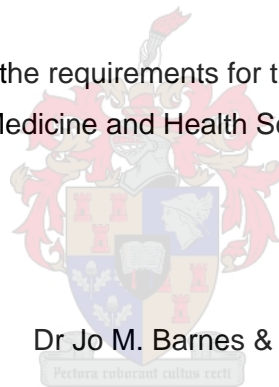


**The impact of caring for a school-going visually impaired child in Cape Town, Western Cape
on the home caregiver and the rest of the family – the health, socio-economic and
psychological health burdens**

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Thesis presented in fulfilment of the requirements for the degree of Master of Science in
Epidemiology, in the Faculty of Medicine and Health Sciences at Stellenbosch University

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March 2021

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Background: Visually impaired (VI) children need additional care for daily tasks due to their diminished independent living skills (ILS). In learners in Special Educational Needs (LSEN) schools and specially-adapted mainstream schools, occupational therapy and trained assistants help to bridge the gap that diminished ILS pose to their education. However, in impoverished areas of the Cape Metropole, many families cannot afford trained caregivers in their homes. Typically a maternal figure fulfils the responsibilities of caring for the VI child as well as for the rest of the household; such a person then becomes the VI child's primary home caregiver.

Aims and Objectives: The main focus of the study was to determine the caregiving load and its impact on the caregiver's physical, mental and emotional well-being.

Methods: The cross-sectional study used a questionnaire consisting of a self-designed questionnaire based on issues from literature on the subject and the validated Caregiver Strain Questionnaire – Short Form (CGSQ-SF). The CGSQ-SF provides qualitative data on the noticeable, emotional, and overall impact of caregiving. During prescheduled home interview sessions, the caregivers completed the questionnaires. The mixed research method used measurable data such as financial status and qualitative data, such as the emotional experiences associated with caring for a VI child.

The University of Stellenbosch ethics committee (S13/03/049) and the Western Cape Education Department (20130704-13796) approved the study. Professor M. Kidd of the Centre for Statistical Services at the University of Stellenbosch carried out the statistical analyses, Mann-Whitney U tests and Kruskal-Wallis tests analysed the relationship of variables with CGSQ-SF scores.

Results: Of the population of 320 VI learners from the only school for the VI in the Cape Metropole, 150 learners resided at home during the school term. According to the inclusion criteria, only 95 of the 150 home caregivers were eligible. The study obtained consent from 73 caregivers. The CGSQ-SF scoring showed that the majority of the 73 caregivers experienced moderate strain in terms of overall (55/73; 75.3%), objective (57/73; 78.1%) and subjective internalised caregiver strain (55/73; 75.3%). Elevated caregiver strain frequently occurred with these factors: financial difficulty; diminished ILS; and reluctance to spend time away from the VI child.

Conclusion: All the caregivers experienced a considerable caregiving load and subsequently substantial caregiver strain level. All the participating households experienced both poverty and caring for a VI child. This bias in the design made it difficult to attribute what strainload was due to

either of these variables. It was not possible to determine whether having a VI child increased the household's strain compared to those who did not have a VI child. The confounding nature of the design made it challenging to unravel the relationship between poverty and caregiver strain due to the presence of a VI child. Qualitative information from the caregivers suggested that they did not view their child's special needs as the only cause for the financial struggles they face and that their biggest concern was their child's future as a disabled adult.

Keywords: Caregiver strain, independent living skills, caregiving load

OPSOMMING

Agtergrond: Visueel gestremde (VI) kinders benodig addisionele hulp vir hul daaglikse take as gevolg van hul verminderde onafhanklike lewensvaardighede (ILS). In skole vir kinders met spesiale opvoedkundige behoeftes (LSEN) en hoofstroom-skole met spesiale-aangepassings kan arbeidsterapeute en opgeleide assistente help om die gaping te oorborg wat die verminderde vermoëns van sulke kinders vir opvoeding inhou. In behoeftige areas van die Kaapse Metropool kan baie families dit egter nie bekostig om opgeleide versorgers in hul huisomgewing in diens neem nie. In so 'n huishouding sal 'n volwasse persoon tipies die verantwoordelikhede vir die versorging van die VI kind onderneem asook vir al die ander persone in die huishouding. So 'n persoon word dan die VI kind se primêre tuisversorger.

Doelwitte en Opjektiewe: Die hooffokus van die studie was om die las op die versorgers te bepaal en om te bepaal wat die impak op die ligamlike, verstandilike en die emotionele gesondheid van die versorgers is.

Metodes: Die dwarsdeursnitstudie het gebruikgemaak van 'n gekombineerde vraelys wat bestaan uit 'n self-ontwerpte vraelys wat gebaseer is op kwessies wat in die wetenskaplike literatuur voorkom asook die gevalideerde "Caregiver Strain Questionnaire – Short Form" (CGSQ-SF). Die CGSQ-SF meet die waarneembare, emosionele, en totale impak op versorgers. Gedurende vooraf geskeduleerde huisbesoeksessies het die versorgers die vraelys beantwoord. Die studie het 'n gekombineerde benadering gebruik om beide kwantifeerbare data soos die ekonomiese status te meet asook kwalitatiewe data soos die emosionele ondervinding wat gepaardgaan met die versorging van die VI kind.

Die Universiteit van Stellenbosch se etiese kommiteë (S13/03/049) en die Wes-Kaapse Onderwys Departement (20130704-13796) het die studie goedgekeur. Professor M. Kidd van die Sentrum van Statistiese Konsultasie van die Universiteit van Stellenbosch het die statistiese ontledings uitgevoer. Die die CGSQ-SF resultate se verband met die ander veranderlikes in die studie is bepaal met behulp van Mann-Whitney U toetse en die Kruskal-Wallis toetse.

Resultate: Uit die populasie van 320 VI leerders van the enigste skool vir die VI in die Kaapse Metropool het 150 leerders gedurende die kwartaal tuis ingewoon. Volgens die insluitingskriteria het slegs 95 van die 150 tuisversorgers gekwalifiseer vir die studie. Toestemming was verkry van 73 versorgers. Volgens die CGSQ-SF resultate het die meerderheid van die 73 versorgers matige ooreising in terme van algehele stremming (55/73; 75.3%) , objektiewe stremming (57/73; 78.1%) en subjektief geïnternaliseerde stremming (55/73; 75.3%) getoon. Verhoogde ooreising van

versorgers het die meeste saam voorgekom met die faktore soos finansiële probleme; verminderde ILS; en 'n onwilligheid om tyd weg van hul VI kind te spandeer.

Gevolgtrekking: Al die versorgers het 'n aansienlike versorgingslas en gevolglike ooreising gerapporteer. Al die deelnemende huishoudings het beide armoede ondervind en 'n VI kind gehad. Hierdie sydigheid in die studieontwerp het dit moeilik gemaak om die spesifieke stremmingslading wat aan die versorging van 'n VI kind toegeskryf kan word te onderskei van die effek van armoede. Dit was ook nie moontlik om te bepaal watter mate van huishoudelike stremming aan die teenwoordigheid van die VI kind toegeskryf kan word in vergelyking met huishoudings sonder so 'n kind nie. Kwalitatiewe inligting het daarop gedui dat versorgers nie die kind se spesiale behoeftes sien as die enigste oorsaak van die stremming wat hulle ondervind nie. Hulle grootste bekommernis was die toekoms van hulle kind as 'n gestremde volwassene.

Sleutelwoorde: Versorgers ooreising, onafhanklike lewensvaardighede, versorgingslas

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LIST OF ABBREVIATIONS/ACRONYMS

ADHD	Attention Deficit Hyperactivity Disorder
AFSUN	African Food Security Urban Network
AIDS	Acquired Immunodeficiency Syndrome
AUDIT	Alcohol Use Disorders Identification Test
AUDIT-C	Alcohol Use Disorders Identification Test for Consumption
BIC	Burden Index of Caregivers
BSI	Brief Symptom Inventory
CABA	Child and Adolescent Burden Assessment
CDQ	Client Diagnostic Questionnaire
CES-D	Centre for Epidemiologic Studies Depression Scale
CGSQ-SF	Caregiver Strain Questionnaire-Short Form
DS	Down's Syndrome
EBP	Escala de Bienestar Psicológica
EFA	Exploratory factor analysis
FAD	Family Assessment Device
FAS	Fetal Alcohol Syndrome
FBEP	Fort Bragg Evaluation Project
GCS	General Cognitive Score
HIV	Human Immunodeficiency Virus
HREC	Health Research Ethics Committee

ICD-10	International Classification of Diseases and Related Health Problems – 10th Revision
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILS	independent living skills
INMA project	Environment and Childhood Project
ISASA	Independent Schools Association of South Africa
LSEN	Learners with Special Education Needs
MRC	Medical Research Council
NCAST	Nursing Child Assessment Teaching Scale
NIDS	National Income Dynamics Study
ONCE	National Organization of the Spanish Blind
PHQ-9	9-item Patient Health Questionnaire
PIP	Pediatric Inventory for Parents
PSI-FF	Parental Stress Index Full Form
PSI/SF	Parental Stress Index Short Form
PSLSD	Project for Statistics on Living Standards and Development
RSES	Rosenberg Self-Esteem Scale
SASH survey	South African Stress and Health survey
SASSA	South African Social Security Agency
SCID-I	Structured Clinical Interview for <i>DSM-IV</i> Axis I Disorders
SD	Standard Deviation
TB	Tuberculosis

TD	typically developing
TGMD 2	Test for Gross Motor Development Second Edition
VI	visually impaired
WCED	Western Cape Education Department
WHO	World Health Organization

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Chapter 1: Introduction and Literature Review

This chapter gives background information on the impact of caring for a visually impaired (VI) child on the caregiver (also known as the caregiver strain). It further gives the motivation behind this study and concludes with a relevant literature review on the subject.

1.1. Background

This thesis details the investigation of the particular challenges facing home caregivers (hereafter referred to as the “caregiver”) of children with a physical impairment – specifically those VI. The amount of care required usually decreases as children without disabilities transition into adults; this is not the case when caring for a disabled child¹. The following chapters discuss and analyse the topic’s literature background.

Literature provides many studies on the relationship between caregiving responsibilities and the resultant stress responses; from different perspectives, quantifying different subsets of causal factors, and postulating various research opportunities. The central theme of this literature review is the caring requirements of the VI child. Caregiver strain and factors that influence the caregiving burden are of particular interest. Quantitative and qualitative research of caregiver burden is vital in assessing and treating caregiver strain and is discussed in section 1.6. This literature review will not be delving into the burden experienced by professional caregivers, as informal caregivers were the main interest.

1.1.1. Development of independent living skills

There is a diminished development of independent living skills (ILS) and delay in children with either congenital or early-onset significant visual impairment². Coordinated movement development relies on visual cues and subsequent memory, for instance, dressing is first done by the parent or guardian and then copied by the child from memory. VI children have a more challenging time learning these ILS, and adaptive learning and repetition can close this gap.

Hayton, Wall and Dimitrio sought to compare skill development involved in independent dressing between VI and Down’s Syndrome (DS) young children and Typically Developing (TD) young children from England². Along with nine TD participants (age range = 5;06-7;09 years; M = 6;09), nine VI (age range 6;06-10;02 years; M = 8;03) and nine DS (age range: 5;04-10;00 years; M = 7;05 years) participants made up the study population (T=27); all the children could not fasten zips, buttons, fasteners and tie their laces. The intervention study took place over ten weeks. The difficulty

of tasks increased each week. As impaired children take longer to acquire ILS, follow-up appointments took place at one-month and three-months after the intervention period with the VI and TD participants. The intervention provided used an interactive rhyming-story game called “Just Joey”, and buttoning of a regular outdoor coat measured skill development. Before the intervention period, measurements of baseline scores observed that the VI and DS children were further behind in their ILS (VI; $t(6) = 3.31$, $p = .016$; DS; $t(6) = 4.01$, $p = .007$; TD; $t(8) = 9.69$, $p < .001$). During the intervention period, the TD children developed the skills required to unfasten and fasten a coat faster than the other two groups. Because the VI and DS groups skipped sessions due to medical issues, only week four, seven and ten were analysed. The intervention program was successful shown by ANOVA analyses of its benefit on all the groups, scores provided significant results for: zip fastening (Wilks Lambda = 0.117, $F(3, 13) = 37.57$, $p < .001$); zip improvement (Wilks Lambda = 0.116, $F(6, 26) = 8.37$, $p < .001$); popper fastening ability (Wilks Lambda = .003, $F(3, 14) = 1587.69$, $p < .001$); lace fastening ability (Wilks Lambda = .088, $F(3, 14) = 48.10$, $p < .001$); and lace improvement scores (Wilks Lambda = .124, $F(6, 28) = 8.60$, $p < .001$)². At the end of the intervention period, the TD group had successfully acquired all the skills to dress independently. The VI and DS groups had significantly improved from their baseline scores. The DS group did not master any of the skills. The VI group mastered the button fastening skill. During the follow-up sessions with the VI group, all the skills scores except for lace fastening showed improvement at one-month, and all the skills scores continued to increase at three-months. The novel intervention benefit shows that adapting how young children with disabilities learn motor skills helps improve their ILS in at least ten-weeks with a long term benefit even after the intervention concluded.

Wagner and colleagues tested the performance of gross motor skill activities by blind and sighted children aged six to twelve years old³. Visual impairment summer camps across the United States of America provided participants for the study; the control group consisted of sighted children from schools in these areas. The study utilised the Test for Gross Motor Development Second Edition (TGMD 2) to quantify and compare coordinated physical movements’ performance. Gender and age were ruled out as confounding variables as they tried to match the study and control groups as much as possible; Total: $T(47) = 1.70$; $p = 0.096$ and boys: $T(27) = 0.88$; $p = .388$; girls: $T(20) = 1.64$; $p = .116$). The study found that blind children performed worse than sighted children in locomotor activities in total with a median score of 21 (Range= 10.00 – 33.00) versus a sighted median score of 42.00 (Range= 35.00 – 48.00); $p = 0.003$. There was a huge difference in running with median scores of 2.00 (Range= 0.00 – 8.00) versus 8.00 (7.00 – 8.00); and leaping with median scores of 0.00 (Range= 0.00 – 4.00) versus 6.00 (Range= 3.00 – 6.00). Controlling the movements of a ball was also measured. The blind children performed worse than sighted children in object control with a median score of 20.00 (Range= 12.00 – 38.00) versus a sighted median score of 38.50 (Range=

26.00–47.00). There was a big difference in catching with median scores of 2.00 (Range= 0.00 – 4.00) versus 6.00 (Range= 0.00 – 6.00); and kicking with median scores of 4.00 (Range= 0.00 – 7.00) versus 8.00 (Range= 7.00 – 8.00). The authors note that with time and effort, the blind children could perform better at these tasks³. The delay in gross-motor development of VI children would increase reliance on their caregiver.

Children with special needs require not only extra care but different types of care. In 2007 Silva-Smith and colleagues sought to identify which type of support caregivers provided VI patients, by analysing surveys completed by the caregivers of VI patients attending a low vision clinic in Colorado Springs⁴. The participants had to be 18 years or older; be a family member or friend and; identify themselves as the primary support person of the VI patient. The study identified a population sample of 55, but only 28 completed the survey (50.9% response rate). No data on the age range of VI patients was available. Based on the data collected from the aforementioned surveys, the sample of VI patients needed aid with transportation (n=26; 93%), shopping (n=21; 75%), mealtime preparation (n=15; 54%), reading (n=7; 25%), personal care (n=4; 14%), recreational activities (n=4; 14%), and walking (n=2; 7%)⁴. Survey data analysis found that transportation required the highest mean amount of time per week of all the caregiving responsibilities (n=24; 48 hours)⁴. It is important to note that as the study had a small sample size and low response rate (50.9%), there is a possibility of excluding duties. It may not be representative of the sample population. The absence of information on the age range of patients the caregivers tend to, neglects the possibility of age-related needs on caregiving duties. The hypothesis that as VI children age their needs would decrease due to having time to perfect basic tasks is as yet unanswered, as there are no longitudinal data on the care requirements of VI children over time.

1.1.2. The impact on the caregiver

The caregiver's needs often become less important as the disabled child is the priority; subsequently, the caregiver's daily schedule revolves around the child. A study sourced from the Maryland School for the Blind Early Intervention Program and the District of Columbia's Office of Infants and Toddlers with Disabilities found that VI children, and subsequently their caregivers, experienced restrictions in their movements outside the home⁵. A parent questionnaire, the Home Observation for Measurement of the Environment (HOME) Inventory-Disability Adapted Infant/Toddler Version (Visual Impairment), and the Nursing Child Assessment Teaching Scale (NCAST) provided the results⁵. The household's primary caregiver often solely carries the responsibility for nurturing the entire household, resulting in feelings of isolation⁶.

Sola-Carmona and colleagues' cross-sectional study on factors associated with anxiety, well-being and self-esteem in caregivers of VI children further demonstrated the increased susceptibility to distress⁷. The total study population, consisting of 95 parents were from the Almeria province of southern Spain; all VI children were affiliated with the National Organization of the Spanish Blind (ONCE) and received specialised education in this province. Parents of children who were not receiving assistance from the educational orientation department (14 families) and those who refused to give informed consent were excluded from the study ($n=61$)⁷. This study represented 64.2% (61/95) of the source population. Of the study population, 8/61 (13.1%) were blind, 21/61 (34.4%) were VI, and 32/61 (52.5%) were VI and had intellectual and physical disabilities. The VI children's mean age was 9.16 years old ($SD=4.9$). The study utilised a self-designed questionnaire based on literature, the Spanish version of the STAI, the scale of Psychological well-being (Escala de Bienestar Psicológica; EBP), and the Rosenberg Self-esteem Scale (RSES). Mann-Whitney U and Kruskal-Wallis K tests were employed.

Financial stability and leisure time dramatically affected the well-being, anxiety, and self-esteem of the caregiver⁷. Higher levels of anxiety were seen when the caregiver was unemployed ($df=-2.98$; $r=0.388$; $p=0.003$); did not have a technical degree ($df=-2.49$; $r=0.318$; $p=0.013$); had less leisure time ($df=-2.69$; $r=0.344$; $p=0.007$) and; less job prospects ($df=-2.66$; $r=0.340$; $p=0.008$) due to the VI child. Parents who had ample leisure time were happier and more secure psychologically than those who had less of no leisure time than before having the VI child ($df=-2.41$; $r=0.308$; $p=0.16$)⁷. There was a correlation between the caregiver perceiving their health to be in good standing and higher levels of psychological well-being ($df=2$; $r=0.317$; $p=0.02$). Parents whose job opportunities were negatively affected by having a disabled child had lower self-esteem levels than those who did not experience this ($df=-2.63$; $r=0.337$; $p=0.009$). Being adequately informed about the VI child's condition decreases the susceptibility to anxiety in caregivers ($df=-2.57$; $r=0.329$; $p=0.010$). More children in the household increase the caregiver's burden, resulting in more strain and anxiety ($df=-2.10$; $r=0.273$; $p=0.035$)⁷. Worsening of the visual impairment introduces uncertainty and evokes anxiety of the child's condition's unknown outcomes and needs ($df=-2.43$; $r=0.311$; $p=0.015$)⁷. The findings suggest a correlation between the burden of duties placed on the caregiver (caregiving load) and anxiety and psychological well-being of the caregiver⁷. Serious strain potentially raises anxiety levels and negatively affects mental health.

1.2. The significance of Visual Impairment prevalence and incidence estimates on Caregiver strain

As stated by Roberts and Lawton¹; Hayton, Wall and Dimitrio²; Wagner and colleagues³; and Silva-Smith and colleagues⁴, visual impairment and blindness profoundly affect caregiving load and subsequently, caregiver strain. Knowing how prevalent it is, is vital to understanding the reach of chronic stress in caregivers of VI individuals.

Pascolini utilised meta-analysis to estimate the global prevalence of visual impairment, from country-specific population-based representative studies⁸. The study used the International Classification of Diseases and Related Health Problems – 10th Revision (ICD-10)⁹ definition of visual impairment. Qualifying surveys with sample sizes from 1200 to 46000 participants, high response rates (>80%), and data on individuals with visual acuity (VA) of less than 6/18. Searches done up until 30th June 2010 on Medline, World Health Organization (WHO) regional databases, and unpublished data available to WHO/Prevention of Blindness and Deafness procured studies subject to the inclusion criteria; 53 studies from 39 countries met all the inclusion criteria⁸. The WHO region list¹⁰ was used to categorise the meta-analysis studies into six regions. Regional prevalence was estimated using the aforementioned population-based studies and estimates for the countries missing data⁸. The missing data were estimated using a model based on gross domestic product per capita in 2007, World Bank economic-status classification and the prevalence of visual impairment in the age group of 50 years and older – due to the vast number of assessments focusing on this age group⁸.

At the time of the Pascolini study – 2010 – the global population size was estimated to be 6737 million, of that, the study estimated a VI population of 285 million (SD=4.24)⁸. The Pascolini study estimated that the African region's prevalence comprised 9% (26 million) of the 285 million VI population statistic⁸. According to the World Bank classification, extrapolation of the regional prevalence as either low-income or lower-middle-income countries from 19 surveys from African countries met all the inclusion criteria⁸. The source material mirrored the economic status evident in 93.2% (40/46) of this region's countries. The prevalence of visual impairment indicates a need for the care of these individuals.

Recently the ICD-11 definitions were introduced, these definitions about VA (distance VI) remain unchanged for the most part with the addition of a category for individuals who have near vision impairment¹¹. The estimated distance-VI global population was 442 million in 2017¹², defined by the ICD-11 distance visual impairment definition, suggesting an increase in the extent of global visual

impairment from 2010. According to the WHO webpage on blindness and visual impairment, of the estimated global VI population, approximately 19 million were children under 15 in 2017¹².

In 2000, the estimated annual increase in the number of blind children was approximately 50 000¹³. From the WHO study in 2000 in Sub-Saharan Africa, there were 320 000 blind children out of approximately 260 million children under 16, resulting in an estimated prevalence of 1.23/1000 children¹³.

Approximately 11% of South Africa's disabled were sight disabled in 2014, and 97% of those individuals were unemployed^{14,15}. In South Africa, unemployment statistics paint a bleak picture for the VI, concerning their financial dependence on their family, in later life.

The population census ran by Statistics South Africa in 2011¹⁴, used the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH)¹³. The definition states that an impairment has to either have lasted or will last for six or more months and obstruct daily activities and participation in educational, economic or social activities^{15,16}. As children under the age of five-years-old or individuals with psychosocial and specific neurological disabilities could not answer the questions accurately, statistics on them were excluded^{15,16}. Underestimation of the reported overall disability prevalence in South Africa results from this. It only accounts for 38 084 876 individuals of the total population (51.7 million people)¹⁵ and only 73.5% of the 2011 estimated population took part.

According to data collected, 7.5% (2870130 / 38084876) of the South African population had a disability; 11% (315714 / 2870130) were VI^{14,15}. The census data indicated that 4 136 846 of the participants resided in the Western Cape, 10% of the total South African population. The province accounted for 7.7% (24309/315714) of the VI living in South Africa, lower than the Western Cape to South Africa ratio. The proportion of disabled individuals aged five to nineteen years living in South Africa was 718409 / 12359402 (5.8%)^{15,16}.

The census asked if they had "difficulty seeing even when using eyeglasses?" to ascertain how many South African residents were VI^{15,16}. The following were their response choices: "No difficulty"; "Some difficulty"; "A lot of difficulty"; "Unable to do"; and "Unsure". Mild difficulty seeing was assigned when the respondent answered "Some difficulty", and severe difficulty when seeing if they replied "A lot of difficulty" or "Unable to do at all". The mild difficulty was seen more frequently than severe, 9.8% and 1.7% respectively. It was unclear if VI individuals five to nineteen years of age had trouble with the task due to an impairment or lack of development, resulting in the inability to calculate the proportion of VI for this age group accurately^{15,16}. The survey was vulnerable to bias as the

information relied on the respondent's opinion rather than scientific tests, and an individual could respond on behalf of the entire household^{15,16}.

An undercount of VI in South Africa, could also be due to infrequent screening, preventing an accurate rate of emerging cases. Majority of studies^{17–20} on visual impairment report on the prevalence, as they utilise cross-sectional data; this illustrates the proportion. Analysis of data over an extended period would enable the calculation of incidence by comparison of existing cases with new cases during the period²¹; particularly the measurement of risk (number of children developing visual impairment per total children recorded in a period); and incidence rate (number of children developing visual impairment per risk period)²². The risk illustrates the probability of developing visual impairment; while the incidence rate depicts the frequency at which the proportion of cases changed over the risk period. Knowledge of incidence would elucidate factors that increase the likelihood of visual impairment in children and possible prevention methods.

