

**FACTORS INFLUENCING THE BURDEN OF CAREGIVERS OF CHILDREN WITH
CEREBRAL PALSY IN NAMIBIA**

by

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DECLARATION

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I declare that the study on **FACTORS INFLUENCING THE BURDEN OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN NAMIBIA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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ABSTRACT

The aim of this study was to investigate factors that influence the burden of caregiving on the caregivers of children with cerebral palsy (CP) in Windhoek, Namibia. Ethical approval was obtained from researcher's university and Namibia Ministry of Health and Social Services ethics committee. A quantitative, non-experimental, descriptive and cross-sectional design in the form of a survey was used. Total population sampling technique was used to draw 91 respondents drawn from the patient register at the two public hospitals in Windhoek. A questionnaire adapted from the Zarit Burden Interview (ZBI) was used to collect data. Data which was obtained was complete and the researcher paid consistent attention to the data collection process. The results showed the following characteristics to be significantly related to increased burden among caregivers; living in the same household as a child with cerebral palsy, marital status, knowledge and understanding of cerebral palsy, ethnic group and caregiver having previously been treated for a physical ailment. It was recommended that the social grant and housing policies be reviewed, and support groups for caregivers and community awareness on cerebral palsy be introduced.

KEY TERMS: Burden, caregiver, caregiving, cerebral palsy, children, factors.

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DEDICATION

*This study is dedicated to the memory of my late dad, **Solobi Makura**, whose sacrifices directed me to where I am today.*

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LIST OF ACRONYMS AND ABBREVIATIONS

ADLs	Activities of daily living
BPSD	Behavioural and Psychosocial Stress Disorder
CSI	Caregiver Stress Index
CST	Caregiver Stress Theory
CNS	Central Nervous System
CP	Cerebral Palsy
GMFCS-E&R	Gross Motor Function Classification System Expanded and Revised
IBM	International business machines
IUGT	Intrauterine growth restrictions
MoHSS	Ministry of Health and Social Services
NDHS	Namibia Demographic Health Survey
OT	Occupational Therapy
SPSS	Statistical package for the social sciences
UNICEF	United Nations Children's Fund
UNISA	University of South Africa
USA	United States of America
WHO	World Health Organisation
ZBI	Zarit Burden Interview

CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Cerebral Palsy (CP) has been identified as the most disabling physical condition in childhood, with a stable prevalence rate observed in the United States of America (USA) between 1985 and 2002 (Van Naarden Braun, Christensen, Doernberg, Schieve, Goodman & Yeargin-Allsopp 2016:6). In a report published by the Namibian Statistics Agency on 31 May 2016, a total of 98 413 people in Namibia were living with a disability. The findings of that report also indicated a steady increase in the total number of people with disabilities, from 42,932 in the year 1991 to 85,567 in 2001 and 98,413 in 2011 (Namibia Statistics Agency 2016:10). The increase in the number of people with disabilities in Namibia has thus created a national health concern. However, a limiting factor from that report was the lack of detailed statistics on the prevalence of actual disabilities such as CP in Namibia.

In a study that was conducted to determine the perceptions of caregivers for children with CP on the support they were getting, it has been found that health care professionals mostly focused on the health and well-being of the patient with CP, often ignoring the burden that comes with the care of that person by the family, thereby providing little support to the caregiver (Pfeifer, Silva, Lopes, Matsukura, Santos & Pinto 2014:367). At least one of the studies that have been conducted specifically targeting caregivers of children with CP have highlighted back pain secondary to repetitive lifting of the children, myofascial pain syndrome and thoracic outlet syndrome as the health concerns (Sharan, Ajeesh, Rameshkumar & Manjula 2012:1893).

Activities performed by a caregiver include all basic self-care tasks such as bathing, assisting the recipient to carry out prescribed home programs like therapeutic visits and hospital appointments, and ensuring correct positioning in bed and on the wheelchair. These activities then impact on a caregiver's life as being a health burden

since the activities are done on a long-term basis, thus affecting the caregivers' quality of life (Fatudimu, Hamzat & Akinyinka 2013:133).

Based on the discussion above, this study investigated factors in the Namibian population that influence the burden of care on caregivers for children with CP. It should be noted that throughout this study, the concepts caregivers and primary caregivers are used interchangeably.

1.2 BACKGROUND TO THE STUDY

In a study focusing on gross and fine motor functions for children with CP in Nigeria, it was concluded that topographical distribution of symptoms influence gross motor function, thereby influencing prognosis of rehabilitation (Obempe, Johnson, Olaogun & Ogunleye 2013:9). Therefore, this means that the child with CP will require assistance in activities of daily living for life. This assistance in the Namibian context often comes through informal caregiving by a family member or parent. The task of caregiving results in additional responsibilities on the caregivers' daily lives, and occupies the caregivers' time, energy, and attention. Caregivers are thus an important part of the Namibian healthcare system.

In a study conducted in Spain to determine predictive factors and burden for caregivers for children with CP, anxiety was not found as a predictor of caregiver burden but rather a response in acute life situations (Marron, Redolar-Ripoll, Nieto, Guillamon, Hernandez & Gomez 2013:773). Other findings from the same study found depression as a predictor of burden for life lasting situations such as caregiving for a child with CP. Anxiety and depression in caregivers may negatively impact their capacity for social and community engagement. Another important finding was how the degree of disability in a child with CP was found to be a huge and significant contributor to the burden of care (Marron et al 2013:772). It was therefore interesting to analyse this variable in the Namibian population since patients presenting at occupational therapy (OT) clinics have variable levels of severity of CP disability.

The variable which has been found to influence caregiving burden is self-efficacy (Marron et al 2013:773). Self-efficacy has been defined as an individual's confidence in fulfilling a given task (Dumbauld, Black, Depp, Daly, Curran, Winegarden & Jeste

2014:489). In the Namibian context, it was deemed interesting to find if self-efficacy, coupled with Christian beliefs influence the burden of caregiving.

