the University of Stellenbosch.
2. It had been explained to us that the aim of the study is to determine the impact of care giving on primary caregivers of persons who suffered a stroke and were rehabilitated at the Western Cape Rehabilitation Centre during the period 1 January 2006 and 31 December 2006.
3. It was explained to us that an interview will be conducted to complete questionnaires. It was also explained that an in-depth interview will be conducted at a later stage with some of the participants.
4. It had been explained to us that all information will be dealt with confidentially. The information may be used for the thesis, publication in scientific journals, and /or presentations to professionals. The researcher will protect the identities of participants even when reporting results.
5. We had been informed that we may refuse to participate in this project and that we may withdraw from the project at anytime without any negative influence to future services.
6. We participate voluntarily in this research project and was not forced in anyway to participate.
7. We are aware that we may withdraw from the research at anytime without penalty.
8. We are aware that we will not incur any costs by participating in this project and we are aware that we will not benefit financially from participating.
9. I, the patient, am aware that even if I refuse to participate my caretaker can still participate in the research should s/he consent to it.
10. An interpreter has explained all these points to us and it is clearly understood by us. (For Xhosa speaking primary caregivers and patients only).

**PATIENT SIGNATURE:**

Signed at.....on.....2003

.....  
(Patient)

.....  
(Witness)

**CAREGIVER SIGNATURE:**

Signed at.....on.....2003

.....  
(Caregiver)

.....  
(Witness)

**STATEMENT BY RESEARCHER:**

**I, SOELAYLAH A M HASSAN STATE THAT:**

- 1. I have explained the information in this document to .....
- 2. I have invited him/her to ask me questions in the case of uncertainty.
- 3. The conversation was held in English/Afrikaans.

Signed at.....on.....2007

.....  
Researcher (S. Hassan)

.....  
Witness

**STATEMENT BY INTERPRETER:**

**I, .....STATE THAT:**

- 1. I have explained the information in this document to.....
- 2. I have invited him/her to ask questions in the case of uncertainty.
- 3. The conversation was held in Xhosa.

**IMPORTANT NOTICE**

Dear Participants,

Thank you for agreeing to participate in this project. You're willingness is much appreciated. Should you have any further queries or questions about the research project please do not hesitate to contact me at the following numbers:

- 1. (021) 3702443 (work) or
- 2. 0826495127 (cell)

Thank you,

(Miss) Soelaylah Hassan.

## APPENDIX 5

### DATA CODING FORM A

**PATIENT INFORMATION**

**SECTION A  
DEMOGRAPHIC DETAILS**

*For office use only*

1. RESEARCH NUMBER OF PATIENT:

2. PATIENTS NAME:

3. FOLDER NUMBER:

4. GENDER:

MALE	FEMALE
------	--------

5. AGE IN YEARS:

<small>&lt;19</small> <small>1</small>	<small>19 -29</small> <small>2</small>	<small>30 - 39</small> <small>3</small>	<small>40 - 49</small> <small>4</small>
<small>50 - 59</small> <small>5</small>	<small>60 - 69</small> <small>6</small>	<small>70 - 79</small> <small>7</small>	<small>&gt;80</small> <small>8</small>

6. ETHNIC GROUP:

AFRICAN	COLOURED	INDIAN	WHITE	OTHER*1
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\*1 IF OTHER PLEASE SPECIFY .....

7. EDUCATIONAL LEVEL:

<small>NO FORMAL EDUCATION</small> <small>1</small>	<small>GRADE 1 - 3</small> <small>2</small>	<small>GRADE 4 - 6</small> <small>3</small>	<small>GRADE 7 - 9</small> <small>4</small>
<small>GRADE 10 - 11</small> <small>5</small>	<small>GRADE 12</small> <small>6</small>	<small>1 - 3 YRS TERTIARY ED.</small> <small>7</small>	<small>&gt; 3 YRS TERTIARY ED.</small> <small>8</small>

8. HOME LANGUAGE:

ENGLISH	AFRIKAANS	XHOSA	OTHER*2
---------	-----------	-------	---------

\*2 IF OTHER PLEASE SPECIFY .....