1.3. The motivation behind this study

This study intended to create an opportunity to provide information on crucial problems South African caregivers may face daily, to help plan and provide support. An assessment of these caregivers' needs, who bear the extra burden of looking after a VI child while also carrying the full responsibilities of caring for a family, often constraining financial and social circumstances, provided the necessary information.

Interviewing caregivers of learners from government-funded schools ensured that the family's financial status did not affect enrollment at the school. The Western Cape Education Department (WCED) website provided a list of schools specialising in teaching blind learners. The website listed two schools, and only one was in Cape Town namely Athlone School for the Blind²³. The only other school in this province is situated in Worcester which is 110 km away. It was not possible to visit the caregivers in that town to take down data personally and thus the study was limited to the Athlone School in Cape Town. Thus the study sourced parents/guardians who were the caregivers of VI children who attended Athlone School for the Blind. The study examined the extent and effect of the challenges faced by these caregivers daily.

1.4. Aetiology of Caregiver Strain

The impact of caregiver strain on physical and mental stress²⁴ and factors that affect caregiver strain²⁵, for example, socio-economic status and personality, have been studied for decades.

Caregiver strain manifests as physical symptoms such as headaches and may also modify their physiology²⁶.

Longitudinal studies with caregivers of children with different conditions, from various socio-economic status, and differing frequency of caregiver strain, depressive symptomatology, and anxiety would give more insight into the impact of chronic stress physically, mentally and physiologically.

1.4.1. The manifestation of chronic stress

Symptoms associated with chronic stress are most recognisable in the manifestation of stressor responses, namely anxiety, depression and stress²⁷.

Clinical depression can have detrimental effects on the cardiovascular, immune, metabolic and neurological systems, while it can predispose the individual to, amongst others, insulin resistance, hypertension, atherosclerosis and forgetfulness²⁷. It also has a debilitating impact on the quality of life. Globally women are at a higher risk than men of developing depression²⁸. In South Africa, the lifetime prevalence of depression obtained from the first nationally representative epidemiological survey, the South African Stress and Health (SASH) survey was 9.8% across all age groups²⁹. SASH was conducted from 2003 to 2004 and surveyed 4351 adults of all races and ethnic groups in South Africa. Females were determined to be 1.75 times more likely than males to develop depression²⁹.

The impact of parental stress among caregivers has long been studied (see the systematic review by Cousino and Hazen³⁰). Parental stress is commonly measured using the 36-item Parental Stress Index, Short Form (PSI/SF)³¹; it identifies potential parental behaviour problems, difficulties in adjusting to the child's condition and the overall stress due to parenting responsibilities. Other tools available are the 42-item Pediatric Inventory for Parents (PIP)³².

In 2000, Vedhara and colleagues scrutinised the stressors involved in chronic stress experienced by caregivers and the stress responses³³. After the initial interview in follow-up assessments three and six months later, the researchers collected further data to elucidate the stressors' longitudinal impact. Fifty spousal caregivers of patients diagnosed with dementia took part in the study; as the related symptoms do not fluctuate unexpectedly³³. The patient list of the Bristol Memory Disorders Clinic provided participants for the study. All the caregivers were white individuals, mean age of 72 years (SD= ± 8 years) and the majority (49/50) were retired. The mean household income was \$21712 (SD= $\pm \$13899$)³³. The study also utilised a control group of 67 non-caregivers, closely matching with the caregiver group for age (69 ± 4 years), gender, ethnicity (100% white), employment status (61/67

retired), and socio-economic status (\$220385; SD= ±\$11575). The stressors under investigation were stressful life events (Geriatric Social Readjustment scale), daily struggles (Hassles and Uplifts Scale), and caregiving load (Burden Interview scale)³³. The Geriatric Social Readjustment scale measures the frequency and severity of major life events in the elderly. The Hassles and Uplifts scale assesses the frequency and severity of minor negative and positive experiences. The Burden Interview scale assesses the overall caregiver challenges and the level of caregiver strain. Investigations into coping mechanisms used the Significant Others scale (Social support), Culture-Free Self-Esteem Inventory (Self-esteem), the Ways of Coping Scale (Coping approaches), and the Savage Personality Screening Scale (Self-concept). The stress responses focused on were anxiety, depression – both measured using the Savage Personality Screening Scale – and stress (Global Measure of Perceived Stress)³³. One-way analysis of variance tests showed that there was no difference in the frequency of stressor exposure. Significant differences were seen in coping mechanisms: self-mediated coping ($F= 10.75$; $p=.001$), acceptance ($F=4.72$; $p=0.032$), self-esteem ($F=7.91$; $p=0.006$), ideal support ($F=57.95$; $p<0.0001$), and self-concept ($F=6.11 \pm 0.02$). The results substantiate that caregivers are less likely to develop coping mechanisms such as self-controlled coping and accepting responsibility; they have lower self-esteem levels, poor self-image and; desire a more involved support system³³. The study results corroborated the propensity among caregivers to exhibit significantly higher levels of anxiety ($F=10.58$; $p=0.002$), depression ($F=16.00$; $p<0.0001$), and stress ($F=10.94$; $p=0.001$) than non-caregivers.

According to the Pearson's correlation coefficient bivariate calculations the degree of anxiety correlated positively with self-controlling coping ($r=0.430$; $p<0.01$); the degree of depression showed a negative correlation with social self-esteem ($r=-0.291$; $p<0.05$), planful problem-solving coping ($r=-0.366$; $p<0.05$), and positive reappraisal coping ($r=-0.312$; $p<0.05$); and the degree of stress correlated positively with seeking social support coping ($r=0.292$; $p=0.05$)³³. These different correlations debunk the misguided notion of the interchangeability of the terms anxiety, depression and chronic stress. Severity and duration of caregiving showed no significant correlations with anxiety, depression and stress for the study population. Over the 6-month follow-up period, the impact of stressful life events and caregiving load remained consistent, whereas the influence of daily hassles fluctuated³³. The study is not representative of the sample population due to the lack of ethnic and socio-economic diversity in the study group; studying the stressors and stress responses in a country-wide study including all representative groups would remedy this. Global representative studies comparing those with caregiving responsibilities and those without, would provide accurate risk ratios of the stressors and stress responses.

These findings suggest that caregivers generally carry the burden of caring for an individual with a disorder and draw attention to its possible negative health impact. Studies into the plight of caregivers of VI patients and VI children further elucidate the specific needs of caring for the VI.

Braich and colleagues studied the relationship between caregiver strain factors and the risk of depression in caregivers of blind patients attending the Krishna Devi Dalmia Eye Hospital in Rampur, India³⁴. Caregivers of patients who had a best-corrected VA of <20/200 in the better eye and no other medical condition that would require additional assistance participated in the study. The researchers completed the questionnaires in one-on-one interviews with the caregiver in the hospital staff's presence and the patient's absence. The study comprised 548 caregivers, but as 26 surveys had incomplete data statistical analysis, it included only 522 surveys (95% response rate). The researchers modified the Burden Index of Caregivers 11TH revision (BIC-11), a validated caregiver strain measurement scale, to exclude questions on "service-related burden" as the caregivers were not personnel³⁴. The Centre for Epidemiologic Studies Depression Scale (CES-D) was used to determine the risk of caregiver depression³⁴. Mean overall BIC scores showed that caregivers of patients with a VA of no light perception (BIC=16.71; SD= ± 8.24) had higher BIC scores than those caregivers of patients with a VA of between 20/200 and 10/200 (BIC=7.00; SD= ± 2.37), indicating that an increase in the degree of visual impairment corresponds with a higher burden on the caregiver ($p<0.0001$). According to Silva-Smith and colleagues⁴; Vedhara and colleagues³³; and Braich and colleagues³⁴, the time required for and intensity of caregiving duties are critical influencers of caregiver strain. Chi-square tests on factors relating to caregiver strain substantiate the importance of time spent caregiving (Odd's ratio= 7.77; $p<0.0001$) and the intensity of caregiving duties (Odd's ratio= 5.71; $p<0.0001$). Lower family income showed to be significant (Odd's ratio= 0.31 ($p=0.00817$) for caregivers from households with a monthly income of 2500 to 6000 Rupees (Approximately R517 to R1241)³⁴. Depression showed a higher prevalence in the group with no light perception (43/89; 48%) than those with a VA of between 20/200 and 10/200 (45/282; 16%)³⁴, indicating that an increase in caregiving load may result in a higher predisposition to depression. The absence of a control group and the simultaneous investigation of family income and caregiving load confounds the causality of depression predisposition for the study. The study was vulnerable to observational bias due to a great deal of the study population being illiterate³⁴ resulting in hospital staff having to complete the survey on behalf of these caregivers.

In 2016, Khare and colleagues found no evidence of increased disability being a predictor of caregiver depression; the relationship with caregiver strain was not explored³⁵. The cross-sectional study took place in a tertiary-level teaching hospital in New Delhi. The study consisted of 49 caregivers of VI patients with best-corrected VA of <20/200 in the better eye; this is a low sample

size, resulting in it being unrepresentative of the population at large and missing significant associations. The CES-D provided data on caregiver depression. The sample's average caregiver depression score out of 60 was 43.2 ± 5.71 , indicating a 72% likelihood of caregiver depression³⁵. The Caregiver Burden Scale measured caregiver strain, and the majority of the participants reported moderate burden ($n=32$; 65.3%) and only 13/49 caregivers reported severe burden³⁵. The absence of data on the number of hours spent providing care, type of care and whether the severity of disability influences caregiver strain, restricts caregiver strain's aetiology and its association with depression for the study sample.

1.4.2. The Symptomology and Epidemiology of Caregiver Strain

Stress hormones are released in response to stress, promoting acclimatisation to the stressor, which is a generally advantageous occurrence³⁶. Chronic stress may have detrimental effects on the body and brain³⁶. The seminal work on caregiver strain can be traced back to 1955 when Clausen and Yarrow³⁷ first studied prolonged chronic stress affecting caregivers.

Further investigation into the response to chronic stress by Lazarus and Folkman (1984) found that coping mechanisms exist as strategies which either, address the problem by managing the distress caused or the emotional response to the problem by regulating it^{38,39}. These strategies are not always conscious choices and can occur concurrently or simultaneously. Examples of problem-focused and emotion-focused coping strategies by caregivers of disabled individuals are adaptations to their homes and participation in social support groups respectively^{38,39}.

1.5. Burden experienced by the household

A safe home environment is essential in every child's upbringing; this is especially important for disabled children. A disabled child's home has to promote independence, privacy, and social interaction with the rest of the family^{40,41}. Most home designs do not consider the needs of disabled individuals. A home that is not modified restricts the family; negatively impacting the child's development and the caregiver's health⁴¹. As most home layouts do not leave allowance for disability adaptations, insufficient space is a considerable issue⁴¹. The experience of adapting the home can be an emotional one, as it forces the family to confront the reality of the child's disability. Consideration of current and future needs is required and the effect it would have on the family's movement and social interactions, for adaptations to improve the child's development⁴¹. The primary focus of most modifications is to facilitate ease in daily activities for the disabled child, ranging from the installation of ramps and railings to the widening of doors^{42,43}. There is a need to select portable and temporary adaptations as families renting a property cannot install permanent fixtures⁴¹.

1.5.1. Poverty

A compilation report released by Statistics South Africa in 2016, which covered survey data from 2011 to 2015, shows an increase in poverty for the country (53.2% to 55.5%) and the Western Cape (33.7% to 37.1%)⁴⁴. Due to the high levels of poverty and unemployment in South Africa, social grants' disbursement is essential⁴⁴. Households having at least one disabled member are more prone to unemployment and associated severe poverty. They tend to have more expenses, resulting in an increased financial dependency on social protection^{45,46} and anxiety experienced by the caregiver^{47,48}. The National Treasury reported expenditure on social grants of R164.9 billion in 2016/2017; this was an extra R21 billion than in the 2014/2015 financial year⁴⁴. South African Social Security Agency (SASSA)⁴⁹ is in charge of social protection allocation.

South African residents undergo a means test, to evaluate their income and assets to determine if their income is insufficient to support them in order to access a social grant⁴⁹. In this study participants' households received one or more of the following social grants: Child support (R330 per month), Caregiver dependency (R1410 per month), Disability (R1410 per month) and Older person grant (R1410 per month)⁴⁹. The caregiver dependency grant is available to those caring for a care-dependent child younger than 18 years old. These VI children qualify for the disability grant after turning 18 years old until they are 59 years old.

Food insecurity – the frequency of a lack of food over four weeks – affects all poverty-stricken households, especially households with disabled individuals. According to the case study done by the African Food Security Urban Network (AFSUN) surveying 6452 low-income urban South African households, approximately 80% of the 1060 Cape Town households studied were food insecure⁵⁰. Low food security may be associated with reduced physical and mental health, though these effects are temporary if the degree of food insecurity is minor^{50,51}.

1.5.2. Substance use in the household

In 2016, using the Alcohol Use Disorders Identification Test (AUDIT) and AUDIT-C (C for Consumption) Taylor and colleagues investigated the risk factors associated with alcohol dependence and binge drinking in children's caregivers Kwa-Zulu Natal, South Africa⁵². The study sourced data derived from the Asenze study; out of the 14,425 households, 1434 (9.9% of the study population) completed assessments were analysed. The Client Diagnostic Questionnaire (CDQ) assessed caregiver mental health. However, in this instance, caregiver mental health was not significant as a causal factor ($p=0.4$ and $p=0.2$ for AUDIT and AUDIT-C, respectively). Some of the variables recorded include gender-based violence, smoking, their Human Immunodeficiency Virus

(HIV) or Acquired Immunodeficiency Syndrome (AIDS) status, and having a disabled child. Multivariate analyses of the associative relationship with AUDIT and AUDIT-C scores found that gender-based violence at the hands of their partner ($p=0.0003$ and $p<0.0001$); the caregiver being a cigarette smoker ($p<0.0001$ for both); the caregiver being HIV-positive ($p=0.0025$ and $p=0.0127$); having a disabled child ($p=0.0045$ and $p=0.0291$) to be significantly associated with binge-drinking and alcohol dependence⁵². The positive associations between having a disabled child and binge-drinking ($p=0.0291$); and alcohol dependence ($p=0.0045$), could indicate that the increased caregiving load augments the caregiver's stress in abuse and overconsumption of alcohol. The impact of gender-based violence in the home is detrimental to the child's well being. There is a logical assumption that having a disabled child would add to the caregiving load.

The inference of whether drinking preceded caregiving or vice versa is not possible as it was a cross-sectional study. Only 42/1434 (3.2%) were "High-Risk drinkers" as defined by the AUDIT; this is very low compared to the national prevalence of 9%⁵³ – could be due to bias. The study was unrepresentative of the source population. Data collection was open to self-report bias, due to the stigma of shame associated with alcohol abuse in front of a young child; resulting in under-reporting. Interviews took place with only the child's primary caregiver; this biases the results as alcohol abuse in the household profoundly affects the child. Due to selection bias, the impact of household alcohol abuse is not possible.

1.5.3. Transition in gender and age of heads of households

Traditionally women take on the role of caregiver, due to gender normative ideals and cultural views⁵⁴. Post-apartheid has seen a "feminisation" of poverty⁵⁵. The average annual household income for South Africa in 2011 was R103 204. On average male-headed households earned well above this at R128 329, and due to the gender gap, this was nearly double the average for female-headed households (R67 330)¹⁴. Gender disparity has increased to 47.5% from 37.5% in 2008⁵⁶.

The labour force proportion by gender has remained relatively equal from 2011 to 2017, with women (45.3/100) versus men (54.7/100) only having a 9.4% difference in 2017^{14,57}. Even though unemployment rates were also similar between the genders (women: 29.8% to men: 26.0%), women are more likely to live below the poverty line⁵⁷. Women experience greater severity and depth of poverty compared to males^{16,44}.

Rogan used data from the 1993 project for statistics on living standards and development (PSLSD) – approximately 9000 households; and the 2008 National Income Dynamics Study (NIDS: 2008)⁵⁵.

He found that female-headed households are significantly more vulnerable to income poverty than male-headed; 9.4% to 6.8% respectively⁵⁵. Impoverished women depend on the child support grant to supplement their income to afford primary resources for their dependants⁵⁵. Social protection alone cannot close the continuously expanding gender gap.

In recent years, the postponement of the culturally acceptable age at which women bear children and improvements in medicine has resulted in an older generation of parents than previously seen¹⁴. The older generation experiences more severe poverty than the younger generation – as they tend to have less material and social resources⁵⁸. In 2015, – those older than forty-five years old – had a depth of poverty rate of between 16.3% to 18.8% and severity of poverty SAMPI score range of 2.6 to 2.9⁴⁴. Older adults were more likely to be closer to extreme and severe poverty than their younger counterparts⁴⁴. More grandparents act as the primary caregiver in the absence of the children's parents – especially in rural and impoverished areas, either due to the HIV/AIDS epidemic or job availability in the region. The HIV/AIDS epidemic has resulted in an increase in mortality in the younger generation, particularly the working age. This disease orphans many children who then have to be primarily cared for by their grandparents. The loss of this young generation has far-reaching economic consequences⁵⁴. After sixty-five years of age, chronic illness, forgetfulness, confusion, and physical stamina decline are more likely. The increased age of these heads of households translates to an uncertain financial future for their household, as there is no scope for the VI child's provisions if they are no longer able to provide for them. There is a need for adequate support structures to help these grandparents transition to the primary caregiver, especially in impoverished settings⁵⁹. All caregivers experience high levels of psychological and financial strain, especially elderly individuals⁶⁰. These elderly caregivers must fulfil the role usually held by younger adults with the energy levels, material and social resources, and longevity to cope.

1.6. Quantification of Caregiver Strain

There are numerous tools available today to measure the strain experienced by an individual. Examples of these tools are the Structured Clinical Interview for *DSM-IV* Axis I Disorders (SCID-I)²⁸ and the 9-item Patient Health Questionnaire (PHQ-9)⁶¹. However, these tests are not specific to the unique situation of the caregivers. It was Grad and Sainsbury (1963) who introduced the measurement of caregiver strain^{37,62}. The discovery of the two components of caregiver strain, objective and subjective strain, further advanced the field of caregiver strain⁶³. These components allowed different causes of caregiver strain to be quantified. Objective caregiver strain indicates the impact that observable negative aspects of caring for the child the parent/guardian and home caregiver experience. Subjective caregiver strain indicates the caregiver's feelings associated with

the subjective-related aspects^{63–66}. A family can simultaneously experience a high objective strain and a low subjective strain or vice versa⁶⁴. When more family members assist the primary caregiver, they have a lower objective strain; and a higher objective strain when the care receiver requires more attention⁶⁴. Objective and subjective strain have different causes, and therefore, different interventions are needed.

Messer and colleagues created the Child and Adolescent Burden Assessment (CABA) in 1996⁶⁷; sourcing caregivers from other more extensive studies namely: The Great Smoky Mountain Study⁶⁸ (1015); Assessing Coordinated Care study⁶⁹ (121) and; the Child and Adolescent Psychiatric Assessment⁶⁷ (19). The assessment tool included objective and subjective strain measurements.

Miyashita and colleagues developed the (BIC) in Mie Prefecture, Japan, for research into the care burden experienced by caregivers of patients with neurological conditions⁷⁰. The study sourced 1909 family caregivers of patients in a neurological disease registry (1577) and those treated for cerebrovascular accidents at the Brain Attack Center Oota Memorial Hospital (322). Prospective participants answered the questionnaires by mail, and 52.6% (1005/1909) responded. Due to incomplete data, the statistical analysis took place on only 646/1909 (33.8%) questionnaires⁷⁰. Questions in the BIC relied on the caregivers to identify areas of burden in their lives, for example, self-rating their distress to caregiving.

The CGSQ initially measured the strain of caring for an emotionally disturbed child on their caregiver by analysing data collected based on the previous six months; 984 families were recruited from the Fort Bragg Evaluation Project (FBEP) to validate it⁶⁵. The caregivers in the study were primarily mothers (85%). The CGSQ survey consists of 21 questions addressing disruption of family and social life, time constraints, adverse mental and physical health effects, financial strain, anxiety, embarrassment and the child-caregiver relationship. Exploratory factor analysis (EFA), correlational analyses and nested model comparison using confirmatory factor analysis validated the CGSQ⁶⁵. The EFA ascertained if the survey measured both objective and subjective strain. Correlational analyses compared the data, collected at the same data point, from the CGSQ with the two other instruments: the Family Assessment Device (FAD) and the Brief Symptom Inventory (BSI). The FAD measured how well a family communicated, solved problems and functioned as a unit. The BSI measured caregiver stress in the past seven days not necessarily due to the child's issues through a 53 symptom checklist. Nested model comparisons confirmed the measurement of components of caregiver strain identified in the EFA. The study identified that subjective strain consists of internalised and externalised strain. Subjective internalised caregiver strain pertains to the

caregiver's feelings due to the observable burden, and subjective externalised caregiver strain refers to the caregiver's negative feelings towards the child⁶⁵.

The Caregiver Strain Questionnaire-Short Form (CGSQ-SF) is a condensed version of the CGSQ.⁶⁶ A survey consisting of 10 questions measuring caregiver strain in the previous month was a more concise and focused version of its predecessor, allowing quicker reporting⁶⁶. Caregiver strain as a whole, objective strain and subjective internalised caregiver strain, are measured. The omission of subjective externalised caregiver strain was due to relatively weaker internal consistency and questionable predictive validity⁶⁶. The Cronbach's alpha values are satisfactory: total score equals 0.9; objective caregiver strain equals 0.88 and; subjective internalised strain equals 0.82⁶⁶. The questionnaire had a positive skewness, due to more values on the left-side and outliers being on the right. The 2007 Manual of the Peabody treatment progress battery⁶⁶ identified the subjective internalised strain question on feelings of guilt to be problematic. The reliable chance index found that with a 75% confidence level, a difference of more than 0.51 points for the total score, 0.58 points for the objective strain, and 0.80 for the subjective internalised strain is not due to chance. Benefits of the CGSQ-SF are that it is quick; instead of relying on the caregivers to identify themselves as stressed, the answers in its subsets and its entirety, quantify caregiver strain; and it uses simple, concise questions.

Comparison of implementation of the various tools to measure strain in different settings should be made with caution, as they tend to neglect the importance of cultural-sensitive influences.

1.7. Treatment options for caregiver strain

In the caregiver's daily life support systems need to be established or reinforced. The caregiver should voice feelings or concerns for the child in a safe, non-judgemental space to lower caregiver strain. Pre-existing medical conditions and a lack of support predispose individuals to strain irrespective of the level of care required by the care receiver²⁸. Increased knowledge of what makes a caregiver more susceptible to being overwhelmed will aid professionals and families in decision-making concerning the care provided⁶⁴. Khooshab and colleagues studied the impact of Life Skills Training (LST) on parenting stress⁷¹. Their non-blinded randomized control study analysed the parenting stress of 52 Iranian mothers of blind seven to twelve-year-old children attending the only school for the blind in Shiraz. Baseline readings, using the Parenting Stress Index Full Form (PSI-FF) for both the case and the control group, showed high parenting stress levels. The training of the case group consisted of five two-hour sessions over five consecutive weeks. The sessions focused on: self-awareness; emotional coping strategies; identifying stress and coping with it;

problem-solving and decision-making; empathy and interpersonal relationship skills⁷¹. At the end of the five weeks, the case group had significantly lower parenting stress levels ($p < 0.001$), the control had no significant changes. After the study, the control group gained access to the LST program through one lecturing session and educational books and CDs⁷¹.

Support groups may be beneficial to households with a disabled individual as they can better understand the disorder suffered by the impaired individual, possibly improving their relationship^{72,73}. Mutual support groups consist of families with children with disabilities who create an environment in which they can share struggles without fear of judgment. Parents of disabled children can feel stigmatised, alone, isolated and guilty; mutual support groups allow them to be in an environment where they feel accepted and understood by individuals who can empathize⁷²⁻⁷⁴. Regular participation in the mutual support group can help build self-esteem and confidence and decrease self-blame and guilt. Sharing their struggles in a positive space alters their view of their disabled child resulting in an improved relationship with their child due to better knowledge and acceptance of their disability. Mutual support groups also present opportunities for a socially-enriched life and recovery of some normalcy and a chance to revel in their positive experiences such as any achievements and progress their disabled child has made⁷²⁻⁷⁴. Spiritual support and community disability organisations can help maintain a social network and provide strength and solace when caregivers and households encounter obstacles^{75,76}.

Another option to alleviate caregiver strain is respite care using a short-term service such as a care centre. It allows the caregiver some time to him/ herself. Still, the benefits are short-lived as the underlying factor of lack of social integration is not tackled to provide a long-term benefit to ensure that the caregiver maintains a support system while caring for the individual^{77,78}. It may also increase stress as there can be anxiety about the quality of care given by the respite caregiver and the stigma of needing a break from caring for the child⁷⁸.