In a study conducted to determine the types of subjective burden of caregiving and factors affecting informal caregivers for patients with dementia in China, it was found that caregivers who lived in the same household as the care recipient had a greater social burden, higher emotional burden, higher physical burden and higher developmental burden (Wang, Xiao, He, Ullah & De Bellis 2014:992). In Namibia, the option for caregivers for children with CP is to stay with the care recipients. There are no day-care or institutional facilities available for children with physical and neurological deficits to receive developmental stimulation. This study therefore sheds more light on whether sharing the same household by children with CP and their family has a negative impact on their livelihood.

Other factors which have been found to be closely linked to a higher burden of caregiving include being a female caregiver, the care recipient's age, being unemployed and the financial burden related to direct costs for managing the care recipient's disability and premorbid conditions (Wang et al 2014:991). In some studies regarding caregivers, the findings have revealed satisfaction with social support provided by immediate family members (Pfeifer et al 2014:367; Wang et al 2014:989). There is, however, a need to define the type of social support for caregivers in Namibia that they receive from their families and to find ways for mobilising the needed support from the community. It has been found in previous studies regarding caregiving for children with cerebral palsy that young mothers who in most instances are unemployed are the majority of those struggling to cope with caregiving for children with CP (Pfeifer et al 2014:366). A similar scenario can be seen with those attending outpatient occupational therapy at two (2) public hospitals in Windhoek, Namibia.

As observed from the literature discussed above, there are various factors that have been linked with the burden of caregiving for people with various disabilities, although it was mostly CP. These factors cannot be generalised to the Namibian population of caregivers for children with CP since the studies were not done locally, therefore a need was identified to conduct this cross sectional descriptive study in Windhoek, Namibia. The aim of this study was to investigate factors that influence the burden of caregiving on the caregivers of children with CP in Namibia.

1.3 STATEMENT OF THE RESEARCH PROBLEM

Based on a study conducted to determine musculoskeletal disorders among caregivers in India following multilevel surgery, findings revealed that caregivers for children with CP in that setting had been found to suffer from musculoskeletal disorders such as myofascial pain syndrome, fibromyalgia syndrome and thoracic outlet syndrome (Sharan et al 2012:1893). However, Namibia does not have published studies of the factors that influence the burden of caregiving for children with CP by caregivers. This has created a knowledge gap to policymakers and health care professionals on possible challenges among the caregivers for children with CP. The researcher has observed that most of the caregivers are single mothers who report that the biological fathers do not support them financially or morally in caring for the child with CP. On average, the children with CP are hospitalised for at least a week annually, possibly secondary to some negligence on the caregivers' part. The researcher has also observed that both outpatient clinics at the two public hospitals in Windhoek, Namibia, the majority of the caregivers do not attend therapy at scheduled times owing to lack of transport fees.

The researcher, being an occupational therapist, has further observed that there is an increased number of clear negligence cases with the intention to cause harm on the child with CP and depressive episodes with suicidal ideations of caregivers of children with cerebral palsy in Namibia. It has also been noted that depression might be an underlying cause or factor of these suicidal tendencies of caregivers. The researcher assumed that these suicidal tendencies and depression of caregivers might be due to their burden of caregiving of CP children. These have led to this formal study that focused on the investigation of factors that influence the burden of caregiving for children with CP on caregivers in Namibia.

1.4 PURPOSE OF THE STUDY

The aim of this study was to investigate factors that influence the burden of caregiving on the caregivers of children with CP in Windhoek, Namibia.

1.5 RESEARCH OBJECTIVES

The research objectives of this study are the following:

- To determine factors that influence the burden of caregiving on caregivers for children with CP in Namibia;
- To describe the burden of caregiving on caregivers for children with CP;
- To identify the challenges that are faced by caregivers in caring for children with CP and
- To identify strategies that lessen the burden of caregivers for children with CP.

1.6 RESEARCH QUESTIONS

The research questions are the following:

- What are the factors that influence the burden of caregiving on caregivers for children with CP?
- What is the burden of caregiving for children with CP on caregivers?
- What are the challenges faced by caregivers in caring for children with CP?

1.7 DEFINITION OF CONCEPTS

A conceptual definition is the abstract meaning of concepts under study, while an operational definition is referred to as the operations that the researcher must perform to measure the concept (Polit & Beck 2012:52).

1.7.1 Caregiver

Caregiving is the physical, emotional or social care provided by a parent, family member or friend to an individual that has a chronic illness or disability that hinders him/her from performing daily activities such as bathing, feeding or toileting on his/her own (Barker 2014:55). The term caregiver can apply in institutional or non-institutional setting. In this study a caregiver is an individual who provides unpaid care for a child with CP for a minimum of six (6) months. The care provided includes assistance of all self-care tasks such as bathing, toileting, feeding and mobility.

1.7.2 Caregiver burden

Caregiver burden has been defined as the physical, psychosocial and financial construct that an adult caring for another person with severe functional impairments and limitations. The child with a disability often is completely dependent on the environment and the adult in to meet common daily tasks which then often challenges the adult carer to adjust their supposed daily schedules and accommodate the child with a disability (Giovannetti, Pagani, Sattin, Covelli, Raggi, Strazzer, Castelli, Trabacca, Martinuzzi & Leonardi 2012: 1). In this study caregiver burden will be all psychological, financial, social and musculoskeletal challenges that caregivers for children with CP in Namibia are facing.

1.7.3 Cerebral palsy

Cerebral palsy can be defined as an early onset in childhood permanent chronic disability of the central nervous system (CNS) affecting posture, tone and movement (Dias & Dias 2017: 001). Based on this study, cerebral palsy is referred to as a medical condition that presents with motor and fine motor difficulty in the affected child resulting in total dependence on the caregiver for managing daily activities such as feeding, bathing and mobility.

1.7.4 Children

The African Child Policy Forum (ACPF) under the convention on the rights of the child has defined a child as any person below the age of eighteen (African Child Policy Forum 2013: 1). In this study children are CP recipients of care below the age of eighteen (18).

1.7.5 Financial costs

Financial costs relate to direct monetary expenditure related to the care of the person with an impairment or loss of income secondary to being a full-time caregiver (Lai 2012:1). In this study financial burden is the perceived financial strain being incurred by the caregiver directly owing to the responsibility of caregiving for the child with CP.