For office use only

9. EMPLOYMENT STATUS AT THE TIME OF THE STROKE:

EMPLOYED 1	UNEMPLOYED 2	PENSIONER / RETIRED 3
---------------	-----------------	--------------------------

10. TOTAL MONTHLY INCOME OF THE PATIENT PRIOR TO THE STROKE:

NO INCOME 1	STATE DG/OAP 2	< R1000.00 3	R1000.00 - R2000.00 4
R2001.00 - R3500.00 5	R3501.00 - R5000.00 6	R5001.00 - R7500.00 7	R7501.00 - R10000.00 8
> R10000.00 9			

11. CURRENT TOTAL MONTHLY INCOME OF THE PATIENT:

NO INCOME 1	STATE DG/OAP 2	< R1000.00 3	R1000.00 - R2000.00 4
R2001.00 - R3500.00 5	R3501.00 - R5000.00 6	R5001.00 - R7500.00 7	R7501.00 - R10000.00 8
> R10000.00 9			

12. MARITAL STATUS:

SINGLE 1	MARRIED 2	DIVORCED 3
WIDOWED 4	COHABITING 5	SEPARATED 6

13. NUMBER OF MINOR OR DEPENDENT CHILDREN:

0 0	1 1	2 2	3 3	4 4	> 4 5
--------	--------	--------	--------	--------	----------

14. CURRENT ACCOMMODATION:

HOUSE 1	FLAT 2	SHACK/WENDY HOUSE 3
RETIREMENT VILLAGE 4	MAISONETTE 5	OTHER 6

\*3 IF OTHER PLEASE SPECIFY .....

For office use only

15. HOW DOES THE PATIENT ACCESS THE COMMUNITY?

INDEPENDENTLY 0	ASSISTED BY 1 PERSON 1	ASSISTED BY 2 PERSONS 2	ASSISTED BY MORE THAN 2 PERSONS 3
DOES NOT ACCESS COMMUNITY AT ALL 4			

16. DO THESE PERSONS WANT REMUNERATION?

YES	NO	N/A
-----	----	-----

17. RUNNING WATER INSIDE THE HOUSE:

YES	NO
-----	----

18. ELECTRICITY:

YES	NO
-----	----

**SECTION B  
HEALTH STATUS OF THE PATIENT**

19. DATE ADMITTED TO WCRC WITH THIS STROKE?

20. HOW MANY STROKES DID THE PATIENT SUFFER?

1 STROKE	2 STROKES	3 STROKES	4 AND MORE STROKES
----------	-----------	-----------	--------------------

21. NAME THE PATIENTS RISK FACTORS AND OTHER HEALTH CONDITIONS:

(Please mark **all** the appropriate boxes with an **X**.)

HYPERTENSION 1	DIABETES 2	CHOLESTEROL 3	CARDIAC PROBLEM 4
OBESITY 5	SMOKER 6	NEUROLOGICAL CONDITIONS 7	NERVOUS CONDITION/STRESS 8
ARTHRITIS 9	CANCER 10	LUNG PROBLEM 11	TUBERCULOSIS 12
OTHER****1 13			

\*\*\*1 IF OTHER PLEASE SPECIFY .....

QUESTION CONTINUES ON NEXT PAGE (NO:22)

For office use only

22. INDICATE TOTAL NUMBER OF HEALTH CONDITIONS BY MARKING THE APPROPRIATE BOX WITH X  
(Calculate "Other" as one health condition.)

None	One	Two	Three	> Three
------	-----	-----	-------	---------

23. IS THE PATIENT COMPLIANT WITH MEDICATION AND OTHER HEALTH ADVICE?

YES	NO
-----	----

24. UNRESOLVED EFFECTS OF THE STROKE:

LEFT HEMIPLEGIA 1	RIGHT HEMIPLEGIA 2	COMMUNICATION PROBLEMS 3	SWALLOWING PROBLEMS 4
INCONTINENCE 5	PERCEPTUAL/ COGNITIVE PROBLEMS 6	MEMORY PROBLEMS 7	PERSONALITY CHANGES 8

25. DATE OF HOSPITALISATION AT WCRC:

--	--	--

26. DATE OF DISCHARGE AT WCRC:

--	--	--

27. LENGTH OF STAY IN DAYS AT WCRC:

--	--	--

PREMORBID STATUS:

28. PHYSICAL:

FULLY INDEPENDENT 1	NEEDED SUPERVISION 2	NEEDED ASSISTANCE 3	FULLY DEPENDENT 4
------------------------	-------------------------	------------------------	----------------------

