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2017

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The impact of Care Giving on the Quality of Life of Caregivers of Patients with Schizophrenia

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment for the requirements for the degree of Master of Medicine in Psychiatry

Johannesburg, 2017

Declaration

I, Thokozani Mtshali, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in Psychiatry at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Dr Thokozani Mtshali

On this 25th day of May 2017

Publications and presentations

This work has never been published or presented at a congress.

Dedication

This project is dedicated to my husband, parents, and sister, for your unwavering support and love

Abstract

Introduction: Schizophrenia is a chronic mental illness, which is often characterized by a relapsing course with resultant effects on most areas of functioning due to the disability associated with it. The presence of any of the symptoms of schizophrenia can be extremely distressing for the families or caregivers who care for the patient. The term caregiver burden arose following the deinstitutionalization of mental health patients that was associated with integration of patients with severe mental illnesses into the community. Limited data of caregiver burden and its relationship with quality of life (QOL) is available in South Africa. The aim of the present study is to describe the nature of caregiver burden and to describe the relationship between caregiver burden and QOL.

Methods: The study is descriptive and cross-sectional in nature and was conducted at Chris Hani Baragwanath Academic Hospital from February 2014 to October 2014. Data was collected from caregivers of patients with schizophrenia in the form of questionnaires. Caregiver burden was assessed by the use of a Caregiver Strain Index questionnaire with a score greater than 7 suggesting a high caregiver burden. Quality of life was assessed with the World Health Organization Quality of Life brief questionnaire; it is scored on six domains each of which contributes to the caregiver's overall impression of their quality of life.

Results: Of the 127 participants identified for the study, eight six participated. Significant factors associated with higher caregiver burden were as follows: increased number of admissions per year, caring for adults less within the ages of 46-55 years,

caring for patients with psychosocial stressors and living in a household with 3 to 4 people.

Conclusion: The relationship between caregiver burden and caregiver QOL suggested that as caregiver burden increases, QOL decreases.

Acknowledgements

Thanksgiving to my heavenly Father my provider and the source of my strength. Through Him all things are possible.

Dr Motlana, my supervisor for the supervision rendered

Dr Friedlander, my co-supervisor for constant availability and invaluable input provided

Dr Petra Gaylard, for assisting with statistical analysis

Thandaza Shayingca, I would not have been able to do this without you love

The special women in my life, for their on-going support and prayers

Bhekisiwe Maphalala

Mazi Mtshali

Linda Mtshali

Ntombiyokuphila Shayingca

oMama bomthandazo

My family and friends

The caregivers who took part in my study, the nursing staff that assisted with translation, I thank you all.

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1. INTRODUCTION

Being a caregiver of a patient with a mental illness may prove to be a challenging task. Furthermore, caring for a patient with a severe mental illness, which is chronic in nature, may put a considerable burden on the caregiver. International research looking at caregivers of patients with schizophrenia has suggested these caregivers may experience burden, however there is a dearth of South African research addressing this topic.

South African public psychiatric services during the apartheid era were riddled with inconsistencies in the provision of health care. [1] During this period there was a significant reliance on institutions for the chronically mentally ill and on large hospitals to provide on-going mental health care. The government, post 1997, released a document describing the new vision for health care. The aim of the vision for mental health was to achieve services that were "community-based". [1]
Institutions were abolished in an aim to improve the quality of life of patients with schizophrenia and other psychiatric illnesses. [2]

The term "informal caregivers" [3] came into existence as patients were integrated into the community. Their families, who were ill equipped, were entrusted with the task of caring for their relatives with schizophrenia in an informal manner, something they had never been expected to do previously.

Studies on the caregiver burden have been inconsistent in their findings regarding which factors are associated with higher levels of burden. Factors that are hypothesized to result in increased burden include; lack of social support for the caregivers themselves, levels of unemployment, low educational attainment in caregivers, more severe symptoms, [4] along with increased number of psychotic episodes, poor understanding of mental illness due to lack of information from mental health care workers and caring for patients with schizophrenia and with comorbid substance use. A Nigerian [5] study on caregiver burden suggested that the employment status of the patient and the educational status of the caregiver impacted on levels of burden. They found that patients that were unemployed were higher financial burdens for their families and that caregivers without formal education experienced more burden.

According to the revised South African local disease burden, the disability-adjusted life-years (DALYS) have resulted in mental illness being ranked the third most disabling group of pathologies, after HIV/AIDS and other infectious diseases. [6] The South African Stress and Health study (SASH) showed a 30.3% lifetime prevalence of mental illnesses. [7]

About schizophrenia

Schizophrenia is among the mental illness that has a severely negative effect on the quality of life of patients. It has been well described both in literature and research as a psychotic disorder that results in disturbances of thought patterns, behaviour and mood. The lifetime prevalence of schizophrenia has been reported to be 1%. [8] It is a chronic mental illness, which is often characterized by a relapsing course with

resultant effects on most areas of functioning due to the disability associated with it. Initially it was believed that schizophrenia results in progressive deterioration over the course of the illness, but literature has refuted that suggestion. Rather it has been shown to be a neurodevelopmental disorder in which cognitive function is poor from the outset. As more research has been conducted it is now apparent that cognitive dysfunction is evident even prior to the onset of psychosis. A study found that intelligence testing in children that later developed schizophrenia was low at the baseline of ages 4 and 7 when compared to children who went on to develop mood-related psychotic disorders. [9]

Schizophrenia can consist of positive symptoms, negative symptoms, and symptoms that affect cognition. The presence of negative symptoms, poor adherence to medication and comorbid substance use has been shown to be predictive of a poor outcome in schizophrenia. [10] In the recent past literature has suggested negative and cognitive symptoms are more closely linked to functioning when compared with positive symptoms. [11]

Symptoms in schizophrenia

Positive symptoms, as listed in the Diagnostic Statistics Manual (DSM) consist of hallucinations, delusions, disorganization (in speech or behaviour) and catatonia. [36] Negative symptoms can include emotional withdrawal, social withdrawal, poor motivation and diminished drive, flattened affect, and decreased speech production amongst other symptoms. There has been a sparked interest in schizophrenia research with regards to developing medication that will target negative symptoms, as this

group of symptoms has proven difficult to treat with current antipsychotic medications, and the presence of these symptoms have been associated with poor functional outcomes. Literature has often described how these symptoms tend to persist when positive symptoms have settled. A study by Hunter et al that looked at the relationship between negative symptoms and psychosocial functioning found that negative symptoms had a significant impact on the functional scales used in their study. [12] It is not difficult to understand why the presence of these symptoms could affect function. For example, if a patient is apathetic and lacks motivation in finding or sustaining employment this could pose a challenge; the same would apply for initiating and maintaining social and/or intimate relationships.

Cognition has also proven to be an area of interest in schizophrenia research of late. Two entities have been described in literature, neurocognition and social cognition. According to the Measurement and Treatment Research for Improving Cognition in Schizophrenia (MATRICS) group neurocognition consists of executive function domains, such as attention, problem solving, verbal comprehension and working memory among other symptoms. Social cognition on the other hand has had varying definitions; the most commonly used being "mental operations underlying social behaviour". [13] Both neurocognition and social cognition are closely linked to day-to-day functioning.

Studies on neurocognitive impairment have not consistently shown uniform deficits in the above domains and that may be due to schizophrenia being a heterogeneous, complex disorder. It was previously believed that cognitive impairment in schizophrenia deteriorates over time, but research lacked consistency in this regard,

however it seems that impairments may be somewhat stagnant. [14] Impairments in neurocognitive domains are likely to have implications on cognitive remediation and daily activities such as decision-making.

Social cognition is an area in research that has been and is receiving substantial interest of late. It consists of emotional processing, social perception, social knowledge, theory of mind and attributional bias. [15] The combination of these components enable a person to form healthy social relationships and the awareness and recognition of social cues, that are vital in everyday function as it relates oneself to other human beings. Deficits in social cognition noted in schizophrenia have an impact on daily functioning and community functioning, which has been described by Fett et al [13] as behaviours of everyday functioning such as independent living.

The presence of any of the symptoms of schizophrenia can be extremely distressing for the families or caregivers who care for the patient, as they may either blame themselves for the illness, or resent their ill relative for robbing them of happiness and stability. [16] Caregivers may also experience rejection and feel misunderstood by people in their community as a result of the mental illness of their relative.

Cost associated with schizophrenia

The cost of schizophrenia, also known as the cost of illness, can be subdivided into direct costs, intangible costs and indirect costs. [17] Direct costs are described as the actual financial amounts of money involved in the care of patients with schizophrenia. Costs have been described in both the public and private sectors. Included in these

direct costs are admissions which could be a result of index presentations as well as relapses due to any cause, out-patient consultations, including to dual diagnosis centres for substance rehabilitation, medication, investigations, occupational therapy and other necessary therapies. Costs to the Department of Social Services and Welfare have come about due to issuing of disability grants as many patients have not been able to work as a result of the impact schizophrenia has on their functioning.

Intangible costs refer to the negative effects of having a mental illness, like depression that may be experienced by the caregiver or the patient as a result of the impact of the illness.

Indirect costs arise from resources lost due to the illness. These include loss of productivity and the ability to work due to the reason stipulated above; costs to the criminal justice system as a result of crimes committed by mentally ill persons; and, the cost to families which include effects on social activities and loss of working hours, which could negatively impact on earnings for the caregiver or family of the patient. [17] It is the presence of these indirect costs that may have a bearing on the caregivers experiencing a significant burden of care.

Challenges in South Africa

In South Africa, one of the greatest challenges that stemmed from redirecting the core focus of mental health from institutions to the community is the dire socio-economic state of most families. In the greater Johannesburg area, many of the patients that access mental health services from the public sector are under enormous financial

constraints, as often both the patient and caregiver are unemployed. Patients with schizophrenia usually qualify for disability grants and for many families this grant is the only source of income. Some of these patients exist in dismal conditions; where they have to share minute living spaces with many family members. [18]

Additional challenges faced by the public mental health sector since the move to community psychiatry, is that of frequent hospital admissions resulting from poor compliance to medication and stigma associated with mental illness. Often times patients feel embarrassed to continue care at local clinics, which are near to their homes. This is due to negative perceptions associated with the clinics by community members. Community members tend to label the local clinics as clinics for 'mad people'. As a result of these negative perceptions many patients choose to not attend follow-up visits. Patients also relapse due to inconsistencies in availability of medication at clinics and hospitals. [18] In some instances clinics, and even the hospitals, run out of different medication stocks for indefinite periods. During these times patient medications have to be changed to ensure that the patient is covered, even though his/her response (efficacy and/ or tolerability) to the alternative medication is not known. These frequent re-admissions may result in patients "remaining well for only short periods of time", [18] which negatively impacts on quality of life. There are also limited long-term placement facilities in South Africa for severely mentally ill patients. Following the closure of institutions, these facilities seek to offer temporary relief to the caregivers of the severely mentally ill patient.

Definition of the Caregiver Burden

Many researchers have suggested various definitions for caregiver burden. There are two common descriptions. One describes a psychological circumstance that is associated with economic, emotional, physical and social concerns that occur as a result of caring for a patient. [19] The second and most popular description in literature is that of the objective and subjective burden. The objective burden relates to the effect of the patient on the household; disruptions to the caregiver such as loss of income, daily chores and social isolation, whereas the subjective burden relates to burden as perceived by the caregivers, such as guilt, anger, stigma. [20]

Satorius [21] described stigma in mental illness as "the negative attitude (based on prejudice and misinformation) that is triggered by a marker of illness". It negatively affects patients and their families and often results in discrimination of some form. Health care professionals at times, discriminate against patients with severe mental illnesses when medically unstable, resulting in neglect of their physical ailments.

A South African [22] study looking at patient's perceptions of community attitudes towards having schizophrenia found that 65% of patients felt they experienced discrimination due to their illness. The authors found that the experience of discrimination increased in proportion to the number of admissions.

There is limited data regarding South African caregiver's experience of stigma when caring for persons with schizophrenia. In spite of this, mental health fraternities in South Africa have prioritised anti-stigma campaigns. [23]

Quality of life in caregivers

Quality of life (QOL) and caregiver burden have often been referred to synonymously in literature. QOL is thought to look at various aspects of an individual, such as physical and mental health, financial standing, social interactions as well as fulfilment of life goals. It has been suggested in literature that the above areas can be affected in caregivers as a consequence of them being socially isolated, due to the stigma associated with having a mentally ill relative. It has further been suggested that there is a financial burden that could be related to missing days at work in order to accompany the relative with schizophrenia for doctors visits, and that recurrent relapses may result in loss of income. Caregiver burden has also been associated with a reduction in the caregivers QOL. [24] Furthermore research has documented that the effect of care giving on the caregiver's health, mental and/or physical, is dependent on the patient, the caregiver and their environment. [17]

Some researchers described poor health among caregivers, which included mental illnesses such as anxiety and depression, along with some caregivers having infectious diseases, which could possibly have resulted from a decline in the caregivers' immunity. [24]

Research has shown that women, mothers in particular, comprise the largest group amongst the caregivers and as a group they also have the worst QOL. Similarly spouses were reported to have challenges with striking a balance between various roles including bearing the financial burden for the family and rearing children. However, children were found to be a protective factor in the relationship, [25] which may affect QOL. There is also literature, [27] which describes children who were themselves caregivers for their mentally ill parents. This literature shows that these children experience a higher burden when compared to other relationship groups. Over and above the information stated above, it has also been suggested that there are

a few more consistent factors, which adversely affect the QOL of caregivers. These include scarce spare time, financial load and grief due to inability to re-establish the patient's former level of functioning. [24]

Several studies have made mention of specific predictors of high levels of burden. Included in these predictors are: older age for both the caregiver and patient, lower level of education of the patient and caregiver, which often results in a decrease of employment opportunities, male patients; poor social support and relatives who use maladaptive coping mechanisms, such as denial and avoidance. [28]

Another factor believed to increase the level of burden is that of patient symptom severity. [8] This manifests itself in unsettling behaviours, which include disruptive behaviours. [25] Some researchers have suggested that a shorter period of diagnosis, six months or less has been linked to higher caregiver burden level, [29] this may possibly be due both the family and patient adjusting to a new diagnosis of severe mental illness. In a study that was conducted using a socio-cultural stress, appraisal and coping model it was hypothesized that a patient's behaviour would be influenced by cultural factors that relatives find burdensome and this would influence how these caregivers perceive burden and how they interact with the patient. [30]

Coping Mechanisms Utilised by Caregivers

Caregivers have displayed certain coping mechanisms to help them deal with their relatives' illness and resultant behaviour. Among the commonly reported mechanisms in various studies are; the use of denial and avoidance, which was found mostly in parents as opposed to spouses, and the use of substances by males. [25] One study found

that caregivers often sought assistance and reassurance from their relatives as opposed to health care professionals. [2] Another study found that families which belonged to religious groups obtained relief from their belief in their chosen faith rather than finding relief in the religious rituals themselves. [25]

The Position of Literature Opposing the Caregiver Burden

Having stated the above, opposing literature has been found stating that not all caregivers feel burdened by caring for their relatives. [31] The concept of "positive caring" was described in a study, where the focus of caregiving was on the experience and satisfaction felt by the caregiver. In these instances the caregiver felt fulfilled and rewarded by the act of caring for their relative.

It was also noted in this study that the caregivers' self-esteem was positively affected by being there for their relatives in their greatest time of need. [32] Some caregivers have reported becoming more accepting and more considerate towards their relative and his/her mental illness, which in turn allows for better coping and reduced strain. Those caregivers that did not feel burdened were reported to receive social support from health care professionals. [2]

The terms caregiver burden and caregiver strain are used interchangeably in the study.

1.1 Study objectives

- To describe the nature of caregiver burden, whether it is high or low, when taking the caregivers emotional response to care giving to account.
- To describe the relationship between caregiver burden and the caregiver's quality of life
- The key research question is to study the relationship between caregiver strain index and quality of life dimensions.

Materials and methods

2.1 Introduction

The study was descriptive and cross-sectional in nature. It was conducted at Chris Hani Baragwanath Academic Hospital (CHBAH), located in Soweto, Johannesburg. The outpatient department at CHBAH provides extensive multidisciplinary mental health services for patients with psychiatric diagnoses. Patients can be referred to/by psychiatrists, psychologists, occupational therapists and social workers. Each of these departments run extensive programs which are tailored, as much as possible, to the individual needs of the patient.

2.2 Study design

Caregivers of patients with schizophrenia accompanying their relatives were randomly identified. They were approached to participate in the study that consisted of two questionnaires that were in English and IsiZulu as well as two forms to collect demographic information. The WHOQOL-BREF quality of life and the Caregiver Strain Index (CSI) questionnaires were used to evaluate quality of life (QOL) and caregiver burden respectively.

The World Health Organization Quality of Life Assessment Group developed a QOL questionnaire (WHOQOL-100) that was both extensive and time consuming. In order to develop a questionnaire that was appropriate for settings with time constraints, such as clinical settings a shortened version was developed by the same group. Instead of 100 items, the WHOQOL-BREF was reduced to 26 items that consist of four domains

and two additional questions specific to overall QOL and health. The four domains include perceptions of physical health, psychological health, social relationships and the environment. The questionnaire was tested in twenty field centres within 18 countries, including a number of African countries, where good construct validity was ascertained. [37] A study conducted by Lucas-Carrasco [38] in Spain that looked at validating both the WHOQOL-100 and the WHOQOL-BREF in patients with schizophrenia and their caregivers and patients with physical illnesses found that the WHOQOL-BREF was a reliable tool to describe QOL.

The CSI is a screening tool that is meant to give an idea of caregiver burden. It consists of 13 items and is scored out of thirteen. A score above seven is suggestive of caregiver strain and the closer the score is to thirteen the higher the level of caregiver strain for that particular caregiver. It was initially developed [39] in 1983 and studied in caregivers of elderly patients with cardiac illnesses and recent hip surgery. It was adapted from a study that had a questionnaire that consisted of 10 items, sleep disturbance, physical and financial strain of caring were added resulting in a total of 13 items.

The primary investigator assisted illiterate caregivers, and in the event where the participants and the investigator did not speak the same language nursing staff assisted with translation.

2.3 Study population and sample

The sample size estimation was based on the key research question, namely the relationship between CSI and the QOL dimensions. The relationship was determined by Pearson's correlation coefficient. Based on a significance level of 5%, a power of 80% and the detection of a medium effect size (absolute value of correlation coefficient of 0.3 of greater), the sample size was estimated at 84. It was proposed that the researcher aim for a minimum sample size of 84, but continues to gather data within the time frame of the research to increase the sample size as much as possible.

2.4 Inclusion and Exclusion Criteria

The study included caregivers on the grounds that they were above 18 years of age, were living with the patient or spending most of their time with the patient, the relative under their care had a primary diagnosis of Schizophrenia that was one year or longer. A diagnosis of schizophrenia was made using the diagnostic statistical manual IV (DSM IV) and documented in the patient file.

The caregiver was excluded from the study if he/she was receiving any psychological intervention during the time of the study, if he/she had any degree of cognitive impairment, if he/she was caring for more than one mentally ill or physically disabled person and if the relative they cared for had a co-morbid personality disorder as part of their diagnosis. The investigator made an informal verbal assessment of cognitive impairment in the caregiver by a brief enquiry into a history of developmental delay,

level of education, being condoned passed and/or repeating grades in primary school and sustaining a head injury.

The presence of comorbid personality disorders in patients included in this study, may negatively influence the caregiver's perception of caring, especially patients with cluster B personality disorders as they may be sometimes experienced as difficult or demanding. The investigator, referring to the initial clerk in the out patient file, was able to exclude personality disorders made using the multi-axial DSM IV diagnosis.

2.5 Ethics Approval

Ethics approval was obtained from the Human Research Ethics Committee at the University of Witwatersrand, Johannesburg. Ethics number M130838.

2.6 Data collection

Data was collected over a period of eight months over different days depending on the primary investigator's availability on site.