1.7.6 Primary caregiver

A primary caregiver is an adult who assumes the most responsibility for the healthcare needs and decisions for a child (Villarreal, Turner, Jo, Park, Gemmen, Pircon, Castrejon, Hausdorff 2017: 2). A primary caregiver in this study is an adult who has been performing the most basic tasks for the CP child for a minimum period of six (6) months before the study.

1.8 RESEARCH SETTING

The research setting was at an out-patients departments of the two public hospitals where the care recipients were being rehabilitated. These two public hospitals are also the two national referral hospitals in Namibia.

1.9 RESEARCH DESIGN AND METHODOLOGY

1.9.1 Research design

A quantitative, non-experimental, descriptive and cross sectional design was used in the form of a survey to investigate factors that influenced the burden of caregiving for children with CP on caregivers. As a cross sectional descriptive study, the data were collected at the same point in time from the same respondents (Brink, Van der Walt, Van Rensburg 2012:101).

1.9.1.1 Quantitative design

A quantitative descriptive study design is a non-experimental technique that is used to describe variables (Athanasou, Di Fabio, Elias, Ferreira, Gitchel, Jansen, Malindi, McMahon, Mpofo, Nieuwenhuis, Perry, Panulla, Pretorius, Seabi, Sklar, Theron & Watson 2012:112). In this study different variables that describe the burden of caregiving for children with CP were described. The dependent variables were age group, marital status, care recipient living with, level of education and care recipients'

level of disability. The independent variables were musculoskeletal, emotional wellbeing perceived social and financial challenges.

1.9.1.2 Descriptive design

This type of study is designed to observe, describe and document the characteristics of the group under study and provide data for theory development (Polit & Beck 2017:206). In this study, factors that characterised the burden of caregiving for children with CP were determined based on the study objectives.

1.9.1.3 Cross sectional design

Cross sectional studies are useful in describing facts and relationships at a fixed point in time of an identified phenomenon or fact of a population (Polit & Beck 2017:168). In this study a cross sectional study design was used to identify the challenges that are faced by caregivers in caring for children with CP.

1.9.2 Research methods

Research method is referred to as the techniques employed by the researcher in structuring the study (Polit & Beck 2012:12). The quantitative method was used for data collection. Numerical data was collected using a questionnaire and statistical methods were used to analyse the gathered data.

1.9.2.1 Research population

A population is the entire group of individuals that is of interest to the researcher and meets the inclusion criteria for the study (Brink et al 2012:131; Burns & Grove 2009: 290). The population was all primary caregivers of children with CP in Namibia that met the inclusion criteria.

A proportion of the target population of which the researcher has access to is called the accessible population. This group may be limited to a certain region, district or institution (Brink et al 2012:132). The accessible population for the study were the

caregivers of children with CP who are registered and are being rehabilitated at either of the two public hospitals.

A total of one hundred and twenty (120) caregivers of children with CP who are registered with either the physiotherapy or occupational therapy departments at the two public hospitals were targeted.

1.9.2.2 Sampling technique and sample

A sample may be defined as the subset of a population that has been selected to be the respondents in a particular study (Burns & Grove 2009:91). Sampling approach may either be probability/random or non-probability sampling (Brink et al 2012:134). Total population sampling which is a type of purposive sampling was used. This was also based on the researcher's knowledge of the population under study. Purposive sampling technique is an example of a non-probability approach. The sampling frame was all caregivers for children with CP appearing on the registers of either the physiotherapy or occupational therapy departments at the two public hospitals. These two public hospitals are also the two national referral hospitals; therefore it was easier to access the respondents from their clinics. A total of one hundred and twenty (120) caregivers for children with CP were on the registers of both the occupational therapy and the physiotherapy departments at the two public hospitals. Ninety-one (91) respondents agreed to participate in the study.

1.9.2.3 Inclusion and exclusion criteria

Inclusion or exclusion criteria are those traits of a respondent that will either be included or excluded from the target population (Burns & Grove 2009:291).

The inclusion criteria were the following:

- A confirmed CP diagnosis by the paediatrician using a medically approved format for the child being cared for by the caregiver.

- The caregiver should have been a primary caregiver for a child with CP for a minimum of six (6) months and he/she should have been informally providing the caregiving services. Furthermore, he/she was not paid to be a caregiver.
- The care recipient should be registered on the patient register of either occupational therapy or physiotherapy departments at the two public hospitals.

The exclusion criteria pertained to the caregivers of CP children diagnosed as delayed milestones or failure to thrive.

1.9.2.4 Data collection instrument

The process of data collection in a quantitative study involves gathering accurate, valid and meaningful data that is primarily intended to answer the research questions of the study being conducted (Polit & Beck 2012:293).

1.9.2.4.1 Development of an instrument

After identifying the respondents, the next step was the selection of an appropriate data collection instrument to measure each variable either in terms of its conceptual or operational terms (Polit & Beck 2012:294). A questionnaire was an instrument which was used. The researcher considered the research objectives while developing it. It was developed by adapting the Zarit Burden Interview tool (refer to Annexure 8). This was a self-administered type of a questionnaire. Authors of the Zarit Burden Interview tool were contacted to ask them for permission to adapt their tool for the purpose of this study (refer to Annexure 6). Their response was positive and it is attached (refer to Annexure 7). Permission for adapting the tool was granted so as to measure the subjective burden and depression amongst caregivers respectively.

The questionnaire was written in the English language. The questions were unambiguous and they were clarified as the researcher used the service of an interpreter during data collection. Clarification was made by using the vocabulary easily understood by the caregivers in Namibia. It consisted of close-ended and open-ended questions (refer to Annexure 9). The types of questions were made to follow

the Likert scale format and also consisted of some questions requiring yes or no responses.

1.9.2.4.2 Pre-testing of the questionnaire

The process of pre-test is done with a small group of individuals who belong to the same population as the respondents so that the research instrument can be evaluated and refined (Polit & Beck 2017:268).