29 MENTAL:

GOOD MEMORY 1	FAILING MEMORY 2
------------------	---------------------

30. REHABILITATION OUTCOME LEVEL AT THE TIME OF DISCHARGE:

PHYSIOLOGICAL MEDICAL INSTABILITY 0	PHYSIOLOGICAL (MEDICAL) STABILITY 1	BASIC REHABILITATION OUTCOME 2	INTERMEDIATE REHABILITATION OUTCOME 3
ADVANCED REHABILITATION 4	PRODUCTIVE ACTIVITY 5		

31. REHABILITATION OUTCOME AT THE TIME OF THE STUDY?

PHYSIOLOGICAL (MEDICAL) INSTABILITY 0	PHYSIOLOGICAL (MEDICAL) STABILITY 1	BASIC REHABILITATION OUTCOME 2	INTERMEDIATE REHABILITATION OUTCOME 3
ADVANCED REHABILITATION 4	PRODUCTIVE ACTIVITY 5		

**\*\*FOR OFFICE USE ONLY**

32. THE BARTEL INDEX SCORE:

>20 1	21 - 40 2	41 - 60 3	61 - 80 4
81 - 100 5			

## Appendix 6

### THE BARTEL INDEX

Research number of patient:

<u>Activity</u>	<u>Score</u>
<b>Feeding</b>	
0 = unable	
5 = needs help cutting, spreading butter, etc., or requires modified diet	
10 = independent	-----
<b>Bathing</b>	
0 = dependent	
5 = independent (or in shower)	-----
<b>Grooming</b>	
0 = needs help with personal care	
5 = independent face / hair / teeth / shaving	-----
<b>Dressing</b>	
0 = dependent	
5 = needs help, but can do about half unaided	
10 = independent (including buttons, zips, laces, etc.)	-----
<b>Bowels</b>	
0 = incontinent (or needs to be given an enema)	
5 = occasional accident	
10 = continent	-----
<b>Bladder</b>	
0 = incontinent, or catheterized and unable to manage	
5 = occasional accident	
10 = continent	-----
<b>Toilet use</b>	
0 = dependent	
5 = needs some help, but can do something alone	
10 = independent (on and off, dressing, wiping)	-----
<b>Transfer (Bed to chair and back)</b>	
0 = unable	
5 = major help (one or two people, physical), can sit	
10 = minor help (verbal or physical)	
15 = independent	-----
<b>Mobility (On level surfaces)</b>	
0 = immobile or < 50 yards	
5 = wheelchair independent including corners, > 50 yards	
10 = walks with help of one person (verbal or physical) > 50yards	
15 = independent (but may use any aid, e.g. stick) > 50 yards	-----
<b>Stairs</b>	
0 = unable	
5 = needs help (verbal, physical, carrying aid)	
10 = independent up and down	-----
<b>TOTAL: (0 – 100):</b>	-----

**APPENDIX 7  
DATA CODING FORM B**

**CAREGIVER INFORMATION**

**SECTION A  
DEMOGRAPHIC DETAILS**

*For office use only*

1. RESEARCH NUMBER OF PATIENT:

2. CAREGIVERS NAME:

3. GENDER:

MALE	FEMALE
------	--------

4. AGE IN YEARS:

<19 <small>1</small>	19 - 29 <small>2</small>	30 - 39 <small>3</small>	40 - 49 <small>4</small>
50 - 59 <small>5</small>	60 - 69 <small>6</small>	70 - 79 <small>7</small>	>80

5. ETHNIC GROUP:

AFRICAN	COLOURED	INDIAN	WHITE	OTHER
---------	----------	--------	-------	-------

\*1 IF OTHER PLEASE SPECIFY .....

6. EDUCATIONAL LEVEL:

NO FORMAL EDUCATION <small>1</small>	GRADE 1 - 3 <small>2</small>	GRADE 4 - 6 <small>3</small>	GRADE 7 - 9 <small>4</small>
GRADE 10 - 11 <small>5</small>	GRADE 12 <small>6</small>	1 - 3 YRS TERTIARY ED. <small>7</small>	> 3 YRS TERTIARY ED. <small>8</small>

7. HOME LANGUAGE:

ENGLISH	AFRIKAANS	XHOSA	OTHER
---------	-----------	-------	-------

\*2 IF OTHER PLEASE SPECIFY .....