1.8. Overview of thesis

In summary, the study of caregiver strain from an epidemiology viewpoint would help identify causal and exacerbating factors and recommendations for awareness campaigns. The remainder of this thesis will detail the aim of this study (Chapter 2), recount the methodology utilised (Chapter 3), report the findings (Chapter 4), as well as analyse the data and make recommendations for future research (Chapter 5).

Chapter 2: Research Aims

The previous chapter provided the foundation for this study. This chapter states the desired outcome of the cross-sectional investigation and the factors which may influence caregiver strain.

2.1. Background

VI children encounter educational and social development learning obstacles. Learners attending Special Educational Needs (LSEN) schools and specially-adapted mainstream schools attend to these barriers. With the help of educators and trained assisting staff, VI children are taught coping techniques and are prepared for adult life. In their home environment, VI children need individualised care to assist with ILS such as brushing teeth or preparing a sandwich.

In the Cape Metropole, there is only one government-funded school for the VI. The school also caters to the educational requirements of a few children who are intellectually impaired but are not VI. However, this does not result in any VI children being turned away for admission. All the school's learners from surrounding areas may live in the hostel on the school grounds. Trained caregivers assist hostel learners. The study's focus was the parents who preferred for their children to reside at home, as in these cases an untrained family member typically acts as the child's home caregiver. During the data-gathering it emerged that many of the VI children who reside at home did so because their caregivers could not afford the hostel fees. Thus the group residing at home permanently represent the poorer end of the income scale.

The home caregiver cares for the VI child as well as the rest of the household. The additional household responsibilities place a strain on the caregiver; who often is without relief.

The study aims to investigate the attributes and challenges related to the care of a VI child between nine and 19 years of age attending the only government-funded school for the VI in Cape Town to assess the magnitude of the problem and make recommendations for the better assistance of caregivers and members of the household.

2.2. Study area

The only government-funded school for VI children in the Cape Town metropolitan area is situated in Bellville and had 320 children enrolled in 2013. After accommodating all VI children,

enrolment of a few children with other special needs was allowed. In 2013, 150 children attended the school but did not reside in the school hostel. The school has grown slightly since then, with 350 children attending the school in January 2020; of which 150 children reside at home.

This study design comprises a cross-sectional survey of the entire population of nine to 19-year-old VI children from the school. All caregivers in the study resided in the Cape Metropolitan area and were the VI child's primary home caregiver. They opted not to have the VI child stay in the school hostel and were therefore directly responsible for the day-to-day home care of the VI children in this study. This hostel is available to students living in the Cape Metropole and surrounding areas at R350 per month. Families not utilising the hostel reported that it was due to the hostel's additional cost to the R250 per month school fees or "their child wanting to stay at home".

2.3. Aims and Objectives of the present study

2.3.1. Overall Aim

An investigation into the effects of caring for a VI child in the nine to 19-year-old age group – attending the school for VI children in Cape Town but residing at home – on the caregiver and other household members.

2.3.2. Objectives

- a) An assessment of the demographic characteristics of the caregiver and the household (e.g. age, gender, work status, size of the rest of the family, socio-economic characteristics, home help, blood relationship to the impaired child).
- b) An assessment of the particular attributes or needs associated with the VI child (demographics, school level, transport needed, particular health issues especially neurological issues and amount of health care needed, the primary source of care, learning disabilities, ILS).
- c) An assessment of the particular challenges the caregiver or needs he/she may have (psychological, social and physical needs, own health status, membership of formal or informal support groups).

- d) An assessment of the impact of the special care needed by such a child on the other household members – opportunity costs of the care, effect of time spent on the impaired child, supervision required.

Chapter 3: Methods

This chapter will describe the study design, study population, sampling and the construction of the self-designed questionnaire used in this study. It also includes a discussion of data management, data analysis, and ethical considerations.

3.1. Design of the study

The primary focus was the caregivers of the VI children who attended the school but resided at home. Selection of caregivers relied on the fact that they looked after a VI child attending the government-funded school for the VI at home. Participation was voluntary.

Following permission from the WCED, the school provided the contact information of parents of nine to 19-year-old VI children and appointments were then telephonically scheduled with potential caregivers. Initially, the study planned to interview the adult members of the household, but due to scheduling difficulties, I decided it would only be practicable to interview the caregiver. The information leaflet outlining the study's aims was given and explained to them during the appointments and any concerns addressed. If the caregivers were interested, they completed the consent form. Where necessary a translator accompanied me to explain the study in a language with which the participant was fluent.

In order to preserve anonymity, a sealed box with a postal slot stored the completed consent forms. The separation of the questionnaires and consent forms assured anonymity further. An anonymous questionnaire, translated into all three local languages, was used for gathering data. Completing the questionnaire was done in the caregiver's home with the principal investigator and translator's guidance if one was required. These appointments were not sound recorded. Caregivers could choose not to answer questions which caused them discomfort or end the interview at any time. A report of the information obtained from these questionnaires is in the results chapter.

This study utilised a cross-sectional survey administered by semi-structured face-to-face interviews with an interpreter's aid if one was required, in English, Afrikaans or Xhosa. A self-designed questionnaire was also completed (described under Research Tools below). The questionnaire responses consisted of shorthand to ensure quick data capturing. The survey's role was to determine the factors related to a VI child's home-based care and their direct and indirect effect on the caregiver.

3.1.1. Sampling

Selection of the caregivers from the government-funded school for the VI depended on the following inclusion criteria concerning the children:

1. The presence of visual impairment.
2. They were between nine and 19-years-old.
3. They resided at home during the school term.

Out of the 150 VI children residing at home, 95 were between nine and 19 years old. All the eligible caregivers agreed to a face-to-face appointment to find out more about the study; seventy-three chose to participate. The main reasons why caregivers' declined were that they were not fond of questions of a personal nature, or they did not have the time to do the interview. The study population as a whole were from previously disadvantaged backgrounds.

3.2. Research tools

The study used both quantitative and qualitative research methods to gather information on the caregiver strain. Quantitative research is commonly used in epidemiology, as it provides data which can easily be statistically analysed to measure relationships between multiple factors⁷⁹. In contrast, qualitative research aids the understanding of an under-examined problem and explores how a participant reacts to, perceives, and experiences an event⁷⁹. Qualitative information is specific to the study population and cannot be extrapolated⁸⁰.

The survey consisted of two sections: the self-designed questionnaire which provided demographic data of the caregivers and their households; and the CGSQ-SF which explored qualitative factors which possibly influence caregiver strain. The CGSQ-SF served as the measuring tool for qualitative factors of caregiver strain by exploring the caregiver's perspective on the impact of having a VI child on their life. Because strain is a complex issue, it is essential for both these research methods to be used together. Different socio-economic demographics have different experiences with caregiver strain, and solely focusing on quantitative factors disregards the importance of sociocultural-dependent issues (see the critical discussion by Bastawrous M⁸¹).

3.2.1. Self-designed questionnaire construction

The self-designed questionnaire was adapted from Thashlin Govender's Masters' thesis of 2012⁶⁰, with additions drawn from recurrent literature themes of the concerns when caring for disabled children^{1,4,5} and its impact on their families, especially the home caregiver. The questions included culture-dependent variables such as income, meals and support structure.

3.2.1.1. Aspects of the self-designed questionnaire

1. Household Health
2. Substance use
3. Household income
4. Social grants
5. Food security status
6. The diminished ILS and subsequent dependency of the VI child on his/her caregiver

3.2.2. Caregiver Strain Questionnaire – Short Form (CGSQ-SF)

The Caregiver Strain Questionnaire Short-Form (CGSQ-SF)^{65,66} self-scoring form is a validated research tool used to quantify the level of caregiver strain experienced and its components, objective and subjective internalised caregiver strain. The CGSQ-SF is standardised, which assumes that every culture experiences strain in the same manner.

3.2.2.1. Aspects of the CGSQ-SF

The form consisted of ten questions with the answer options ranging from “not at all” to “very much”. The first six questions covered the tangible negative aspects of caring for a VI child which quantified the objective caregiver strain. The four remaining questions regarded the caregiver's feelings towards their tasks quantified the subjective internalised strain⁶⁴. The combined objective and subjective strain scores calculated the overall caregiver strain.

3.3. Ethical aspects of the study

This study was approved on the 10th of June 2013 by the Health Research Ethics Committee (HREC) of the Faculty of Medicine and Health Sciences of Stellenbosch University. The study

followed the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. The ethics registration number for this study is S13/03/049. Permission was obtained from the Western Cape Education Department (WCED) to carry out the research and access the learners' contact details on 5th July 2013 (Reference 20130704-13796).

3.4. Data management and analysis

Data collected from the questionnaires were captured in a Microsoft Excel spreadsheet and transferred by a statistician at the Centre for Statistical Analysis at the University of Stellenbosch into Statistica version 13.0 (StaSoft Inc. 2013, USA) for further analyses. I entered the data, and the statistician verified them. The study supervisor and the statistician monitored data integrity during the investigation and reporting of the data.

I carried out basic statistical analyses. In contrast, more sophisticated statistical analyses of the data were selected and analysed by Professor M. Kidd of the Centre for Statistical Services at the University of Stellenbosch. The use of non-parametrical analyses compared the variables: Mann-Whitney U test calculations for two independent variables; and Kruskal-Wallis test calculations for more than two independent variables.

Chapter 4: Results

The previous chapter discussed the study's research methods. This chapter presents the results and their subsequent interpretation in the order of the self-designed questionnaire and CGSQ-SF. The possible relationships between the objectives as discussed in Chapter 2.3.2 and the CGSQ-SF scores are also presented.

4.1. Demographics of caregivers in the study

According to the inclusion criteria, only 95 of the 150 home caregivers were eligible. The study obtained consent from 73 caregivers (23% non-response). All 73 caregivers completed a self-designed questionnaire and the CGSQ-SF. All of the 73 caregivers were female, and the vast majority, 72 caregivers, reported that all the household members were South African citizens. One participant declined to comment on the nationality of members of her household. The children ranged from ten to 19 years old,

All of the caregivers were female home caregivers. The caregivers' ages ranged from 30 to 68 years old; 39/73 of the caregivers were between 30 and 49 years old. The study caregivers' median age was 39 years, with a mean age of 40 years (SD= 8.36) (Figure 1). The caregivers' relationship to the VI child was either mother (67/73, 91.7%) or grandmother (6/73, 8.3%). The six grandmothers were aged between 40 and 68 years old and unemployed.

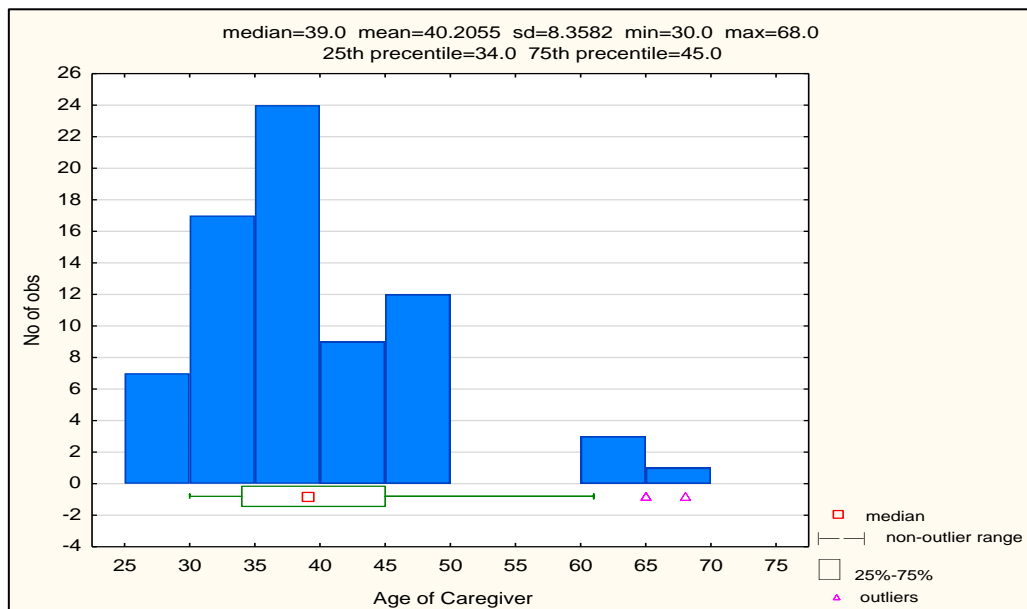


Figure 1: Age distribution of the caregivers

Of the 71 caregivers who reported their highest school grade completed, 38 had only primary school level education (Figure 2). It is important to note that 18/71 of the caregivers reported an educational standard of Grade 4 or below. Individuals with this education level might be functionally illiterate if they received no other training in reading⁸². None of the caregivers had a tertiary level of education.

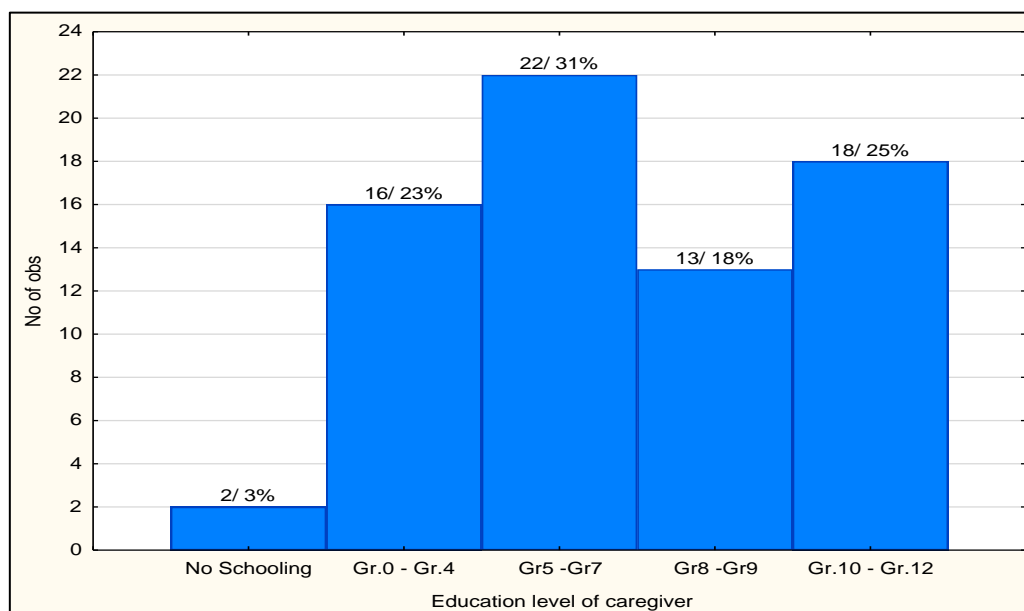


Figure 2: Educational status of the caregivers

Figure 3 illustrates that 75% of the main income contributors were younger than 45 years old, with two outliers in the 65 to 75-year-old age group. Table 4.1 presents the highest education level obtained for the main income contributors. One of the households had no adult income contributor, and 19 households declined to comment on the main income contributor's education level. The highest education standards for caregivers who were also the main income contributors were grade 8 or grade 9. The median age for main income contributors was 40 years old (Figure 3). In terms of education, 34.2% of the main income contributors had between Grade 10 and 12 education, and only one had a tertiary qualification (Table 4.1).

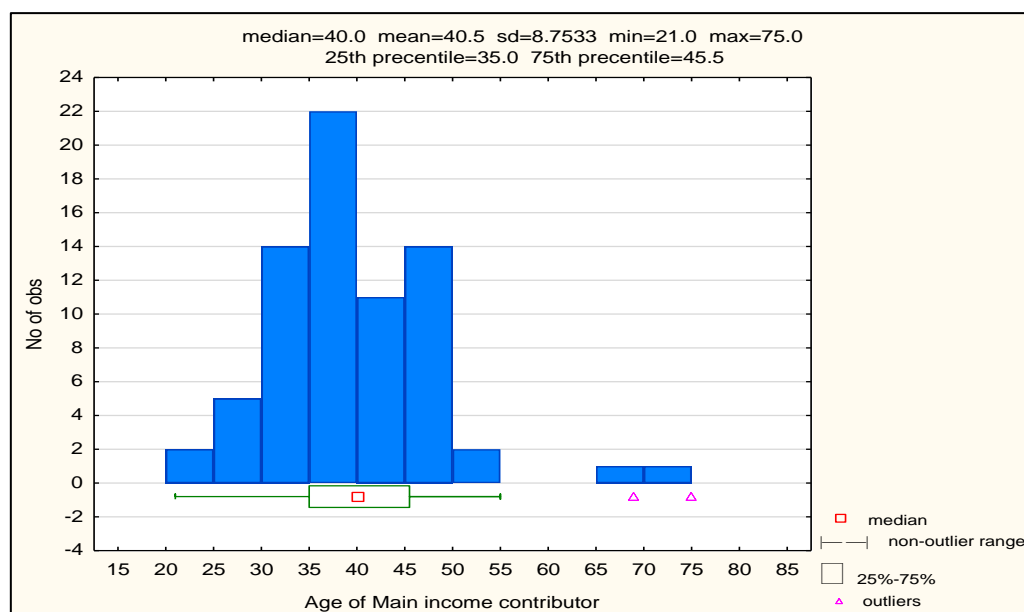


Figure 3: Age of main income contributor

Table 4.1: Education level of the main income contributors by Gender

Table 4.	Female-headed households		Male-headed households		Total	
	n	%	n	%	n	% of the study
No schooling	0	0.0	2	3.8	2	2.7
Grade 0-4	0	0.0	3	5.7	3	4.1
Grade 5-7	4	7.5	8	15.1	12	16.4
Grade 8-9	0	0.0	10	18.9	10	13.7
Grade 10-12	3	5.7	22	41.5	25	34.2
Tertiary level	0	0.0	1	1.9	1	1.4
Total	7	13.2	46	86.8	53	72.6

4.2. The financial status of the households in the study

The average monthly household income range of the study population is R1200 to R2499. Figure 4 illustrates the caregivers' total monthly income; 47/72 households earned more than R1200 per month. There were more male-headed (50/72) households than female (22/72) in the study. Those with a male main income contributor earned more. All female-headed households received a social grant, with 45 of the male-headed receiving a social grant.

The majority of the households (68/73) in the study received at least one social grant; 7/73 were reliant on these social grants as their sole income, including the household with a female VI child's social grant as the only contributor to the household income (Table 4.2). This household consisted of three members with no other children; the other adult was the VI child's unemployed older sister. Moderately sized households were typical in households where monthly income was between R1200 and R2499 (13/28; 46%) (Table 4.3).

Figure 5 shows that most of the main income contributors were employed full-time (44/72) and six households with adult income contributors were dependent on social grants.

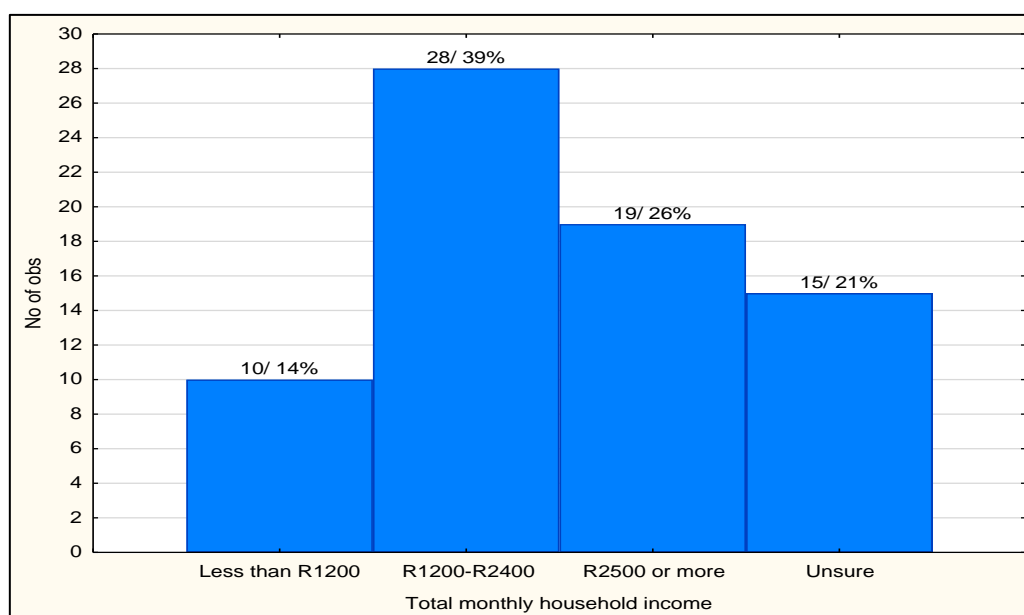


Figure 4: Total monthly household income

Table 4.2: Economic status of the caregivers' households

Characteristic	Female-headed households		Male-headed households		Total	
	n	%	n	%	N	% of study
	22	30.1	50	68.5	*73	100
Monthly Income						
Less than R1200	4	5.5	5	6.8	*10	13.7
R1200 - R2499	14	19.2	14	19.2	28	38.4
R2500 or more	1	1.4	18	24.7	19	26.0
Unsure	3	4.1	12	16.4	15	20.6
Social grants						
VI Child	22	30.1	45	61.6	67	91.8
Caregiver	7	9.6	4	5.5	11	15.1
Rest of household	5	6.8	5	6.8	10	13.7
Awaiting approval	1	1.4	0	0.0	1	1.4
Employment status						
Full time	7	9.6	37	50.7	44	60.3
Irregular	4	5.5	2	2.7	6	8.2
Part time	6	8.2	9	12.3	15	20.5
Social grants	5	6.8	1	1.4	6	8.2

* Including household where the only income is that of the female VI child's social grant

Table 4.3: Household size versus Monthly income

Household size	Monthly income		
	Less than R1200	R1200-R2499	R2500 or more
Less than 4	5	12	4
5-7	4	13	15
8-9	1	3	0

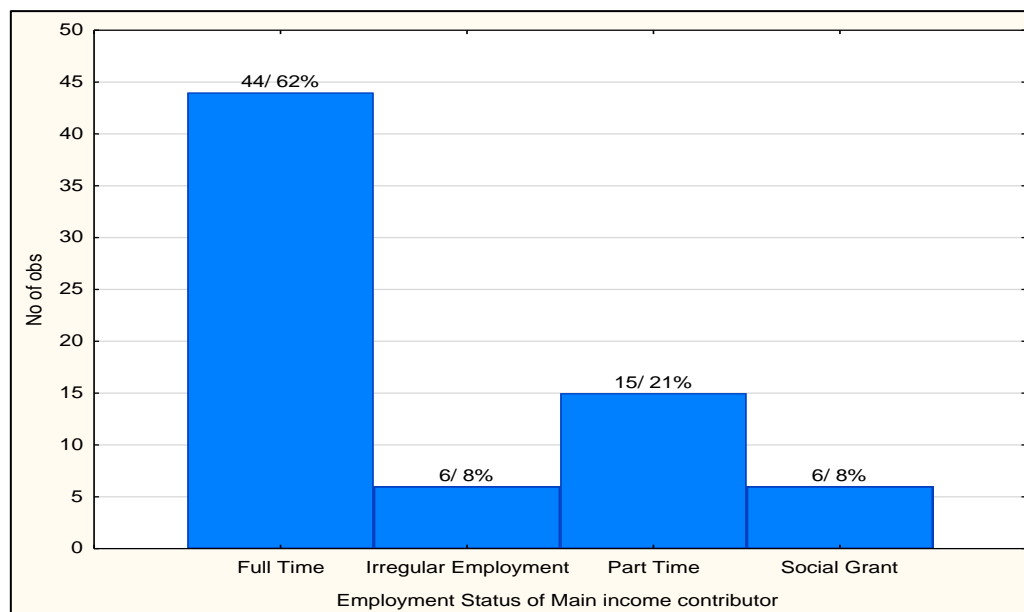


Figure 5: Employment status of main income contributor

Out of the study population, three households declined to answer whether they were receiving social grants or not. One participant stated that she had applied for a social grant for herself, and at the time of the interview was awaiting approval. She was also the irregularly employed main income contributor and was a “char” (domestic worker); her VI child’s disability grant also contributed to the household income.

Figure 6 shows that 50/73 of the caregivers were unemployed, and 23/73 were employed. Eight of the households had caregivers who were also the main income contributors. Food insecurity and the inability to afford transportation to healthcare or the child’s school evidenced that these households were financially constrained. Two out of three caregivers who were irregularly employed contributed to households with a total monthly income of less than R1200. Those employed fully (2/8) or part-time (3/8) were part of households earning between R1200 and R2499. Two households had an additional social grant recipient; none were the caregivers themselves.