The purpose of this pre-test was:

- To determine if the data collection instrument was measuring what it was intended to. To find how long it took for the respondents to complete the questionnaire;
- To identify practical problems with the implementation of the data collection process and
- To check its validity and reliability. Content validity of the data collection instrument was checked by the research supervisor, statistician and multidisciplinary experts in the rehabilitation of children with cerebral palsy (CP) and their caregivers.

Pre-testing of the instrument was conducted over a period of four (4) days.

To ensure privacy, the setting for data collection was in a private office at the occupational therapy department at one of the two public hospitals.

The researcher filed and locked the pre-tested and modified questionnaires and informed consent forms (refer to Annexure 9 and 10) in a lockable cabinet and the researcher was the only person with access to them. The cabinet was inside a private office in the occupational therapy department.

1.9.2.3 Data collection

Data collection is the process of gathering information for the intention of answering an identified research problem (Polit & Beck 2017:725). Data was collected after the pre-testing of the instrument and after approval for conducting the study had been granted by the Research and Ethics committee of the Department of Health Studies

at the University of South Africa (UNISA) (refer to Annexure 1b), and after permission to conduct the study had been granted by the research unit of the Ministry of Health and Social Services (refer to Annexure 3). Permission was also granted by the medical superintendents at the two public hospitals that were used in the study (Annexure 12 and Annexure 13).

The potential respondents on the registers of both the physiotherapy and occupational therapy departments at the two public hospitals were telephonically contacted by the researcher inviting them to participate in the study. The respondents who agreed to participate in the study were then scheduled to complete the questionnaire with the researcher at the public hospitals. A total number of ninety-one (91) respondents participated in the study.

A bilingual occupational therapy assistant was used as an interpreter throughout the data collection process. The interpreter was requested to sign a confidentiality binding contract (refer Annexure 11). Data collected was stored electronically while the questionnaires and the signed informed consent forms were securely stored. After the data collection respondents were each given fifty (N\$50) Namibian dollars as transport money.

1.9.2.4 Data analysis

Descriptive statistics were used in order to analyse the data set. Different techniques were used in converting the descriptive data into knowledge (Brink et al 2012:179). These are described in detail in chapter three (3) which is the methodology chapter. Information obtained from the descriptive statistics was in the form of frequencies of a particular response by the respondents (Du Plooy-Cilliers, Davis & Bezuidenhout 2014:210-212).

A statistician was consulted to assist in the analysis and presentation of the data. Associations and differences were calculated with the statistical package International business machines (IBM) statistical package for the social sciences (SPSS) version 24, 0, while patterns of relationships were presented graphically (Brink et al 2012:178).

Inferential statistics were used to make inferences to the population under study, while descriptive statistics expressed as percentages were reported for categorical variables (Brink et al 2012:180). Since outcome data obtained from the respondents were independent from the next respondent, a chi-square test for the trend was used to analyse the data collected and drawing conclusions from the data (Brink et al 2012:191). Finally, data were presented in the form of tables and figures.

1.10 VALIDITY AND RELIABILITY

1.10.1 Validity

Validity is the evaluation of a research to determine if it measures what it is meant to measure (Du Plooy-Cilliers et al 2014:256). The following types of validity were addressed:

- Internal validity;
- External validity;
- Content validity;
- Construct validity;
- Face validity and
- Criterion related validity.

1.10.2 Reliability

Reliability can be defined as the credibility and consistency of the measurement method in ensuring that research findings may be reproduced if the study is repeated (Burns & Grove 2009:332; Du Plooy-Cilliers et al 2014:254).

The different types of reliability which were addressed are the following:

- Inter-rater;
- Test-retest and
- Internal consistency.

Validity and reliability are fully discussed in Chapter 3, which is the research design and methodology chapter.

1.11 ETHICAL CONSIDERATIONS

Ethics can be defined as the professional code of conduct that forms the basis of a researcher's attitude and behaviour throughout the research process (Du Plooy-Cilliers et al 2014:263).

1.11.1 Researcher specific ethical considerations

Data were collected after approval for conducting the study had been granted by the Research and Ethics committee of the Department of Health Studies at the University of South Africa (UNISA) (refer to Annexure 1b), and permission to conduct the study had been granted by the research unit of the Namibian Ministry of Health and Social Services (refer to Annexure 3). Permission was also requested for conducting the study from the two public hospitals' medical superintendents (refer to Annexures 12 and 13). Permission was also granted to use the questionnaire which was adapted from the Zarit Burden Interview (refer to Annexure 8).

1.11.2 Respondents' specific ethical considerations

- **Informed consent**

Before completing the questionnaires, the respondents signed informed consent forms in duplicate (refer to Annexure 10). Throughout the study the researcher emphasised that the respondents were free to withdraw from the study at any moment without facing any penalty since participation was voluntary. Before respondents completed the data collection information, all information pertaining to the aims, objectives and significance of the study was explained to them in a language they understood better. An interpreter was further used in cases where the respondents struggled to understand instructions that were in English whilst they were completing the questionnaire. The researcher ensured the privacy of the respondents by allowing

them to complete or respond to the structured questionnaire (refer to annexure 9) in a private room at one of the two public hospitals, free from intrusion by outsiders.

- **Anonymity**

The respondents were requested not to use their own names while completing the questionnaires but rather to use only initials so that anonymity could be maintained. Furthermore, identifying information such as address or email address was not collected from the respondents. In reporting the results from the study, it was done in a manner that did not link individual caregivers to the responses given by ensuring that no detailed descriptions of the caregivers or care recipients were done.

- **Confidentiality**

The researcher did not gather information in hidden formats without respondents' knowledge. The researcher refrained from sharing private information about the respondents without their permission. The statistician and interpreter were requested to sign a confidentiality binding contract in that regard (refer to annexure 11). The identity of the respondents remained anonymous in the study report and they will also be anonymous in all publications.

Only the researcher had access to raw data from the study. Electronic data of questionnaires and results on the laptop were password protected.

1.12 SIGNIFICANCE OF THE STUDY

The study aimed at providing information for policymakers, health personnel and social services on the medical, social and psychological challenges that caregivers for children with CP in Namibia encounter. Furthermore, the results from the study will be presented to the Ministry of Health and Social Services (Namibia) so that this can be used to inform the ministry in the formulation of relevant policies in community-based

rehabilitation that might result in improving the lives of children with physical disabilities and their caregivers.