8. EMPLOYMENT STATUS AT THE TIME OF THE STROKE:

EMPLOYED <small>1</small>	UNEMPLOYED <small>2</small>	PENSIONER / RETIRED <small>3</small>
------------------------------	--------------------------------	---

9. DID YOU HAVE TO RESIGN TO TAKE ON CARETAKING DUTIES?

YES	NO
-----	----

For office use only

10. MONTHLY INCOME PRIOR TO THE PATIENTS STROKE:

NO INCOME 1	STATE DG/OAP 2	< R1000.00 3	R1000.00 - R2000.00 4
R2001.00 - R3500.00 5	R3501.00 - R5000.00 6	R5001.00 - R7500.00 7	R7501.00 - R10000.00 8
> R10000.00 9 *** STATE DISABILITY GRANT / OLD AGE PENSION			

11. CURRENT MONTHLY INCOME:

NO INCOME 1	STATE DG/OAP 2	< R1000.00 3	R1000.00 - R2000.00 4
R2001.00 - R3500.00 5	R3501.00 - R5000.00 6	R5001.00 - R7500.00 7	R7501.00 - R10000.00 8
> R10000.00 9			

12. REMUNERATED FOR YOUR CAREGIVING:

YES	NO
-----	----

13. WAS THE PATIENT LIVING WITH YOU PRIOR TO THE STROKE?

YES	NO
-----	----

14. WHAT IS YOUR RELATIONSHIP TO THE PATIENT?

HUSBAND / WIFE 1	PARENT 2	CHILD 3
GRANDCHILD 4	AUNT / UNCLE 5	NIECE / NEPHEW 6
FRIEND 7	PAID CARETAKER 8	OTHER 9

\*3 IF OTHER PLEASE SPECIFY .....

15. MARITAL STATUS:

SINGLE 1	MARRIED 2
DIVORCED 3	WIDOWED 4
COHABITING 5	

16. MINOR OR DEPENDENT CHILDREN:

0 0	1 1	2 2	3 3	4 4	> 4 5
--------	--------	--------	--------	--------	----------

**SECTION B  
CARE TAKING DUTIES**

*For office use only*

17. APPROXIMATELY HOW MANY HOURS (HRS) PER DAY DO YOU SPEND ON CARETAKING DUTIES?

< 2 HRS 1	2 - 4 HRS 2	5 - 7 HRS 3	8 - 10 HRS 4	> 10 HRS 5
--------------	----------------	----------------	-----------------	---------------

18. WHAT DOES YOUR CARETAKING DUTIES ENTAIL?

MAXIMUM CARE 1	MODERATE CARE 2	ASSISTANCE 3	SUPERVISION 4
-------------------	--------------------	-----------------	------------------

19. WHO ASSISTS YOU?

NO-ONE 1	YOUR CHILDREN 2	HOME-BASED CARE 3
NEIGHBOUR / S 4	RELATIVE / S 5	DOMESTIC 6
FRIEND / S 7	REHABILITATION / HEALTH STAFF 8	OTHER 9

**\*\*1 IF OTHER PLEASE SPECIFY** .....

20. APPROXIMATELY HOW MANY HOURS PER DAY ARE YOU REQUIRED TO DO HOUSEHOLD DUTIES?

0 HRS 1	< 2 HRS 2	2 - 4 HRS 3	5 - 7 HRS 4	8 - 10 HRS 5	> 10 HRS 6
------------	--------------	----------------	----------------	-----------------	---------------

21. HOW OFTEN DO YOU HAVE TIME OUT? (Explain the concept.)

NEVER 1	1 - 3 hrs per week 2	4 - 6 hrs per week 3	1 - 3 hrs per day 4
1 day per week 5	1 weekend per month 6	Every alternate weeken 7	OTHER 8

**\*\*2 IF OTHER PLEASE SPECIFY** .....

**SECTION C  
CARETAKERS' HEALTH STATUS**

*For office use only*

22. MARK ALL YOUR HEALTH CONDITIONS WITH AN X  
IN THE APPROPRIATE BOX:

HYPERTENSION 1	DIABETES 2	LUNG PROBLEMS 3	CARDIAC PROBLEMS 4
ARTHRITIS 5	CHOLESTEROL 6	CANCER 7	TUBERCULOSIS 8
NEUROLOGICAL PROBLEMS 10	BACK PROBLEMS 10	NERVOUS CONDITION/ STRESS 11	Other 12

\*\*\*1 IF OTHER PLEASE SPECIFY .....