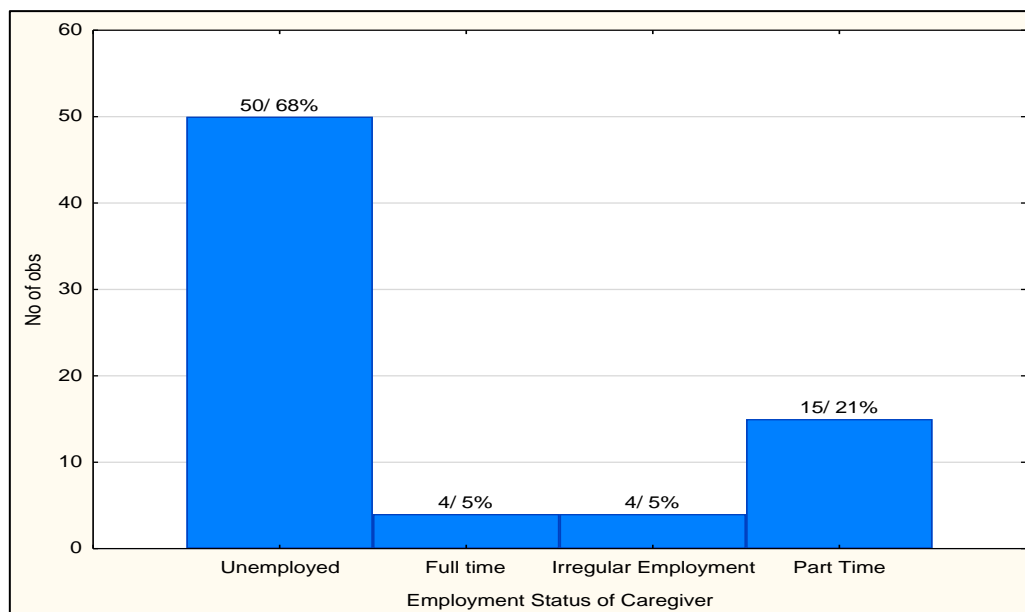


Figure 6: Employment status of Caregiver

4.3. Household composition in the study

The ages of the VI children ranged from ten years old to 19 years old (Figure 7). The median number of adults in the household was two (58.9%); only 9/73 households had the caregiver as the only adult, and the rest had three or more adults in the household (21/73; 28.8%). Only 5.5% (4/73) households had more than one family unit residing in the home. Households had between five and seven members (39/73) (Table 4.4), with only 24 households having no other children besides the VI child (Figure 8). Of these households, 17 had at least one other adult in the home, with their relationship to the VI child being one of the following: father, grandparent, sibling or uncle. The households with more than one child, generally only had one family unit (47/49; 95.9%). Female-headed households tended towards smaller households (18/22; 82%), whereas 70% of male-headed households had moderately sized households (35/50). Forty-nine households contained other children. The majority (36/49) of these households had more than one other child.

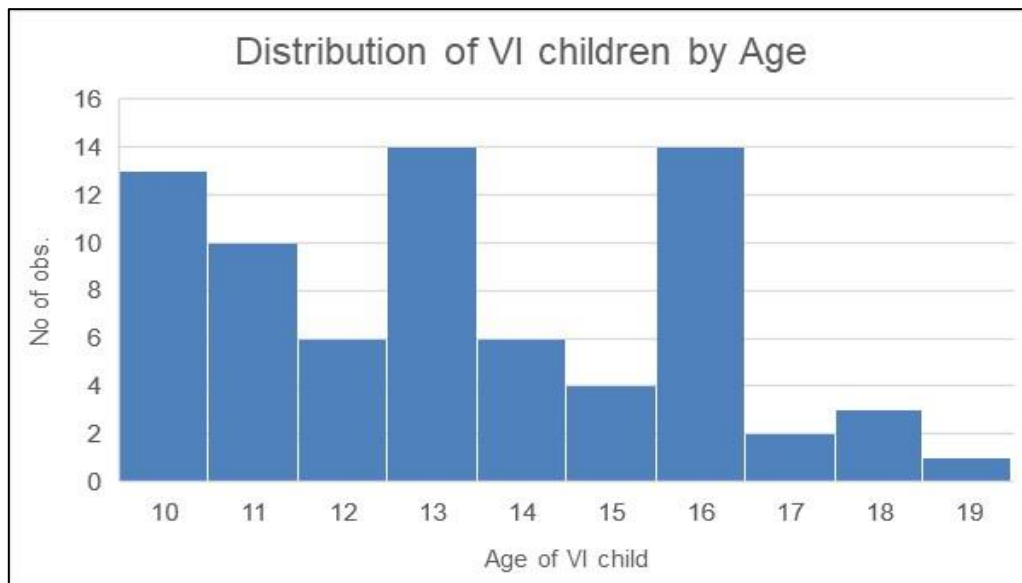


Figure 7: Age of the VI child

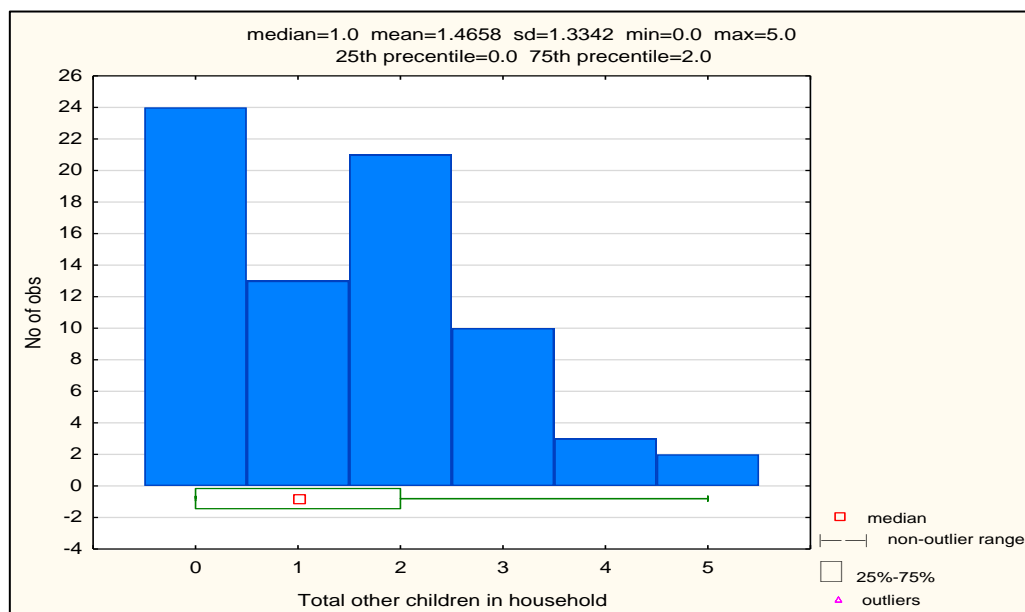


Figure 8: Total other children in the household

Table 4.4: Household composition in the study

Total members	n	%	Female-head	Male-head
Four members or less	29	39.7	18	10
5-7 members	39	53.4	4	35
8-9 members	5	6.8	0	5

4.4. The health of the caregivers' households

The caregivers' households used government-funded health care (59/64) or private doctors (6/64). One household utilised both types of services. Many of the caregivers reported that members of their household experienced illness symptoms in the two weeks before the interview, 51 households answered yes (Table 4.5). These households either treated the illness at home (21/51) or utilised professional health care (40/51) – private doctor or government day hospital. Ten households utilised both a home treatment and professional healthcare; this depended on the severity of the symptoms and how successful home treatment was. The study's caregivers utilised various transportation types to seek medical care at the local clinic or private practice. The majority (47/73) routinely walked, and in the case of an emergency, they called for an ambulance or used private transport. The cost of a return trip ranged from R10 and R19. Those who asked a neighbour for transport to the clinic during an emergency paid for petrol. Twenty-nine (29/73) households were unable to afford to visit medical care on occasion. The majority of caregivers were satisfied (65/70) with the service at their health centre.

Table 4.5: Symptoms experienced in the household

Symptoms experienced in the household	No. of households
Body and Hand sores	3
Boils	1
Coughing more than one week	12
Cramps / Abdominal Pain	10
Diarrhoea	14
Eye infection	13
Fever	8
Headaches	11
Itchy skin or rash	10
Lice / Nits	5
Loss of appetite and weight	2
Nausea	8
Night Sweats	3
Ringworm	1
Shortness of Breath	3
Tiredness and Weakness of the body	13
Vomiting	6

Seventy-one households answered questions related to infectious disease; 23/71 were unsure of their members' status.

Table 4.6 details the reported infectious and chronic health conditions in the household. Of the households undergoing treatment for infectious diseases, three were for tuberculosis (TB) and 45 were for HIV/AIDS. There were 18 caregivers with hypertension; four were elderly (60-68 years old) caregivers. Twenty-two households reported other disabilities or health concerns; 3/22 households did not specify the disability. One caregiver from a household undergoing treatment for TB reported having experienced both cramps and diarrhoea in the two weeks before the interview.

Table 4.6: Infectious disease and chronic conditions reported by the household

Characteristic	Number of households	% of study
Infectious disease		
TB	3	4.1
AIDS	45	61.6
Unsure	23	31.5
Caregiver's health		
Hypertension	18	24.7
Diabetes*	1	1.4
High Cholesterol*	1	1.4
The health of other members of the household		
Intellectual disability	4	5.5
ADHD	6	8.2
Cancer	1	1.4
Epilepsy	1	1.4
Asthma	5	6.8
Scabies	2	2.7
Bronchitis	1	1.4

* In addition to hypertension

Figure 9 illustrates the substances used in 70 households; all these households had at least one smoker. Three households were unsure whether any of their members were using any substance. Caregivers who doubled as the main income contributor (8/72) were all smokers aged between 30 and 40 years old; one also reported to consume alcohol.

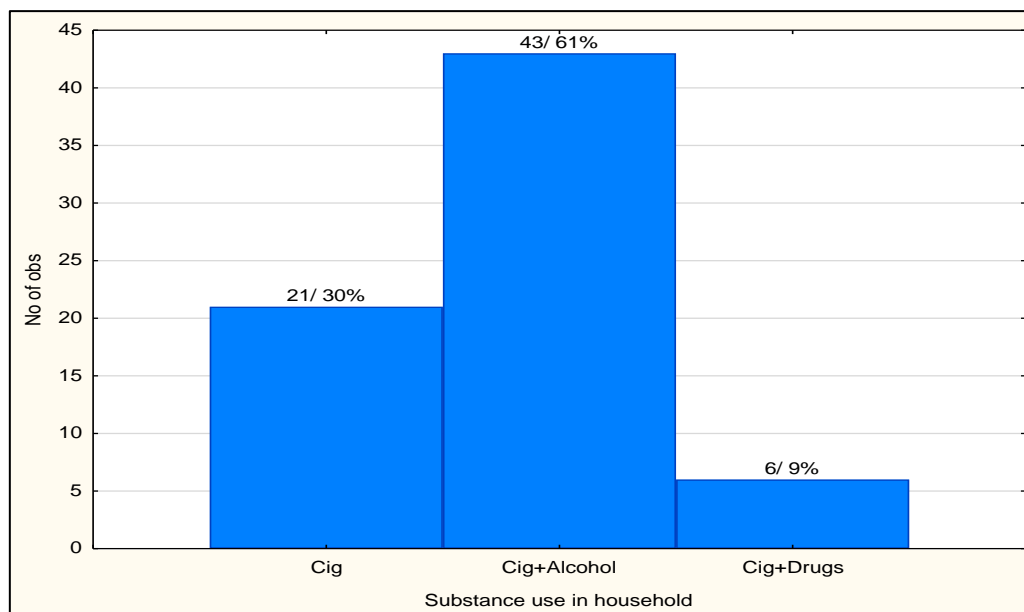


Figure 9: Substance use in the caregivers' households

4.5. Daily activities of the caregivers

The school provided transportation to school for all the students at a fee of R50 per week. However, parents paid what they could afford. Two caregivers opted to use private transport. Most of the caregivers paid between R20 and R39 per week for transport. Roughly half (39/73) of the caregivers kept their children at home when routine transport was missed, with 41/73 reporting that they had experienced an inability to afford transport to the school.

In addition to their caregiving duties, caregivers were also responsible for household duties, including ironing (63/73), laundry (61/73), meal preparation (58/73), and washing the dishes (54/73). Other tasks included shopping (3/73), sewing (2/73) and gardening (1/73).

4.6. Day-to-day living arrangements and care of the VI child

The caregivers commented on their households' meal frequency and whether they experienced a lack of food in the four weeks before the interview to determine if they had food security issues (Figure 10 and Figure 11). One participant was reluctant to comment on their household's status of food insecurity. Excluding the caregiver who declined to comment on food security, 50% (36/72) of those who commented did not experience food insecurity. Caregivers from households with a monthly income less than R2500 were more likely to be

severely food insecure indicated by the frequency of lack of food ten or more times in the past four weeks (23/72; 32%) (Table 4.7).

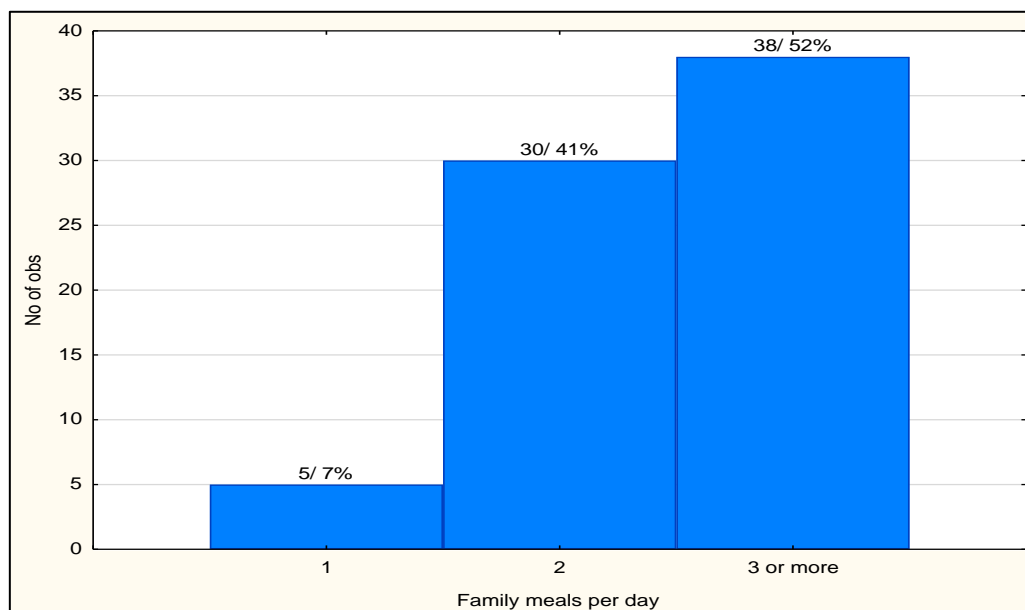


Figure 10: Frequency of family meals per day in the household

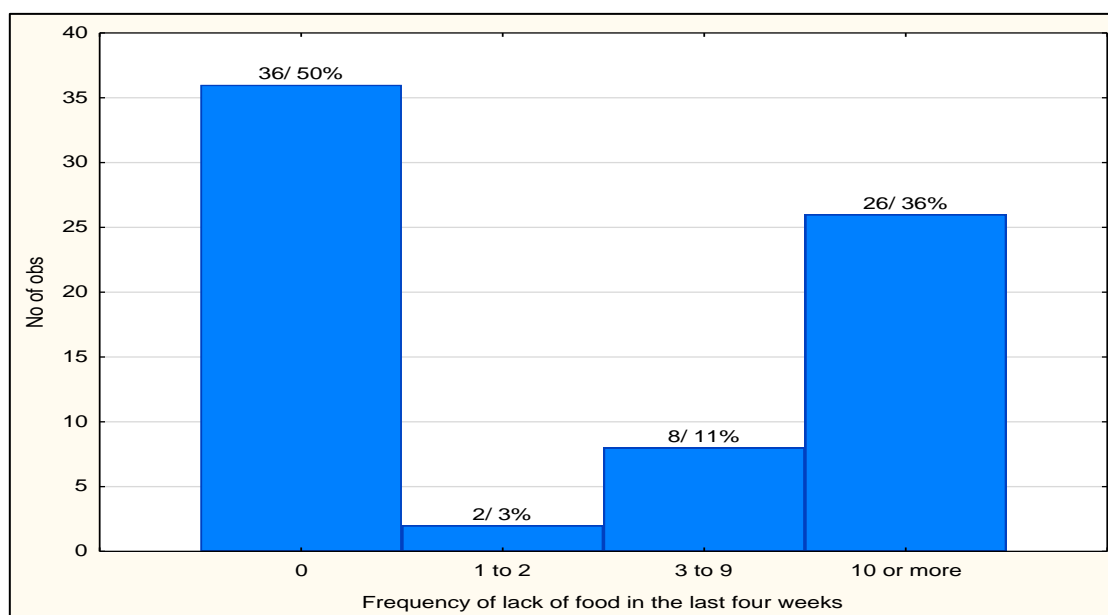


Figure 11: Frequency of lack of food

Table 4.7: Monthly income versus Food insecurity

Total monthly household income	Frequency of lack of food in the last four weeks				Total
	None	1 to 2	3 to 9	10 or more	
Less than R1200	2	0	1	7	10
R1200-R2499	5	2	5	16	28
R2500 or more	18	0	0	1	19
Unsure	11	0	2	2	15
Total	36	2	8	26	72

Most caregivers were unsure whether there were safe places to play in the house as there was no designated area solely for play. Adaptations to the house for the VI child were non-existent in most homes (62/73), as these parents did not feel their home needed adapting for their VI child, but rather their child needed to memorise the layout. The modifications 11/73 households made were as follows: safety gates at the front and back doors (6/11); ramps instead of stairs (6/11); railings inside the home and on the outdoor porches (9/11); or beepers at the door to alert when someone was entering or exiting (2/11).

All 73 of the caregivers reported that their VI child diagnosis was at birth. Eleven households reported that their VI child had an additional disability, three declined to specify. Of the remaining eight; five had attention deficit hyperactivity disorder (ADHD), one had fetal alcohol syndrome (FAS), one had epilepsy, and one had an intellectual disability of unknown cause. Five households had other members with a disability; one household had both an intellectually impaired male main income contributor and caregiver. Six members of the rest of the households had a disability, two of these were male main income contributors: one with an intellectual disability, and the other declined to specify. There were two instances where the VI children's siblings were diagnosed with FAS. Two of the caregivers were intellectually impaired, and one of them had ADHD. One VI child who did not have an additional disability was receiving treatment for cancer.

When asked how problematic it was to adapt their relationships with the rest of the household and their community to the child's disability requirements, 34/65 answered that it was a challenging experience (Figure 12). Eleven caregivers further commented on their adaptation

to their new reality. Caregivers turned to their faith, their community or experience to help them adjust. Caregiver number 3 commented that all their children were a 'gift from God' and that their household found strength in religion. Both parents had to face additional challenges in their lives as intellectually impaired individuals and how they parent their children. Caregiver 11 attributed how she adapted her relationships to the continued support of her community, for which she worked as a domestic worker in exchange for food or old clothes. Caregiver 15 said she took comfort in that she had experience raising a child with a disability, as her 15-year-old is intellectually impaired. Caregiver 39, who lived with her mother and has a 12-year-old son with FAS, stated that God 'would not give them more than they could handle'. Caregivers 19, 23, 28, 36, 42, and 44 were both the caregiver and main income contributor, they approached the situation as it being part of a divine plan and that everything would work itself out. Her community health workers emotionally supported Caregiver 30, who is HIV positive and has an HIV positive child.

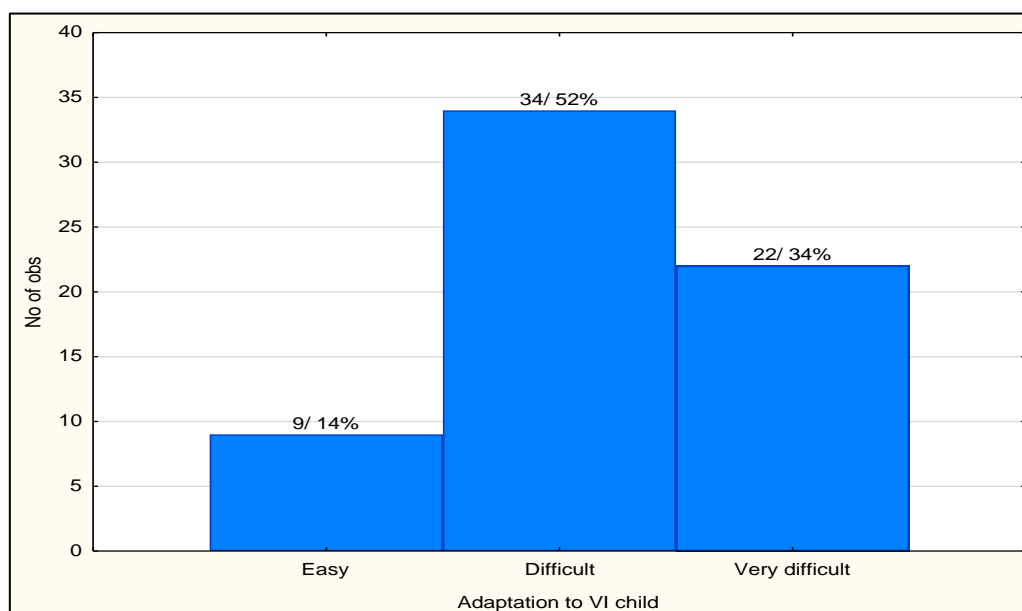


Figure 12: Adaptation to the VI child

Care requirements were not associated with the age of the VI child, but rather the required assistance. Frequency of assistance with specific tasks at home was similar across all the age groups (Table 4.8). Sixty-one caregivers had to assist their VI child with tasks: 26 had VI children aged between 10 and 12 years old, and 35 had VI children in the age range of 13 to 18 years. All of these children had difficulty with ILS. The tasks most of the children required assistance with were dressing, brushing their teeth and bathing.

Table 4.8: Tasks VI child needs assistance with

Task	Age of VI child			n	% of study
	10-12	13-15	16-19		
Applying toothpaste to a toothbrush	3	1	1	5	6.8
Brushing teeth	24	14	9	47	64.4
Running a bath	2	1	1	4	5.5
Bathing	23	13	10	46	63.0
Washing hair	3	0	0	3	4.1
Using the toilet	6	4	3	13	17.8
Taking out clothes	3	0	1	4	5.5
Dressing	25	19	10	54	74.0
Eating	8	2	0	10	13.7
Writing	2	4	3	9	12.3
Counting	3	0	0	3	4.1
Using the stairs	2	4	1	7	9.6
Moving around outside	3	2	2	7	9.6

Many of the caregivers (60/71) were reluctant to spend time away from their child (Figure 13). The availability of emergency respite from their support system was extremely likely (71/73). These individuals' relationship to the child was one of the following: Parent (6/71); Sibling (12/71); Aunt or uncle (15/71), Grandparent (18/71); or Family friend or neighbour (20/71). None of the caregivers met with a support group.

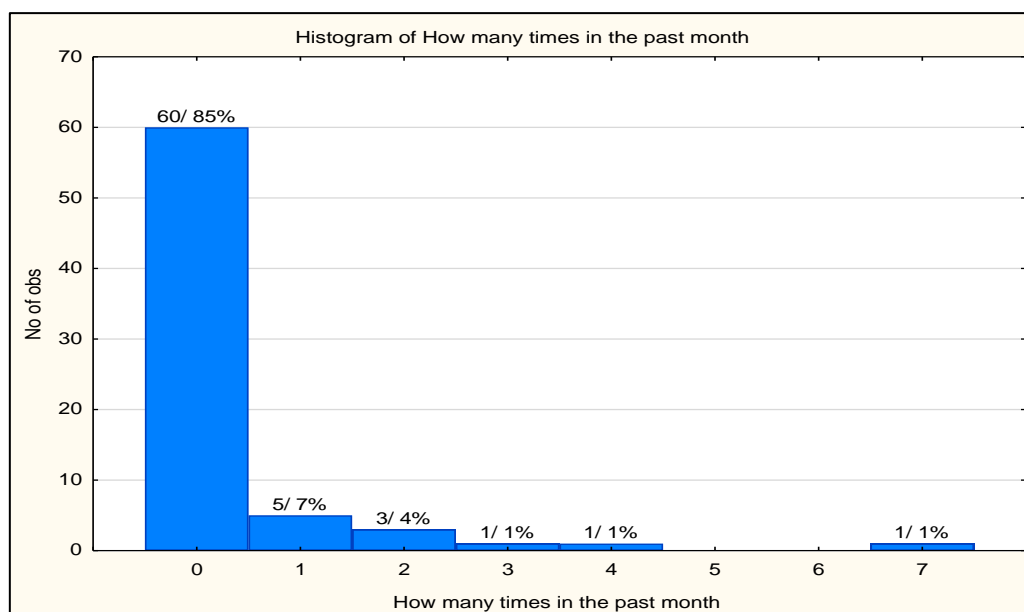


Figure 13: Time away from the VI child

4.7. CGSF-SF scores of the caregivers

The caregiver strain questionnaire – short form (CGSQ-SF) ascertained the observable and internal effects of caring for a VI child on the primary caregiver. Two sections comprised the CGSQ-SF, questions alluding to objective and subjective internalised caregiver strain, questions 1 to 6 and questions 7 to 10 respectively. The questions that indicate objective caregiver strain focused on the impact of the VI child's needs on the participant's time, finances, and household relationships. Caregivers reported the experiences of their household in the month leading up to the interview. The Cronbach's alpha values from the 2007 Manual of the Peabody treatment progress battery were, overall caregiver strain 0.90; objective caregiver strain 0.88 and subjective internalised caregiver strain 0.82.