The results provided baseline information on the burden of caregiving in Namibia and will inform further studies that can be done in investigating the role and relevance of informal caregiving in Namibia. By raising awareness on the burden of caregiving for children with CP on caregivers, health care professionals will be better informed on the family dynamics to be considered while providing interventions to the child with CP. The results further highlighted the importance of a holistic approach in rehabilitation.

1.13 SCOPE AND LIMITATIONS OF THE STUDY

Total population sampling which is a type of purposive sampling technique was used in getting respondents for the study, therefore the research findings can be analytically generalised for the Namibian country at large. However, they cannot be statistically generalised since the list of potential respondents may be incomplete or some may prefer not to participate in the study.

The researcher was an Occupational Therapist working with the care recipients and caregivers from whom data were collected. Thus, the researcher and caregiver relationship from the therapy sessions may have had an influence on the responses by the caregivers.

1.14 STRUCTURE OF THE DISSERTATION

The structure of the dissertation is presented in Table 1.1 below:

Table 1.1 Structure of the dissertation

Chapters	Title	Description of the chapter
1	Introduction	An overview and background to the study and study objectives. Research design, methodology, and conceptual and operational definitions are discussed in this chapter.
2	Literature review	It covers the information from the literature related to the study.
3	Research design and methodology	The research design, data collection instrument and methodology, and ethical principles considerations for the study are discussed in chapter 3.
4	Data analysis, presentation and interpretations of the results	Research results are analysed, presented interpreted and in chapter 4
5	Discussion of the results, limitations recommendations and conclusion	Conclusions and recommendations from the research results are discussed in chapter 5.

1.15 CONCLUSION

This chapter covered an overview of the study. The objectives of the study are to investigate the factors that influence the burden of caregiving for CP children in Namibia and the effect it has on the care recipients. The research design and methodology of the study were discussed. The ethical considerations and significance of study were also discussed. The next chapter presents the literature review.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In Chapter 1 the background, research purpose, research design and methodology were briefly discussed. In this chapter, the reviewed literature is presented. To ensure that literature selected was relevant, appropriate and useful, sources used had to be less than five (5) years old with the exception of literature for defining caregiver burden theory and definitions. Scope of literature was selected from online journal publications, public health and nursing textbooks and Namibian government publications. Previous studies relating to caregiver burden and study objectives were reviewed.

The following topics were addressed from the reviewed literature sources:

- Discussion of cerebral palsy, definition, prevalence, signs and symptoms and causes;
- Care of a child with cerebral palsy internationally, in an African context and in Namibia;
- Definition of caregiver burden and the factors influencing caregiver burden;
- Coping strategies with caregiver burden among different caregivers and
- Primary healthcare strategies and the prevention of caregiver burden.

2.2 DISCUSSION OF CEREBRAL PALSY

2.2.1 Definition and description of cerebral palsy

Cerebral palsy (CP) refers to a group of wide ranging non-progressive neurological, physical, cognitive, communicative and behavioural disorders that are caused by damage to the developing foetal or infant's brain (Oskoui, Coutinho, Dykeman, Jette & Pringsheim 2013:511).

CP leads to gross functional limitations which usually result in secondary complications such as contractures and scoliosis deformity. Epilepsy usually accompanies the motor disorders, thereby causing behavioural and participation restrictions in activities of daily living (Rosenbaum, Paneth, Levinton, Goldstein & Bax 2007:9).

Four major dimensions are used in classifying a child with CP, namely:

- Motor abnormalities that classify the child according to the type and nature of the disorder as well as the extent to which the child is affected;
- Accompanying impairments classify the child according to later developing motor impairments or the non-motor impairments and how these are presenting, for example seizures, and hearing and speech impairments;
- Anatomical and neuro-imaging findings classify the child according to the parts of the body that are affected, for example all four limbs and
- Causation and timing classify the child according to the exact cause, if known, and when it happened (Rosenbaum et al 2007:12).

In a study done in Kampala, Uganda, to describe the CP subtypes as well as to describe common comorbidities, 75.6% had learning disabilities and it was found to be the commonest comorbidity, followed by 45% of the children having epilepsy (Kakooza-Mwesige, Forsberg, Eliasson & Tumwine 2015:5).

2.2.2 Prevalence of cerebral palsy

In a comprehensive systematic review to get an intensive and detailed update on the prevalence of CP globally, it was estimated that prevalence of CP was 2.11 per 1000 live births (Oskoui et al 2013: 511). Prevalence of CP in relation to gestational age was found to be the highest amongst pre-term babies weighing less than 1500g (59,18 per 1000 live births) compared to babies born weighing more than 2500g (1,33 per 1000 live births). In relation to gestational age, the highest prevalence was also found for babies born before twenty-eight (28) weeks gestational age (111 per 1000 live births) as compared to babies born after thirty-six (36) weeks gestational age who had a prevalence rate of 1,35 per 1000 live births (Oskoui et al 2013:511).

2.2.3 Causes of cerebral palsy

Factors which have been linked as causes for CP include acute hypoxia beginning in labour and neonatal encephalopathy (MacLennan, Thompson & Gecz 2015:780, 781). Risk factors associated with high prevalence of CP include preterm birth, bacterial and viral intrauterine infections, intrauterine growth restrictions (IUGT), antepartum

haemorrhage, tight nuchal chord and threatened miscarriage (MacLennan et al 2015:781).

A cross sectional descriptive study was conducted at a public tertiary hospital in the Ugandan capital city of Kampala to describe the CP subtypes, gross and fine motor functions as well as to describe common comorbidities. While a normal child develops the ability to finger feed in the last few months of their first year, twenty (20) children with CP in that study had lost this ability after suffering from post-natal CP which had been likely caused by cerebral malaria or meningitis (Kakooza-Mwesige et al 2015:7). Implications of these findings inform public health practitioners to ensure that preventative measures are put in place to curb new cases of CP caused by meningitis or cerebral malaria.