23. INDICATE TOTAL NUMBER OF HEALTH CONDITIONS BY  
MARKING THE APPROPRIATE BOX WITH AN X:  
(Calculate "Other" as one health condition.)

None 0	One 1	Two 2	Three 3	> Three 4
-----------	----------	----------	------------	--------------

24. ARE YOU ABLE TO ATTEND DOCTORS' APPOINTMENTS & / OR  
CHECK-UPS & / OR COLLECT YOUR MEDICATION AS REQUIRED?

YES	NO	N / A
-----	----	-------

25. WHEN YOU NEED TO ATTEND TO A MATTER OUTSIDE THE HOME,  
DO YOU HAVE SOMEONE TO TAKE RESPONSIBILITY FOR THE  
PATIENT IN YOUR ABSENCE?

YES	NO
-----	----

26. DO YOU HAVE TIME FOR SOCIALIZING OR RECREATIONAL /  
SPORTING ACTIVITIES?

YES	NO
-----	----

**SECTION D  
ON STROKE AND STROKE CARE**

*For office use only*

27. WERE YOU TOLD WHAT A STROKE IS?

YES	NO
-----	----

--

28. IF YES, WHO TOLD YOU?

THE INITIAL ATTENDING DOCTOR 1	THE NURSE 2	THE PHYSIOTHERAPIST 3	THE OCCUPATIONAL THERAPIST 4
THE WARD DOCTOR AT WCRC	THE SOCIAL WORKER 6	YOU KNEW WHAT A STROKE IS	OTHER 8

--

**IF OTHER PLEASE SPECIFY** .....

29. EXPLAIN IN YOUR OWN WORDS WHAT A STROKE IS?

DID NOT UNDERSTAND 1	PARTLY UNDERSTOOD 2	FULLY INFORMED 3
-------------------------	------------------------	---------------------

--

30. DID YOU AT THAT STAGE UNDERSTAND WHAT YOU WERE TOLD?

YES	NO
-----	----

--

31. DID YOU FEEL COMFORTABLE TO APPROACH ANY OF THE PROFESSIONALS IF YOU DID NOT UNDERSTAND?

YES	NO	N/A
-----	----	-----

--

32. HAVE YOU CARED FOR A RELATIVE WITH A STROKE OR OTHER DISABLING CONDITION BEFORE?

YES	NO
-----	----

--

33. WHO REFERRED THE PATIENT TO THE WCRC?

SELF-REFERRED 1	PRIMARY/SECONDARY/TERTIARY HOSPITALS 2	GENERAL PRACTITIONER 3	FRIEND/RELATIVE 4
COMMUNITY NURSE 5	PHYSIOTHERAPIST 6	OCCUPATIONAL THERAPIST 7	OTHER 8

--

**\*\*\*\*1 IF OTHER PLEASE SPECIFY** .....

For office use only

34. WERE YOU GIVEN ANY CHOICE IN THE MATTER?

YES	NO
-----	----

35. HOW LONG DID THE PATIENT WAIT TO BE ADMITTED TO WCRC?

DIRECT TRANSFER 1	< 1 WEEK 2	1- 2 WEEKS 3
2 - 3 WEEKS 4	3 - 4 WEEKS 5	> 4 WEEKS 6

36. WHERE WAS THE PATIENT DURING THIS WAITING PERIOD?

HOSPITAL 1	OTHER CARE FACILITY 2	AT HOME 3	OTHER 4
---------------	--------------------------	--------------	------------

IF OTHER PLEASE SPECIFY

.....

37. IF THE PATIENT WERE WAITING AT HOME, DID THE CARER RECEIVE ANY TRAINING BEFORE THE PATIENT WAS DISCHARGED?

YES	NO	N / A
-----	----	-------

38. COULD THE CARER COPE WITH THE CARE RESPONSIBILITY AT THE TIME?

YES	NO	N / A
-----	----	-------

39. ON ADMISSION TO THE WCRC WERE YOU MADE TO FEEL WELCOME?

YES	NO
-----	----

40. WAS THE REHABILITATION PROGRAMME EXPLAINED TO YOU?

YES	NO
-----	----

41. DID YOU UNDERSTAND YOUR ROLE IN THE PROGRAMME?

YES	NO
-----	----

42. WERE YOU INCLUDED AS PART OF THE TEAM?

YES	NO
-----	----

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43. WHO DETERMINED THE REHABILITATION GOALS?