For inpatients, the investigator obtained the patient diagnoses in the files along with the caregiver contact details. Caregivers of inpatients were approached in one of two ways; they were identified by the primary investigator with the assistance of nursing staff, who would indicate which caregiver came to see which patient, during visiting hours. Alternatively the primary investigator would contact the caregiver telephonically to make an appointment for the caregiver to meet the primary investigator at CHBAH. All participants were informed of the study and if they fulfilled study criteria and gave informed consent, questionnaires were handed to them for completion. The primary investigator was available at the time of questionnaire completion to clarify any questions when required. Data from caregivers of inpatients was collected over the weekends.

The primary investigator, with the assistance of the nursing staff, screened outpatient files with a diagnosis of schizophrenia. The files of the patients that attended the clinic on days when the primary investigator was available on site were selected for screening. Caregivers of patients with schizophrenia were approached whilst in the waiting room; if they fulfilled the study criteria and gave informed consent, the caregiver completed the questionnaires. Some outpatients attended the clinic on their own, due to various reasons such as being stable for a few months or; financial constraints preventing the caregiver from attending, etc. Caregivers responsible for

outpatients that attended alone were contacted telephonically to make an appointment to meet with the primary investigator. Nine caregivers that fulfilled criteria could not meet the primary investigator due to personal reasons. They were interviewed telephonically. Refer to Appendix B for data collection sheets.

2.7 Data analysis and interpretation

Data analysis was carried out using SAS(statistical analysis software) version 9.3 for Windows.

The X^2 test was used to assess the relationships between categorical variables. Fisher's exact test was used for 2 x 2 tables or where the requirements for the X^2 test could not be met. The strength of the associations was measured by Cramer's V and the phi coefficient respectively. The following scale of interpretation was used:

0.50 and above	high/strong association
0.30 to 0.49	moderate association
0.10 to 0.29	weak association
below 0.10	little if any association

The relationship between continuous and categorical variables was assessed by the t-test (or ANOVA for more than two categories). Where the data did not meet the assumptions of these tests, a non-parametric alternative, the Wilcoxon rank sum test (or the Kruskal-Wallis test for more than two categories) was used. The strength of the associations was measured by the Cohen's d for parametric tests and the r-value for the non-parametric tests. The following scale of interpretation was used:

0.80 and above	large effect
0.50 to 0.79	moderate effect
0.20 to 0.49	small effect
below 0.20	near zero effect

The relationship between two continuous variables was assessed by Pearson's correlation coefficient. Where the data did not meet the assumptions of these tests, a non-parametric alternative, Spearman's rank correlation coefficient was used. The strength of the associations was measured by interpreting the absolute value of the correlation coefficient. The following scale of interpretation was used:

0.50 and above	large effect
0.3 to 0.49	moderate effect
Below 0.3	small effect

The 5% significance level was used throughout, unless specified otherwise.

3. Results

3.1 Study group

One hundred and twenty seven potential caregivers were initially approached to participate in the study, 31 were excluded, as they were not the main responsible caregivers for the patients. 96 participants were identified as appropriate for the study. 4 did not give consent, one was reported to be under age (17 years of age) during questionnaire completion and 2 did not complete the CSI form (the study was centred around this measure). A total of 89 respondents were included in the study.

Patient and caregiver characteristics were compared against the caregiver strain index scores (which indicates level of burden) in order to show if any demographic category had a statistically significant impact on the caregiver burden.

3.2 Demographics

3.2.1 Patient demographics

See table 1 to view summarized demographics.

Table 1. Patient Demographics

		n	%	P-values in relation to CSI scores >=7
Age (years)	18-35	23	25.84	**0.047**
	36-45	27	30.34	
	46-55	20	22.47	
	55+	19	21.35	
Gender	Male	64	71.91	1.00
	Female	25	28.09	
Admission status	Inpatient	16	17.98	0.27
	Outpatient	73	82.02	
Employment status	Unknown	2	2.25	0.08
	Unemployed, not on a disability grant	14	15.73	
	Unemployed, on a disability grant	65	73.03	
	Employed	8	8.99	
Number of admissions per	Unknown	8	8.99	**0.030**
	1	57	64.04	

year over last 5 years	2	13	14.61	
	3	9	10.11	
	4	1	1.12	
	5	1	1.12	

Age

The age range of the patients was 18-85y (mean 45y; sd 13y). The majority of patient's ages ranged from 36-45 years of age 30.34% (n=27). See figure 3.1.

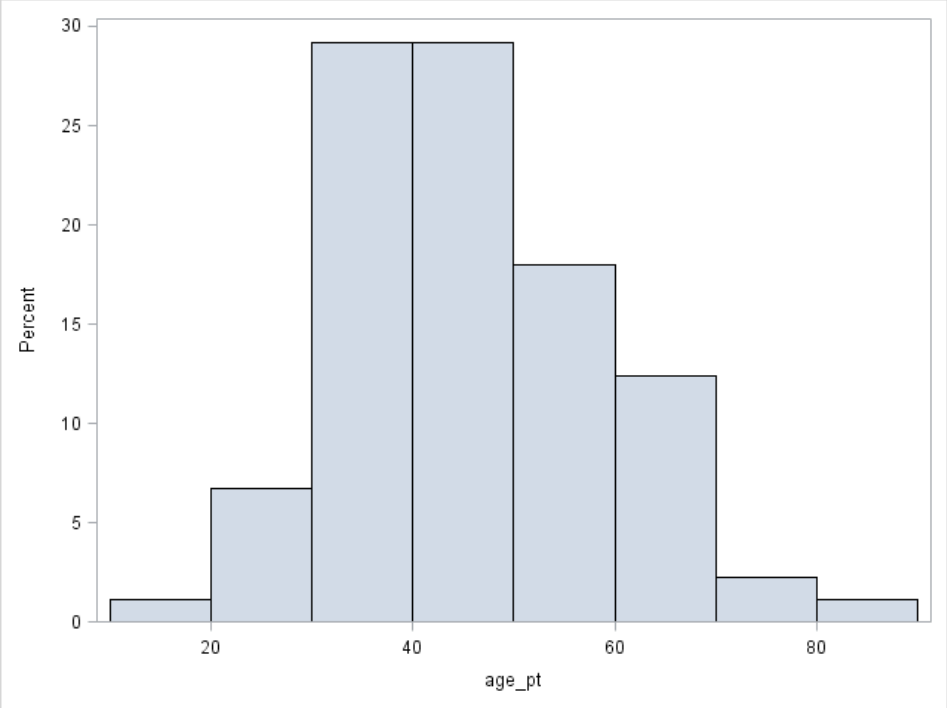


Figure 3. 1 The distribution of patient ages is shown above. For further analysis, the ages were grouped as 18-35/36-45/46-55/56y+

Gender

71.9% of the patients were male.

Admission status

82.0% of the patients were outpatients.

Employment status

Two participants had incomplete data and as a result could not be included. Only 9.0% of the patients were employed. 88.8% were unemployed, of whom 82.3% (65/79) were receiving a disability grant.

Number of years since diagnosis

The number of years since diagnosis ranged from 1 to 45 years (mean 17y; sd 10y). This variable was grouped as 1-9/10-15/16-20/21y+, as shown in figure 3.2. One person did not complete this section in the questionnaire.

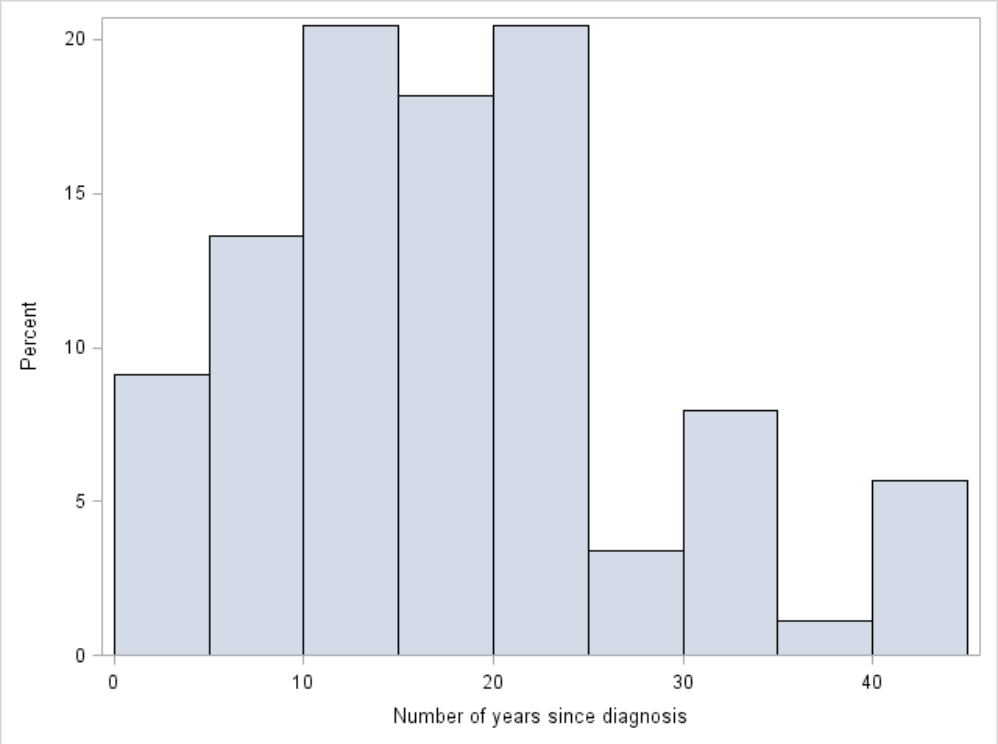


Figure 3.2 Distribution of number of years since diagnosis

Number of admissions per year over the last 5 years

Most patients (64.0%) had had one admission per year over the last 5 years. When analysing patient admission data with CSI there was statistical significance in patients

with a higher admissions number of admissions. None of the patients in this study had less than one admission per year.

For further analysis, 3 to 5+ admissions per year were combined.

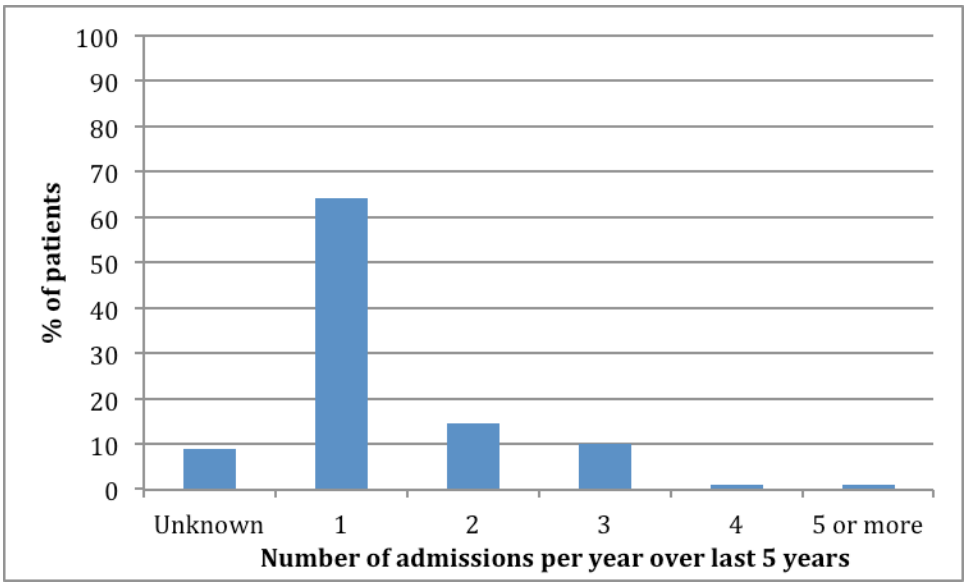


Figure 3.3 Number of admissions per year

Other psychiatric diagnoses

18.0% (n=16) of the patients had one or more other psychiatric diagnoses.

Substance abuse / dependence

18.0% of the patients had a substance abuse or dependence problem.

Psychosocial stressors

6.7% (n=6/89) of the patients had one or more psychosocial stressors, however 20 people did not indicate presence or absence of psychosocial stressors.

3.2.2 Caregiver demographics

See table 2 for summarised caregiver demographics.

Table 2. Caregiver Demographics

		n	%	P-values in relation to CSI scores >=7
Age (years)	18-29	9	10.11	0.44
	30-49	18	20.22	
	50-59	29	32.58	
	60-70	19	21.35	
	>70	13	14.61	
Gender	Male	20	22.47	0.80
	Female	69	77.53	
Level of education	Unknown	1	1.12	0.69
	No formal education	5	5.62	
	Grade 1-7	25	28.09	
	Grade 8-11	29	32.58	
	Matriculated	21	23.60	
	Tertiary incomplete	1	1.12	
	Tertiary completed	7	7.87	
Monthly Income	Unknown	4	4.49	0.65
	Unemployed	31	34.83	
	<R3000	38	42.70	
	R3000-R10000	12	13.48	

	R10001-R20000	1	1.12	
	>R20000	3	3.37	
Relationship to patient	Mother	27	30.34	0.55
	Father	6	6.74	
	Spouse	4	4.49	
	Sibling	22	24.72	
	Child	9	10.11	
	Other	21	23.60	
Numbers of family members living in same household	Unknown	4	4.49	0.030
	2	16	17.98	
	3	20	22.47	
	4	15	16.85	
	5	10	11.24	
	6 or more	24	26.95	
Religion	Unknown	2	2.25	0.30
	Christianity	81	91.01	
	Islam	1	1.12	
	Hinduism	1	1.12	
	Other	4	4.49	
Practicing religion	Unknown	13	14.61	0.31
	No	22	24.72	
	Yes	54	60.67	
CSI>=7	No	34	38.20	
	Yes	55	61.80	

Age

The age range of the caregivers was very wide, as shown in figure 3.4. The majority of the caregivers were aged 50-59 (32.58%).

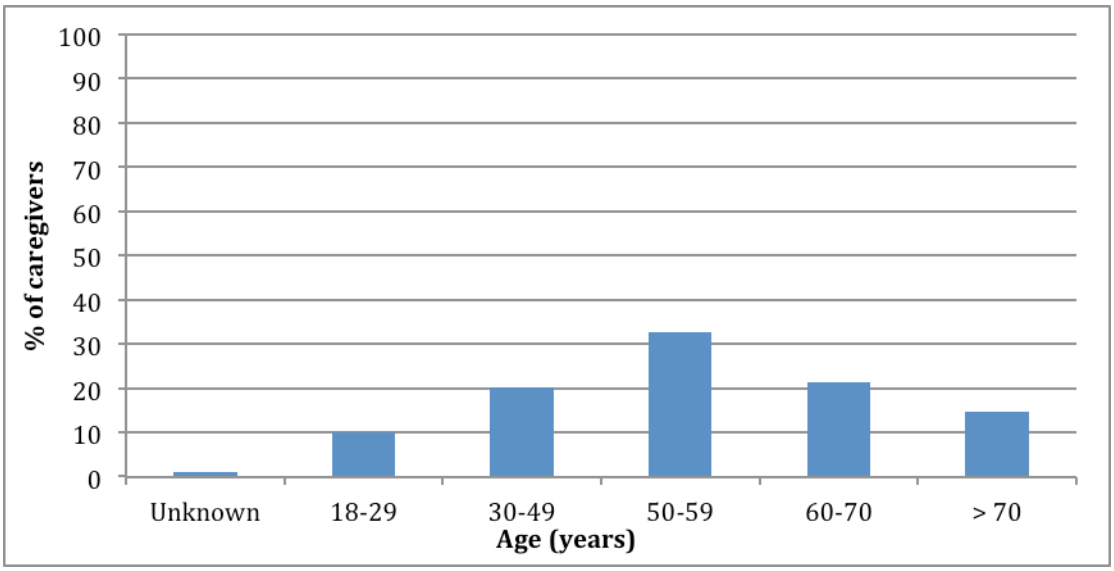


Figure 3.4 Distribution of ages for caregivers

Gender

77.5% of the caregivers were female.

Education

The majority of caregivers had incomplete secondary school (32.6%) or only primary school (28.1%) education. A further 23.6% had matriculated. See figure 3.5 below.

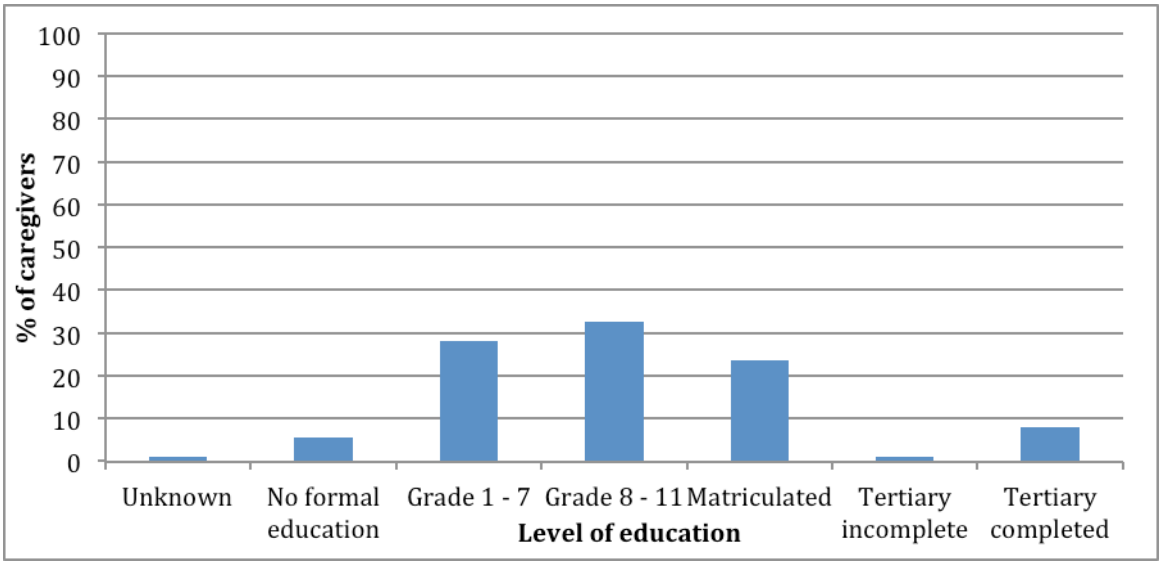


Figure 3.5 Caregiver level of education

Income

Four people did not complete the income section. 42.7% of the caregivers were earning below R 3,000 p.m., while 34.8% were unemployed. The top three income categories were combined. There was no significant difference among the income brackets.

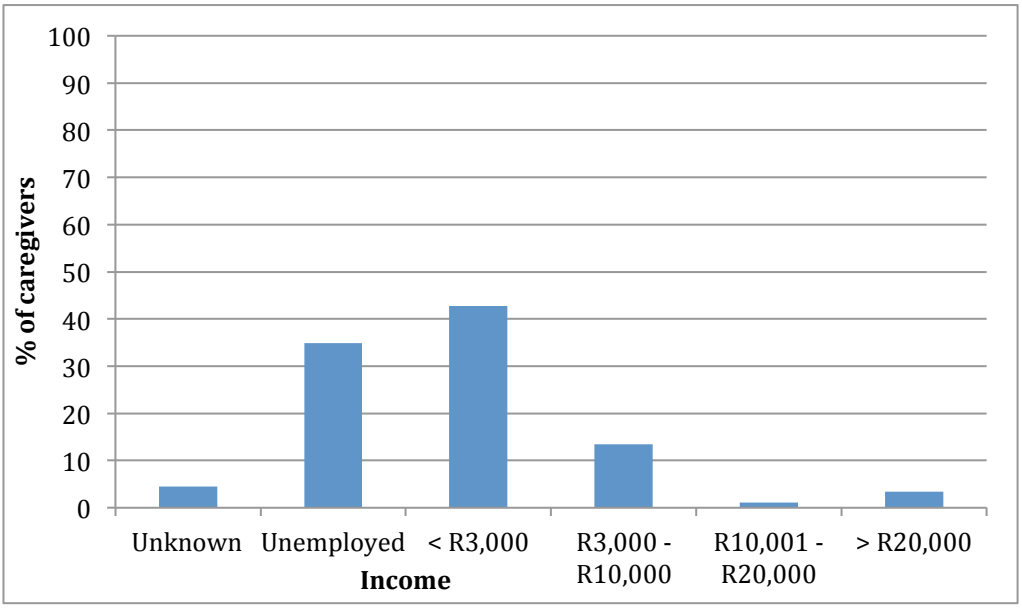


Figure 3.6 Caregiver income status

Relationship to patient

The caregivers were primarily the mothers (30.3%) and siblings (24.7%) of the patients as shown in figure 3.7. There was no significant difference in the type of relationship the caregiver shared with the patient and the level of caregiver burden (p=0.24).