According to the reliability analysis of my data, the objective strain had a Cronbach's alpha of 0.76 (Table 4.9), which is adequate, as stated in Khanna's validation of the CGSQ⁸³.

Table 4.9: Reliability analysis of Objective strain questions

Alpha and 95% CI calculated in R=0.76(0.65, 0.84) Summary for scale: Mean=14.3000 Std.Dv.=4.19575 Valid N:70 (Spreadsheet7 in Q Cronbach alpha: .761839 Standardized alpha: .769278 Average inter-item corr.: .374223						
variable	Mean if deleted	Var. if deleted	Stdv. if deleted	Itm-Totl Correl.	Squared Multp. R	Alpha if deleted
Interruption of personal time resulting from the child's problems?	10.93	12.81	3.58	0.47	0.50	0.74
You're missing work or neglecting other duties because of the child's problems?	11.83	12.54	3.54	0.57	0.69	0.71
Disruption of family routines due to the child's problems?	11.94	12.20	3.49	0.65	0.63	0.69
Any family member having to do without things because of the child's problems?	12.60	12.30	3.51	0.60	0.54	0.70
Financial strain for your family as a result of the child's problems?	12.39	12.32	3.51	0.44	0.44	0.75
Disruption or upset of relationships within the family due to the child's problems?	11.81	13.58	3.69	0.34	0.26	0.77

According to the reliability analysis, the subjective strain had a Cronbach's alpha of 0.48 (Table 4.10), this is lower than the objective strain questions alpha and is unsatisfactory. A reason for this could be that these questions refer to varying emotional states, between which the reliability test cannot distinguish.

Table 4.10: Reliability analysis of Subjective strain questions

Alpha and 95% CI calculated in R=0.48(0.28, 0.64) Summary for scale: Mean=14.6667 Std.Dv.=2.46096 Valid N:72 (Spreadsheet7 in Q Cronbach alpha: .482257 Standardized alpha: .510166 Average inter-item corr.: .216778						
variable	Mean if deleted	Var. if deleted	Stdv. if deleted	Itm-Totl Correl.	Squared Multp. R	Alpha if deleted
How sad or unhappy did you feel as a result of the child's problems?	10.39	3.85	1.96	0.33	0.33	0.36
How worried did feel about the child's future?	10.13	4.64	2.15	0.31	0.31	0.41
How guilty did you feel about the child's problems?	11.86	3.62	1.90	0.24	0.09	0.47
How tired or strained did you feel as a result of the child's problems?	11.63	3.65	1.91	0.29	0.11	0.41

According to the reliability analysis, the objective and subjective strain questions combined had a Cronbach's alpha of 0.63 (Table 4.11). The lower alpha value could be due to the addition of the subjective strain questions.

Table 4.11: Reliability analysis of the CGSQ-SF

Alpha and 95% CI calculated in R=0.63(0.40, 0.77) Summary for scale: Mean=6.02415 Std.Dv.=1.12623 Valid N:69 (Spreadsheet7 in Q Cronbach alpha: .629913 Standardized alpha: .634153 Average inter-item corr.: .464293						
variable	Mean if deleted	Var. if deleted	Stdv. if deleted	Itm-Totl Correl.	Squared Multp. R	Alpha if deleted
CGSQ-SF scale1	3.64	0.37	0.61	0.46	0.22	
CGSQ-SF scale2	2.38	0.49	0.70	0.46	0.22	

The caregivers' were asked: if their leisure time was interrupted, 37% (27/73) of the caregivers replied that it had been moderately; if caregiving affected their work and other duties, 49.3% (36/73) replied that it rarely did; if their family routines were disrupted, 45.2% (33/73) replied that it rarely did; if there were any significant opportunity costs associated with the child's disability, 53.4% (39/73) replied that that was not their experience; if the child's disability placed additional financial strain on the family, 47.9% (35/73) replied that was not their situation; and if the child's special needs negatively impacted familial relationships, 46.6% (34/73) replied that it did marginally.

Table 4.12: Reported answers to questions 1 to 6 from the CGSQ-SF

In the past month:									
Question 1: How much of a problem was an interruption of personal time resulting from the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
2	2.7	12	16.4	27	37.0	20	27.4	12	16.4
Question 2: How much of a problem was your missing work or neglecting other duties because of the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
7	9.6	36	49.3	20	27.4	5	6.8	4	5.5
Question 3: How much of a problem was the disruption of family routines due to the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
11	15.1	33	45.2	19	26.0	7	9.6	3	4.1
Question 4: How much of a problem did any family member have with doing without things because of the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
39	53.4	20	27.4	5	6.8	5	6.8	2	2.7
Question 5: How much of a problem was a financial strain for your family as a result of the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
35	47.9	19	26.0	9	12.3	5	6.8	5	6.8
Question 6: How much of a problem was disruption or upset of relationships within the family due to the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	n	%	n	%
10	13.7	34	46.6	14	19.1	12	16.4	3	4.1

The feelings the caregivers had concerning their VI child's needs, future, and how tired they were due to these needs were of interest in the questions related to subjective internalised strain. In the context of the feelings of the caregiver as a result of their child's special needs in the month before the interview they reported: how sad they felt, 52.1% (38/73) replied that they felt distraught; how worried they felt, 63% (46/73), replied they felt distressed; how guilty they felt, 35.6% (26/73) replied they rarely felt guilty; and how strained they felt, 35.6% (26/73) replied they rarely felt strained, but it is important to note that 25/73 (34.2%) reported moderate strain.

Table 4.13: Reported answers to questions 7 to 10 from the CGSQ-SF

In the past month:									
Question 7: How sad or unhappy did you feel as a result of the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	N	%	n	%
1	1.4	4	5.5	7	9.6	22	30.1	38	52.1
Question 8: How worried did feel about the child's future?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	N	%	n	%
0	0.0		0.00	7	9.6	20	27.4	46	63.0
Question 9: How guilty did you feel about the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	N	%	n	%
9	12.3	26	35.6	16	21.9	16	21.9	6	8.2
Question 10: How tired or strained did you feel as a result of the child's problems?									
Not at all		A Little		Somewhat		Quite a bit		Very Much	
n	%	n	%	n	%	N	%	n	%
1	1.4	26	35.6	25	34.2	10	13.7	11	15.1

The reported answers from the CGSQ-SF quantified the objective, subjective internalised and overall caregiver strain. According to the scoring form, each answer was assigned a value between one and five, with "Not at all" equalling one and "Very much" equalling five. Objective caregiver strain scores are sub-divided into Low (less than 1.5), Medium (1.5 – 3.0) and High (more than 3.0). Subjective internalised caregiver strain scores are sub-divided into Low (less than 2.0), Medium (2.0 – 4.0) and High (more than 4.0). Overall caregiver strain scores

are sub-divided into Low (less than 1.9), Medium (1.9 – 3.3) and High (more than 3.3). Table 4.14 presents the data on the caregivers' caregiver strain scores. The mean scores for overall and objective caregiver strain are 2.9 and 2.0 respectively; which classify as a medium strain for both. The mean score for the subjective strain was 3.5, which translates into a high subjective internalised strain. The high subjective internalised strain could indicate that the caregiver's emotional toll is significant enough to affect the caregiving burden. Roughly 75% of the caregivers scored medium for each category of caregiver strain; 49/73 and 50/73 had medium caregiver strain scores for overall caregiver strain in conjunction with a medium objective and subjective internalised caregiver strain scores respectively. Forty-six (46/73) scored a medium for both objective and subjective internalised caregiver strain simultaneously.

Table 4.14: Classification of study caregivers according to the CGSQ-SF

	Overall Caregiver Strain							
	Low		Medium		High		Total	
	N	%	n	%	n	%	n	%
	0	0.0	55	75.3	18	24.7	73	100
Objective caregiver strain								
Low	0	0.0	2	2.7	0	0.0	2	2.7
Medium	0	0.0	49	67.1	8	11.0	57	78.1
High	0	0.0	4	5.5	10	13.7	14	19.2
Subjective internalised caregiver strain								
Low	0	0.0	0	0.0	0	0.0	0	0.0
Medium	0	0.0	50	68.5	5	6.8	55	75.3
High	0	0.0	5	6.8	13	17.8	18	24.7

4.8. CGSQ-SF scores of self-designed questionnaire aspects

Comparisons between data obtained from the self-designed questionnaires and CGSQ-SF scores utilised the Mann-Whitney U test and Kruskal-Wallis test calculations.

There were no significant correlations with Overall Caregiver strain for the following factors:

Employment status of the caregiver ($p=0.30$); Infectious disease in the household ($p=0.37$); Financially unable to go to school ($p=0.12$); Social grants – Both VI child and Caregiver ($p=0.53$); Social grants received by another member of the household ($p=0.78$); Total monthly

household income ($p=0.17$); Family meals per day ($p=0.25$); Frequency of lack of food ($p=0.09$); Infectious diseases ($p=0.16$); Other health problems or disabilities ($p=0.92$); Substance use in the household ($p=0.19$); Total other children in the household ($p=0.50$); Safe places to play ($p=0.09$); Home adaptations ($p=0.09$); Helping VI child with brushing teeth ($p=0.21$); Helping VI child with eating ($p=0.09$); Helping VI child with writing ($p=0.86$); Helping VI child use stairs ($p=0.30$); Helping VI child with moving around outside ($p=0.85$); Food preparation ($p=0.65$); Washing the dishes ($p=0.74$); Cleaning ($p=0.32$); Laundry ($p=0.99$); Ironing ($p=0.86$); Child minding ($p=0.78$); and Time away from child ($p=0.06$).

There were no significant correlations with objective caregiver strain for the following factors: employment status of main income contributor ($p=0.08$); the employment status of caregiver ($p=0.51$); infectious diseases ($p=0.37$); other health problems or disabilities ($p=0.29$); social grants – both the VI child and caregiver ($p=0.85$); and total other children in the household ($p=0.86$).

There were no significant correlations with subjective internalised caregiver strain for the following factors: Employment status of the caregiver ($p=0.28$); Financially unable to go to the clinic ($p=0.40$); Financially unable to go to school ($p=0.48$); Family meals per day ($p=0.50$); Frequency of lack of food ($p=0.35$); Social grants – Both VI child and Caregiver ($p=0.27$); Social grants received by another member of the household ($p=0.78$); Total monthly household income ($p=0.81$); Total other children in the household ($p=0.35$); and Feelings of inability to leave their child ($p=0.37$).

There was a significant correlation between objective and subjective strain scores ($p<0.01$) (see Figure 14).

2.1 Spreadsheet101

Spreadsheet7 in Questionnaire Data.stw							
	1 variable 1	2 variable 2	3 Pearson	4 Pearson p-val	5 Spearman	6 Spearman p-val	7 # cases
1	Education level of caregiver	Objective strain	-0.30	0.01	-0.28	0.02	71
2	Household size	Objective strain	-0.06	0.63	-0.02	0.84	73
3	Total other children in household	Objective strain	0.11	0.35	0.16	0.18	73
4	Family meals per day	Objective strain	-0.20	0.09	-0.25	0.03	73
5	Frequency of lack of food in the last four weeks	Objective strain	0.23	0.05	0.26	0.03	72
6	Subjective strain	Objective strain	0.46	<0.01	0.48	<0.01	73

Figure 14: Objective strain versus Subjective strain

4.8.1. Household health

Figure 15 and Figure 16 illustrate that being financially unable to seek medical care increases the likelihood of a higher overall caregiver strain ($p=0.02$, Mann-Whitney U test) and objective caregiver strain scores ($p\leq 0.01$, Mann-Whitney U test) compared with those that were not.

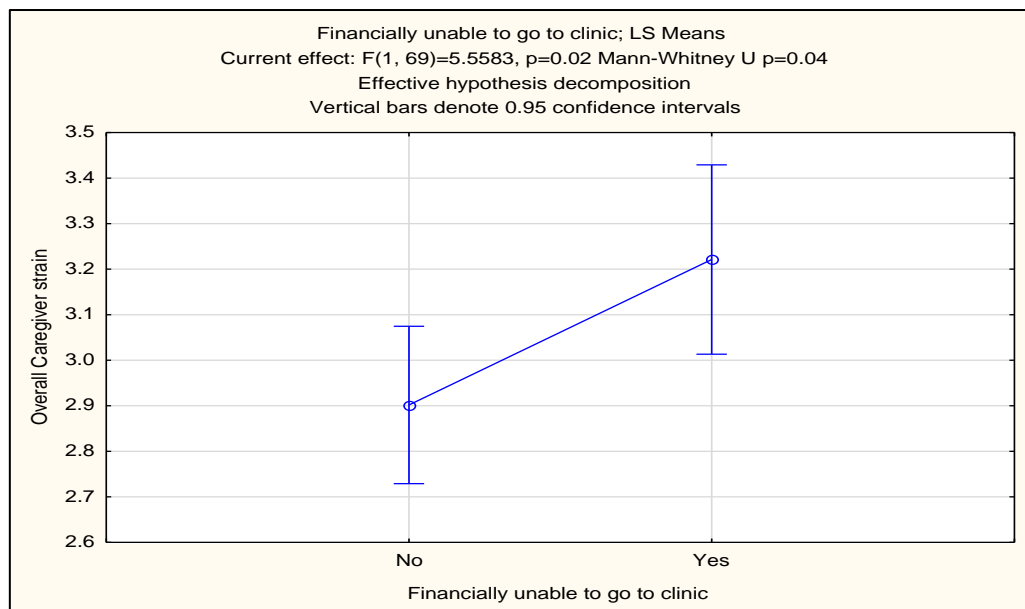


Figure 15: Financially unable to go to clinic versus Overall caregiver strain

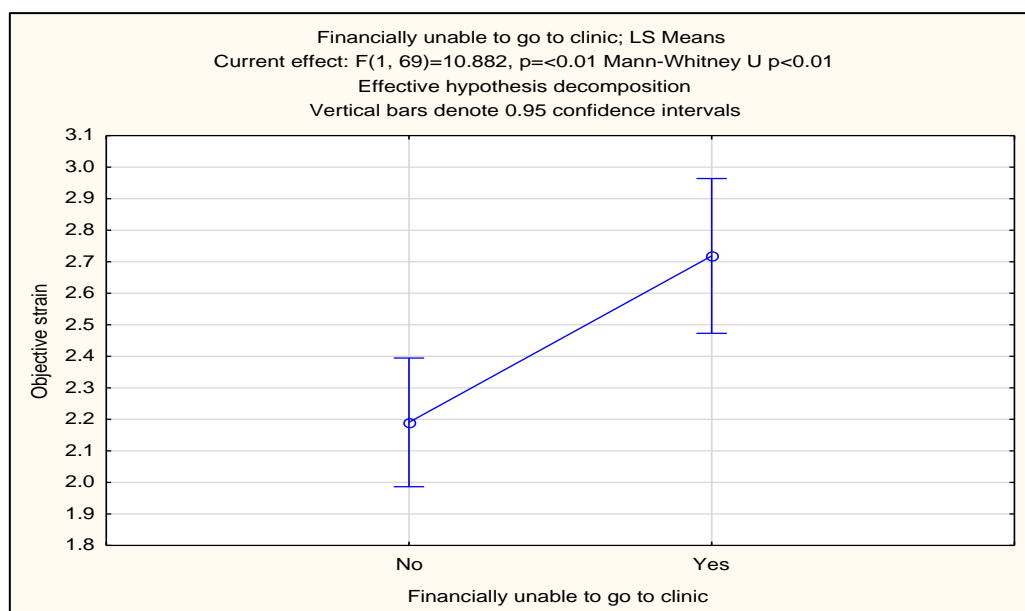


Figure 16: Financially unable to go to the clinic versus Objective caregiver strain

4.8.2. Transportation to school

Objective caregiver strain scores were higher in those unable to afford transport to the school than those who were able ($p=0.05$, Mann-Whitney U test) (Figure 17).

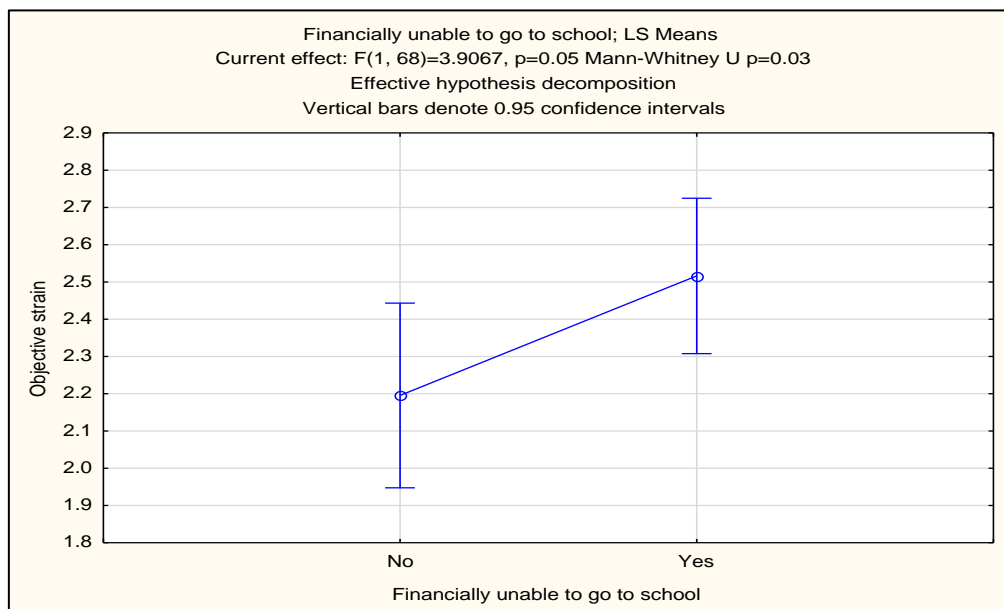


Figure 17: Financially unable to go to school versus Objective caregiver strain

4.8.3. Household income

Those that were employed full-time generally had caregivers with lower scores for overall caregiver strain ($p=0.02$, Kruskal-Wallis test), objective caregiver strain ($p=0.03$, Kruskal-Wallis) and subjective internalised strain ($p=0.03$ Kruskal-Wallis test). Caregivers from households with irregular employed main income contributors had the highest scores across the board (Figure 18 and Figure 19).

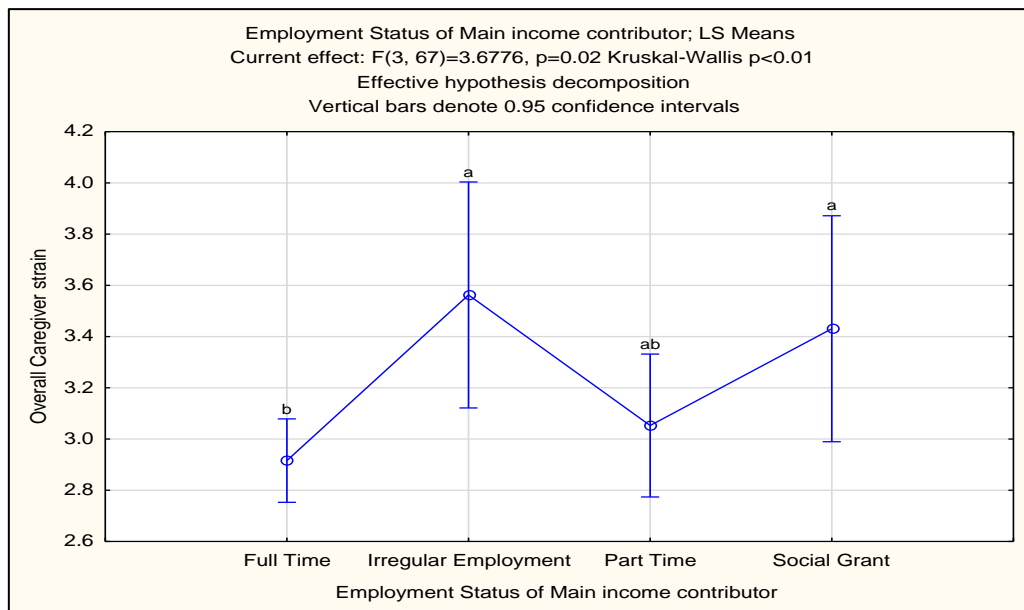


Figure 18: Employment status of Main income contributor versus Overall caregiver strain

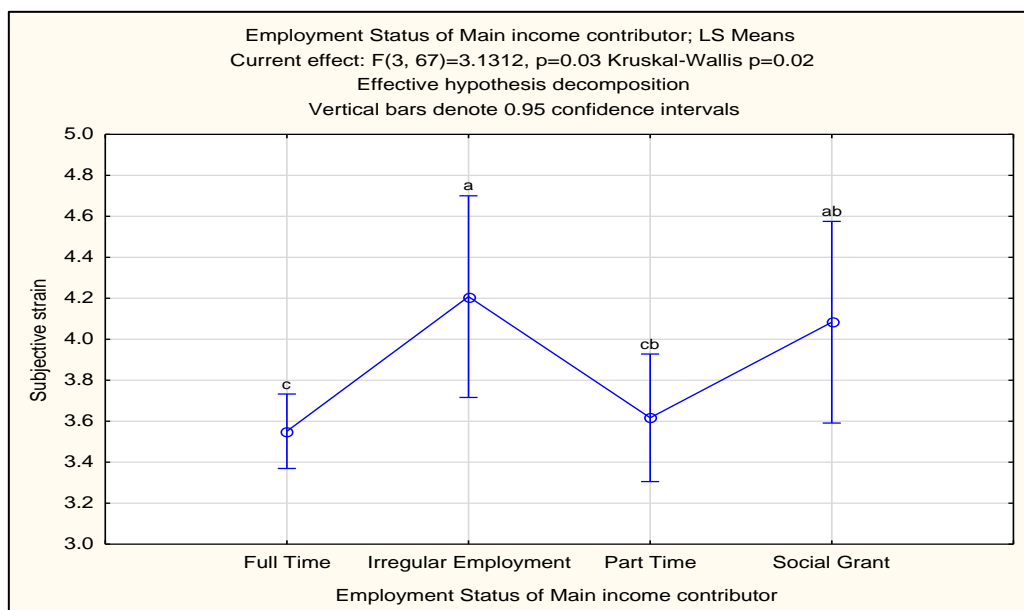


Figure 19: Employment status of Main income contributor versus Subjective internalised caregiver strain

Objective caregiver strain scores illustrated in Figure 20 shows a trend of caregivers from households with a lower monthly income having higher scores ($p=0.01$, Kruskal-Wallis test).