2.2.4 Symptoms of cerebral palsy

The following are some of the symptoms associated with CP:

- Delayed motor development;
- Abnormalities of muscle tone;
- Atypical postures;
- Asymmetrical muscle tone, strength, reflexes, posture and coordination and
- Persistent infantile reflexes such as the moro and asymmetrical tonic neck reflexes (Liptak & Murphy 2011:1322).

2.2.5 Characteristics of the caregiver populations

In a mixed method type study in Kilifi, Kenya, which was conducted to find potential physical health effects of caring for a child with moderate to severe motor impairments, a caregiver was identified as the one spending proportionately more time with a child than any other person (Geere, Gona, Omondi, Kifalu, Newton & Hartley 2012:383).

From the reviewed studies, it was found that the time that a primary caregiver had looked after care recipient varied from six (6) months to five (5) years, with a common pattern of a minimum of one year (Wijesinghe, Cunningham, Fonseka, Hewage & Ostbye 2015:90; Dambi, Jelsma & Mlambo 2015: 3).

Another common characteristic among the caregivers was that they were predominantly the biological mothers of the children with CP while grandmothers were the other common group of caregivers (Dambi et al 2015:4, 5; Wijesinghe et al 2015:88). Unlike in developed countries or at formal care facilities, the average caregiver in developing countries stays with the care recipient with the extended family, in some instances it may even be up to nine (9) people staying within the same household (Barlindhaug, Umar, Wazakili & Emaus 2016:3).

The caregivers who participated in the caregiving burden studies were an average age of thirty (30) years old, with 61% of them being unemployed, 30% informally employed and 9% formally employed. Of these caregivers, at least 65% had secondary education while 20% had tertiary education (Dambi et al 2015:4).

Other studies looking at caregivers' burden found that the majority (more than 50%) of caregivers are females, with an average of below high school level of education (Ma, Lu, Xiong, Yao & Yang 2014:187). Caregivers in this particular study reported that their own health had worsened since they started caregiving duties; however, they did not specify exactly which aspect of their health had been affected (Ma et al 2014:187). Similar to previous research findings, older age caregivers have been found to be associated with more burden, while other caregiver characteristics such as marital status had no influence on caregiver burden.

What is lacking in the trends is an explanation why females are the more likely caregivers than males. In an editorial article that aimed to summarise previous work pertaining to gender differences, it was indicated that some studies have put forth the stress coping theory as an alternative explanation for having more females than males as caregivers. Furthermore, the review article also indicated that culture and ethnicity influence gender disparities in communities (Sharma, Chakrabarti & Grover 2016:12).

2.2.6 Factors associated with caregiver burden

Factors which have been found to affect burden of caregiving have been identified as:

- Physical/musculoskeletal burden - this relates to chronic fatigue and damage to the physical health of the caregiver (Wang et al 2014:990);
- Developmental - Developmental burden can be defined as the time lost from doing what is appropriate for people of one's age (Wang et al 2014:992);
- Time dependency burden – it is the perceived burden due to time restrictions due to demands of the caregiving (Wang et al 2014:992);
- Psychological and emotional burden – this refers to negative feelings towards the care recipient and strong feelings of being overwhelmed which often results in depression, anxiety and guilt feelings for not enjoying their caregiving role (Wang et al 2014:990);
- Social burden – this refers to misunderstandings and conflicts which arise in the family secondary to care decisions. It can also be the inability to engage in social participation by the caregiver owing to their caregiving role resulting in feelings of isolation and loss of social relationships (Razani, Kakos, Orieta-Barbalace, Wong, Casas, Lu, Alessi & Josephson 2007: 1417);
- Financial burden – this is the financial challenge arising from costs directly related to the care recipient (Lai 2012:7) and
- Health of care recipient – this is the burden related to the severity of the chronic medical diagnosis of the care recipient.

2.3 CARE OF A CHILD WITH CEREBRAL PALSY

Literature that focuses specifically on the care of a child with CP is lacking globally. Most studies have rather focused on challenges, aetiology and prevalence. Knowledge of CP amongst the community in Ghana was found to be lacking since 38,5% of participants shared that members of the community had blamed them for causing their child's disability, while 9,6% of the respondents had been advised to terminate the life of their child with CP. Poor insights into the child's condition and low educational levels usually leave the caregivers vulnerable to depression and susceptible to societal cultural attacks (Olawale, Deih & Yadaar 2013:162).

2.4 CAREGIVER BURDEN

2.4.1 ABC-X Theory

The concept of caregiver burden has been understood after a review of different conceptual models of caregiving. The effect of family crises or challenges is largely dependent on the recognition and management of the stressful event in their lives.

One model which was used to understand the effect of family crises was Reuben Hill's ABC-X Theory of family crisis. This theory was developed by Reuben Hill, who as a social scientist, was assigned to look at the impact of war casualties of American families in 1951. The theory is used in family development to describe the process of how families survive and endure over a lifespan. The ABC-X theory provides a framework that conceptualise how structural factors, extra familial resources, resource strains, and family caregiver perceptions influence outcomes of stress such as caregiver burden (Rosino 2016:1).

Factor A were structural factors which included characteristics of the recipient of care, while Factor B were resource strains of the caregiver which could strain coping abilities. In the expanded ABC-X theory, Factor C pertains to how the caregiver perceived the stressful situation (Rosino 2016:2).

2.4.2 Caregiver Stress Theory

The model was used to predict the extent of caregiving stress using demographic characteristics of carer, objective measurements of the caregiving tasks such as time spent, social support provided to the carer by the family and community, social roles of the carer and other stressful life events (Tsai 2003:137). The theory therefore helped in explaining and understanding the stress faced by caregivers and their relationships while caring for an ill relative, and in the study, specifically stress in caring for a child with CP. Assumptions while using the theory were that:

- Caregivers can respond to environmental changes;

- Caregivers' perceptions will influence how they respond to the environmental stimuli;
- How caregivers adapt is influenced by environmental stimuli and their adaption level and
- Chronic caregiving has a direct bearing on the caregivers' effectors such as their marital satisfaction, self-esteem, role enjoyment and physical function (Tsai 2003:137).