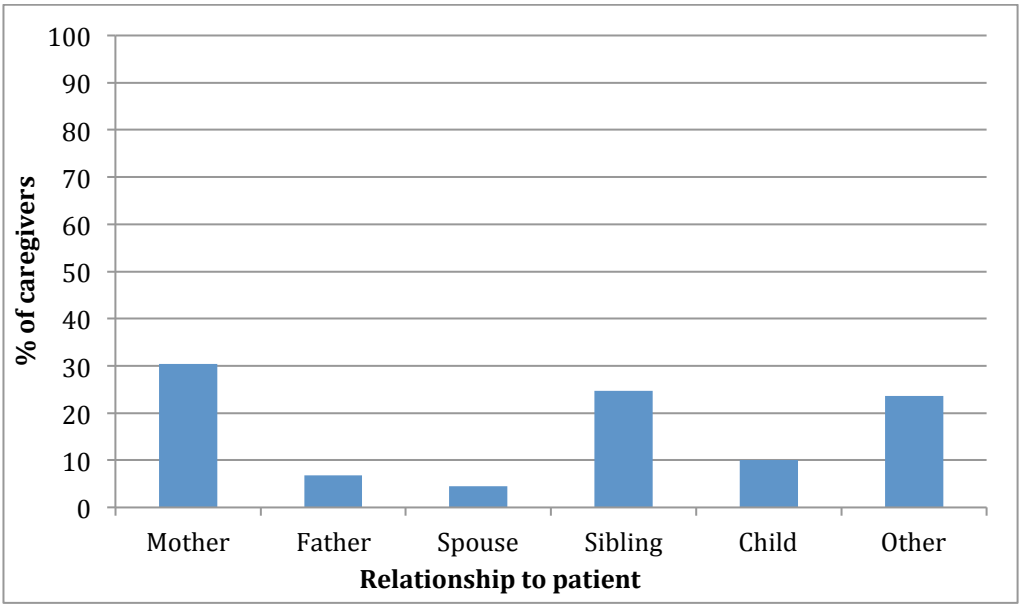


Figure 3.7 Relationship to patient

Number of family members living in same household

Up to 15 family members in the household were reported. 4 people did not complete this section on the questionnaire. Refer to figure 3.8.

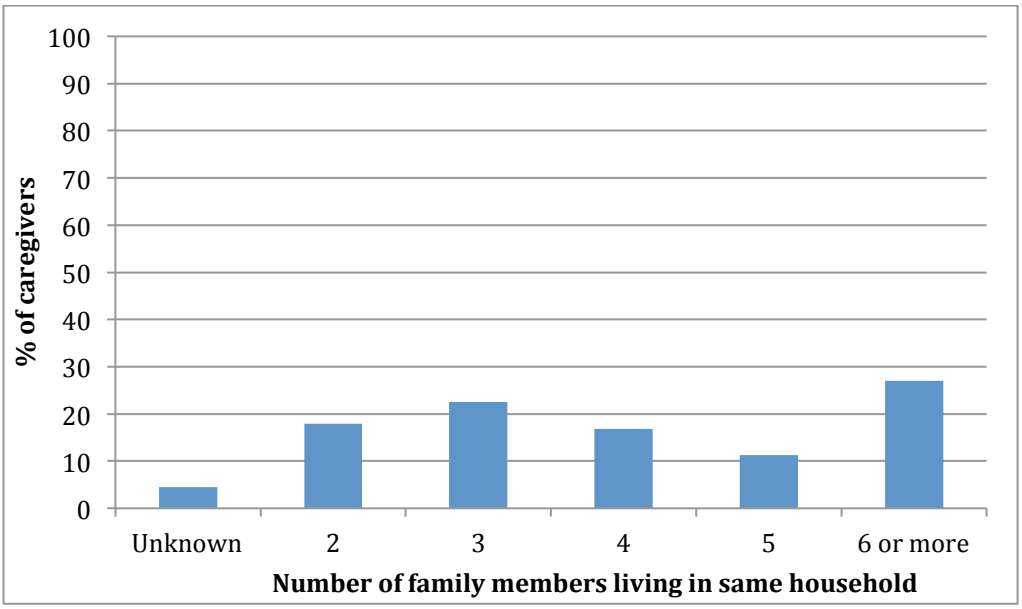


Figure 3.8 Number of family members in the household

Number of years spent caring for patient, since diagnosis

There was a considerable spread in the responses; many caregivers had a spent a substantial number of years caring for their patient. 19 caregivers had spent 2-5 years and a further nineteen spent 6-10 years caring for the patient, whilst 26.97% (n24/89) spent more than 15 years caring for the patient. There was no significant difference in years spent caring for the patient when compared to high caregiver burden (p=0.49). Refer to figure 3.9

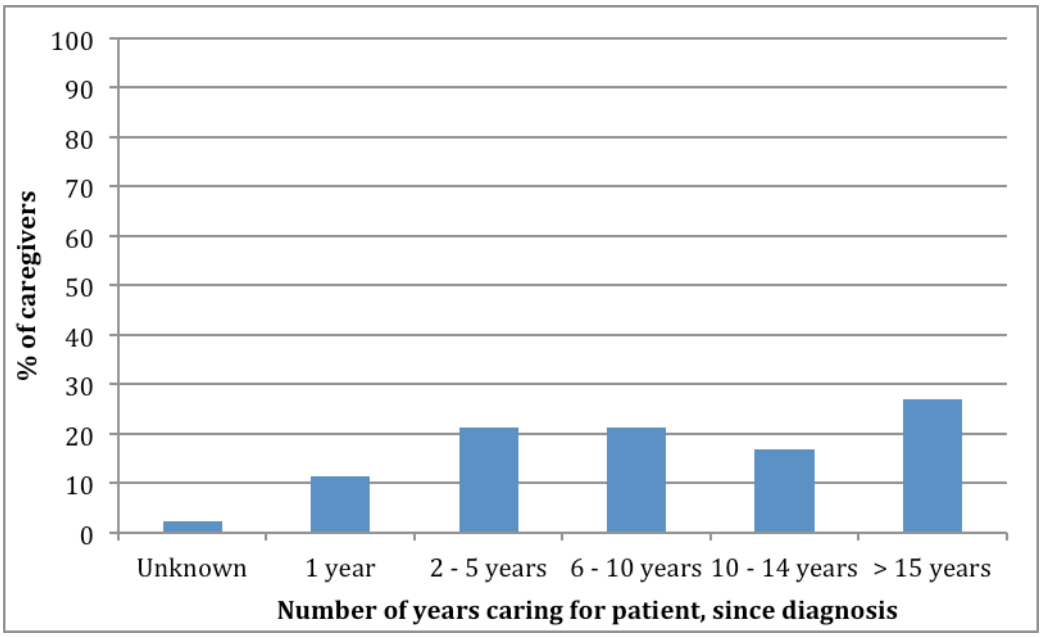


Figure 3.9 Number of years caring for patient, since diagnosis

Type of household

61 caregivers reported living in formal households.

Religion

The majority of caregivers reported that they belonged to the Christian religion (n=81). This variable was not used in further analysis, since the non-Christian groups were too small. Of the 91.1% of Christian caregivers 60.7% of them (n=54) reported that they practiced their religion and 13 participants did not indicate whether they practiced their religion or not. There was no significant difference between those who reported practicing their religion and those who did not (p=0.57).

3.3 Caregiver Strain Index

A score of 7 or higher in the CSI indicates higher levels of caregiver strain. The scores are fairly normally distributed around a mean of 7.3(mean=7.3; sd=2.3); 61.8% of the caregivers had a CSI >= 7.

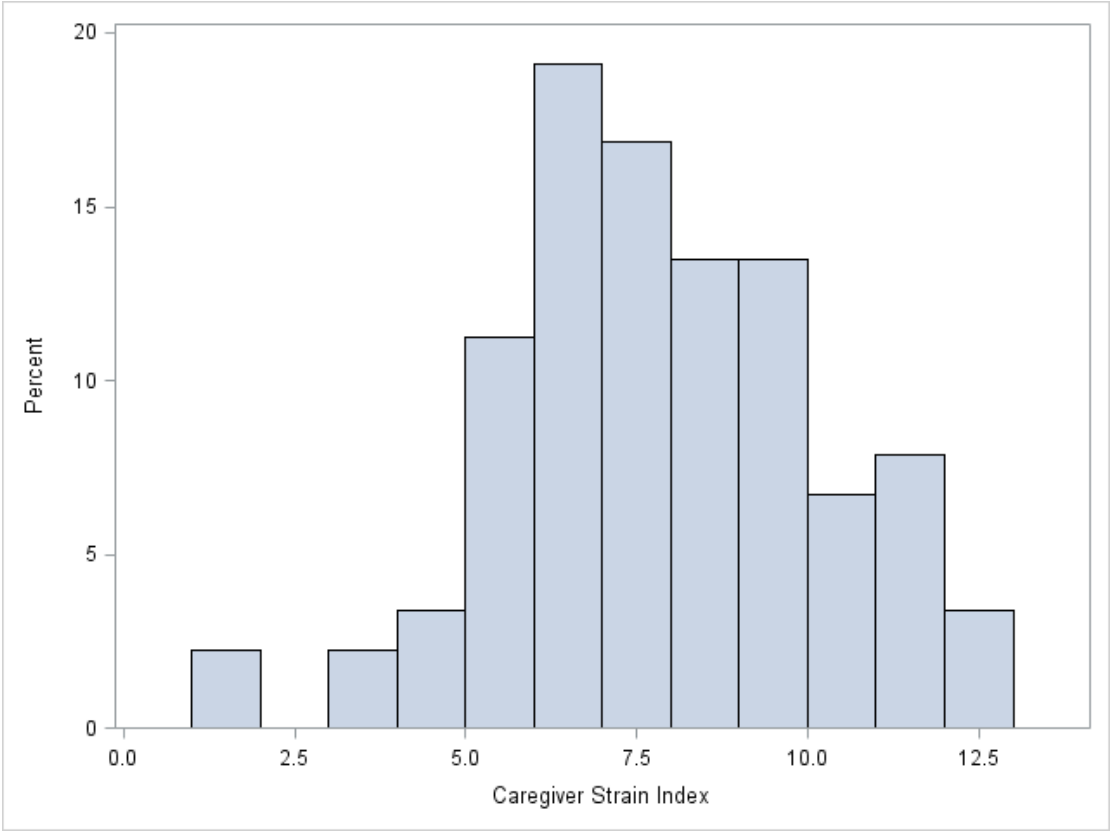


Figure 3.10 CSI scores

To understand the nature of the caregiver burden in more detail, the proportion of respondents who answered 'Yes' to each of the 13 CSI items is shown in figure 3.11 below. The three most common items (>80% of respondents indicated these) were feeling overwhelmed, and being upset by behaviour and changes in the patient.

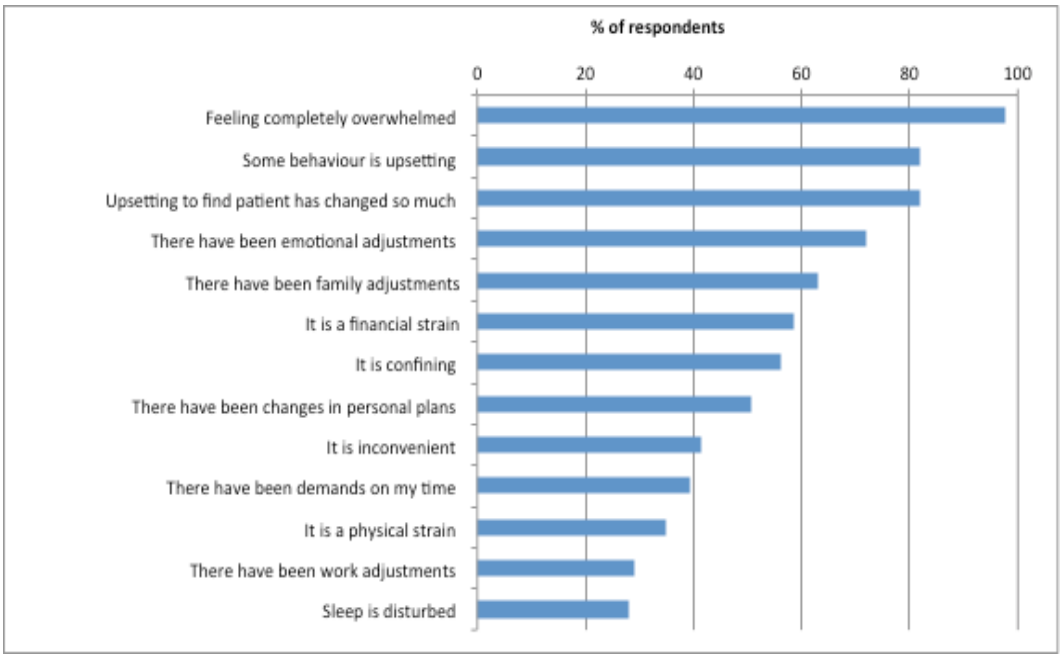


Figure 3.11 Caregivers response to various CSI components

3.4 Quality of life scores

The QOL questionnaire consists of 6 domains. These domains are composed of the following aspects; overall rating of quality of life and physical health, specific physical health domain, psychological domain, social relationships domain and an environment domain.

Table 3. Univariate statistics for the 6 QOL scores

QOL score	N	Mean	Std Dev	Minimum	Maximum	Median	25th Pctl	75th Pctl
How would you rate your quality of life?	89	3.6	0.9	1	5	4	3	4
How satisfied are you with your health?	88	3.8	1.0	1	5	4	3	4
QOL: Physical Health	89	69.7	19.1	21.4	96.4	75.0	60.7	82.1
QOL: Psychological	89	72.0	14.5	29.2	100.0	75.0	66.7	79.2
QOL: Social Relationships	89	62.7	18.8	8.3	100.0	66.7	50.0	75.0
QOL: Environment	89	56.3	17.4	15.6	100.0	56.3	46.9	67.9

The 6 QOL scores were compared with each other in an attempt to see if some reflect a higher QOL than others, see figure 3.12 below.