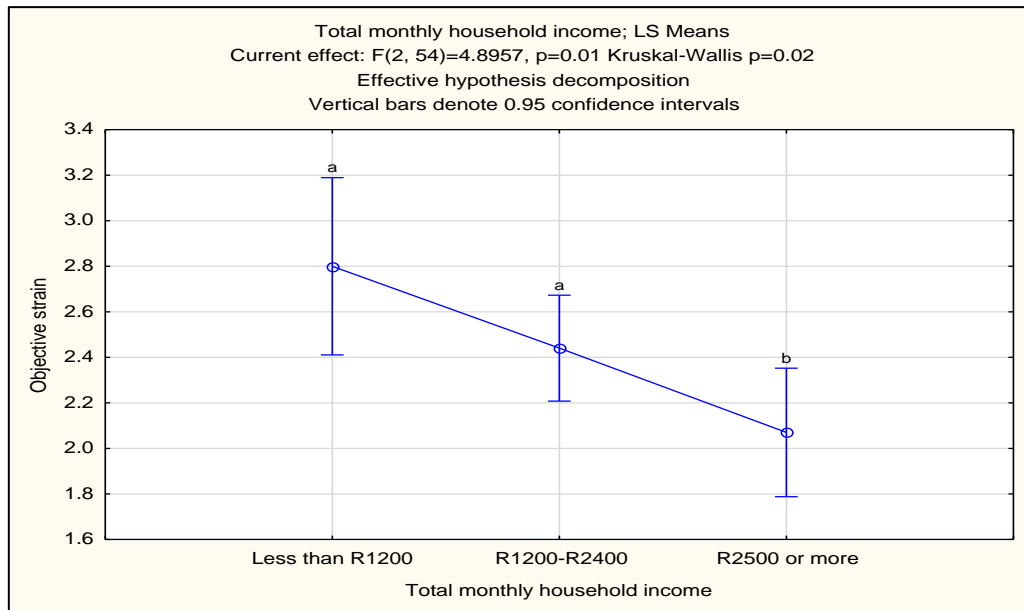


Figure 20: Total monthly household income versus Objective caregiver strain

4.8.4. Social grants

Households with other members receiving a social grant had caregivers with higher objective caregiver strain scores ($p \leq 0.01$, Mann-Whitney U test) (Figure 21).

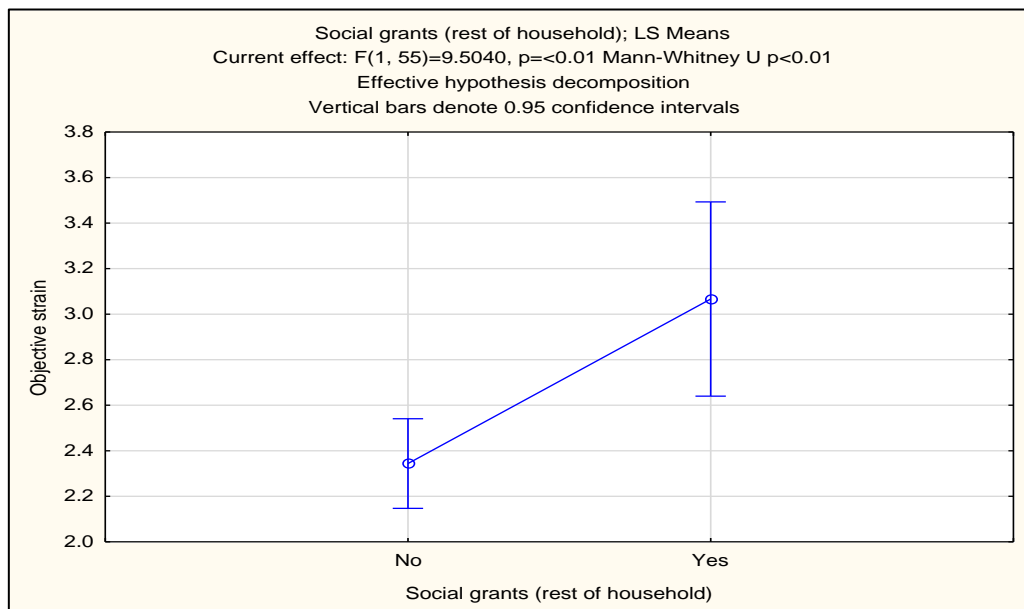


Figure 21: Social grants – Rest of the household versus Objective caregiver strain

4.8.5. Food security status

Mann Whitney U tests in Figure 22 and Figure 23 show that households that experienced a lack of food four weeks before the interview had higher scores for overall caregiver strain ($p=0.02$) and objective caregiver strain ($p\leq 0.01$) than that of those that had food.

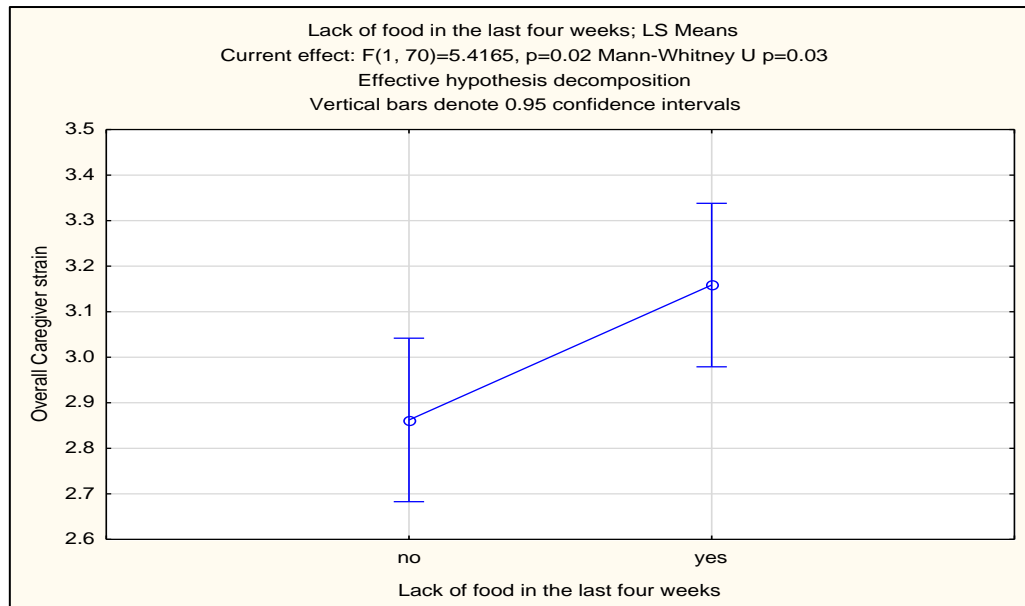


Figure 22: Lack of food versus Overall caregiver strain

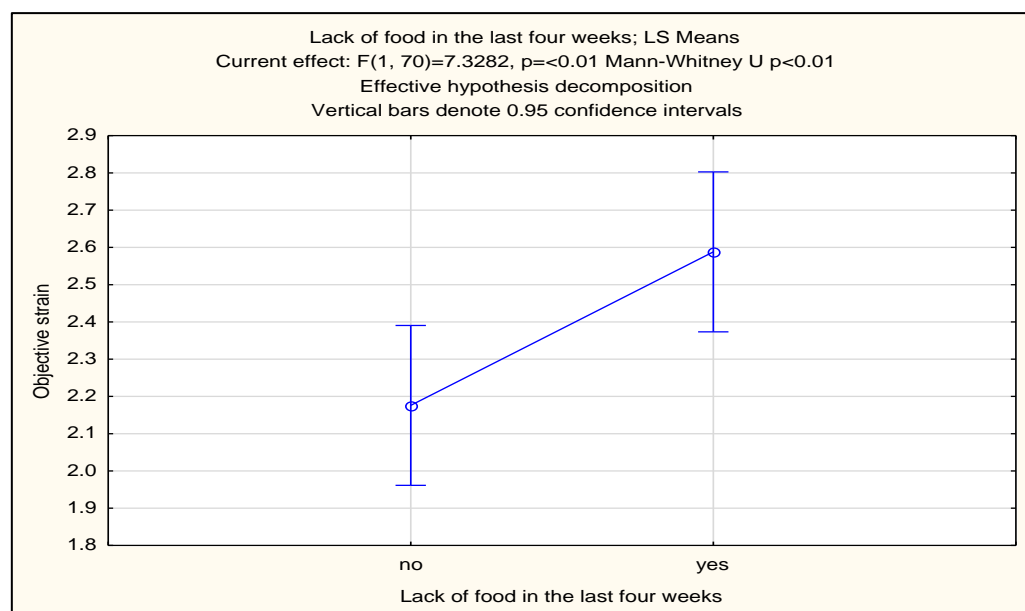


Figure 23: Frequency of lack of food versus Objective caregiver strain

4.8.6. The dependency of the VI child on the caregiver

There was no significant correlation between objective strain and the age of the VI child ($p=0.51$) (Table 4.15).

Table 4.15: Correlation between Objective strain and Age of VI child

1 correlations

Spreadsheet7 in Questionnaire Data.stw						
1	2	3	4	5	6	7
variable 1	variable 2	Pearson	Pearson p-val	Spearman	Spearman p-val	# cases
1 Objective strain	Age of VI child	-0.06	0.51	-0.07	0.56	73

Figure 24 and Figure 25 illustrate that scores for both overall caregiver strain ($p=0.05$, Mann Whitney U test) and objective caregiver strain ($p=0.03$, Mann Whitney U test) were lower where caregivers' felt that their VI child had a safe place to play. Figure 26 shows that those caregivers whose households had made home adaptations had lower subjective internalised strain scores than those who had not ($p=0.03$, Mann Whitney U test).

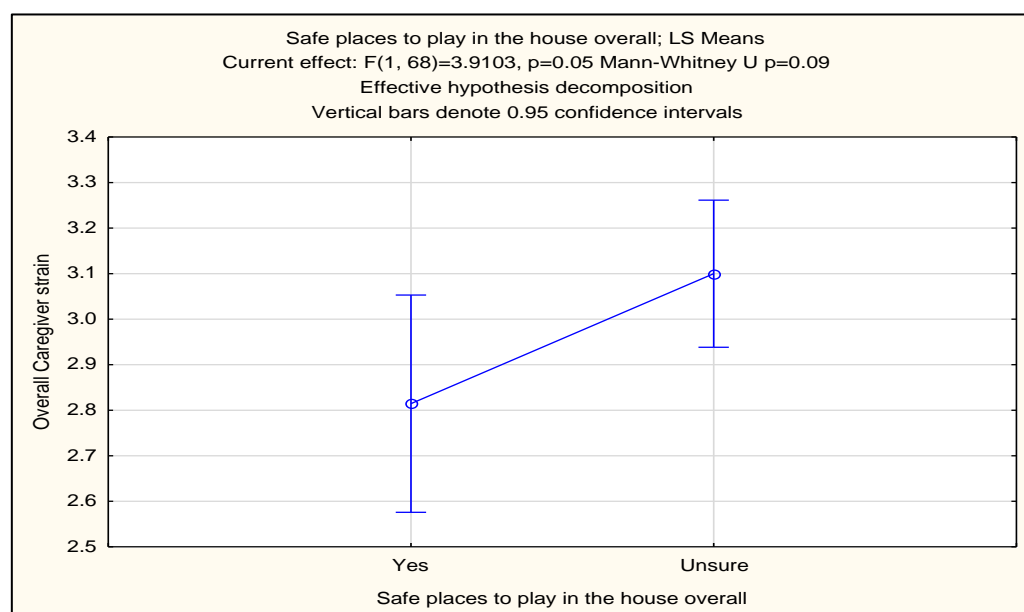


Figure 24: Safe places to play versus Overall caregiver strain

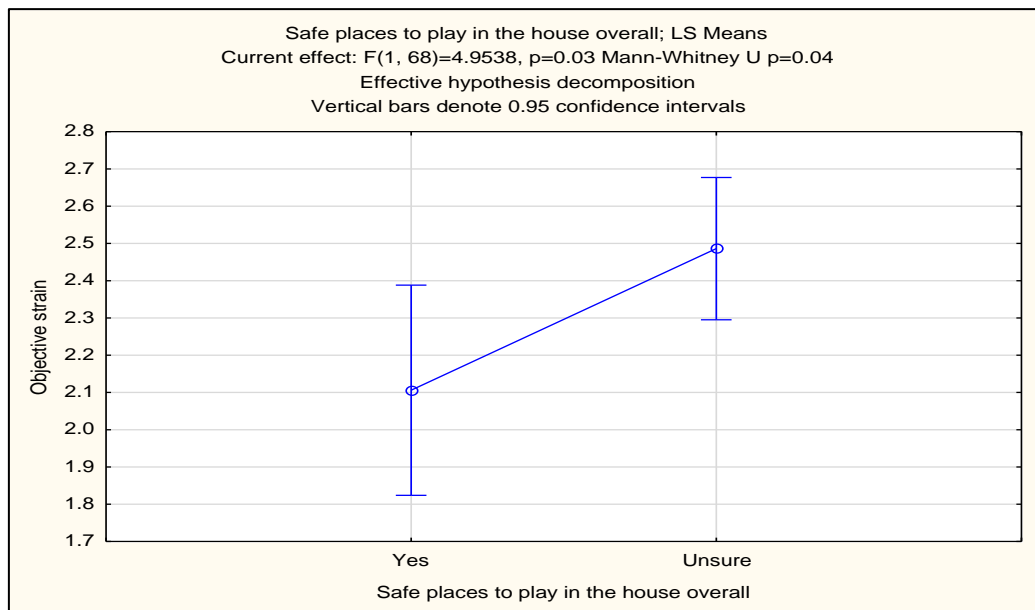


Figure 25: Safe places to play versus Objective caregiver strain

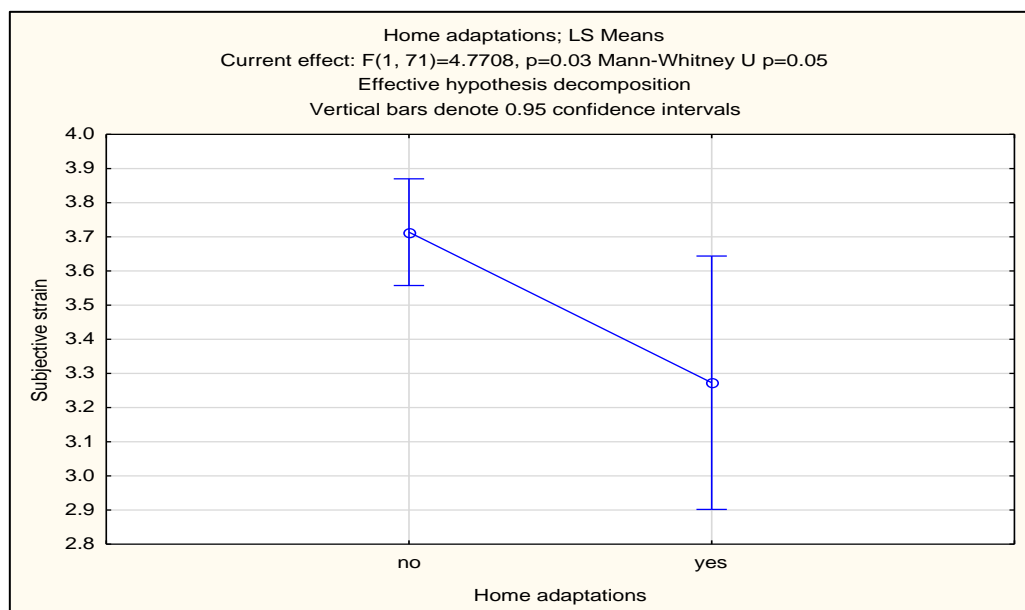


Figure 26: Home adaptations versus Subjective internalised caregiver strain

Figure 27 and Figure 28 illustrate that those who found the experience very difficult had higher scores for overall caregiver strain ($p=0.03$, Kruskal-Wallis test) and subjective internalised strain ($p=0.01$, Kruskal-Wallis test) than those that adapted with no trouble.

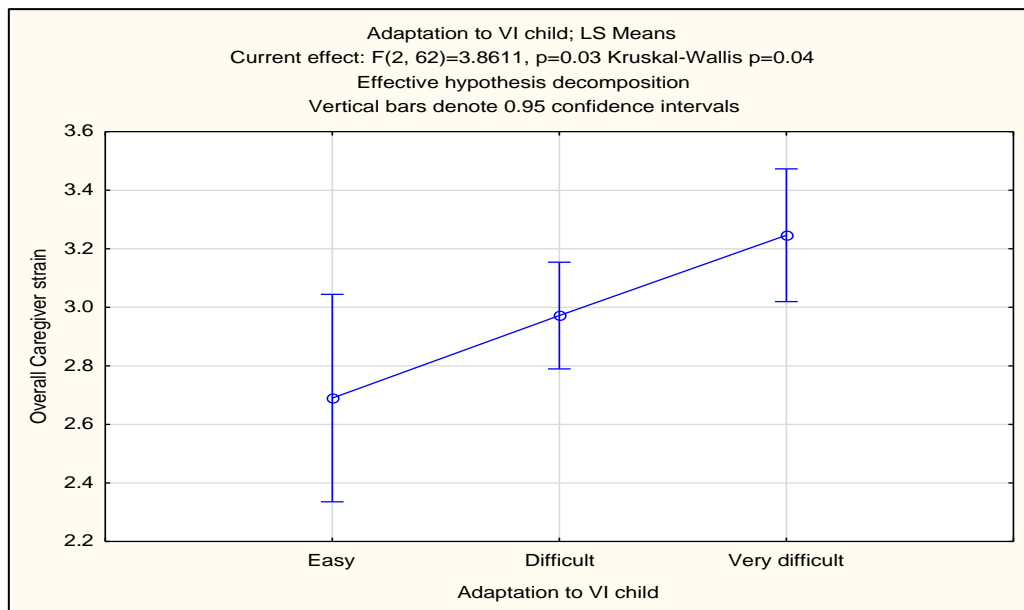


Figure 27: Adaptation to VI child versus Overall caregiver strain

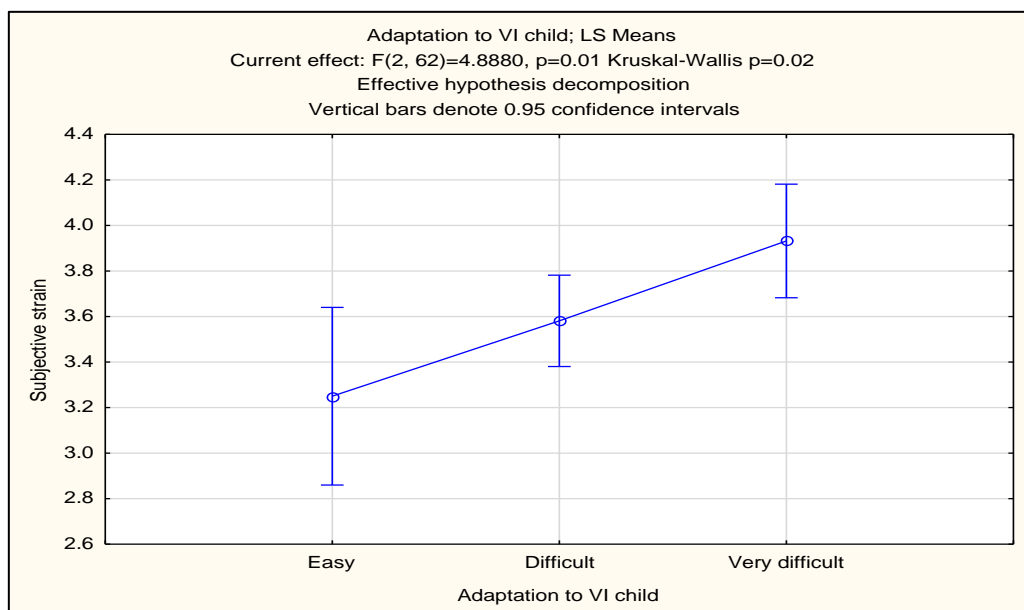


Figure 28: Adaptation to VI child versus Subjective internalised caregiver strain

Figure 29 shows that those who took a reprieve had lower objective caregiver strain scores ($p=0.01$, Mann Whitney U test).

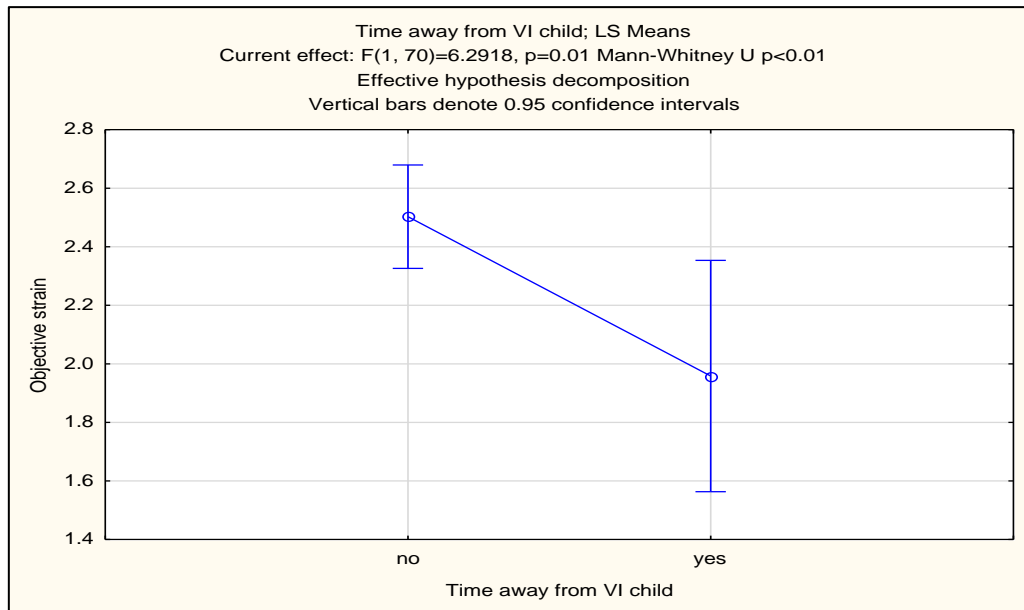


Figure 29: Time away from VI child versus Objective caregiver strain

Figure 30 to Figure 35 illustrate that higher overall and objective caregiver strain scores were seen when VI children required assistance with the following: dressing; bathing; and using the toilet. Figure 36 illustrates that those needing assistance with eating had higher objective caregiver strain scores than those that were able.