The caregiver stress theory (CST) can be summarised into three main categories which feed onto each other, which are the input (focal, contextual and residual stimuli), control process and output/adaptive mode (Figure 2.2 below).

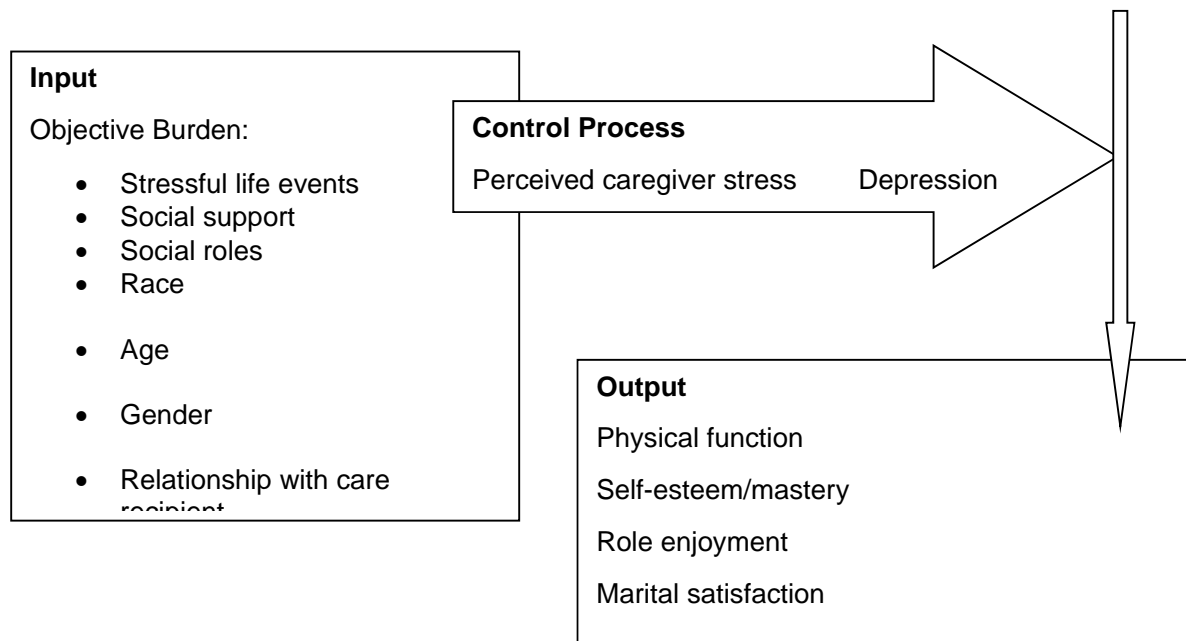


Figure 2.2 Caregiver Stress Theory (Tsai 2003:137).

Input

Focal stimuli - a focal point in the objective caregiving situation are the tasks and responsibilities such as the amount of time spent in performing caregiving tasks. These tasks then initiate coping mechanisms in the caregivers' life. When these tasks affect other aspects of the caregivers' lives such as their finances and relationships, it is then called contextual stimuli (Tsai 2003:140).

Contextual stimuli - this includes social support, social roles and stressful life events. Caregivers who had unresolved stressful life events will experience more stress than those who did not. CST proposes that if a caregiver has high quality of support he/she will be more likely to be less stressed than those with less social support. The third aspect of social roles suggests that the more roles the caregiver has, the better equipped mentally and physically he/she is in coping with caregiving stress (Tsai 2003:140).

Residual stimuli - this includes the caregivers' race, age, gender and relationship to the care recipient. Race is viewed as having a direct bearing on personal beliefs and values.

The theory suggests that older people will have better coping mechanisms to stress than young people since they have had more life experiences. Females are hypothesized as more likely to be prone to caregiving stress than males, while the relationship between the care recipient and the caregiver also had a direct influence on caregiver stress (Tsai 2003:141).

Control

This is the link between the input processes and the adaptive processes commonly manifested through caregiver depression and stress (Tsai 2003:141).

Output

The output section of the caregiver stress model comprises of categories of caregiver responses to stress. According to Tsai (2003:142), these are:

- Physical function - this specifically refers to physiological functions such as activity, rest, nutrition and neurological functioning;
- Self-esteem/mastery - mastery referred to the caregiver's ability to control things/tasks while self-esteem is defined as how important the caregiver felt in relation to themselves and others;

- Role enjoyment - the theory describes role enjoyment as the caregiver's presenting behaviour in relation to the major social role and
- Marital satisfaction - an effective adaptive response is indicative of high marital satisfaction.

The CST has been found to be relevant for families of chronically ill people thus it was found to be a good guide and reference for this study about children with CP since it is a chronic and permanently disabling medical condition.

2.5 PERSPECTIVES OF CEREBRAL PALSY

2.5.1 Developed countries perspective

- ***Physical/musculoskeletal burden***

In an Iranian qualitative study to explore co-occupations of mothers caring for their children with CP, it was found that the most important tasks that caregivers did included dressing and undressing the child, bathing, and feeding, as well as bathroom and toiletry activities. These activities often involve a lot of physical strain on the caregiver (Dalvand, Hosseini, Rassafaini, Samadi, Khankeh & Kelly 2015:453). The extent of assistance will then be dependent on the severity of the disability.

The results from the in-depth interviews of the same study in Iran also identified another physical strain contributing factor which is when parents accompany their children to school. The parents assumed the primary role of assisting with positioning, mobility and general care of the child since they complained that the quality of care services is poor at schools. These caregivers also complained that accompanying their children to school is not only time consuming but affects them physically and mentally (Dalvand et al 2015:455).

In a cross sectional study to determine the factors associated with the subjective burden among caregivers for adults with dementia in a Hunan province in China, a correlation between caregivers' employment status, duration of dementia and

behavioural and psychological symptoms of dementia (BPSD) of care recipients were significantly related to physical distress (Wang et al 2014:993).