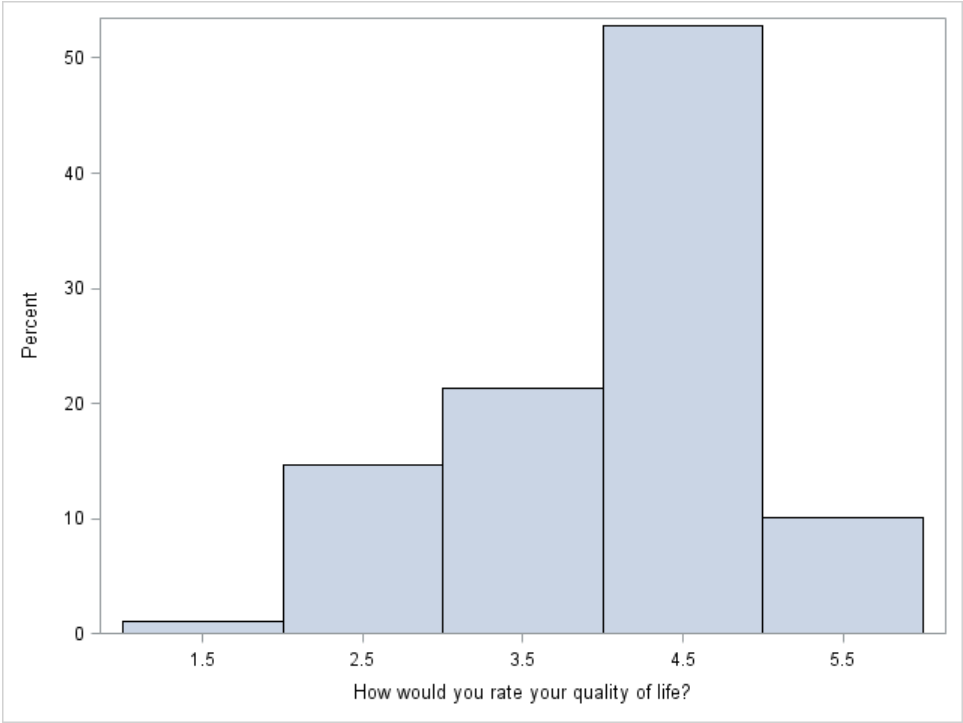


Figure 3.12 QOL rating score

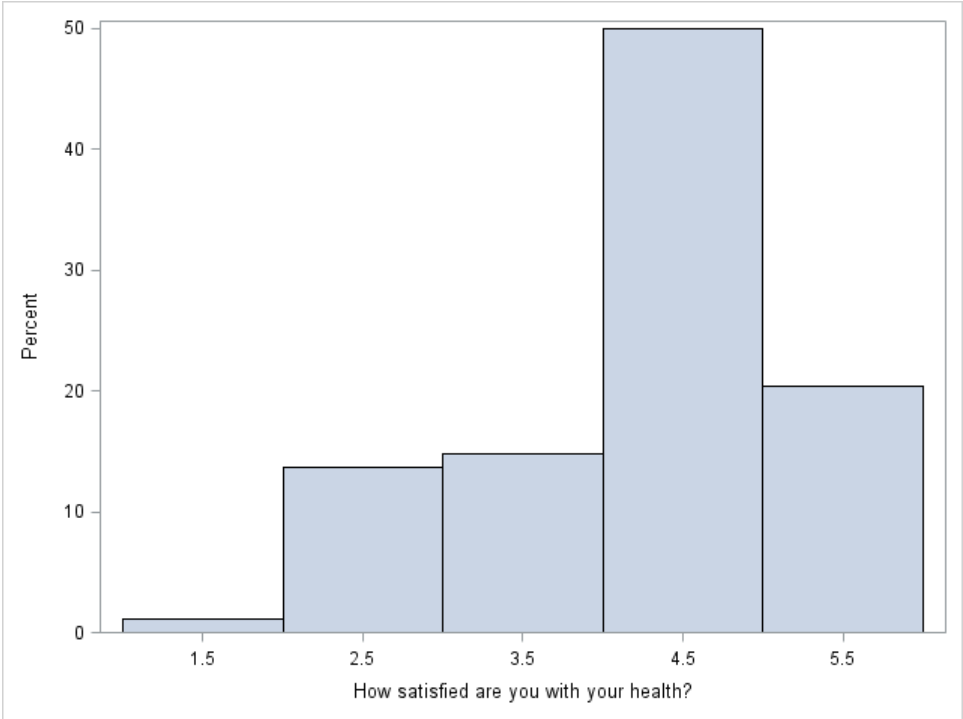


Figure 3.13 Satisfaction with health score

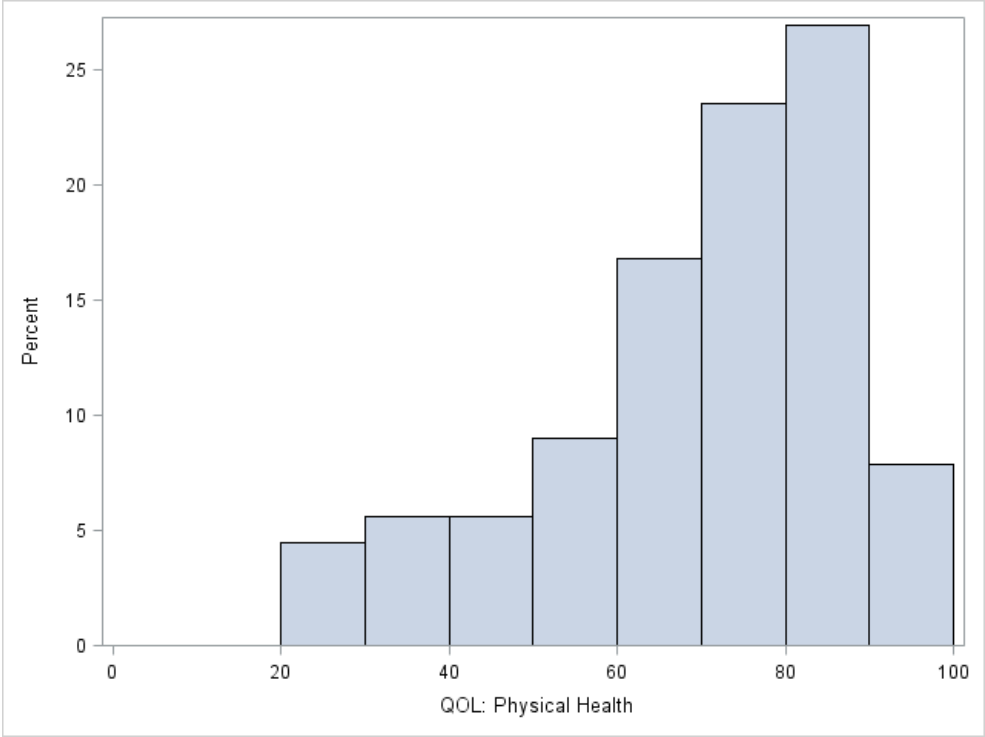


Figure 3.14 QOL physical health score

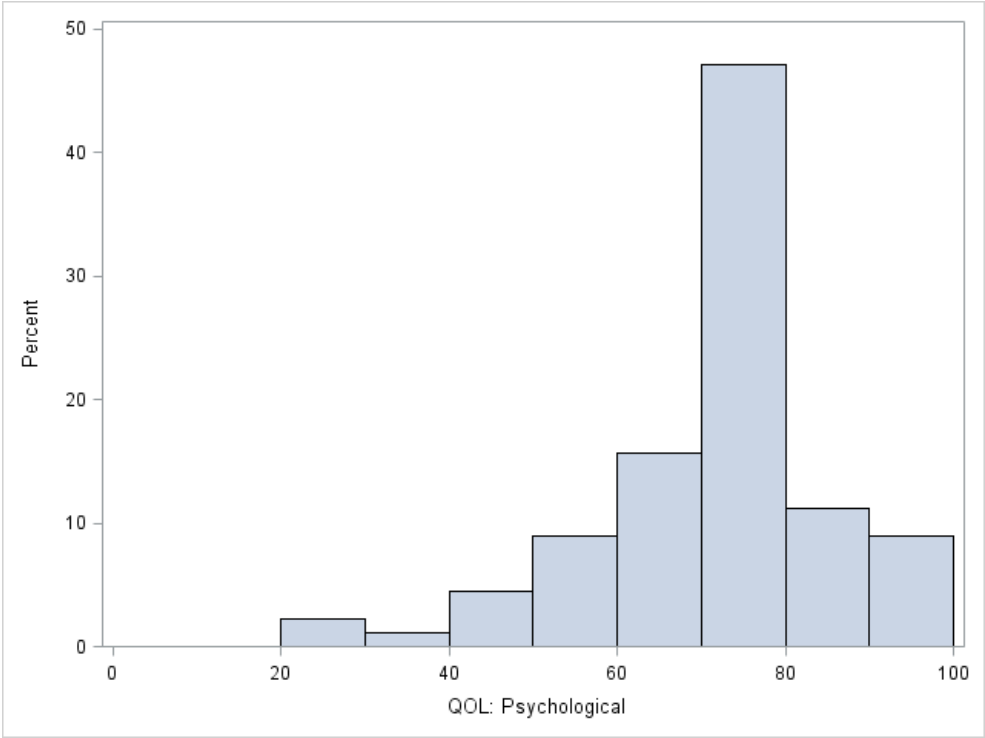


Figure 3.15 QOL psychological perspective score

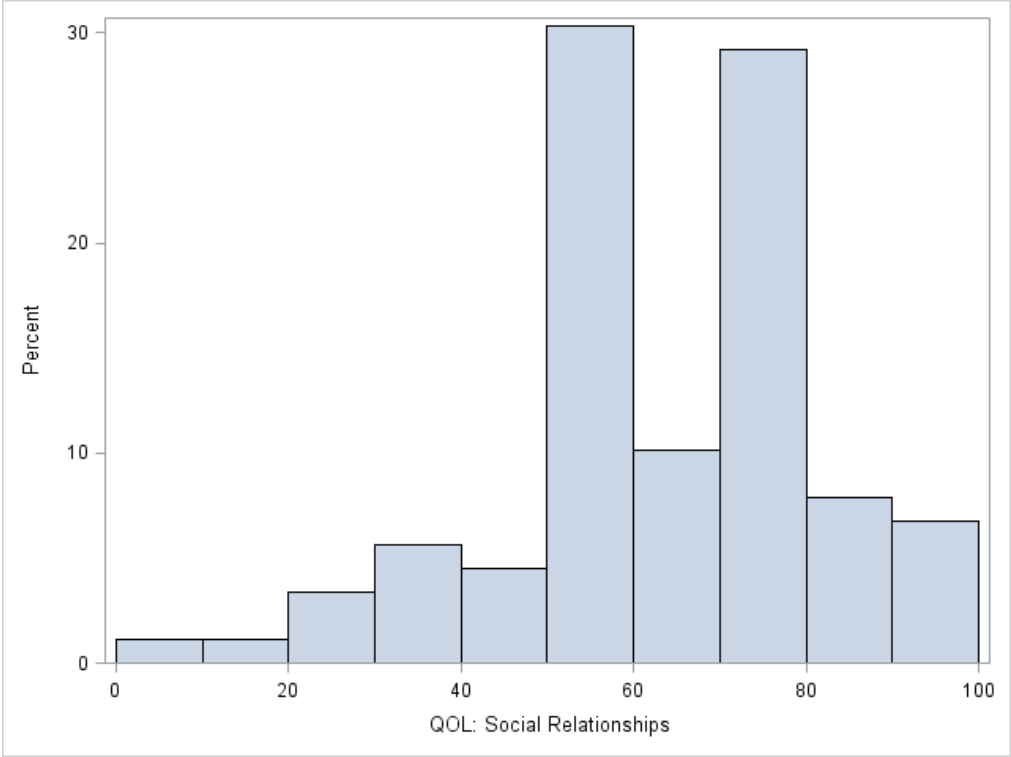


Figure 3.16 QOL social relationships score

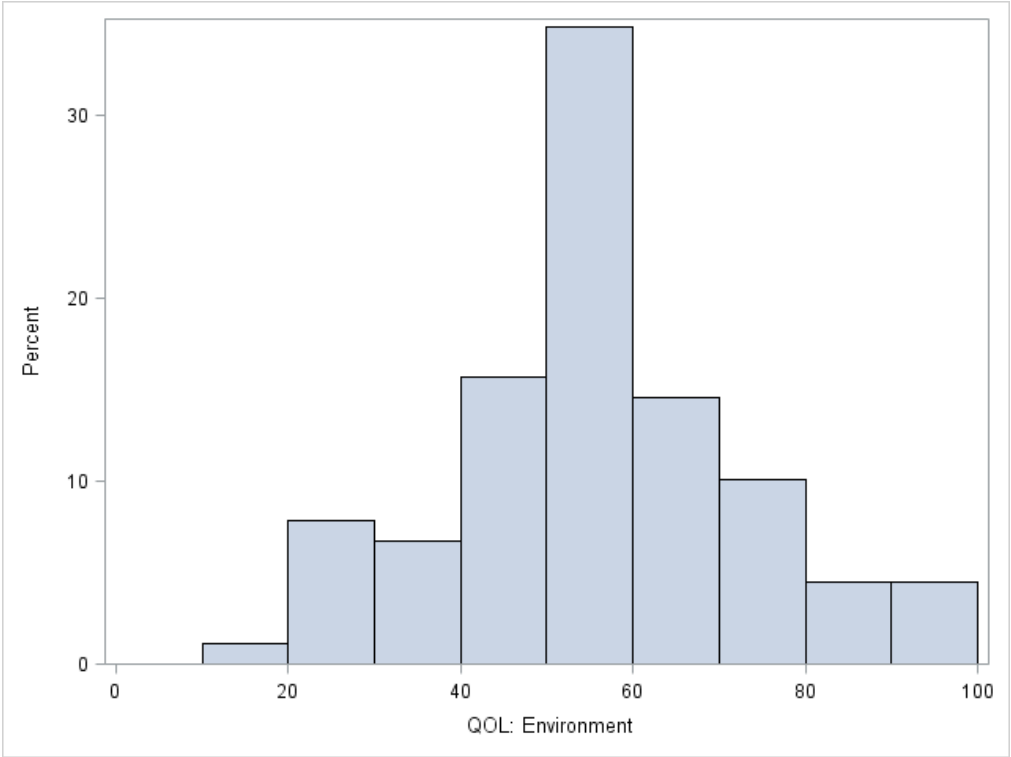


Figure 3.17 QOL environment score

- Comparing the two individual questions, the responses to satisfaction with health were more positive than those for quality of life (mean 3.8 vs 3.6 on a scale of 1-5; mean difference 0.19±0.17; paired t-test; p=0.026).
- Comparing the four dimensions, which are given on a scale of 0-100, we find the following significant differences (repeated measures model; post-hoc comparisons adjusted for multiple comparisons)
    - Higher score for Physical Health than Social Relationships QOL (mean 69.7 vs 62.7; mean difference 6.9±4.2; p=0.0016)
    - Higher score for Physical Health than Environment QOL (mean 69.7 vs 56.3; mean difference 13.4±3.4; p<0.0001)
    - Higher score for Psychological Health than Social Relationships QOL (mean 72.0 vs 62.7; mean difference 9.2±3.4; p<0.0001)
    - Higher score for Psychological Health than Environment QOL (mean 72.0 vs 56.3; mean difference 15.7±2.6; p<0.0001)
    - Higher score for Social Relationship than Environment QOL (mean 62.7 vs 56.3; mean difference 6.4±3.6; p=0.0007).

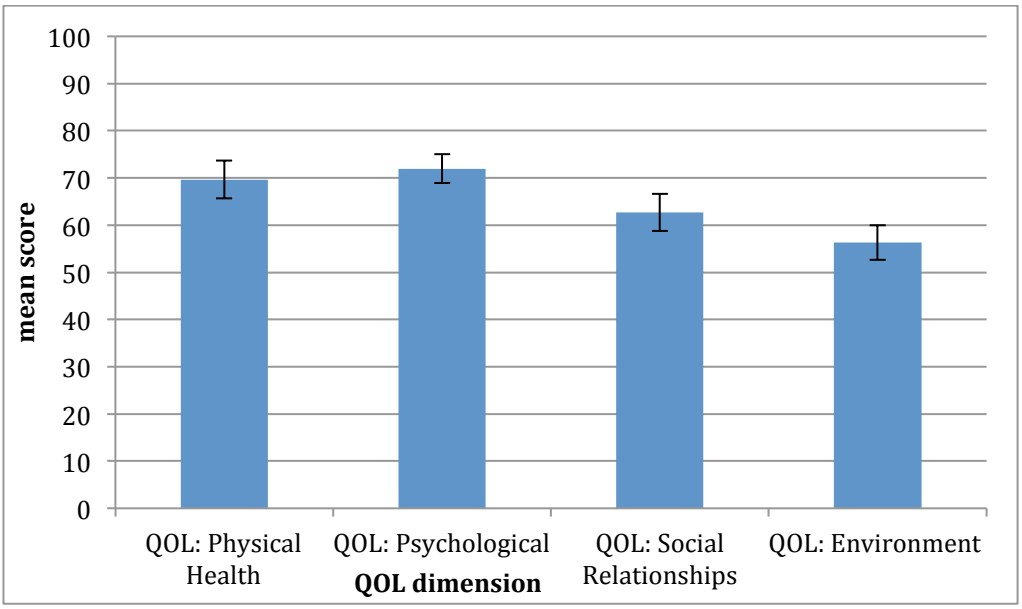


Figure 3.18 QOL domains comparison

3.5 Relationship between CSI and QOL dimensions

The association between the CSI and each of the QOL dimensions was determined by Spearman's rank correlation coefficient (since not all the QOL dimensions were normally distributed, which is a requirement for the use of Pearson's correlation coefficient).

The Spearman's rank correlation coefficient for each aspect of QOL with CSI is shown in table 4 below. All six correlation coefficients were significantly different to zero, and were negative, indicating the expected relationship: as caregiver burden increased, QOL decreased.

Table 4. Association between CSI and each QOL domain

How would you rate your quality of life?	-0.525
How satisfied are you with your health?	-0.443
QOL: Physical Health	-0.385
QOL: Psychological	-0.449
QOL: Social Relationships	-0.341
QOL: Environment	-0.327

The relationships are illustrated by means of scatterplots, shown in figures 3.13-3.18.