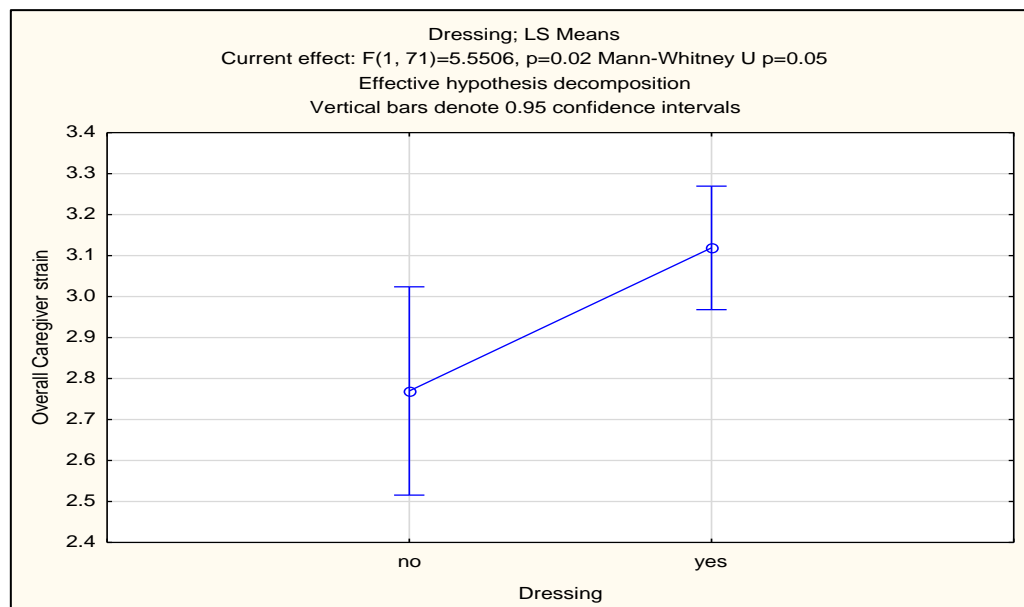


Figure 30: Dressing versus Overall caregiver strain

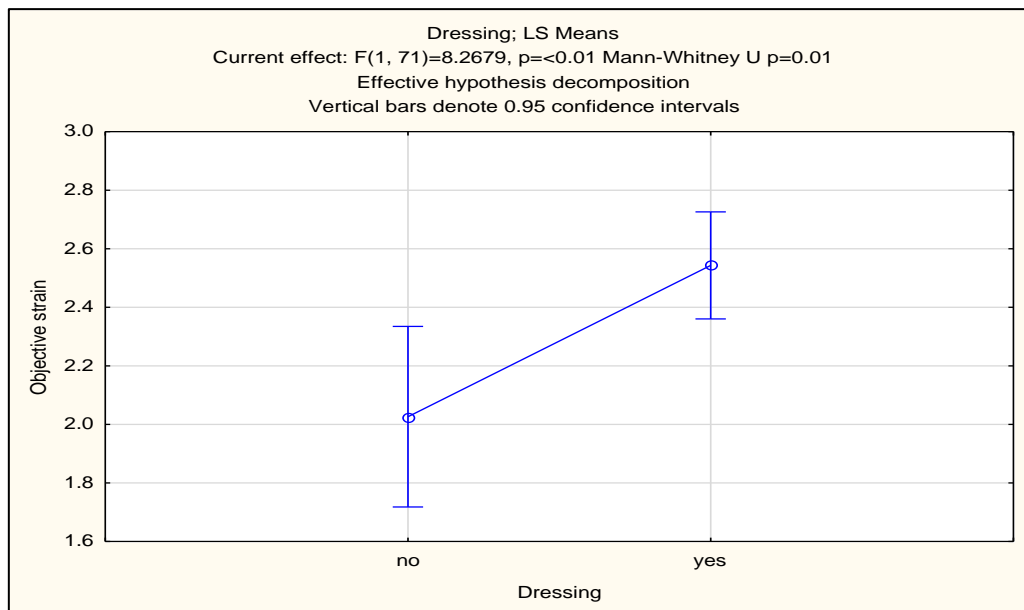


Figure 31: Dressing versus Objective caregiver strain

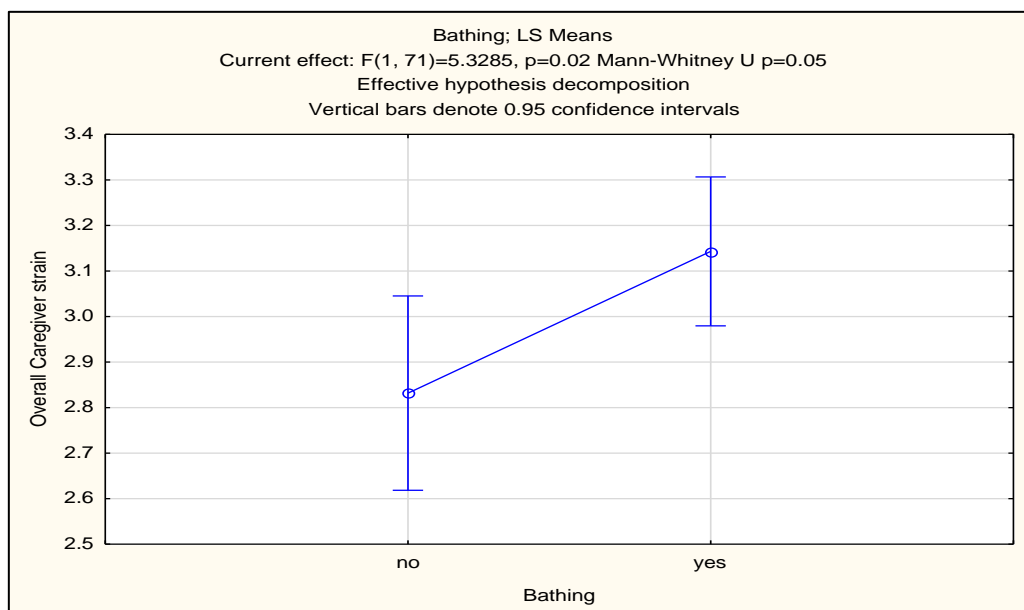


Figure 32: Bathing versus Overall caregiver strain

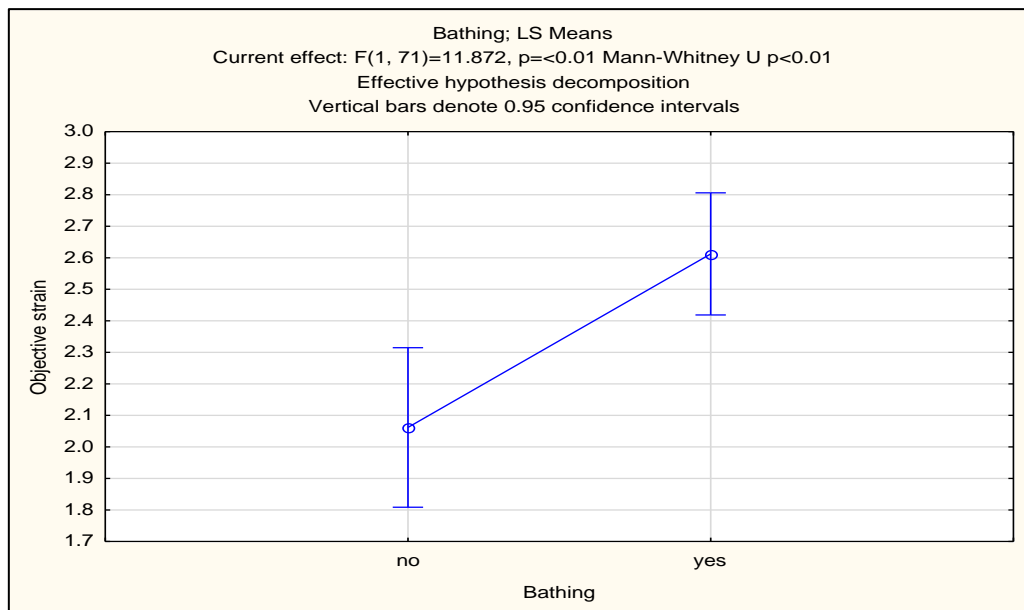


Figure 33: Bathing versus Objective caregiver strain

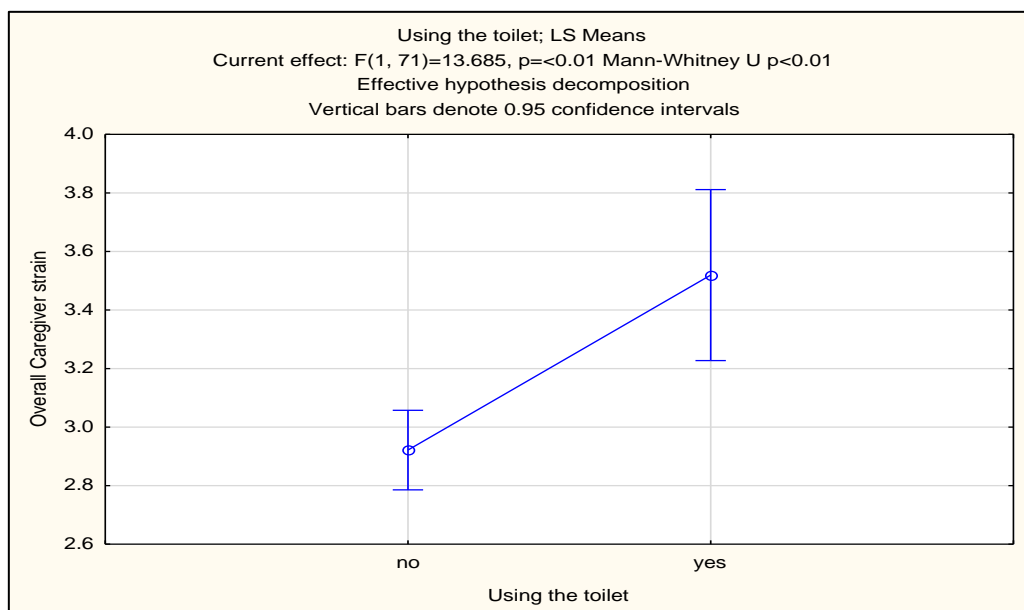


Figure 34: Using the toilet versus Overall caregiver strain

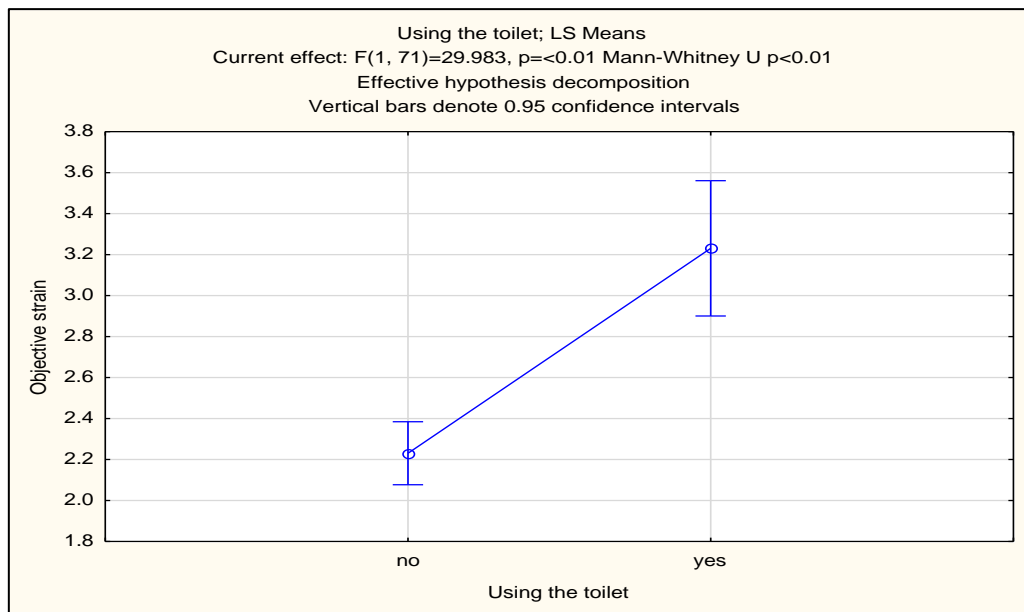


Figure 35: Using the toilet versus Objective caregiver strain

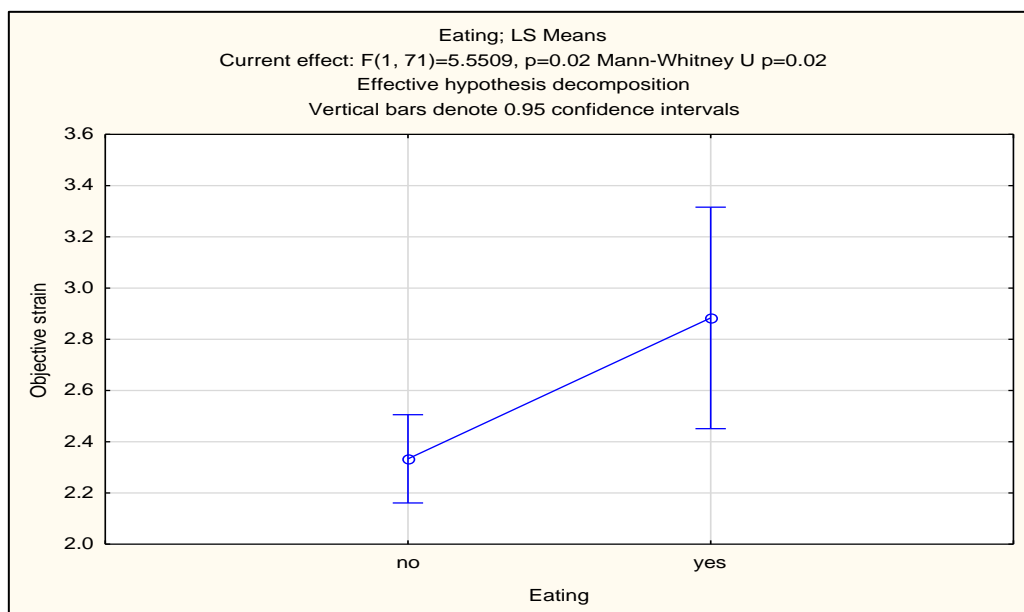


Figure 36: Eating versus Objective caregiver strain

Chapter 5: Discussion

5.1. Introduction

The study sought to identify particular challenges, referred to as the caregiving load, of familial caregivers of a subset of VI children attending the only government-funded school for the blind in the Cape Metropole area, the Athlone School for the Blind. There is only one government-funded LSEN school for VI children in Cape Town. There is no private LSEN school for VI children registered with the Independent Schools Association of South Africa (ISASA)⁸⁴. The only other school for the blind in the province exists in Worcester, a town 110 km away. It was not possible to travel there repeatedly for face-to-face interviews with caregivers. Requiring those caregivers to provide answers over the phone or by mail would seriously damage any comparability between the two data sets.

During my preliminary interview, the school's principal assured me that parents or guardians of VI and blind children born in the Western Cape are referred to the school, to reserve their child's acceptance into the LSEN school. The primary focus of the investigation was to determine the relationship between diminished ILS and caregiving strain. There may be a link between elevation in the following factors and caregiver strain scores: financial difficulty; diminished ILS; and reluctance to spend time away from the VI child.

5.2. Study findings from the self-designed questionnaire

A quarter of the caregivers reported a secondary school qualification; none had a tertiary level qualification (Figure 2). Lack of maternal education is associated with parental stress and its causal factors⁸⁵. Cognitive function influences the level of care required; this suggests fewer cognitive deficits would result in a lower caregiving load. González and colleagues investigated the link between parental caregiver education and their children's cognitive development⁸⁶. They sourced their 855 families from the INMA (INfancia y Medio Ambiente / Environment and Childhood) project. The McCarthy Scales of Children's Abilities was used to assess cognitive development: General Cognitive Score (GCS). When maternal caregivers had a university degree, their education level versus GCS comparative regression scores reported higher β values than those with only a secondary school qualification ($\beta=15.4$ and $\beta=9.2$ respectively)⁸⁶. When paternal caregivers had a university degree, their education level versus GCS comparative regression scores reported higher β values than those with only a secondary

school qualification ($\beta=11.0$ and $\beta=4.8$ respectively)⁸⁶. The higher β values suggest that parental caregiver education has a positive relationship with GCS scores, most significantly maternal education ($\beta=15.4$ versus $\beta=11.0$).

5.2.1. Household finances

The study population consisted of households who could not afford the school hostel. The mean household income range for the study is R1200 to R2499. However, all the households in the study qualified for SASSA grants, which indicated that the households qualified for additional financial support via the means test⁴⁹.

A ratio of 5:1 female-headed households relied on social grants as their sole income. There was an indication of a gender gap for main income contributors, as two in three males and one in three females held full-time employment and earned a monthly income of more than R1200 (Table 4.2). However, as the ratio of male-headed and female-headed households (ratio 2.4:1), as defined by the gender of the main adult income contributor, was significantly disproportionate it is unclear if the gender gap for the study is valid. As suggested in the Introduction and Literature Review, female income contributors experienced financial strain due to income poverty, but this was also the experience of male- and child-income contributed households.

Half of the study households had between five and seven members (Figure 8 and Table 4.3). Space was limited as the homes tended to be on the smaller side, with multiple children sharing a room and the lounge area often doubling as a bedroom to accommodate everyone. A high proportion of the homes have attempted to maximise accommodation by building “wendy-houses” on the property. However, as property dimensions are small, this further restricted the ability of the VI child to move around unassisted.

Unsurprisingly households with a low monthly income reported a high frequency of food insecurity (Table 4.7). In addition to this, one in seven households earned less than the upper-bound poverty line (UBPL) for the study period in 2015, suggesting they had to sacrifice their food expenditure to afford non-food essentials. Caregiving duties rarely left time for employment, as the seven out of ten caregivers were unemployed, and the rest tended to hold part-time employment, depicted in Figure 6. Households, where the caregivers are also the

main income contributor, experience greater food insecurity and were more likely to be unable to afford transport to medical care or alternative transportation to school for their VI child, stated in the results section 4.2.

5.2.2. Composition of the household

In the study, the median number of adults in the household was two (58.9%); on average households were large (between five and seven members); and tended to have additional children (49/73; 67%), as seen in Table 4.4 and Figure 8. A household consisting of multiple family units was not typical (4/73; 5.5%).

5.2.3. Household health

In South Africa, there is a notable divide in the quality of healthcare received between the lower-income and upper-income groups⁸⁷. Morudu and Kollamparambil's investigation into how unforeseen out-of-pocket medical expenses and their effect on food expenditure differs between the two income-brackets; as the lower-income group tends to sacrifice healthcare quality (private versus public) for food security⁸⁷.

In the current study, nearly half of the households had previously experienced an inability to afford transportation to access medical care (29/73). In determining the utilisation and affordability of healthcare to the participating households, healthcare utilisation was more dependent on transportation availability and affordability than healthcare quality.

Substance use by a household member was reported in some form in nearly all the households (96%), with smoking being the leading type (Figure 9). The smoking of cigarettes was in conjunction with alcohol consumption (61%) and drugs (9%). The prevalence of smokers presented in Figure 9 (96%) showed that at least one member smoked in most homes.

South Africa is ranked 8th in reported TB cases (3% of the global total)⁸⁸. TB was the leading underlying natural cause of death from notified causes of death in South Africa for 2016 (29 513 / 460 236; 6.5%)⁸⁹. Per South Africa's high TB burden, the study found that 4.1% of the study population had at least one household member undergoing treatment. Murray and colleagues (2003) investigated the impact of stigma on TB diagnosis delay in impoverished

sectors of the Western Cape⁹⁰. The stigma of uncleanness and the suspicion of concomitant HIV results in extreme underreporting and TB-testing reluctance⁹⁰.

In 2018, the WHO estimated that 37.9 million people were living with HIV⁹¹. My study's HIV/ AIDS prevalence of 61.6%, is high compared to the 2019 national estimate⁹² (7 970 000/ 58 780 000; 13.5%) and the 2018 provincial estimate⁹³ (46000/1557 000; 3.0%).

5.2.4. Day-to-day routine

Some of the challenges experienced were lack of safe places to play in the home for the children (Figure 24 and Figure 25) and difficulty with social integration (Figure 27 and Figure 28).

In most cases, the allocation of safe places to play was absent. Families did not see their child's impairment as something to adapt to consciously, but rather a "fact of life". Of the 11 caregivers who gave further comments, eight attributed their faith in a higher power as the critical approach to coping with having a VI child.

The challenges caregivers encountered daily typically stemmed from a lack of independence by the VI child. Fifteen-percent of the study households made efforts to lessen the load by implementing home adaptations to allow the child to move around independently (see section 4.8.6). VI children mostly relied on memorising their home's layout. Spending time away from the VI child was not the norm, as only 13/71 (18.3%) spent at least one day off from their caregiving duties (Figure 13).

Recognition of the challenges of caring for a VI child was widespread, with 75% of the caregivers reporting significant coping difficulties and a quarter experiencing immense pressure to succeed in their daily tasks (Figure 12). Following Sola-Carmona and colleagues' findings⁷, the absence of time out from a demanding caregiving load will likely associate with an increase in anxiety.

5.3. Study findings from the CGSQ-SF

Each subsection of the CGSQ-SF scores indicates the depth of burdens and their outlook on the situation. Caregiver strain and caregiving load suggest a positive associative relationship

for all the factors in the study. However, due to the confounding effect of studying poverty and its related factors, simultaneously with caring for a VI child, the absolute association is elusive.

5.3.1. Qualitative information

The caregivers' gave their perspective on their experiences the month before the interview. They answered questions relating to the observable effects (Table 4.12) and the emotional and mental effects of caring for a VI child (Table 4.13). Questions about the 'child's problems' in the CGSQ-SF were interpreted as the impact of their child's visual impairment, their child's experiences in their home environment and being non-TD (Table 4.12 and Table 4.13). The CGSQ-SF scoring form (Annexure 7:) recorded that all the caregivers in the study experienced a substantial degree of overall caregiver strain, that is either medium (55/73; 75.3%) or high caregiver strain (18/73; 24.7%) (Table 4.14). It is essential to remember that as these questions are personal, caregivers can give socially desirable answers.

Table 4.12 represents the answers to the first six questions of the CGSQ-SF, about how the caregiving load impacts daily life. The caregiving load leaves little time for leisure, illustrated by nearly half of the study population reporting that their "personal time" was interrupted due to their child's VI (32/73; 43.8%). Missing work or neglecting other duties did not seem to be a big issue for 59% (43/73) of the caregivers, possibly due to 68% (50/73) of the caregivers being unemployed. Bearing in mind, that the diagnosis of these VI children took place at birth as reported by the caregivers, family routines would have been developed or adjusted around their special needs years before the interview. Caregivers tended to report a slight disruption to family life (52/73; 71.2%), and 53.4% reported that no family member had to go without something, as a result of prioritizing the disabled child's wants and needs above other members of the household. The findings suggest that having a VI child did not increase financial strain, with 47.9% (35/73) answering 'Not at all'. As per section 0, the caregivers' households had financial struggles as they could not, for example, afford the school hostel; 26/73 (36%) of the households had experienced ten or more instances of food insecurity in the month before the interview (Figure 11). My experience with the caregivers was a reluctance to attribute their struggles to their child's disability.

Table 4.13 represents the four questions about the caregiver's feelings towards their child's disability and the extra care required. Sorrow about the child's disability plagued 52.1% of the caregivers, indicating their longing for the child not to carry this 'burden'. Worry about their

child's future may stem from feeling powerless to change their child's visual impairment, as 46/73 (63.0%) answered this worried them a tremendous amount. These emotions reiterate the challenging nature of caring for a VI child stated in section 5.2.4.

Caregivers interpreted the question "How guilty did you feel about the child's problems?" as feelings of 'if they were doing enough' in aid of their child's experience of being VI; which is a difficult topic to broach with the caregivers due to its sensitive nature. A small portion (26/73; 35.6%) of caregivers reported rarely feeling 'guilt' over not being able to do more for their child's experience with their visual impairment; nine caregivers stated that they never felt guilty (Table 4.13). Whether this is the truth is unclear due to social desirability bias, as the caregivers that 'never felt guilty' reported feeling that their children were a divine gift and that their higher power would not give them more than they could handle. The two most frequent answers to the question about whether they felt tired or strained by their child's disability, were "A little" (26/73; 35.6%) and "somewhat" (25/73; 34.2%). These caregivers did not identify themselves as strained due to their child's visual impairment, whether that is accurate or due to social desirability bias is uncertain.

As the questionnaire is a qualitative research tool, the results do not take into account sociocultural influences. The absence of sociocultural influence obscures the financial hardships the households in the study faced due to the rising levels of poverty in South Africa, specifically the areas where the caregivers resided (as discussed in detail in 0).

5.3.2. Quantitative relationships

5.3.2.1. Household finances versus Caregiver strain

Mann-Whitney U tests of financial constraints in accessing healthcare on overall and objective caregiver strain scores indicate that it may affect the caregiving load. It coincided with elevated overall caregiver strain scores in Figure 15 ($p=0.02$) and Figure 16 ($p\leq 0.01$), respectively. There was an elevation in scores for both overall (Figure 15) and objective strain (Figure 16) if there was an inability to afford transportation to school. The direct burden of not being able to afford alternative transportation to school for the VI child was also of concern for the caregiver, as seen in Figure 17. However, worries about future financial deficits did not have a statistically significant association with elevated caregiver strain. In determining whether financial stability – indicated by the main income provider's employment status – impacted caregiver strain, Kruskal-Wallis analyses (Figure 18 and Figure 19) support that a stable,

reliable income is beneficial to the caregiver's well-being. A notable decline from severe to moderate levels of subjective internalised caregiver strain and overall strain scores occurred when the main income contributors held full-time employment compared to those who held irregular employment. A significant correlation between lower monthly household income and higher caregiver strain illustrated in Figure 20 suggests that financial stability is vital. The average earning for the household has a negative association with stress levels. In instances where other members of the caregiver's household received a social grant the caregiver reported higher levels of objective strain (Figure 21); this could further illustrate that poverty has a detrimental effect on the caregiver's well-being.

Statistical analysis in the study comparing food insecurity and overall caregiver strain found a significant positive correlation (Figure 22 and Figure 23). The caregiver's household's financial struggles and the inability to afford transportation to the clinic showed a positive relationship with caregiver strain illustrated in Figure 15 and Figure 16. The association between financial instability and a higher potential for anxiety among caregivers is known⁷. However, it is also the case in poverty-stricken households without VI children⁹⁴. Causality among poverty and anxiety is complicated as many of their factors interrelate^{7,94}.

5.3.2.2. Household composition and health versus Caregiver strain

There was no significant correlation between substance use by a household member and caregiver strain ($p=0.21$). There was no significant correlation between the number of other children in the household and CGSQ-SF scores. Kruskal-Wallis analyses of a household member having either TB or HIV and overall caregiver strain showed no significant correlation ($p=0.37$). However, this does not rule out these as potential influencers of caregiver strain, as the results are solely valid for this particular sample and underreporting of these factors is common.

5.3.2.3. Day-to-day routine versus Caregiver strain

In determining the impact of support groups on caregiver strain, the findings were lacking as none of the caregivers sought help from a support group. Evidenced by the caregivers' experiences, the mounting responsibilities placed on them increased the strain experienced, as seen in section 4.8.6. Households where the children could be more independent and move freely had lower caregiver strain scores. Those caregivers who took a break tended to have

lower objective strain scores (Figure 30); indicating that taking time to focus on themselves lowered their caregiver strain. Building on Sola-Carmona and Colleagues' association, loosening the reins and taking time out significantly lowers anxiety risk⁷.