THE PATIENT 1	THE PATIENT AND THE FAMILY/CAREGIVER 2	THE PATIENT, FAMILY & THE PROFESSIONALS 3	THE PROFESSIONALS ONLY 4
------------------	--	---	--------------------------------

44. WERE YOU TRAINED TO CARE FOR THE PATIENT PRIOR TO THE PATIENT'S FIRST WEEKEND AT HOME?

YES	NO
-----	----

45. COULD YOU SHARE YOUR EXPERIENCES AND FEARS WITH ANY OF THE PROFESSIONAL AFTER THE FIRST WEEKEND OUT?

YES	NO
-----	----

46. DID YOU FEEL COMFORTABLE TO ASK QUESTIONS OR COMPLAIN IF YOU OR THE PATIENT WERE UNHAPPY OR UNSURE?

YES	NO
-----	----

47. DO YOU FEEL THAT YOU RECEIVED ADEQUATE SUPPORT DURING THE REHABILITATION PROGRAMME?

YES	NO
-----	----

48. WERE YOUR NEEDS MET DURING THE REHABILITATION PROGRAMME?

YES	NO
-----	----

49. SINCE THE DISCHARGE FROM THE REHABILITATION CENTRE WHAT TYPE OF FOLLOW-UP SERVICES DID YOU AND THE PATIENT RECEIVE?

NONE 1	HOME-BASED NURSING CARE 2	OUT-PATIENT FOLLOW- UP AT WCRC/CHC 3	COMMUNITY REHABILITATION FACILITY 4
ADULT DAYCARE FACILITY 5	RESPIRE CARE 6	OTHER 7	

IF OTHER PLEASE SPECIFY

.....

50. WERE THESE SERVICES ADEQUATE?

YES	NO	N/A
-----	----	-----

For office use only

51. WHAT EXTRA ASSISTANCE IN THE COMMUNITY (PROFESSIONAL OR OTHERWISE WOULD HAVE EASED YOUR CARETAKING BURDEN?

NONE 1	HOME-BASED NURSING CARE 2	OUT-PATIENT FOLLOW-UP AT WCRC/CHC 3	COMMUNITY REHABILITATION FACILITY 4
ADULT DAYCARE FACILITY 5	RESPITE CARE 6	OTHER 7	

IF OTHER PLEASE SPECIFY .....

52. ON A USUAL DAY HOW MUCH STRESS/STRAIN DO YOU EXPERIENCE?

1	2	3	4

5	6	7

53. HOW SATISFIED ARE YOU WITH YOUR LIFE?

1	2	3	4

5	6	7

**\*\*FOR OFFICE USE ONLY**

*For office use only*

54. SATISFACTION WITH LIVING STATUS SCORE:

LIVING SITUATION	SOCIAL RELATIONSHIP	EMPLOYMENT/ WORK	SELF AND PRESENT LIFE
1	2	3	4
SCORES	SCORES	SCORES	SCORES
1. 0 - 4 =	5. 0 - 4 =	12. 0 - 4 =	11. 0 - 4 =
2. 0 - 4 =	6. 0 - 4 =	13. 0 - 4 =	14. 0 - 4 =
3. 0 - 4 =	7. 0 - 4 =		15. 0 - 4 =
4. 0 - 4 =	8. 0 - 4 =		16. 0 - 4 =
	9. 0 - 4 =		17. 0 - 4 =
	10. 0 - 4 =		18. 0 - 4 =
<b>TOTAL: =</b>	<b>TOTAL: =</b>	<b>TOTAL: =</b>	<b>TOTAL: =</b>

55. CAREGIVER STRAIN INDEX SCORE:

NUMBER OF ANSWERS:	NUMBER OF ANSWERS:
YES =	NO =
1	2

## APPENDIX 8

### CAREGIVER STRAIN INDEX (CSI)

Questionnaire: I am going to read a list of things, which other people have found to be difficult in helping out after someone comes home from the hospital.