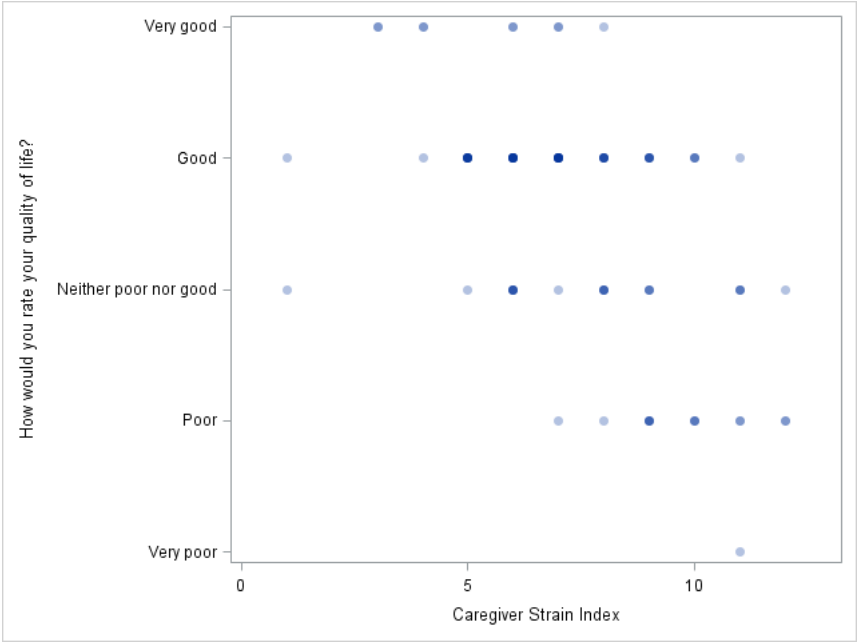


Figure 3.19 Relationship between CSI and overall QOL question

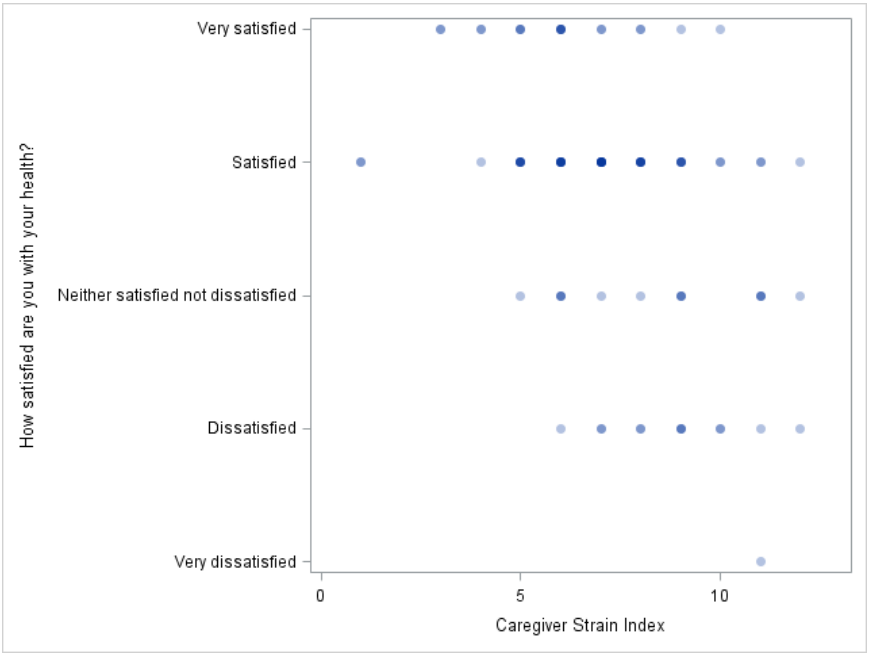


Figure 3.20 Relationship between CSI and overall health question

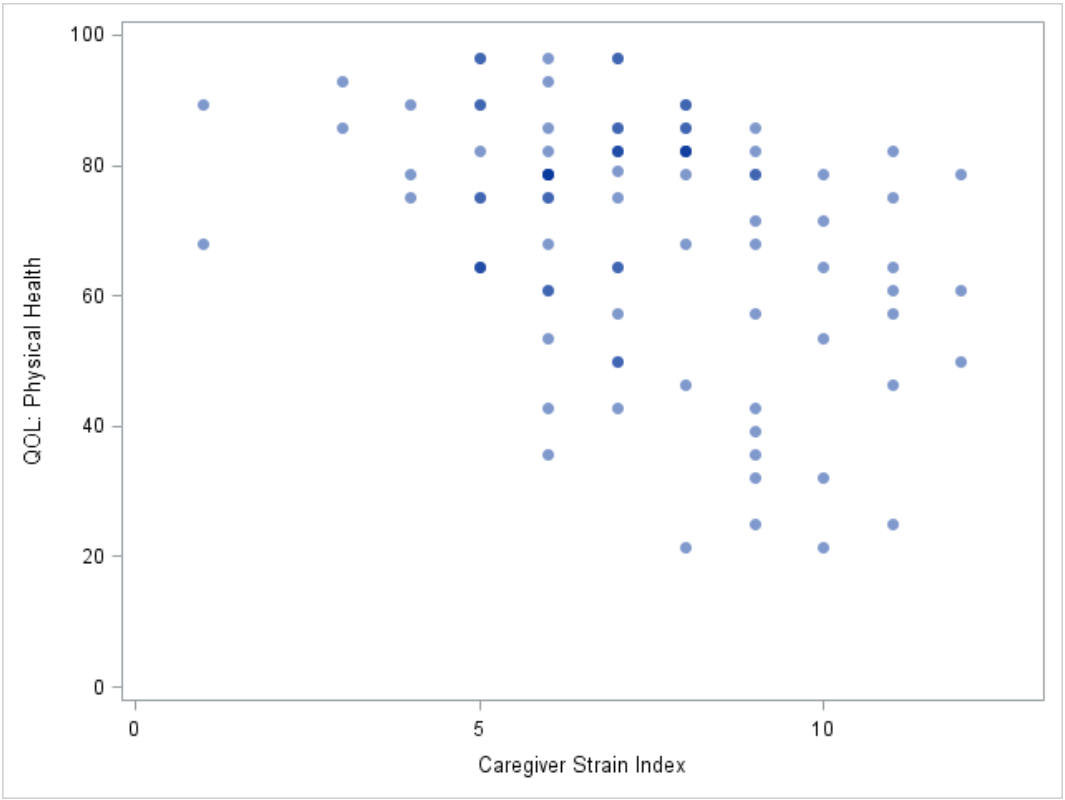


Figure 3.21 Relationship between CSI and physical health domain

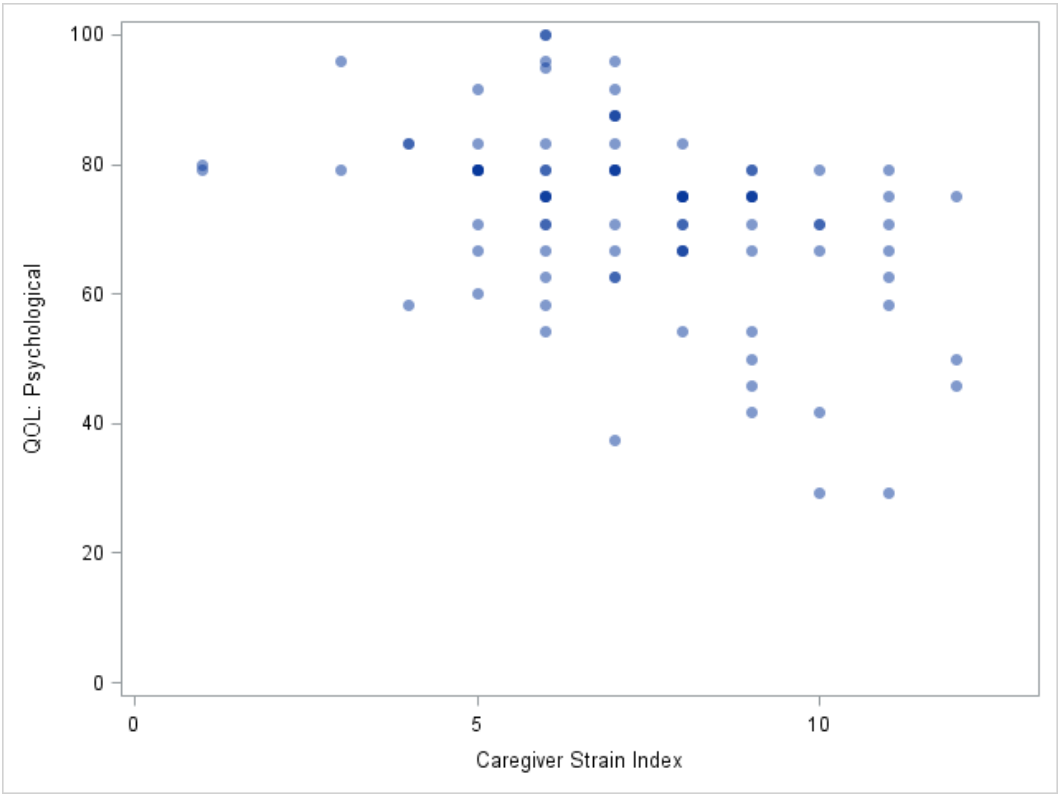


Figure 3.22 Relationship between CSI and psychological domain

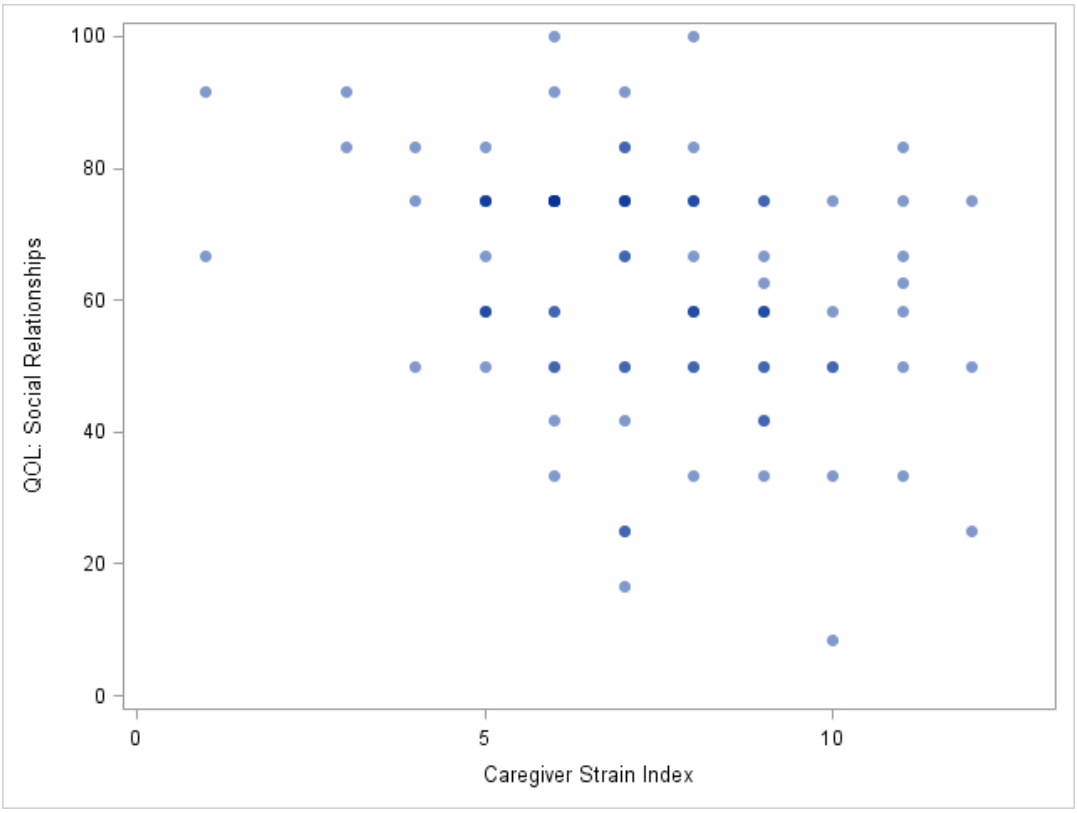


Figure 3.23 Relationship between CSI and social relationships domain

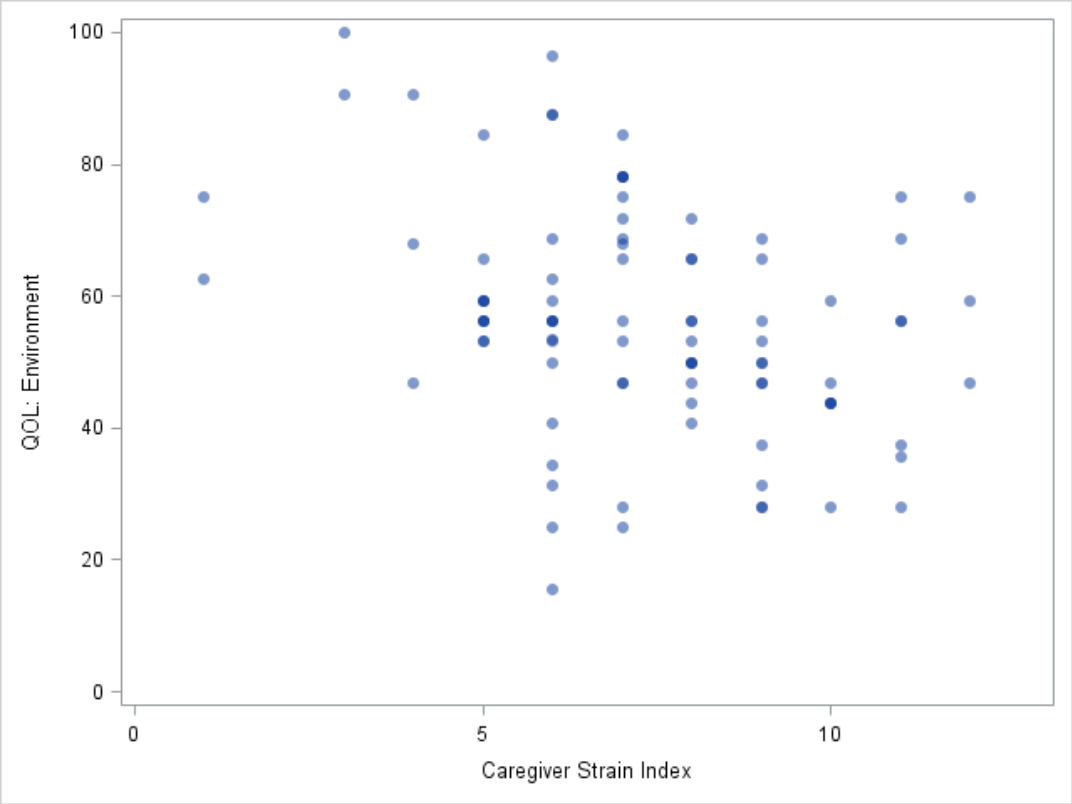


Figure 3.24 Relationship between CSI and environment domain

3.6 Factors affecting CSI score

Each of the patient and caregiver characteristics was analysed for its relationship with the CSI score. The following significant results were found:

- Patient admission per year over the last 5 years (p=0.030). Post-hoc tests, using the Tukey-Kramer adjustment for unequal group sizes showed that the CSI for 3 or more admissions was significantly higher than that for 1 admission. The effect size was large (Cohen's d=0.91).

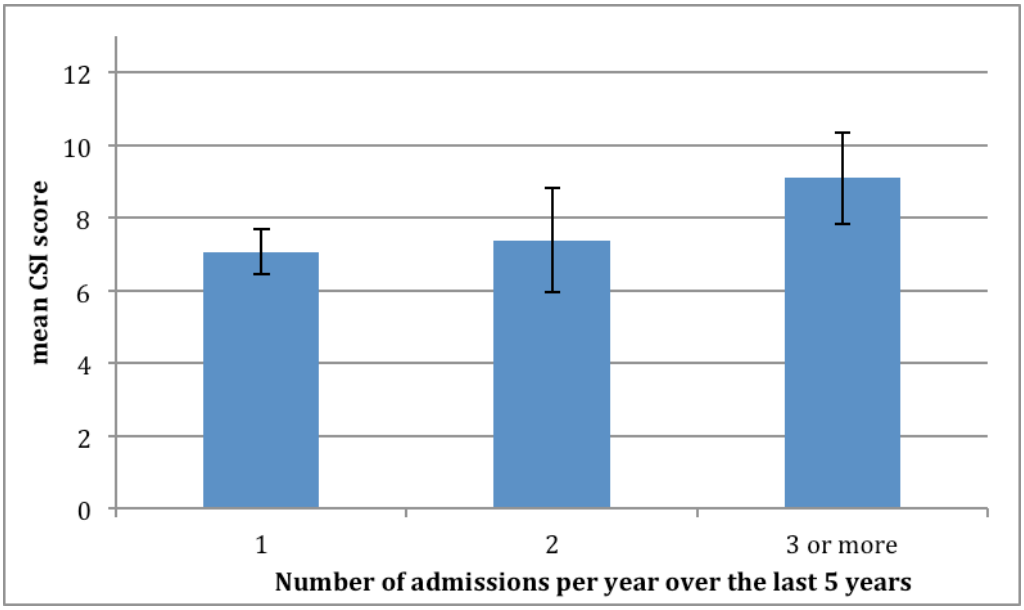


Figure 3.25 Patient admission number affecting CSI score

An alternative method used was to assess each of the patient and caregiver characteristics for its relationship with the CSI score, dichotomised as >=7 (high level of stress) or <7 (lower level of stress). The following significant results were found:

- Patient age (p=0.047). Fewer caregivers of older patients (56y+) experienced high levels of stress, particularly compared to caregivers of patients in the 46-55y age group. The effect size was moderate (Cramer's V=0.30).

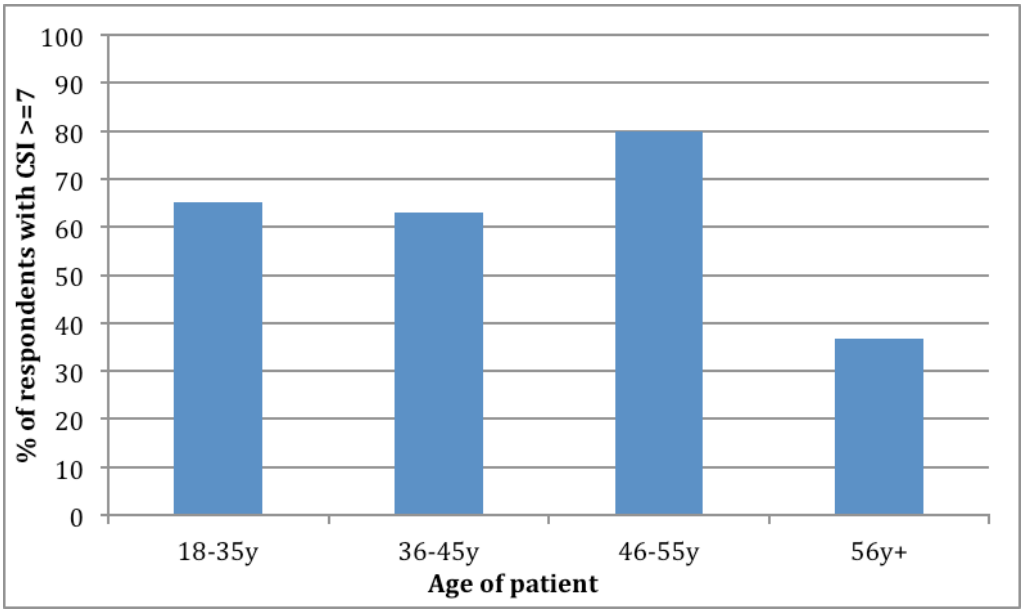


Figure 3.26 Patient age groups affecting CSI score

- Psychosocial stressors (p=0.036). More caregivers of patients with psychosocial stressors experienced high levels of stress (100.0%), compared to caregivers of patients without psychosocial stressors (54.0%). The effect size was weak (Cramer's V=0.26).
- Number of family members in same household (p=0.030). Those with 3 or 4 family members in the household appeared to show more stress than those with fewer (i.e. just caregiver + patient) or more family members in the household. The effect size was moderate (Cramer's V=0.36).

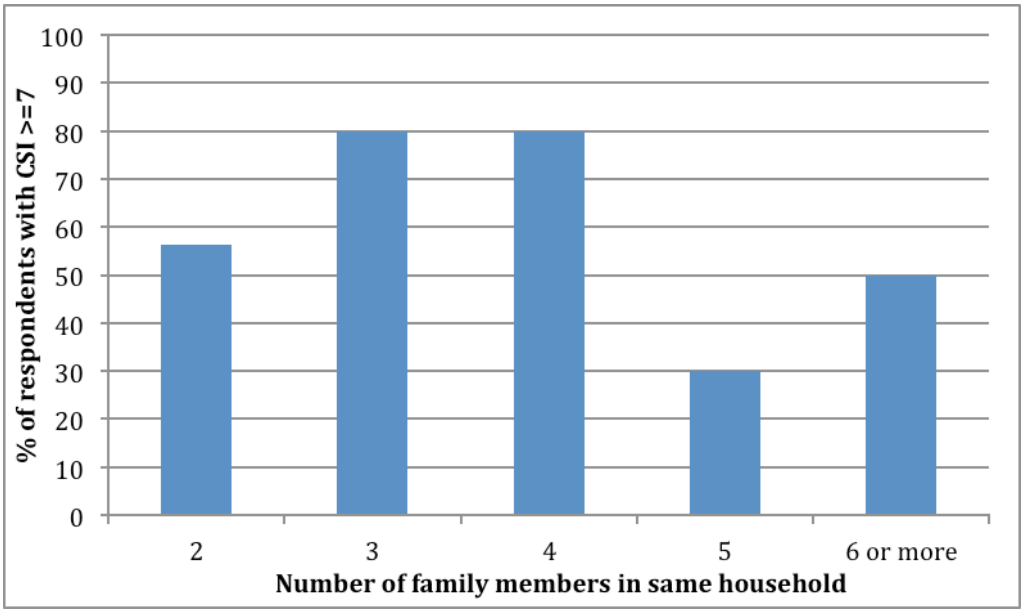


Figure 3.27 The impact of the number of family members in a household on CSI score

4. Discussion

a. Factors that cause a higher level of caregiver strain:

i) Patient related factors

In this study, statistically significantly higher levels of caregiver strain were associated with caring for adults as opposed to caring for the elderly. This is similar to a finding by Roychaudhuri et al [41] who observed a greater burden in cares of younger adults. The reasons for this could be that younger adults have greater physical vitality than the elderly, possibly frail relative, which could result in difficulties with containing aggression during a relapse. Younger adults have better mobility and as a result could have greater access to substances, which are often co-morbid with schizophrenia and render the illness more difficult to manage. Furthermore, it is possibly more socially acceptable and less stigmatizing to care for an elderly person than a physically healthy, seemingly capable and productive young person. This study did not agree with findings by Rammohan et al [25] which stated that caring for older patients resulted in higher caregiver burden.

The patients in this study were mostly males that have been living with a diagnosis of schizophrenia for many years. A possible reason for this finding could be that male patients were less likely to manage/cope without a caregiver. It may be possible that the caregivers of male patients may encounter greater difficulty in caring for the male patients, and therefore, come to present at the hospital more frequently in order to receive assistance. Another possible reason for this finding is that, as studies have suggested, the majority of caregivers in this study are females. Female caregivers may find it difficult to adequately manage male patients, especially if they are difficult. Other studies [42-44] have suggested that there possibly is a higher incidence of

schizophrenia in males, although the prevalence appears to be equal in both sexes. The reasons behind higher incidence rates in males are not conclusive, however, it has been documented that male patient often presents with more severe course of illness that is associated with a poorer functional outcome. This may result from male patients presenting more frequently in the acute stage of illness with symptoms of violence and use of comorbid substances.

The literature has suggested that caring for male patients may be more challenging for caregivers due to increased levels of aggression when mentally unwell. A study by Gater et al [32] has described that caring for male patients with schizophrenia is associated with a higher level of caregiver strain. However, it is important to note that this study did not find an association between male patients and high caregiver burden.

The admission status of the patients seemed to have no bearing on caregiver burden. The significance of this finding was not established due to the distribution of inpatient and outpatient samples. It can be assumed that caregivers of inpatients may report a higher burden of care that can be associated with their relapsed relative, conversely they may experience temporary respite due to the ill relative being admitted and thus away from the home environment. It has been shown, however, that the caregiving experience is negatively or positively affected by caregiver resilience, type of symptoms (negative or positive) and their severity and relative prolonged periods stability (remission) of the patient's symptoms [4,26].

A positive association between the number of patient admissions per year and caregiver strain was found. The more times a patient is admitted the higher the burden of care for the caregiver. This finding was significant. One would expect this association to be made on the basis that frequency of admissions in the population with schizophrenia may be due to poor compliance, resulting from poor or no insight, co-morbid substance abuse and perhaps greater difficulties in providing comprehensive supervision by caregivers. Although, the duration of hospitalization is beyond the scope of this study, but is a possible contributory factor towards caregiver burden, as may be difficulties associated with the presence of treatment resistant schizophrenia.

Lack of employment is a major source of concern for both patients and caregivers who use state owned hospitals due to widespread poverty. Although no statistical significance was found to link the unemployment of the patient and caregiver to burden of care, it is still a matter of importance, as unemployment is known to be a contributing factor in the development and perpetuation of mental illness. It is surprising to not find the impact of unemployment on the caregiver burden in the study, but this is perhaps due to the majority of patients receiving a disability grant, which may offer much needed financial respite to families with no source of income at all. In addition to this, the population studied comes from a community with generally high unemployment, which perhaps may be the norm.

Surprisingly the majority of patients were documented as non-substance users, whereas it is shown in psychiatric literature that there is a strong link between schizophrenia and substance, particularly cannabis, use. [33] Any psychiatric patient

with a dual diagnosis poses a challenge with regards to treatment. [34] In the patient with schizophrenia and comorbid substance use, the presentation may be complex and render the patient more susceptible to relapse and disruptive behaviour. It would be logical to deduce that this would also affect caregivers. This study, however, did not find that correlation; the possible explanation for this finding may be due to inadequate documentation by the clinical staff responsible for documenting in the patient's file, or more possibly, due to the lack of reporting of substance use by the patients themselves. Another reason may be due to the fact that dual diagnosis patients are seen at the dual diagnosis clinic at Chris Hani Baragwanath and not the general psychiatric outpatients clinic. The majority of patients did not have comorbid axis I diagnoses.