The degree to which the caregivers adapted their relationships with their households and community and the stigma of expressing caregiver burden, impacted their caregiving load perception.

The VI children, despite their age, relied on the caregiver's help with ILS such as dressing (54/73; 74%), brushing teeth (47/73; 64.4%), bathing (46/73; 63%), using the toilet (13/73; 17.8%), and eating (10/73; 13.7%) (Figure 30 to Figure 36). Diminished ILS added to the caregiving load and subsequently increased the severity of caregiving strain for the study population, as indicated by the positive associative relationship between caregiving load and caregiving strain. Needing assistance when using the toilet resulted in a dramatic increase in caregiver strain intensity from medium to high for overall and objective strain (Figure 34 and Figure 35), illustrating that the ability to do this essential activity independently was vital for lowering the caregiving load. Due to the VI child's increased needs, the caregiver had less time to socialise, further restricted by the stigma of taking a break from their caregiver duties.

5.4. Limitations of the study

The source population of VI learners comprises two nearly equal groups: VI learners who resided in the hostel (170/320; 53%) and VI learners residing at home (150/320; 47%). After employing the inclusion criteria, 95 caregivers were eligible; of which 73 consented to participate (73/150; 48.7%). The study population is too small to yield findings representative of all home caregivers of VI children attending the LSEN school. It is also far too small to come to conclusions about the problem of caregiver strain nationwide. The addition of interviews with the caregivers of the VI children residing in the hostel would represent the impact of having a VI child on the household – even though the child is only home for the long school holidays, June and December.

The reason the children in this study was not residing in the school hostel was that the caregivers could not afford the boarding fees. Thus the VI children in the study represented the most financially needy families in the source population. Furthermore, the level of hands-on care needed by a 10 year old VI child differs considerably from that of a 19 year old. The

study did not differentiate between the age groups of the children and treated them as one homogeneous group.

Completion of questionnaires relied on the caregiver reporting data for herself and her household, exposing the study to recall bias. The addition of follow-up appointments over two weeks with the caregiver and other household members, would lessen recall bias and provide insight into the impact of caring for a VI child on the other household members.

No caregiver strain survey specifically customised for the caregivers of VI children exists. I chose the CGSQ-SF, as it measures both objective and subjective internalised strain experienced by caregivers of children. The CGSQ-SF is a validated measure of caregiver strain of caregivers of children with emotional disturbances⁶⁶, its application in caregiver strain of caregivers of VI children has been untested. Question nine, "How guilty did you feel about the child's problems?" (Table 4.13) is vague and therefore, open to interpretation by the caregiver.

Reliability test scores for the CGSQ-SF using my findings (Table 4.9, Table 4.10, Table 4.11) were significantly lower than the 2007 Manual of the Peabody treatment progress battery⁶⁶. The difference could be due to the Likert scale's interpretation by the study's caregivers, due to my smaller sample size (N=73) in comparison with Peabody (N=493). The low Cronbach alpha value for subjective internalized caregiver strain could be due to difficulty to distinguish answering options for emotional questions.

The inherently personal nature of the questions exposes the study to social desirability bias. The caregivers could report answers that they deemed socially acceptable and this may not always be accurate. In retrospect, the addition of follow-up questions as to why they did not attend support groups would determine if it was due to availability, time restrictions or personal choice. I would convert the question regarding feeling uncomfortable spending time away from the VI child to an open-ended question on why they do not spend time away from their child. Moreover, the emotions tied to this, as the current question of 'Do you feel like you cannot leave your impaired child', is vague about the motivation behind their response.

The cross-sectional, descriptive nature of the study prevents the generalisation of caregivers' experiences to the source population. The study variables' confounding nature is that an elevation of caregiver strain could be due to multiple variables associated with each other.

Due to the study design's unrepresentative nature, calculation of prevalence is only applicable for the study population. Due to the 23% (22/95) non-response bias, there is a possibility of missing essential findings and subsequent potential associations.

5.5. Conclusions

There is not enough research on the unmet needs of caregivers on a global and local scale⁹⁵. Many caregivers are reluctant to seek assistance when the burden of caring for a VI child becomes unbearable and when it eventually affects their health. This thesis provided a glimpse into the struggles facing these caregivers of VI children. In the present study, these caregivers were financially disadvantaged and subsequently unable to access support structures. Kiely, Leach and Olesen found that the financial hardships and the onset of mental health problems are likely linked, but untangling poverty factors to give a direct cause is challenging⁹⁴. The heavy load of caring for the VI child while managing their households may place extra strain on them financially, physically and emotionally. However, the addition of a control group would give a definitive association.

The study's findings substantiated many of the daily challenges other caregivers faced as reported in the literature; elevated caregiver strain occurred with these challenges. Underreporting health problems and not seeking medical help is a huge problem affecting these individuals, creating a further obstacle to caregiver strain treatment. Sola-Carmona and colleagues and Taylor and colleagues suggest that households with a disabled child have a more challenging time financially than those without a disabled child^{7,52}. However, due to the absence of a neighbourhood-match control, substantiation is not possible. According to calculations, these caregivers experienced substantial levels of objective strain; as 71/73 caregivers presented with either medium (57/73; 78.1%) to high (14/73; 19.2%) observable caregiver strain (Table 4.14). All of them presented with either moderate (55/73; 75.3%) or severe (18/73; 24.7%) emotional distress resulting from their daily challenges according to the CGSQ-SF. Overall, caregiver strain scores further illustrated that intervention programs for these caregivers are a necessity. The relationship between objective and subjective strain ($p < 0.01$), shows that not only is the tangible caregiving load responsible for caregiver strain but also the perception of the caregiving load (see section 4.8). The reality that only one of the factors – 'Needing assistance when using the toilet' (Figure 34 and Figure 35) – revealed a unilateral shift from medium to high overall and objective caregiver strain scores suggests that caregiver strain is multi-factorial. The Cronbach alpha values of objective strain (0.76),

subjective strain (0.48) questions and overall (0.63), shows that the questions regarding the emotional impact of the caregiving load should have more distinct scale choices.

The mixed research method, suggests that the caregivers in the study group do not view their child's special needs as the singular cause for the financial struggles they face and that their biggest concern is their child's future as a disabled adult. There is a dearth of research into the plight of caregivers of VI children in South Africa and Africa in general. This mixed-method study highlights the need to fill this gap in the literature.

5.6. Recommendations

Despite the descriptive cross-sectional study's weaknesses, it has provided a good jumping-off point in generating hypotheses. These hypotheses would aid the planning of case-control studies. For example, a case-control study to determine the hypothesis's accuracy that "Having a VI child increases the financial struggles facing households in the Cape Metropole". The study population would consist of children born over at least five years at both a government-funded and a private hospital in the Western Cape. New Somerset Hospital and Christiaan Barnard Memorial Hospital would be my recommendation, located approximately 3.4 kilometres apart. The monitoring of caregivers newly embarking on their roles (pre-exposure) would provide baseline results. This study design would explain prolonged exposure of caregiving on caregivers from different socio-economic backgrounds, the impact of contrasting educational support (seen in government-funded schools and private institutions), compared with neighbourhood-matched controls. These studies would provide insight into what makes caregivers more susceptible to subjective burden; aiding in designing interventions for the objective, subjective internalised and overall caregiver strain.

Academic studies on the challenges caregivers face, their perceptions of caregiver strain and the caring requirements of VI children is vital for the construction of caregiver strain measurement tools specifically designed for our diverse cultural and socio-economic demographics. The findings of further academic studies would provide data for policy makers to improve the financial and social aid caregivers of VI children receive to reduce the mental health strain of these caregivers.

In general there is far too little emphasis placed on the role of the caregiver in the systems designed to support VI children. This needs to change, especially in the African context. Africa needs localised research tools and studies to back up the policies and management systems

needed to deal with children with a wide range of disabilities, of which VI children is but one example. Context is extremely important since different communities within different cultures cope with disability in widely differing ways.

Future topics on the theme of caregiver strain will need to expand the population coverage for policy makers to take the findings seriously, since policies are almost always drawn up on a national level. For Africa to take this work on board, the field will have to cover many more sites and conditions on the African continent. That is a goal to aspire to.

In the shorter term the government needs to launch mutual support groups in impoverished communities, and schools for the blind. Mutual support groups would alleviate the subjective internalised strain experienced by these caregivers and provide extra support for the rest of the household. Health department awareness campaigns to educate both the local health services and the community on caregivers' needs would decrease the stigma preventing most from seeking respite care and mental health initiatives.

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ANNEXURES

University of Stellenbosch ethics clearance letter

Western Cape Education Department approval letter

Participant information leaflet

Declaration by participant

Declaration by investigator

Declaration by interpreter

Questionnaire used for the study

Caregiver Strain Questionnaire – Short Form scoring form

Annexure 1(a): University of Stellenbosch ethics clearance letter



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Approval Notice Response to Modifications- (New Application)

11-Jun-2013
ST JERRY, Marlyse

Ethics Reference #: S13/03/049

Title: The impact of caring for a visually impaired child in Athlone school for the blind , Cape town on the main caregiver and the rest of the family the health , socio economic and psychological health burdens

Dear Miss Marlyse ST JERRY,

The **Response to Modifications - (New Application)** received on 23-May-2013, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **10-Jun-2013** and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **10-Jun-2013 -10-Jun-2014**

Please remember to use your **protocol number** (S13/03/049) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 0219389207.

Included Documents:

DEC LETTER BARNES

COV LETTER

SYNOPSIS

QUEST

PROTOCOL

CHECKLIST

CV BARNES

APPLIC FORM

DEC LETTER JERRY

LETTER

CV JERRY

IC FORMS

Sincerely,

Mertrude Davids
HREC Coordinator
Health Research Ethics Committee 2

Annexure 1(b): Western Cape Education Department approval letter



Western Cape
Government

Education

Directorate: Research

Audrey.wyngaard2@pgwc.gov.za

tel: +27 021 467 9272

Fax: 0865902282

Private Bag x9114, Cape Town, 8000

wced.wcape.gov.za

REFERENCE: 20130704-13796

ENQUIRIES: Dr A T Wyngaard

Miss Marlyse St Jerry

[REDACTED]
[REDACTED]
[REDACTED]

Dear Miss Marlyse St Jerry

RESEARCH PROPOSAL: THE IMPACT OF CARING FOR A SCHOOL-GOING VISUALLY IMPAIRED CHILD CAPE TOWN, WESTERN CAPE ON THE HOME CAREGIVER AND THE REST OF THE FAMILY – THE HEALTH, SOCIO-ECONOMIC AND PSYCHOLOGICAL HEALTH BURDENS

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Approval for projects should be conveyed to the District Director of the schools where the project will be conducted.
5. Educators' programmes are not to be interrupted.
6. The Study is to be conducted from **15 July 2013 till 30 September 2013**
7. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
8. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number?
9. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
10. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
11. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
12. The Department receives a copy of the completed report/dissertation/thesis addressed to:

**The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000**

We wish you success in your research.

Kind regards.

Signed: Dr Audrey T Wyngaard

Directorate: Research

DATE: 05 July 2013

Lower Parliament Street, Cape Town, 8001

tel: +27 21 467 9272 fax: 0865902282

Safe Schools: 0800 45 46 47

Private Bag X9114, Cape Town, 8000

Employment and salary enquiries: 0861 92 33 22

www.westerncape.gov.za

Annexure 2: Participant information leaflet

Participant Information Leaflet and Consent Form

TITLE OF THE RESEARCH PROJECT:

The impact of caring for a school-going visually impaired child Cape Town, Western Cape on the home caregiver and the rest of the family - the health, socio-economic and psychological health burdens

REFERENCE NUMBER: S13/03/049

PRINCIPAL INVESTIGATOR: Marlyse St. Jerry, MSc Candidate, Department of Community Health, Division of Epidemiology, University of Stellenbosch, Faculty of Medicine and Health Sciences, Tygerberg Campus, South Africa

CONTACT NUMBER: [REDACTED]

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please feel free to ask any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC)** at **Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

- ***What is this research study all about?***

This study will take place in the homes of parents/guardians and/or home caregivers of school-going visually impaired children in the City of Cape Town Metropolitan area. The study will identify the effects of caring for a visually impaired child on the parent/guardian and/or home caregiver. The information for this study will be obtained from a questionnaire which will focus on how having a visually impaired child impacts you and your family. We will be taking down your address, but we will not be taking down any names of you and your family in the interview. This is done so that no one will be able to identify from whom the information was obtained and who is sick or who became ill in your home. This consent form will not be attached to your

answer sheet, so that again no one will be able to find out that this information was provided by you. Once you have completed this consent form, this form will be placed in a sealed box together with all the other forms from your community, for safety purposes. A report of the findings from the study will be sent to your ward councilor, and we will try to make the information available in a community newspaper. We will also send a report to the City of Cape Town offices, so that they know about the impact of caring for a visually impaired child on their parent/guardian and/or home caregiver to aid them in the assistance planning. You can contact Dr J.M Barnes at 021-9389480 if you have any questions or problems or would like to know the results of this study. You may also contact the Human Research Ethics Committee (HREC) at Stellenbosch University at 021-938 9207 if you have any concerns or complaints. You will receive a copy of this information leaflet and consent form for your own records.

- ***Why have you been invited to participate?***

You have been selected as you have a school-going visually impaired child. We want to investigate the health status and any difficulties experienced by parents/guardians and/or home caregivers of visually impaired children.

- ***What will your responsibilities be?***

To please answer the questions as best as you can. You may choose to not answer questions which cause you discomfort.

- ***How long will the questionnaire take?***

Answering the questionnaire will take approximately 40 minutes.

- ***Will you benefit from taking part in this research?***

The results from this study will be summarised and provided to the local, provincial and national government in order to improve planning for healthcare and support. The results will help us understand the needs of parents/guardians and/or home caregivers of visually impaired children.

- ***Are there any risks involved in your taking part in this research?***

The only risks involved in taking part in the study are possible discomfort or distress and we assure you of your anonymity as some of the questions are of a personal nature. If you feel uncomfortable, you may omit any questions you do not want to answer or stop the interview at any time.

Annexure 3: Declaration by participant

Declaration by participant

By signing below, I agree to take part in a research study entitled, The impact of caring for a school-going visually impaired child Cape Town, Western Cape on the home caregiver and the rest of the family - the health, socio-economic and psychological health burdens

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may choose to not answer any questions that cause me discomfort.

Signed at (*place*) on (*date*) 2013.

.....
Signature of participant
(parent/ guardian/ home caregiver)

.....
Signature of witness

Annexure 4: Declaration by investigator

Declaration by investigator

I (name) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (place) on (date) 2013.

.....
Signature of investigator

.....
Signature of witness

Annexure 5: Declaration by interpreter

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)2013

.....
Signature of interpreter

.....
Signature of witness

Annexure 6: Questionnaire used for the study

Good day Sir/ Madam

My name is Marlyse St. Jerry. You are invited to take part in a research project carried out by the Faculty of Medicine and Health Sciences of the University of Stellenbosch. This questionnaire is to determine the impact of caring for a visually impaired child on his/her family. Note that your participation in the study is voluntary and you may opt to stop the questionnaire at any time and may choose to not answer questions which cause you discomfort. All answers and comments will be kept highly confidential. We will not record your name and we promise that no information you give us will be attached to you or anyone living in your home. Please do not hesitate to ask any questions that you may have with this study.

Section 1: Biographical Details

1.1 Please provide us with the following information, so that we can learn more about your family.
Indicate Caregiver(C) and Breadwinner (B)

Code of Person	Role in Household	Age	Is this person disabled?		Sex		Status of individual U – Unemployed F – Full time employed P – Part time employed IRR – Irregular employment S – Scholar C – Child at home A – Adult at home	Educational Status: A – No schooling B – Pre-primary to grade 4 C – Grade 5 to grade 7 D – Grade 8 to grade 9 E – Grade 10 to grade 12 F – Tertiary level U – Unsure	Notes
			Yes	No	Male	Female			
A1									
A2									
A3									
A4									
A5									
A6									

1.2 Are members of the household

Mark the person's choice (✓)

South African Citizens	Yes	
	No	
If no, what is your country of citizenship		
And for how long have you lived in South Africa		

Section 2: Disease and health services

2.1 During the past two weeks, are there symptoms that affected you or persons living in your house?

Symptom	Code of person / persons with symptom										Home treatment (✓)	Visited clinic / Doctor (✓)	Is the person still suffering from the symptom (Y/N)
	A 1	A 2	A 3	A 4	A 5	A 6	A 7	A 8	A 9	A 10			
Diarrhoea													
Fever													
Nausea													
Vomiting													
Cramps / Abdominal pain													
Blood in stools or vomit													
Worms in faeces													
Body / hand sores													
Eye infection													
Coughing													
More than 1 week													
Coughing blood													
Shortness of breath													
Tiredness & weakness of body													
Loss of appetite & weight													
Night sweats													
Headaches													
Nits / Lice													
Itchy skin, rash													
Other:													

2.2 Have any members of your household visited the clinic and/or doctor in the past two months and been diagnosed with an illness/disease?

Code of the person	Illness/disease	Was medicine given for the illness? (Y/N)	Is the illness cured? (Y/N)	Have you or any member in your household suffered from the illness before? (Y/N)

2.3 Are any members of the household on chronic medication?

Mark the person's choice (✓)

Yes	
No	
If yes, specify	for what illness
	names of medication
	at which clinic

*** Note to interviewer: If the answer is yes, ask to see the medication.

2.4 Do you think that people in your household suffer from the following diseases at the moment?

(Optional- Answer is Voluntary)

Mark the person's choice (✓)

	Yes	No	Unsure
TB			
HIV/AIDS			

2.5 What are some of the other health problems or disabilities facing your household?

1.	2.	3.
4.	5.	6.

2.6 Do members of the household take part in using the following substances?

Mark the person's choice (✓)

	Cigarettes	Alcohol	Drugs
Yes			
No			
Unsure			

2.7 What is the name of the clinic that members of your household visit when ill?

2.8.1 How do you get your impaired child to the clinic? (Routinely)

Mark the person's choice (✓)

Walk	
Taxi	
Bus	
Private transport	
Other, specify:	

2.8.2 How do you get your impaired child to the clinic? (Emergency)

2.9 Who accompanies the child to the clinic?

2.10 What does a return trip to the clinic cost (if you need to pay)? R ____, __

2.11 How long does it take to travel to the clinic? _____

2.12 Has there ever been a time when your impaired child needed to visit the clinic, but did not have the money to pay for transport?

Mark the person's choice (✓)

Yes	
No	
Unsure	

2.13 Are you satisfied with the services provided by the clinic?

Mark the person's choice (✓)

Yes	
No	
Unsure	

2.14.1 How do you get your impaired child to school? (Routinely)

Mark the person's choice (✓)

Walk	
Taxi	
Bus	
Private transport	
Other, specify:	

2.14.2 How do you get your impaired child to the school? (When routine transport is unavailable)

2.15 Who accompanies the child to school?

2.16 What does a return trip to school cost (if you need to pay)? R ____, __

2.17 How long does it take to get to school? _____

2.18 Has there ever been a time when your impaired child did not have the money to pay for transport to school?

Mark the person's choice (✓)

Yes	
No	
Unsure	

2.19 Usually, how many meals does your family eat per day?

Ring the person's choice 1 2 3 4 5 6 7 8

2.20.1 Has your family gone without food anytime in the last four weeks?

Mark the person's choice (✓)

Yes	
No	
Unsure	

2.20.2 If yes, how many times in the last four weeks has your family gone without food?

Ring the person's choice 0 1 2 3 4 5 6 7 8 9 10 >10

Section 3: Daily living

3.1 Are there safe places to play for your impaired child in your household?

Mark the person's choice (✓)

Yes	
No	
Unsure	

3.2 Are there safe places to play for your other children in your household? (If applicable)

Mark the person's choice (✓)

Yes	
No	
Unsure	

3.3 Do you or your impaired child receive a social grant?

Mark the person's choice(✓)

Child	
Caregiver	
Both	
Neither	
Other	

3.4 Does any other member of the household receive a social grant?

3.5.1 Who all contributes to the household income?

3.5.2 What is the total monthly household income?

Mark the person's choice(✓)

Less than R1200	
R1200-R2499	
R2500 or more	
Unsure	

3.6 Who takes care of the child when the main caregiver in your household is unable to?

3.7 When was your impaired child diagnosed as visually impaired or blind?

3.8 Does your impaired child have any other impairments or disabilities?

3.9 How has the family adapted to the impairment, socially?

3.10.1 Has any home adaptations been made for your impaired child?

Mark the person's choice (✓)

Yes	
No	

3.10.2 If yes, what adaptations have been made?

3.11 Do you meet with a support group?

Mark the person's choice (✓)

Yes	
No	
If Yes: Name of support group	

3.12 Which of the following activities does your impaired child need assistance with?

		Notes
Brushing teeth		
Bathing		
Dressing		
Eating		
Using the toilet facilities		
Writing		

3.13 Are there any other activities that your impaired child needs help with?

3.14 What are some of your other duties e.g. food preparation, washing up?

3.15 Do you spend time away from your impaired child?

Mark the person's choice (✓)

Yes	
No	
If Yes:	How many times in the past month
If No:	Do you feel like you can't leave your impaired child?
	Yes
	No

Notes:

Caregiver Strain Questionnaire- Short Form (CGSQ-SF)

Place an 'X' in the box that best matches how you feel things have been for you and your family over the past month.

	IN THE PAST MONTH, HOW MUCH OF A PROBLEM WERE THE FOLLOWING:	Not At All	A Little	Some-what	Quite a bit	Very Much
1.	Interruption of personal time resulting from the child's problems?					
2.	You're missing work or neglecting other duties because of the child's problems?					
3.	Disruption of family routines due to the child's problems?					
4.	Any family member having to do without things because of the child's problems?					
5.	Financial strain for your family as a result of the child's problems?					
6.	Disruption or upset of relationships within the family due to the child's problems?					
7.	How sad or unhappy did you feel as a result of the child's problems?					
8.	How worried did you feel about the child's future?					
9.	How guilty did you feel about the child's problems?					
10.	How tired or strained did you feel as a result of the child's problems?					

Bickman, L., Riemer, M., Lambert, E. W., Kelley, S. D., Breda, C., Dew, S. E., & Vides de Andrade, A. R. (2007). *Manual of the Peabody treatment progress battery [Electronic version]*. Nashville, Tennessee: Vanderbilt University, p224-225.

Thank you for taking the time to answer my questions. Again, any information provided by you during the interview will be kept confidential. Your participation in the study is highly appreciated.

Date of interview:	
Time of interview:	
Street Name and House number (This information will be kept strictly confidential)	
	Housing Type:
	Suburb:
Survey Number:	

Annexure 7: Caregiver Strain Questionnaire – Short Form scoring form**Caregiver Strain Questionnaire – Short Form (CGSQ-SF) Scoring Form¹**

Item	Values for Responses					Enter value for selected responses here and calculate scores as instructed		
	Not at all	A little	Some-what	Quite a bit	Very much			
1.	1	2	3	4	5	A		
2.	1	2	3	4	5	B		
3.	1	2	3	4	5	C		
4.	1	2	3	4	5	D		
5.	1	2	3	4	5	E		
6.	1	2	3	4	5	F		
7.	1	2	3	4	5		G	
8.	1	2	3	4	5		H	
9.	1	2	3	4	5		I	
10.	1	2	3	4	5		J	
	Sum of A-F					K		
	K/6							L
	Sum of G-J					M		
	M/4							N
	Sum of L and N							O
	O/2							P

¹ Bickman, L., Riemer, M., Lambert, E. W., Kelley, S. D., Breda, C., Dew, S. E., & Vides de Andrade, A. R. (2007). Manual of the Peabody treatment progress battery [Electronic version]. Nashville, Tennessee: Vanderbilt University, p224-225

CGSQ-SF Scores

Objective strain (L)	
Subjective Internalized strain (N)	
CGSQ-SF Total Score (P)	

Table 1: Interpretation of CGSQ-SF score

Scale	Low	Medium	High
CGSQ-SF Total Score (P)	<1.9	1.9-3.3	>3.3
Objective strain (L)	<1.5	1.5-3.0	>3.0
Subjective Internalized strain (N)	<2.0	2.0-4.0	>4.0

Objective caregiver strain indicates the impact that observable negative aspects of caring for the child has on the caregiver. Subjective internalized caregiver strain indicates the caregiver's feelings associated with these aspects².

² Bickman, L., Riemer, M., Lambert, E. W., Kelley, S. D., Breda, C., Dew, S. E., & Vides de Andrade, A. R. (2007). Manual of the Peabody treatment progress battery [Electronic version]. Nashville, Tennessee: Vanderbilt University, p145-159