Would you tell me whether any of these apply to you? (PLEASE GIVE EXAMPLES)

1. Sleep is disturbed because of my care taking duties  
(e.g. because ..... is in and out of bed or wanders around at night).
2. It is inconvenient to help him/her  
(e.g. because helping takes so much time or it's a long drive over etc).
3. It is a physical strain to take care of him/her  
(e.g. because of lifting in and out of chair; efforts or concentration is required).
4. It is confining to take care of him/her  
(e.g. helping restricts free time or cannot go visiting).
5. There have been family adjustments, because of the care taking  
(e.g. because helping has disrupted routine; there has been no privacy).
6. There have been changes in personal plans, because of the care taking  
(e.g. had to turn down a job; could not go on vacation).
7. There have been other demands on my time (e.g. from other family members).
8. There have been emotional adjustments (e.g. because of severe arguments).
9. Some of his/her behaviour is upsetting  
(e.g. because of incontinence; ..... has trouble remembering things; or ..... accuses people of taking things).
10. It is upsetting to find ..... have changed so much from his/her former self  
(e.g. he/she is a different person than he/she used to be).
11. There have been work adjustments  
(e.g. because of having to take time off).
12. Financial strain.
13. Feeling completely overwhelmed  
(e.g. because of worry about .....; concerns about how you will manage).

## APPENDIX 9

### SATISFACTION WITH LIFE SCALE

**DIRECTIONS:** Below are some questions about how you like your present life.  
Put an **X** through the words that best reflect your feelings about your life at this time.

1. How much do you like the where you live? (today)	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
2. How satisfied are you with the amount of privacy you have in your current living situation?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
3. How satisfied are you with the amount of space you have in your current living situation?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
4. How much do you like the food that you usually eat?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
5. How satisfied are you with the way you spend your evenings and weekends?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
6. How satisfied are you with the number of friends you have?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
7. Do you feel as close to your friends as you would have liked to be?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
8. How satisfied are you with the kind and amount of contact you have with your friends?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
9. How satisfied are you with your current social life?	NOT AT ALL NOT	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL

### SATISFACTION WITH LIFE SCALE

10. How satisfied are you with the kinds of relationships you have with the members of your family?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
11. How satisfied are you with the way you spend your days?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
12. How satisfied are you with the kind of work that you do?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
13. Do you feel that you are working as much as you would like?	NOT AT ALL NOT	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
14. How satisfied are you with your current psychological condition?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
15. How satisfied are you with your present life?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
16. How satisfied are you with yourself on the whole?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
17. Do you feel you get as much enjoyment from life as most people do?	NOT AT ALL	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL
18. Do you feel you have as much freedom as you want?	NOT AT ALL NOT	VERY LITTLE	AVERAGE	A LOT	A GREAT DEAL

## **APPENDIX 10**

### **INTERVIEW SCHEDULE**

#### **(Guideline to questions for the primary caregiver)**

1. Where were you when the patient suffered the stroke and did you know what had happened?
2. How did you feel and how did this affect you when you discovered that the patient suffered a stroke?
3. Did you have any assistance and support during this time?
4. Did you have assistance taking the patient to hospital? Explain how the patient was taken to hospital and what was your experience at the hospital?
5. Do you have any knowledge/information/experience on strokes and what were your feeling, and fears at this stage?
6. How did you experience the service from health professionals? Do you feel that you were well informed on the patients condition, prognosis and were you informed on and referred for rehabilitation after the patients condition was stabilized?
7. How and by whom was the patient referred for rehabilitation services?
8. How long did you wait for the patient to be admitted to the Rehabilitation Centre?
9. Did you know what to expect once the patient was admitted to the Rehabilitation Centre? Who informed you and do you feel you had adequate information.
10. How did you feel once the patient was admitted and were you and the patient welcomed to the Rehabilitation Centre?
11. Did you receive adequate information about the programme and did you understand your role, weekend leave, etc?

12. Have you been trained to care for the patient prior to a weekend home and what was your weekend experience like when the patient was home? Could you cope with the responsibility and could you share your experience and fears with any of the team members?
13. Did you feel part of the programme, i.e. How involved were you with the patient and the team, did you feel comfortable to ask questions or to complain if you or the patient were unsure or unhappy?
14. How did you experience the ward setting and the service/support from team members?
15. How did the stroke affect your personal life in terms of employment, family life, leisure activities, recreational activities and outings, etc
16. How much care is involved and what does your responsibility entail?
17. How are you coping and what support are you getting?
18. Do you feel that you received adequate support/input from health professionals throughout the treatment process?
19. Have you any suggestions that would contribute towards the improvement of services by health professionals that could lessen your burden or the impact that the stroke had on your life?
20. Do you know what a stroke is? Explain to me what a stroke is?