The presence of psychosocial stressors in patients was found to have an impact on caregiver burden. Although the effect size was considered to be weak, the finding was still a significant one. A possible explanation for this is possibly due to the shared environmental factors contributing to psychosocial stress within the same family system. In general psychosocial stressors in mental illness may contribute to the course of illnesses.

ii) Caregiver related factors

The majority of the caregivers included in the study were in the age range of 50-59 and were female, which is in keeping with literature that describes women being tasked with the principal caregiving functions. [2,25] This may be due the presumed caring, nurturing nature of females who may have to care for relatives that nobody

else is prepared to care for. Then again the majority of caregivers are mothers, who may feel a responsibility to care for their ill children. Although not proven in this study, a study suggests that older caregivers experience a higher level of caregiver burden, possibly poor health and a perception of higher demands of care, [27] however a study by Alexander et al [16] that found that being an older caregiver was associated with lower levels of burden. It may be possible that older caregivers may be thought of as experienced in caring or due to the fact that in the African culture, the majority of caregivers in this study, older persons must be respected.

A lower caregiver educational level has been reported to have an impact on burden of care. The majority of caregivers in this study had not matriculated. The association of education and high burden was not found to be significant in this study. Perhaps disadvantages in the educational system during the apartheid regime could have resulted in some caregivers not receiving an adequate education. This could possibly result in their perception of the burden of mental illness being less informed. These caregivers may also experience support arising from a sense of cohesiveness within a community that suffered similar disadvantages.

It was interesting to find no significant link between caregiver burden and the number of years living with a patient with schizophrenia, as schizophrenia is a chronic illness that can be characterised by many relapses due to poor insight and compliance. However, it is possible that the patient that has been living with schizophrenia for many years has good social support and is on the right combination of medication, which may have taken years to establish. Furthermore, in the chronic stage of schizophrenia, negative symptoms more likely predominate than positive symptoms.

These symptoms may be easier for the caregiver to handle, as they may not appear as disruptive as positive symptoms. The caregiver may be more accepting and resigned to the illness of the patient after many years.

Higher caregiver burden was seen in households with 3-4 people living in one household. This study showed a significant association in this area. One would expect higher caregiver burden to be associated with more than six members living in one household as that may indicate the level of poverty, higher chances of family conflict and poorer patient supervision. On the other hand the presence of larger families could result in more people being available to assist in caring for the patient, thus lowering the burden of care for the primary caregiver.

When comparing the two individual stand alone questions on QOL and health, the responses to satisfaction with health were more positive than those for quality of life. The reasons for this may be that it is easier for a caregiver to comment on health, as its effects are tangible (i.e. experiencing pain) as opposed to describing QOL, which is not tangible. However when assessing caregivers perceptions of their physical health, psychological well being, their environment and social relationships significant differences were found between these measures. Perceptions concerning physical health and psychological wellbeing were found to be better than social relationships and environment. This may result from poor support structure in the form of friends and families. Another factor to take into consideration is that the community from which the study was conducted is a disadvantaged one. Therefore, it is highly likely that caregivers and patients may reside in an environment with poor infrastructure.

In this study, the three major aspects impacting on caregiver strain were: feelings associated with being completely overwhelmed; finding some of the patient's behaviour upsetting; and observing changes in the patient as the illness progresses.

A caregiver could experience the above feelings as caring for a patient with a mental illness because the nature of illness is one that is variable and at times unpredictable. Patient may relapse, despite adherence to medication regimine, resulting in aggressive and disruptive behaviours that may be distressing during the course of the illness. This could result in a sense of hopelessness for the caregiver as they navigate from states of stability to stages of high risk when the patient poses a danger to themselves and their caregiver. Patients can also appear apathetic or withdrawn, which can be attributed to medication, negative symptoms or social cognitive dysfunction. Thus the change that the caregiver sees in the patient may be difficult for them to reconcile.

Determining the relationship between caregiver burden and QOL is key to demonstrating the possible impact of caring for a person with schizophrenia. This study found that the each QOL domain was associated with caregiver burden. As the burden increased the QOL decreased. This is consistent with the finding by Caqueo-Urizar et al [24].

b. The impact of disability in patients with schizophrenia on caregiver burden:

Although not a measured outcome in this study, disability in patients with schizophrenia has been described in literature to significantly impact on caregiver burden as well. Disability can occur as a result of residual negative symptoms and

cognitive deficits caused by schizophrenia that have an impact on patient's overall functioning. Zhang et al conducted a study using the World Health Organization Disability Assessment Scale (WHODAS) to establish disability and its effect on caregiver burden. They found that those with higher levels of disability had more prominent negative symptoms and the levels of burden on caregivers were higher. [26] Negative symptoms can have a resultant impact on overall patient functioning and therefore disability. These patients present with difficulties with communication, their speech is limited, and this greatly impacts interactions with others as they may find the patients lack of communication frustrating. Besides difficulties with communication, patients with negative symptoms can present with avolition and emotional blunting, resulting in patients having further difficulties with maintaining healthy relations with others.

c. Limitations associated with this study:

This study had a few limitations. Firstly it was a cross-sectional study in that the caregiver burden is not a fixed entity, and it is expected to change with time. Caregivers were assessed at one point in time and not over a prolonged period. As a result a true reflection of burden may not be ascertained. A study that could follow up caregivers over a period of time could be beneficial in the future. Secondly, the sample size was small. A larger sample may have been powerful enough to identify further relationships or strengthen those found in this group of caregivers. Thirdly, this study did not specify the patients' symptomatology as a variable to be considered, as this would have affected the findings. This could be due to the fact that literature has suggested that negative symptoms, [27] in particular have a poorer prognosis for patients, which could possibly have an impact on the caregiver.

5. Conclusion

The objectives put forward for the study were to describe the nature of the caregiver burden, whether it was high or low, and whether there was a relationship between burden and caregiver QOL. 61.8% (n=55) of caregivers indicated a high level of burden. It was noted that as the burden of care worsened, the quality of life decreased. Therefore higher levels of strain were shown to have an impact on caregiver QOL.

Ideally further research should be conducted in this area, possibly looking at a higher number of caregivers over a longer period. It would also be insightful for future research to consider feasible, cost effective interventions for developing countries that could be implemented to support overwhelmed caregivers.

6. Recommendations

A review [40] looking at various interventions that had been conducted to alleviate the burden of caring, such as support groups for caregivers, found that caregivers may benefit when offered a variety of interventions and that the burden of caring was decreased. In resource strained settings, such as those in developing countries, cost effective interventions such as providing psycho-education to caregivers in their own language and asking them how they are doing when they accompany their ill relatives, is an easily implementable first step that can be of assistance in those

families responsible for patients' well-being on a daily basis. This would undoubtedly improve the care of the individual patient.

Appendix A- Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130838

NAME: (Principal Investigator)	Dr Thokozani Mtshali
DEPARTMENT:	Department of Psychiatry Medical School
PROJECT TITLE:	The Impact of Care Giving on the Quality of Life of Caregivers of Patients with Schizophrenia
DATE CONSIDERED:	30/08/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Mashadi Motlana
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 24/02/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature M130838Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B-Data collection sheet

Caregiver demographics

Age

18-29	30-49	50-59	60-70	>70

Gender

Male	Female

Level of Education

No formal education	Grade 1-Grade 7	Grade 8-Grade 11	Matriculated	Tertiary	
				Completed	Incomplete

Income per month

Unemployed <R3000 R3000-10000 R10000-20000 >R20000

Relationship to patient

Mother	Father	Spouse	Sibling	Child	Other (state e.g. Aunt)

Number of family members living in the same household

Number of years caring for patient since diagnosed

1 year	2-5 years	6-10 years	10-14	>15

Type of household

Informal	Formal

Religion

Christianity	Judaism	Islam	Hinduism	Other

Practicing	Not Practicing

Patient demographics

Age

Gender

Admission status

In-patient	Out-patient

Employment status

Unemployed, not on disability grant	Unemployed, on Disability Grant	Employed

Number of years since diagnosis

Number of admissions per year over the last 5 years

One	Two	Three	Four	More than five

Significant associated factors

Type	Yes	No
Psychiatric diagnosis (other than schizophrenia)		
Substance abuse or dependence		
Psychosocial stressors		

Appendix C- Consent form

Consent form

I, _____ consent to participating in the study entitled: The impact of Care Giving on the Quality of Life of Caregivers of Patients with Schizophrenia.

The questionnaire has been explained to me and I understand the purpose of the study and the extent of my involvement. I have read and understand the attached information leaflet/ the information leaflet has been read to me and I understand it.

I understand that filling in the questionnaire forms part of a research project, and may not provide any direct benefit to me.

I understand that my participation is voluntary. I may withdraw and discontinue participation at any time without prejudice.

_____ _____

Signature Date

_____ _____

Investigator signature Date

Appendix D- CSI

Caregiver strain index

Score: 'Yes' = 1

'No' = 0

"I am going to read a list of things which other people have found to be difficult when helping someone who has an illness."

"Would you please tell me whether any of these apply to you? (give examples)

_____

_ Sleep is disturbed (e.g. because……..is in and out of bed or wanders around at night).

_ It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help).

_ It is a physical strain (e.g. because of lifting in and out of the chair; effort or concentration is required).

_ It is confining (e.g. helping restricts time, or cannot go visiting).

_ There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy).

_ There have been changes in personal plans (e.g. had to turn down job; could not go on vacation/holiday).

_ There have been other demands on my time (e.g. from other family members).

_ There have been emotional adjustments (e.g. because of severe argument).

_ Some behaviour is upsetting (e.g. _____Has trouble remembering things; or _____ accuses people of taking things).

_ It is upsetting to find _____ has changed so much from his/ her former self (e.g. he/ she is a different person than he/ she used to be).

_ There have been work adjustments (e.g. because of having to take time off).

_ It is a financial strain.

_ Feeling completely overwhelmed (e.g. because of worry about _____; concerns about how you will manage).

_ /13 Total

Appendix E-QOL

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you	1	2	3	4	5

	with your health?					

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4.	How much do you need any medical treatment to function in your daily life	1	2	3	4	5
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what	1	2	3	4	5

	extent do you feel your life to be meaningful?					
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5

11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity	1	2	3	4	5

	for work?					
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health	1	2	3	4	5

	services?					
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Appendix F-Turnitin originality report

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13on the Quality of Life of Caregivers of Patients with
Schizophrenia Dr.Thokozani Mtshali
4A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment for the requirements for the degree of Master of Medicine in Psychiatry Johannesburg, 2016 Declaration I, Thokozani Mtshali, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in Psychiatry at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.
ii
17Publications and presentations This work has never been published or presented at
a congress. iii
36Dedication This project is dedicated to my husband, parents, and sister, for your unwavering support and
love iv Abstract Introduction:
55Schizophrenia is a chronic mental illness, which is often characterized by a relapsing course with resultant effects on most areas of functioning due to the disability associated with it. The presence of any of the symptoms of

schizophrenia can be extremely distressing for the families or caregivers who care for the patient. The term caregiver burden arose following the deinstitutionalization of mental health patients that was associated with integration of patients with severe mental illnesses into the community. Limited data of caregiver burden and
27its relationship with quality of life
(QOL) is available
40in South Africa. The aim of the present study is to describe the nature of caregiver
85burden and to describe the relationship between caregiver burden and QOL.
49Methods: The study is descriptive and cross-sectional in nature and was conducted at
Chris Hani Baragwanath Academic Hospital from February 2014 to October 2014. Data was collected from
63caregivers of patients with schizophrenia in the form of questionnaires. Caregiver burden was
assessed by the use of a Caregiver Strain Index questionnaire with a score greater than 7 suggesting a high caregiver burden.
29Quality of life was assessed with the World Health Organization Quality of Life brief questionnaire;
it is scored on six domains each of which
6contributes to the caregiver's overall impression of their quality of life.
Results: Caregiver strain index scores equal to and more than 7 indicated higher
16caregiver burden. Significant factors associated with higher caregiver burden were
as follows: increased number of admissions per year, caring for older adults, caring for patients with psychosocial stressors and living in a household with many people. v Conclusion: The relationship between caregiver burden and caregiver QOL suggested that as caregiver burden increases, QOL decreases. vi Acknowledgements Thanksgiving to my heavenly Father my provider and the source of my strength. Through Him all things are possible. Dr Motlana, my supervisor for the supervision rendered Dr Friedlander, my co-supervisor for constant availability and invaluable input provided Dr Petra Gaylard, for assisting with statistical analysis Thandaza Shayingca, I would not have been able to do this without you love The special women in my life, for their on-going support and prayers Bhekisiwe Maphalala Mazi Mtshali Linda Mtshali Ntombiyokuphila Shayingca oMama bomthandazo My family and friends The caregivers who took part in my study, the nursing staff that assisted with translation, I
17thank you all. vii Table of Contents Declaration Publications and presentations Dedication Abstract Acknowledgements
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16Being a caregiver of a patient with a mental illness
may prove to be a challenging task. Furthermore
13caring for a patient with a severe mental illness, which is
chronic in nature may put a considerable burden on the caregiver. International research looking at caregivers of patients with schizophrenia has suggested these caregivers may experience burden, however there is a dearth of South African research addressing the burden associated with caregiving. South African public psychiatric services during the apartheid era were riddled with inconsistencies
87in the provision of health care. 1 During this period there was
significant reliance on institutions for the chronically mentally ill and on large hospitals for providing on-going mental health care. The government, post 1997, released a document describing the new vision for health care. The aim of the vision for mental health was to achieve services that were “community-based”. 1 Institutions were abolished in an aim
15to improve the quality of life of patients with schizophrenia and
other psychiatric illnesses. 2 The term “informal caregivers” 3 came into existence as patients were integrated into the community. Their families, who were ill equipped, were entrusted with the task of caring for their relatives with schizophrenia in an informal manner, something they had never been expected to do previously. Studies on the caregiver burden have been inconsistent in their findings regarding which factors are associated with higher levels of burden. Factors that are hypothesized to result in increased burden include lack of social support for the caregivers themselves, levels of unemployment or low educational attainment in caregivers, more severe symptoms 4 along with increased number of psychotic episodes, poor understanding of mental illness due to lack of information from mental health care workers and caring for schizophrenic patients with comorbid substance use. A Nigerian 5 study on caregiver burden suggested that the
60employment status of the patient and the educational status of the
caregiver impacted on levels of burden. They found that patients that were unemployed resulted in being higher financial burdens for their families and that caregivers without formal education experienced more burden. According to the revised South African local
6disease burden, the disability-adjusted life-years

(DALYS) have resulted in mental illness being ranked third most disabling group of pathologies, subsequent to
91HIV/AIDS and other infectious diseases. 6
51The South African Stress and Health study (SASH) showed a 30.3% lifetime prevalence
of mental illnesses. 7 About schizophrenia Schizophrenia is among the mental illnesses that can
47has a severely negative effect on the quality of life of
patients. It has been well described both in literature and research and a psychotic disorder that results in disturbances of thought patterns, behaviour and mood. The lifetime prevalence of schizophrenia has been reported to be 1%. 8 It is a chronic mental illness, which is often characterized by a relapsing course with resultant effects on most areas of functioning due to the disability associated with it. Initially it was believed that schizophrenia results in progressive deterioration over the course of the illness, but literature has refuted that suggestion. Instead it has been shown to be a neurodevelopmental disorder in which cognitive function is poor from the outset. As more research has been conducted it is now apparent that cognitive dysfunction is evident even prior to the onset of psychosis. A study found that intelligence testing in children that later developed schizophrenia was low at the baseline of ages 4 and 7 when compared to children who went on to develop mood- related psychotic disorders. 9 Schizophrenia can consist of positive symptoms, negative symptoms, and symptoms that affect cognition. The presence of negative symptoms, poor adherence to medication and comorbid substance use has been shown to be predictors of poor outcome in schizophrenia. 10 In the recent past literature has suggested negative and cognitive symptoms are more closely linked to functioning when compared with positive symptoms. 11 Symptoms in schizophrenia Positive symptoms, as listed in the Diagnostic Statistics Manual (DSM) consist of hallucinations, delusions, disorganization (in speech or behaviour) and catatonia. 36 Negative symptoms can include emotional withdrawal, social withdrawal, poor motivation and diminished drive, flattened affect, and decreased speech production amongst other symptoms. There has been a sparked interest in schizophrenia research with regards to developing medication that will target negative symptoms, as this group of symptoms has proven difficult to treat with current antipsychotic medications, and the presence of these symptoms have been associated with poor functional outcomes. Literature has often described how these symptoms tend to persist when positive symptoms have settled. A study by Hunter et al that looked at the
84relationship between negative symptoms and psychosocial functioning found that
74negative symptoms had a significant impact on the
functional scales used in their study. 12 It is not difficult to understand why the presence of these symptoms could affect function. For example, if a patient is apathetic and lacks motivation in finding or sustaining employment this could pose a challenge; the same would apply for initiating and maintaining social and/or intimate relationships. Cognition has also proven to be an
93area of interest in schizophrenia research
of late. Two entities have been described in literature, neurocognition and social cognition. According to the

43Measurement and Treatment Research for Improving Cognition in Schizophrenia (MATRICS) group
neurocognition consists on executive function domains, such as attention, problem solving, verbal comprehension and working memory among other symptoms. Social cognition on the other hand has had varying definitions; the most commonly used being “mental operations underlying social behaviour”. 13 Both neurocognition and social cognition are closely linked to day-to- day functioning. Studies on neurocognitive impairment have not consistently shown uniform deficits in the above domains and that may be due to schizophrenia being a heterogeneous, complex disorder. It was previously believed that cognitive impairment in schizophrenia deteriorates over time, but research lacked consistency in this regard, however it seems that impairments may be somewhat stagnant. 14 Impairments in neurocognitive domains are likely to have implications on cognitive remediation and daily activities such as decision-making. Social cognition is an area in research that has been and is receiving substantial interest of late. It consists of
34emotional processing, social perception, social knowledge, theory of mind and attributional bias.
15 The combination of these components enable a person to form healthy social relationships and the awareness and recognition of social cues, that are vital in everyday function as it relates oneself to other human beings.
50Deficits in social cognition noted in schizophrenia have an impact on daily functioning and
community functioning, which has been described by Fett et al 13 as behaviours of everyday functioning such as independent living. The presence of any of the symptoms of schizophrenia can be extremely distressing for the families or caregivers who care for the patient, as they may either blame themselves for the illness, or resent their ill relative for robbing them of happiness and stability. 16 Caregivers may also experience rejection and feel misunderstood by people in their community
46as a result of the mental illness of their relative.
Cost associated with schizophrenia The cost of Schizophrenia, also known as the cost of illness, can be subdivided into direct costs, intangible costs and indirect costs. 17 Direct costs are described as the actual financial amounts of money
15involved in the care of patients with schizophrenia.
Costs have been described
24in both the public and private sectors. Included in
these direct costs are admissions which could be a result of index presentations as well as relapses due to any cause, out-patient consultations, including to dual diagnosis centres for substance rehabilitation, medication, investigations, occupational therapy and other necessary therapies. Costs to the department of Social Services have come about due to issuing of disability grants resulting from a substantial number of patients with schizophrenia have been unable to work as a result of the impact of illness on their functioning. Intangible costs refer to the negative effects of having a mental illness, like depression that may be experienced by the caregiver or the patient
58as a result of the impact of the illness.
Indirect costs arise from resources lost due to the illness. These include loss of productivity and the ability to work due to the reason stipulated above; costs to

the criminal justice system as a result of crimes committed by mentally ill persons; and, the cost to families which include effects on social activities and loss of working hours, which could negatively impact on earnings for the caregiver or family of the patient. 17 It is the presence of these indirect costs that may have a bearing on the caregivers experiencing a significant burden of care.
Challenges
24in South Africa In South Africa, one of the
greatest challenges that stemmed from redirecting the core focus of mental health from institutions to the community is the dire socio-economic state of most families. In the greater Johannesburg area, many of the patients that access mental health services from the public sector are under enormous financial constraints, as often both the patient and caregiver are unemployed. Patients with schizophrenia usually qualify for disability grants and for many families this grant is the only source of income. Some of these patients exist in dismal conditions; where they have to share minute living spaces with many family members. 18 Additional challenges faced by the public mental health sector since the move to community psychiatry, is that of frequent hospital admissions resulting from poor compliance to medication and stigma associated with mental illness. Often times patients feel embarrassed to continue care at local clinics, which are near to their homes. This is due to negative perceptions associated with the clinics by community members. Community members tend to label the local clinics as clinics for 'mad people'. As a result of these negative perceptions many patients choose to not attend follow-up visits. Patients also relapse due to inconsistencies in availability of medication at clinics and hospitals. 18 In some instances clinics, and even the hospitals, run out of different medication stock for indefinite periods. During these times patient medications have to be changed to ensure that the patient is covered, even though his/her response (efficacy and/ or tolerability) to the alternative medication is not known. These frequent admissions may result in patients "remaining well for only short periods of time", 18 which negatively impacts on quality of life. There are also limited long-term placement facilities in South Africa
88for severely mentally ill patients. Following the closure of institutions, these facilities seek to offer temporary relief to the caregivers of the severely mentally ill patient. Definition of the Caregiver Burden Many researchers have suggested various definitions for caregiver burden. There are two common descriptions. One describes a psychological circumstance that is associated with economic, emotional, physical and social concerns that occur as a result of caring for a patient. 19 The second and most popular description in literature is that of the
48objective and subjective burden. The objective burden relates to the effect of the patient on the
household; disruptions to the caregivers such as loss of income, daily chores and social isolation, whereas the subjective burden relates to burden as perceived by the caregivers, such as guilt, anger, stigma. 20 Satorius 21 described stigma in mental illness as "the negative attitude (based on prejudice and misinformation) that is triggered by a marker of illness". It negatively affects patients and their families and often results in discrimination of some form. Health care professionals at times, discriminate against patients with severe mental illnesses when medically unstable, resulting in neglect of their physical ailments. A South African 22 study looking at patient's perceptions of community attitudes

towards having schizophrenia found that 65% of patients felt they experienced discrimination due to their illness. The authors found that the experience of discrimination increased in proportion to the number of admissions. There is limited data regarding South African caregiver's experience of stigma when caring for persons with schizophrenia. In spite of this, mental health fraternities in South Africa have prioritised anti-stigma campaigns. 23
69Quality of life in caregivers Quality of life (QOL) and
caregiver burden have often been referred to synonymously in literature. QOL is thought to look at various aspects of an individual, such as physical and mental health, financial standing, social interactions as well as fulfilment of life goals. It has been suggested in literature that the above areas can be affected in caregivers as a consequence of them being socially isolated, due to the stigma associated with having a mentally ill relative. It has further been suggested
81that there is a financial burden that could be related to
missing days at work in order to accompany the relative with schizophrenia for doctors visits, and that recurrent relapses may result in loss of income. Caregiver burden has also been associated with a reduction in the caregivers QOL. 24 Furthermore research has reported concerns that the effect of care giving on the caregiver's health, mental and/or physical, is dependent on the patient, the caregiver and their environment. 17 Some researchers described poor health among caregivers, which included mental illnesses such as anxiety and depression, along with some caregivers having infectious diseases, which could possibly have resulted from a decline in the caregivers' immunity. 24 Research has shown that women, mothers in particular, have been reported as the most common caregivers and are the caregivers with the worst QOL. Similarly spouses were reported to have challenges regarding striking a balance between various roles including bearing the financial burden for the family and rearing children. However, children were found to be a protective factor in the relationship, 25 which may affect QOL. There is also literature, 27 which describes children who were themselves caregivers for their mentally ill parents. This literature shows that these children experience a higher burden when compared to other relationship groups. 9 Over and above the information stated about, it has also been suggested that there are a few more consistent factors, which adversely affect the QOL of caregivers. These include scarce spare time, financial load and grief due to inability to re-establish the patient's former level of functioning. 24 Several studies have made mention of specific predictors of high levels of burden. Included in these predictors are: older age for both the
82caregiver and patient; the lower level of education of the
patient and caregiver which often results in a decrease of employment opportunities, male patients; poor social support and relatives who use maladaptive coping mechanisms, such as denial and avoidance. 28 Another factor believed to increase the level of burden is that of patient symptom severity. 8 This manifests itself in unsettling behaviours, which include disruptive behaviours. 25 Some researchers have suggested that a shorter period of diagnosis, six months or less has been linked to higher caregiver burden level. 29 In a study that was conducted using
80a socio-cultural stress, appraisal and coping model
it was hypothesized that a patient's behaviour would be influenced by cultural factors that relatives find burdensome and this would influence how these

caregivers perceive burden and how they interact with the patient. 30 Coping Mechanisms Utilised by Caregivers Caregivers have displayed certain coping mechanisms to help them deal with their relatives' illness and resultant behaviour. Among the commonly reported mechanisms in various studies are; the use of denial and avoidance, which was found mostly in parents as opposed to spouses, and the use of substances by males. 25 One study found that caregivers often sought assistance and reassurance from their relatives as opposed to health care professionals. 2 Another study found that families which belonged to religious groups obtained relief from their belief in their chosen faith rather than finding relief in the religious rituals themselves. 25 The Position of Literature Opposing the Caregiver Burden Having stated the above, opposing literature has been found stating that not all caregivers feel burdened by caring for their relatives. 31 The concept of "positive caring" was described in a study, where the focus of caregiving was on the experience and satisfaction felt by the caregiver. In these instances the caregiver felt fulfilled and rewarded by the act of caring for their relative. It was also noted in this study that the caregivers' self-esteem was positively affected by being there for their relatives in their greatest time of need. 32 Some caregivers have reported becoming more accepting and more considerate towards their relative and his/her mental illness, which in turn allows for better coping and reduced strain. Those caregivers that did not feel burdened were reported to receive social support from health care professionals. 2 The terms caregiver burden and caregiver strain are used interchangeably in the study. 1.1 Study objectives ? To describe the nature of caregiver burden ? To describe the
72relationship between caregiver burden and the caregiver's quality of life
73Materials and methods 2 .1 Introduction The study was
descriptive and cross-sectional in nature. It was conducted at Chris Hani Baragwanath Academic Hospital (CHBAH), located in Soweto, Johannesburg. 2.2 Study design Caregivers of patients with schizophrenia accompanying their relatives were randomly identified. They were approached to partake in the study that consisted of two questionnaires that were in English and IsiZulu as well as two forms to collect demographic information. The WHOQOL-BREF quality of life
61and the Caregiver Strain Index (CSI) questionnaires were used to evaluate quality of
life (QOL) and caregiver burden respectively. The
42World Health Organization Quality of Life Assessment Group developed a QOL questionnaire (WHOQOL-100) that
was both extensive and time consuming. In order to develop a questionnaire that was appropriate for settings with time constraints, such as research settings a shortened version was developed by the same group. Instead of 100 items, the WHOQOL-BREF was reduced to 26 items that consist of four domains and two additional questions specific to
26overall QOL and health. The four domains include perceptions of physical health, psychological health, social relationships and the environment. The questionnaire was tested in twenty field centres within 18 countries, including Africa, where good construct validity was ascertained. 37 A study conducted by Lucas-Carrasco 38 in Spain that looked at validating both the
66WHOQOL-100 and the WHOQOL-BREF in patients with schizophrenia and

their caregivers and patients with physical illnesses found
76that the WHOQOL-BREF was a reliable tool to describe QOL. The
CSI is a screening tool that is meant to give an idea of caregiver burden. It consists of 13 items and is scored out of thirteen. A score above seven is suggestive of caregiver strain and the closer the score is to thirteen the higher the level of caregiver strain for that particular caregiver. It was initially developed 39 in 1983 and studied in caregivers of elderly patients with cardiac illnesses and recent hip surgery. It was adapted from a study that had a questionnaire that consisted of 10 items, sleep disturbance, physical and financial strain of caring were added resulting in a total of 13 items. The primary investigator assisted illiterate caregivers, and in the event where the participants and the investigator did not speak the same language nursing staff assisted with translation. 2.3 Study population and sample The sample size estimation was based on the key research question, namely the relationship between CSI and the QOL dimensions. The relationship was determined by Pearson's correlation coefficient.
33Based on a significance level of 5%, a power of 80% and the
detection of a medium effect size (absolute value of correlation coefficient of 0.3 of greater), the sample size was estimated at 84. It was proposed that the researcher aim for a minimum sample size of 84, but continues to gather data
75within the time frame of the research to increase the
sample size as much as possible. 2.4 Inclusion and Exclusion Criteria The study included caregivers on the grounds that they were above 18 years of age, were
38living with the patient or spending most of their time with the patient,
the relative under their care had a primary diagnosis of Schizophrenia that was one year or longer. The caregiver was excluded from the study if he/she was receiving any psychological intervention during the time of the study, if he/she had any degree of cognitive impairment, if he/she was caring for more than one mentally ill or physically disabled person and if the relative they cared for had a co-morbid personality disorder as part of their diagnosis. The presence of comorbid personality disorders in patients included in this study, may negatively influence the caregiver's perception of caring, especially patients with cluster B personality disorders as they may be sometimes experienced as difficult or demanding. 2.5
25Ethics Approval Ethics approval was obtained from the Human Research Ethics Committee at the University of
Witwatersrand, Johannesburg. Ethics number M130838. 2.6 Data collection
77Data was collected over a period of eight months over different days depending on the primary investigator's availability on site. For inpatients, the investigator obtained the patient diagnoses in the files along with the caregiver contact details. Caregivers of inpatients were approached in one of two ways; they were identified by the primary investigator with the assistance of nursing staff, who would indicate which caregiver came to see which patient, during visiting hours. Alternatively the primary investigator would contact the caregiver telephonically to make an appointment for the caregiver to meet the primary investigator at CHBAH. All participants were informed of the study and if they fulfilled study criteria and gave informed consent, questionnaires were handed to them for completion. The primary investigator was available at the time of questionnaire completion to clarify any questions when required. Data

from caregivers of inpatients was collected during weekends. The primary investigator, to establish a diagnosis of schizophrenia, screened outpatient files, with the assistance of the nursing staff, of patients that attended the clinic on days when the primary investigator was available on site.
90Caregivers of patients with schizophrenia were approached whilst in the waiting room; if they fulfilled the study criteria and consented the same process of data collection was followed. Some outpatients attended the clinic on their own, due to various reasons such as being stable for a few months, financial constraints preventing the caregiver from attending, etc. Caregivers responsible for outpatients that attended alone were contacted telephonically to make an appointment to meet with the primary investigator. Nine caregivers that fulfilled criteria could not meet the primary investigator due to personal reasons. They were interviewed telephonically. 2.7 Data analysis and interpretation Data
53analysis was carried out using SAS(statistical analysis software) version 9.3 for Windows. The
2X2 test was used to assess the relationships between categorical variables. Fisher's exact test was used for 2 x 2 tables or where the requirements for the X2 test could not be met. The strength of the associations was measured by Cramer's V and the phi coefficient respectively. The following scale of interpretation was used: 0.50 and above high/strong association 0.30 to 0.49 moderate association 0.10 to 0.29 weak association below 0.10 little if any association The relationship between continuous and categorical variables was assessed by the t- test (or ANOVA for more than two categories). Where the data did not meet the assumptions of these tests, a non-parametric alternative, the Wilcoxon rank sum test (or the Kruskal-Wallis test for more than two categories) was used. The strength of the associations was measured by the Cohen's d for parametric tests and the r-value for the non-parametric tests. The following scale of interpretation was used: 0.80 and above large effect 0.50 to 0.79 moderate effect 0.20 to 0. 49 small effect
below 0.20 near zero effect The
37relationship between two continuous variables was assessed by Pearson's correlation coefficient.
2Where the data did not meet the assumptions of these tests, a non-parametric alternative, Spearman's rank
correlation coefficient
2was used. The strength of the associations was measured by interpreting the absolute value of the correlation coefficient. The
2following scale of interpretation was used: 0. 50 and above large effect 0. 3 to 0. 49 moderate effect Below 0. 3 small effect The 5% significance level
89was used throughout, unless specified otherwise. 3. Results 3 .1
Study group One hundred and twenty seven potential caregivers were initially approached to participate in the study, 31 were excluded, as they were not the main responsible caregivers for the patients. 96 participants were identified as appropriate for the study. 4 did not give consent, one was reported to be under age (17 years of age) during questionnaire completion and 2 did not complete the CSI form (the study was centred around this measure).
27A total of 89 respondents were included in the

study. Patient and caregiver characteristics were compared against the caregiver strain index scores (which indicates level of burden) in order to show if any demographic category
16had a statistically significant impact on the caregiver burden.
3.2 Demographics 3.2.1 Patient demographics See table 1 to view summarized 92demographics. Table 1. Patient Demographics n % Age
(years) 18-35 23 25.84 36-45 27 30.34 46-55 20 22.47 55+ 19 21.35 Gender Male 64 71.91 Female 25 28.09 Admission Inpatient 16 17.98 status Outpatient 73 82.02 Employment Unknown 2 2.25 status Unemployed, not on a disability grant 14 15.73 Unemployed, on a disability grant 65 73.03 Employed 8 8.99
3.2.1.1. Age The age range of the patients was 18-85y (mean 45y; sd 13y). The majority of patient's ages ranged from 36-45 years of age 30.34% (n=27). See figure 3.1. Figure 3. 1 The distribution of patient ages is shown above. For further analysis, the ages were grouped as 18-35/36-45/46-55/56y+ 3.2.1.2 Gender 71.9% of the patients were male. 3.2.1.3 Admission status 82.0% of the patients were outpatients. 3.2.1.4 Employment status Two participants had incomplete data and as a result could not be included. Only 9.0% of the patients were employed. 88.8% were unemployed, of whom 82.3% (65/79) were receiving a disability grant. 3.2.1.5 Number of years since diagnosis The number of years since diagnosis ranged from 1 to 45 years (mean 17y; sd 10y). This variable was grouped as 1-9/10-15/16-20/21y+, as shown in figure 3.2. One person did not complete this section in the questionnaire. Figure 3.2 Distribution of number of years since diagnosis 3.2.1.6 Number of admissions per year over the last 5 years Most patients (64.0%) had had one admission per year over the last 5 years. When analysing patient admission data with CSI there was no statistical significance difference between patients with fewer admissions or higher admissions. None of the patients in this study had less than one admission per year. For further analysis, 3 to 5+ admissions per year were combined. Figure 3.3 Number of admissions per year 3.2.1.7 Other psychiatric diagnoses 18.0% (n=16) of the patients had one or more other psychiatric diagnoses. 3.2.1.8. Substance abuse / dependence 18.0% of the patients had a substance abuse or dependence problem. 3.2.1.9 Psychosocial stressors 6.7% (n=6/89) of the patients had one or more psychosocial stressors, however 20 people did not indicate presence or absence of psychosocial stressors. 3.2.2 Caregiver demographics See table 2 for summarised caregiver demographics. Table 2. Caregiver Demographics n % Age (years) 18-29 30-49 50-59 60-70 >70 9 18 29 19 13 10.11 20.22 32.58 21.35 14.61 Gender Male Female 20 69 22.47 77.53 Level of education Unknown No formal education Grade 1-7 Grade 8-11 Matriculated Tertiary incomplete Tertiary completed 1 5 25 29 21 1 7 1.12 5.62 28.09 32.58 23.60 1.12 7.87 Income Unknown Unemployed <R3000 R3000-R10000 R10001-R20000 >R20000 4 31 38 12 1 3 4.49 34.83 42.70 13.48 1.12 3.37 Relationship to patient Mother 27 30.34 Father 6 6.74 Spouse 4 4.49 Sibling 22 24.72 Child 9 10.11 Other 21 23.60 Numbers of family members living in same household Unknown 2 3 4 5 6 or more 4 16 20 15 10 24 4.49 17.98 22.47 16.85 11.24 26.95 Religion Unknown Christianity Islam Hinduism Other 2 81 1 1 4 2.25 91.01 1.12 1.12 4.49 Practicing religion Unknown No Yes 13 22 54 14.61 24.72 60.67 CSI>=7 No Yes 34 55 38.20 61.80 3.2.2.1 Age The age range of the caregivers was very wide, as shown in figure 3.4. The majority of the caregivers were aged 50-59 (32.58%). 27 Figure 3.4 Distribution of ages for caregivers

3.2.2.2 Gender 77.5% of the caregivers were female. 3.2.2.3 Education The majority of caregivers had incomplete secondary school (32.6%) or only primary school (28.1%) education. A further 23.6% had matriculated. See figure 3.5 below. Figure 3.5 Caregiver level of education 3.2.2.4 Income Four people did not complete the income section. 42.7% of the caregivers were earning below R 3,000 p.m., while 34.8% were unemployed. The top three income categories were combined. There was no significant difference among the income brackets. 100 90 80 % of caregivers 70 60 50 40 30 20 10 0 Unknown Unemployed < R3,000 R3,000 - R10,001 - > R20,000 Income R10,000 R20,000 Figure 3.6 Caregiver income status 3.2.2.5 Relationship to patient The caregivers were primarily the mothers (30.3%) and siblings (24.7%) of the patients as shown in figure 3.7.
6There was no significant difference in the type of relationship the caregiver shared with the patient and the level of caregiver burden (p=0.24). 100 90 80 % of caregivers 70 60 50 40 30 20 10 0 Mother Father Spouse Sibling Child Other Relationship to patient Figure 3.7 Relationship to patient 3.2.2.6
23Number of family members living in same household
Up to 15 family members in the household were reported. 4 people did not complete this section on the questionnaire. Refer to figure 3.8. 100 90 80 % of caregivers 70 60 50 40 30 20 10 0 Unknown 2 3 4 5 6 or more
31Number of family members living in same household Figure 3.8 Number of family members in the household
3.2.2.7 Number of years spent caring for patient, since diagnosis There was a considerable spread in the responses; many caregivers had a spent a substantial number of years caring for their patient. 19 caregivers had spent 2-5 years and a further nineteen spent 6-10 years caring for the patient, whilst 26.97% (n24/89) spent more than 15 years caring for the patient.
6There was no significant difference in years spent caring for the patient when compared
to high caregiver burden (p=0.49). Refer to figure 3.9 Figure 3.9 Number of years caring for patient, since diagnosis 3.2.2.8 Type of household 61 caregivers reported living in formal households. 3.2.2.9 Religion The majority of caregivers reported that they belonged to the Christian religion (n=81). This variable was not used in further analysis, since the non-Christian groups were too small. Of the 91.1% of Christian caregivers 60.7% of them (n=54) reported that they practiced their religion and 13 participants did not indicate whether they practiced their religion or not. There was no significant difference between those who reported practicing their religion and those who did not (p=0.57). 3.3 Caregiver Strain Index
71A score of 7 or higher in the CSI indicates higher levels of
caregiver strain. The scores are fairly normally distributed around a mean of 7.3(mean=7.3; sd=2.3); 61.8% of the caregivers had a CSI >= 7. Figure 3.10 CSI scores To understand the nature of the caregiver burden in more detail, the proportion of respondents who answered 'Yes' to each of the 13 CSI items is shown in figure 3.11 below. The three most common items (>80% of respondents indicated these) were feeling overwhelmed, and being upset by behaviour and changes in the patient. Feeling completely overwhelmed Some behaviour is upsetting There have been emotional adjustments
57There have been family adjustments It is a financial strain

It is confining It is inconvenient There have been demands on my time It is a physical strain There have been work adjustments Sleep is disturbed % of respondents 0 20 40 60 80 100 Figure 3.11 Caregivers response to various CSI components 3.4
6Quality of life scores The QOL questionnaire consists of
6 domains. These domains are composed of the following aspects; overall
6rating of quality of life and physical health,
specific
35physical health domain, psychological domain, social relationships domain and an environment domain.
Table 3. Univariate statistics for the 6 QOL scores QOL score
41N Mean Std Dev Minimum Maximum Median 25th Pctl 75th Pctl
56How would you rate your quality of life? 89 3.
6 0.9 1 5 4 3 4 How satisfied are you with your health? 88 3.8 1.0 1 5 4 3 4 QOL: Physical Health 89 69.7 19.1 21.4 96.4 75.0 60.7 82.1 QOL: Psychological 89 72.0 14.5 29.2 100.0 75.0 66.7 79.2 QOL: Social Relationships 89 62.7 18.8 8.3 100.0 66.7 50.0 75.0 QOL: Environment 89 56.3 17.4 15.6 100.0 56.3 46.9 67.9 The 6 QOL scores were compared with each other in an attempt to see if some reflect a higher QOL than others, see figure 3.12 below. Figure 3.12 Histograms for each of the six scores ? Comparing the two individual questions, the responses to satisfaction with health were more positive than those for quality of life (mean 3.8 vs 3.6 on a scale of 1- 5; mean difference 0.19±0.17; paired t-test; p=0.026). ? Comparing the four dimensions, which are given on a scale of 0-100, we find the following significant differences (repeated measures model; post-hoc comparisons adjusted for multiple comparisons) o Higher Physical Health than Social Relationships QOL (mean 69.7 vs 62.7; mean difference 6.9±4.2; p=0.0016) o Higher Physical Health than Environment QOL (mean 69.7 vs 56.3; mean difference 13.4±3.4; p<0.0001) o Higher Psychological Health than Social Relationships QOL (mean 72.0 vs 62.7; mean difference 9.2±3.4; p<0.0001) o Higher Psychological Health than Environment QOL (mean 72.0 vs 56.3; mean difference 15.7±2.6; p<0.0001) o Higher Social Relationship than Environment QOL (mean 62.7 vs 56.3; mean difference 6.4±3.6; p=0.0007). 100
3290 80 70 mean score 60 50 40 30 20 10 0 QOL: Physical
QOL: Psychological QOL: Social QOL: Environment Health QOL dimension
Relationships Figure 3.13 QOL domains comparison 3.5 Relationship between CSI and QOL dimensions The association between the CSI and each of the QOL dimensions was determined by Spearman's rank correlation coefficient (since not all the QOL dimensions were normally distributed, which is a requirement for the use of
45Pearson's correlation coefficient). The Spearman's rank correlation coefficient for
each aspect of QOL with CSI is shown in table 4 below. All six correlation coefficients were significantly different to zero, and were negative, indicating the expected relationship: as caregiver burden increased, QOL decreased. Table 4. Association between CSI and each QOL domain
22How would you rate your quality of life? -0.525 How satisfied are you with your health? -0.443 QOL: Physical Health
-0.385 QOL: Psychological -0.449 QOL: Social Relationships -0.341 QOL: Environment -0.327 The relationships are illustrated by means of scatterplots,

shown in figures 3.13-3.18. Figure 3.14 Relationship between CSI and overall QOL question
14Figure 3.15 Relationship between CSI and overall health question Figure 3.16 Relationship between CSI and physical health domain Figure 3.17 Relationship between CSI and psychological domain Figure 3.18 Relationship between CSI and social relationships domain Figure 3.19 Relationship between CSI and environment domain 3.6 Factors affecting CSI score Each of the patient and caregiver characteristics was analysed for its relationship with the CSI score. The following significant results were found: ? Patient admission per year over the last 5 years
95(p=0. 030). Post-hoc tests, using
the Tukey-Kramer adjustment for unequal group sizes showed that the CSI for 3 or more admissions was significantly higher than that for 1 admission. The effect size was large (Cohen's d=0.91). Figure 3.20 Patient admission number affecting CSI score An alternative method used was to assess each of the patient and caregiver characteristics for its relationship with the CSI score, dichotomised as >=7 (high level of stress) or <7 (lower level of stress). The following significant results were found: ? Patient age (p=0.047). Fewer caregivers of older patients (56y+) experienced high levels of stress, particularly compared to caregivers of patients in the 46- 55y age group. The effect size was moderate (Cramer's V=0.30). Figure 3.21 Patient age groups affecting CSI score ? Psychosocial stressors (p=0.036). More caregivers of patients with psychosocial stressors experienced high levels of stress (100.0%), compared to caregivers of patients without psychosocial stressors (54.0%). The effect size was weak (Cramer's V=0.26). ? Number of family members in same household (p=0.030). Those with 3 or 4 family members in the household appeared to show more stress than those with fewer (i.e. just caregiver + patient) or more family members in the household. The effect size was moderate (Cramer's V=0.36). Figure 3.22 The impact of the number of family members in a household on CSI score 4. Discussion a. Factors that cause
94a higher level of caregiver strain:
In this study, statistically significantly
23higher levels of caregiver strain were associated with caring for
adults as opposed to caring for the elderly. The reasons for this could be that younger adults have greater physical vitality than the elderly, possibly frail relative, which could result in difficulties with containing aggression during a relapse. Younger adults have better mobility and as a result could have greater access to substances, which are often co-morbid with schizophrenia and render the illness more difficult to manage. Furthermore, it is possibly more socially acceptable and less stigmatizing to care for an elderly person than a physically healthy, seemingly capable and productive young person. This finding, however, contradicts the findings by Rammohan et al 25 who found that caring for older patients resulted in higher caregiver burden. The patients were mostly males that have been living with a diagnosis of schizophrenia for many years. A possible reason for this finding could be that male patients were less likely to manage/cope without a caregiver. It may be possible that the caregivers of male patients may encounter greater difficulty in caring for the male patients, and therefore, come to present at the hospital more frequently in order to receive assistance. Another possible reason for this finding is that, as studies have

suggested, the majority of caregivers in this study are females. Female caregivers may find it difficult to adequately manage male patients, especially if they are difficult. Literature has proposed that caring for male patients may be more challenging for caregivers due to increased levels of aggression when mentally unwell. A study by Gater et al 32 has described
39that caring for male patients with schizophrenia is associated with a higher level of
caregiver strain. However,
44it is important to note that this study did not
find an association between male patients and high caregiver burden. The admission status of the patients seemed to have no bearing on caregiver burden. The significance of this finding was not established due to the distribution of inpatient and outpatient samples. It can be assumed that caregivers of inpatients may report a higher burden of care that can be associated with their relapsed relative, conversely they may experience temporary respite due to the ill relative being admitted and thus away from the home environment. It has been shown, however, that the caregiving experience is negatively or positively affected by caregiver resilience, type of symptoms (negative or positive) and their severity and relative prolonged periods stability (remission) of the patient's symptoms 4,26. A positive association between the number of patient admissions per year and caregiver strain was found. The more times a patient is admitted the higher the burden of care for the caregiver. This finding was significant. One would expect this association to be made on the basis that frequency of admissions in the population with schizophrenia may be due to poor compliance, resulting from poor or no insight, co-morbid substance abuse and perhaps greater difficulties in providing comprehensive supervision by caregivers. Although, the duration of hospitalization is beyond the scope of this study, but is a possible contributory factor towards caregiver burden. Lack of employment is a major source of concern for both patients and caregivers who use state owned hospitals due to widespread poverty. Although no statistical significance was found to link the unemployment of the patient and caregiver to burden of care, it is still a matter of importance, as unemployment is known to be a contributing factor in the development and perpetuation of mental illness. It is surprising to not find the impact of unemployment on the caregiver burden in the study, but this is perhaps due to the majority of patients receiving a disability grant, which may offer much needed financial respite to families with no source of income at all. In addition to this, the population studied comes from a community with generally high unemployment, which perhaps may be the norm. Surprisingly the majority of patients were documented as non-substance users, whereas it is shown in psychiatric literature that
78there is a strong link between schizophrenia and substance,
particularly cannabis, use. 33 Any psychiatric patient with a dual diagnosis poses a challenge with regards to treatment. 34 In the patient with schizophrenia and comorbid substance use, the presentation may be complex and render the patient more susceptible to relapse and disruptive behaviour. It could be logical to deduce that this would also affect caregivers. This study, however, did not find that correlation; the possible explanation for this finding may be due to inadequate documentation by the clinical staff responsible for documenting in the patient's file, or more possibly, due to the lack of reporting substance use by

the patients themselves. The majority of patients did not have comorbid axis I diagnoses. The presence of psychosocial stressors in patients was found to have an impact on caregiver burden. Although the effect size was considered to be weak, the finding was still a significant one. A possible explanation for this is possibly due to the shared environmental factors contributing to psychosocial stress within the same family system. In general psychosocial stressors in mental illness may contribute to the course of illnesses. The
65majority of the caregivers included in the study were
in the age range of 50-59 and were female, which is in keeping with literature that describes women being tasked with the principal caregiving functions. 2,25 This may be due the presumed caring, nurturing nature of females who may have to care for relatives that nobody else is prepared to care for. Then again the majority of caregivers are mothers, who may feel a responsibility to care for their ill children. Although not proven in this study, a study suggests that older caregivers experience a higher level of caregiver burden, possibly poor health and a perception of higher demands of care, 27 however a study by Alexander et al 16 that found that being an older caregiver was associated with lower levels of burden. It may be possible that older caregivers may be thought of as experienced in caring or due to the fact that in the African culture, the majority of caregivers in this study, older persons must be respected. A lower caregiver educational level has been reported to have an impact on
86burden of care, the majority of caregivers in this study had not matriculated. The association of education and high burden was not found to be significant in this study. Perhaps the reasons for this may be that the
67majority of caregivers in the study who had a low education
level were slightly older. Due to being disadvantaged in the educational system of the apartheid regime, many caregivers were possibly not adequately educated; their perception of the burden of mental illness may be less informed. These caregivers may also experienced support arising from a sense of cohesiveness within a community that suffered similar disadvantages. It was interesting to find no significant link between caregiver burden and living with a patient with chronic schizophrenia, as schizophrenia is a chronic illness that can be characterised by many relapses due to poor insight and compliance. However, it is possible that the patient that has been living with schizophrenia for many years has good social support and is on the right combination of medication, which may have taken years to establish. Furthermore, in the chronic stage of schizophrenia, negative symptoms more likely predominate than positive symptoms. These symptoms may be easier for the caregiver to handle, as they may not appear as disruptive as positive symptoms. The caregiver may be more accepting and resigned to the illness of the patient after many years. Higher caregiver burden was seen in households with more than 3 people living in one household. This study showed a significant association between those two variables. This is to be expected, especially in homes with a high number which may indicate the level of poverty, higher chances of family conflict and poorer patient supervision all which may
6have an impact on the patient's
wellbeing and indirectly or directly on caregiver strain. When comparing the two individual stand alone questions on QOL and health, the responses to satisfaction with health were more positive than those for quality of life. The reasons for this

may be that it is easier for a caregiver to comment on health, as its effects are tangible (i.e. experiencing pain) as opposed to describing QOL, which is not tangible. However when assessing caregivers perceptions of
6their physical health, psychological well being, their environment and social relationships significant differences were found between these measures. Perceptions concerning physical health and psychological wellbeing were found to be better than social relationships and environment. This may be as a result from poor support structure in the form of friends and families. Another factor to take into consideration is that the community from which the study was conducted is a disadvantaged one. Therefore, it is highly likely that caregivers and patients may reside in an environment with poor infrastructure. In this study, the three major aspects impacting on caregiver strain were: feelings associated with being completely overwhelmed; finding some of the patient's behaviour upsetting; and observing changes in the patient as the illness progresses. A caregiver could experience the above feelings as
15caring for a patient with a mental illness because the nature of
illness is one that is variable and at times unpredictable. Patient may relapse, despite compliance to medication, resulting in aggressive and disruptive behaviours that may be distressing during the course of the illness. This could result in a sense of hopelessness for the caregiver as they navigate from states of stability to stages of high risk when the patient poses a danger to themselves and their caregiver. Patients can also appear apathetic or withdrawn, which can be attributed to medication, negative symptoms or social cognitive dysfunction. Thus the change that the caregiver sees in the patient may be difficult for them to reconcile. Determining the relationship between caregiver burden and QOL is key to demonstrating the possible
79impact of caring for a person with schizophrenia.
This study found that the each QOL domain was associated with caregiver burden. As the burden increased the QOL decreased. This is consistent with the finding by Caqueo- Urizar et al 24. b. The impact of disability in patients with schizophrenia on caregiver burden: Although not a measured outcome in this study, disability in patients with schizophrenia has been described in literature to significantly impact on caregiver burden as well. Disability can occur as a result of residual negative symptoms and cognitive deficits caused by schizophrenia that
6have an impact on patient's
overall functioning. Zhang
6et al conducted a study using the
13World Health Organization Disability Assessment Scale (WHODAS) to establish disability and
its effect on caregiver burden. They found that those with higher levels of disability had more prominent negative symptoms and the levels of burden on caregivers were higher. 26 Negative symptoms can have a resultant impact on overall patient functioning and therefore disability. These patients present with difficulties with communication, their speech is limited, and this greatly impacts interactions with others as they may find the patients lack of communication frustrating. Besides difficulties with communication, patients with negative symptoms can present with avolition and emotional blunting, resulting in patients having further difficulties with maintaining healthy relations with

others. c. Limitations associated with this study: This study had a few limitations. Firstly it was a cross-sectional study in that the caregiver burden is not a fixed entity, and it is expected to change with time. Caregivers were assessed at one point in time and not over a prolonged period. As a result a true reflection of burden may not be ascertained. A study that could follow up caregivers over a period of time could be beneficial in the future. Secondly, the sample size was very small. A larger sample may have been powerful enough to identify further relationships or strengthen those found in this group of caregivers. Thirdly, this study did not specify the patients' symptomatology as a variable considered, as this would have affected the findings. This would be due to the fact that literature has suggested that negative symptoms, 27 in particular have a poorer prognosis for patients, which could possibly have an impact on the caregiver. 5. Conclusion The objectives put forward for the study were to describe the nature of burden, whether it was high or low, and whether there was a relationship between burden and caregiver QOL. 61.8% (n=55) of caregivers indicated 83a high level of burden. It was noted that as the burden of care worsened, quality of life decreased. Therefore higher levels of strain were shown to have an impact on caregiver QOL. Ideally further research should be conducted in this area, possibly looking at a higher number of caregivers over a longer period.

68It would also be insightful for future research to consider feasible, cost effective interventions for developing countries that could be implemented to support overwhelmed caregivers. 6. Recommendations A review 40 looking at various interventions that had been conducted to alleviate the burden of caring, such as support groups for caregivers, found that caregivers may benefit when offered a variety of interventions and that the burden of caring was decreased. In a resource strained settings, such as the ones in developing countries, cost effective interventions such as providing psycho-education to caregivers in their own language and asking them how they are doing when they accompany their ill relatives, is an easily implementable first step that can be of assistance in those families responsible for patients' well-being on a daily basis. This would undoubtedly improve the care of the individual patient. Appendix A Appendix B Caregiver demographics Age 18-29 30-49 50-59 60-70 >70 Gender Male Female Level of Education No formal Grade 1- Grade 8- Matriculated Tertiary education Grade 7 Grade 11 Completed Incomplete Income per month Unemployed <R3000 R3000-10000 R10000-20000 >R20000 Relationship to patient Mother Father Spouse Sibling Child Other (state e.g. Aunt) 64Number of family members living in the same household Number of years caring for patient since diagnosed 621 year 2-5 years 6-10 years 10-14 >15 Type of household Informal Formal Religion Christianity Judaism Islam Hinduism Other Practicing Not Practicing Patient demographics Age Gender Admission status In-patient Out-patient Employment status Unemployed, not on Unemployed, on Disability Employed disability grant Grant Number of years since diagnosis Number of admissions per year over the last 5 years One Two Three Four More than five Significant associated factors Type Yes No Psychiatric diagnosis (other than schizophrenia) Substance abuse or dependence Psychosocial stressors Consent form

70I, _____ consent to participating in the study entitled:
The impact of
Care Giving
13on the Quality of Life of Caregivers of Patients with
Schizophrenia. The
10questionnaire has been explained to me and I understand the purpose of the study and the extent of my involvement. I have read and understand the attached information
leaflet/ the information leaflet has been read to me and I understand it.
10I understand that filling in the questionnaire forms part of a research project, and may not provide any direct benefit to me. I understand that
54my participation is voluntary. I may withdraw and discontinue participation at any time without
prejudice. _____ Signature _____ Date _____
Investigator signature _____ Date
1Caregiver strain index Score: 'Yes' = 1 'No' = 0
"I am going to read a list of things which other people have found to be difficult when helping someone who has an illness."
1"Would you please tell me whether any of these apply to you? (give examples) _____ _ Sleep is disturbed (e.g. because……..is in and out of bed or wanders around at night). _ It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help). _ It is a physical strain (e.g. because of lifting in and out of the chair; effort or concentration is required). _ It is confining (e.g. helping restricts time, or cannot go visiting). _ There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy). _ There have been changes in personal plans (e.g. had to turn down job; could not go on vacation/holiday). _ There have been other demands on my time (e.g. from other family members). _ There have been emotional adjustments (e.g. because of severe argument). _ Some behaviour is upsetting (e.g. _____Has trouble remembering things; or _____ accuses people of taking things). _ It is upsetting to find _____ has changed so much from his/ her former self (e.g. he/ she is a different person than he/ she used to be). _ There have been work adjustments (e.g. because of having to take time off). _ It is a financial strain. _ Feeling completely overwhelmed (e.g. because of worry about _____; concerns about how you will manage). _ /13
Total WHOQOL-BREF The
3following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks. 1. How would you rate your quality of life? 2. Very poor Poor Neither Good Very good poor nor good 1 2 3 4 5
20Very dissatisfied Dissatisfied Neither satisfied nor dissatisfied Satisfied Very satisfied How satisfied are you 1 2 3 4 5 with your health? The
8following questions ask about how much you have experienced certain things in the last four weeks. Not at all A little A moderate Very much An extreme amount amount 3. To what extent do you feel that physical pain 1 2 3 4 5

prevents you from doing what you need to do? 4. How much do you need any medical treatment to 1 2 3 4 5 function in your daily life 5. How much do you enjoy 1 2 3 4 5 life? 6. To
28what 1 2 3 4 5 extent do you feel your life to be meaningful?
57. How well are you able to concentrate? 8. How safe do you feel in your daily life? 9. How healthy is your physical environment? 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
The following questions ask about how completely you experience or were able to do certain things in the last four weeks. Not at all A little Moderately Mostly Completely 10. Do you have enough
1 2 3 4 5
7energy for everyday life? 11. Are you able to accept your bodily appearance? 12. Have you enough money to meet your needs? 13. How available to you is the information that you need in your day- to-day life? 14. To what extent do you have the opportunity for leisure activities? 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
21Very poor Poor Neither Good Very good poor nor good 15. How well are you 1 2 3 4 5
able to get around?
12Very dissatisfied Dissatisfied Neither satisfied nor dissatisfied Satisfied Very satisfied 16. How satisfied are you with your sleep? 17. How satisfied are you with your ability to perform your daily living activities? 18. How satisfied are you with your capacity
1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
9for work? 19. How satisfied are you with yourself? 20. How satisfied are you with your personal relationships? 21. How satisfied are you with your sex life? 22. How satisfied are you with the support you get from your friends? 23. How satisfied are you with the conditions of your living place? 24. How satisfied are you with your access to health
1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5 1 2 3 4 5
52services? 25. How satisfied are you with your 1 2
113 4 5 transport? The following question refers to how often you have felt or experienced certain things in the last four weeks. Never Seldom Quite Very often Always often 26. How often do you have negative feelings 1 2 3 4 5 such as blue mood, despair, anxiety, depression?
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30Appendix C Appendix D Appendix E 1 2 3 4 5 6 7 8
10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 61 62 63 64 65 66 67 68 69 70 71 72 73 74 75 76

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