In a mixed method study in the United States of America which aimed to establish musculoskeletal discomfort, burden of care and caregiving demands among caregivers for adults with physical disabilities, it was found that 95% of caregivers reported musculoskeletal discomforts with the commonest being low back pain. Identified tasks requiring physical input were transfers, mobility, lifting and assistance with activities of daily living such as bathing (Darragh, Sommerich, Lavender, Tanner, Vogel & Campo 2015:750).

- ***Psychological burden***

In a nationwide Japanese study which was conducted to determine the mental health of caregivers for children with disabilities, it was found that at least 50% of caregivers had psychological distress, with at least 8,9% of these having serious mental illnesses. This may be explained by how unsupportive families are or possibly some already existing underlying conditions (Yamaoka, Tamiya, Moriyama, Sandoval Garrido, Sumazaki & Noguchi 2015:6).

Caregivers who reported higher psychological distress had low social support, activity restrictions, were earning lower salaries and residing in rural areas (Yamaoka et al 2015:6; Wijesinghe et al 2015:88). A limitation in the nationwide study done in Japan however, was the failure to explore further on the type of social support mentioned in their study.

Higher incidences of mental health problems have been observed among caregivers without paid employment compared with others (Sawyer, Bittman, La Greca, Crettenden, Borojevic, Raghavendra & Russo 2011:340). This explains the results of a strong correlation that has been found between low income earners and psychological distress in the study done in Japan. This is likely due to higher bills associated with the child with a physical disability which includes hospital care, toiletries and assistive devices. A limitation in this study was that no specific mental

health diagnosis was mentioned and also nothing was mentioned on how those who had psychological distress had utilised medical services (Yamaoka et al 2015:6).

A study which was conducted in China regarding caregivers for adults with dementia revealed that higher emotional distress has been linked to the spouse of care recipient, living with them and being unemployed (Wang et al 2014:989). Furthermore, results from the same study also found that the caregivers perceived distress to be 98, 7%, with the commonest being apathy or indifference at 79,6% then depression was 68,4%, sleep and night time disorders was 59% and anxiety was found to be 53%. They also found a strong link between caregiver distress and Behavioural and Psychosocial Stress Disorder (BPSD).

Severe bio-psychosocial distress for caregivers for dementia patients was linked with caregivers who had been providing care for a significant long time without family support (Wang et al 2014:993).

- ***Time dependent burden***

Having a child with a mobility challenge has been found to be related to at least two hours more caregiving time than those with children who could walk with a walker (Sawyer et al 2011:340). Caregivers that have a higher time dependent burden compared with their peers are those living with the care recipient, have poor family support, are female, unemployed and have financial problems related to care recipient (Wang et al 2014:988).

This lack of support thereby contributes to lack of personal time for leisure for the caregiver. Other activities that the caregivers engage in with the children include being a playmate for the child with CP. A study on children with CP in the Iranian context which aimed at describing experiences of mothers with cerebral palsy, showed that the children had little skills in toy manipulation and exploration since they had fine motor and hand manipulation skills (Dalvand et al 2015:455).

- ***Social burden***

Social burden has been defined as how the caregiver perceives role conflict, specifically time, which they sacrifice providing care instead of performing other duties. Common factors that have been linked with an increased social burden have been residing in the same house as the care recipient, age of caregiver and financial costs related to the medical diagnosis (Wang et al 2014:989). Sharing a household with the care recipient possibly makes the primary caregiver the only person who fully understands the needs and challenges of the CP child, while age specific demands will determine roles which need fulfilment, thereby influencing the extent of the social burden.

The results from a cross sectional study with caregivers for patients with dementia in China indicated that 70% immediate family members gave more social support than the 43% from extended family (Wang et al 2014:989). Caregivers for children with CP in Harare also indicated how their social life had been changed resulting in them having isolated social life since they will be caring for the child with CP (Dambi et al 2015:5).

- ***Developmental burden***

In a descriptive American study that partly aimed to describe burden or psychological distress among family caregivers of clients with dementia, it was found that unemployed caregivers who lived with the child with a disability in the same house experienced more developmental distress as compared to other carers who were not staying with the care recipient (Razani et al 2007:1418).

- ***Health of care recipient***

Frequent hospital visits for emergency care and general management of symptoms has been linked with a higher burden of caregiving (Javalkar, Rak, Phillips, Haberman, Feris & Van Tilburg 2017:6).

Holistic management care of the child with CP by the multidisciplinary team always takes a family centred approach that also demands the caregiver to not only assume the role of accompanying the child for tests and hospital treatments but also to the

home therapist and nurse in providing home based rehabilitation programs as instructed by the therapist and the medical team (Dalvand et al 2015:455).

For those children who have mild to moderate disabilities and are able to attend school, some of them may have poor manual dexterity. The inability of the child with CP to write legibly, write at a fast pace or having good handwriting often leads to a lot of frustration to the child. All these frustrations are aimed at the parents who eventually find themselves with fatigue and frustration (Dalvand et al 2015:456).

2.5.2 Developing countries perspective

- ***Physical health of the caregiver***

Carrying a small child on one's back is a common African practice; however, this practice normally stops when children reach the age of four (4) years. However, for those families with children with physical disabilities that have affected their mobility, this practice of carrying the child continues well into adolescence. This has been found to be a contributing factor for low backache amongst some caregivers (Barlindhurg et al 2016:4).

While it is a common cultural custom of carrying children on an adult's back, it should be noted that some caregivers regard this practice as important but not essential (Geere et al 2012:387). This then means generalising that strapping children with disabilities on one's back causes chronic spinal pain may not be true for everyone. Dambi et al (2015:4) in their study on the experiences of caregivers in caring for a child with CP in Zimbabwe found that at the beginning of the study, caregivers reported physical strain and discomfort on the Caregiver Stress Index (CSI) and pain after the three months of the study period.

Low back pain has been found to be prevalent amongst caregivers of children with physical problems/ailments needing assistance with positioning transfers in either lying or sitting as compared to those with emotional and intellectual disabilities who do not require any physical input (Geere et al 2012:387). The results from this study are comparative with findings from a qualitative study in Ndola, Zambia, which aimed to

describe the challenges faced by caregivers of children with CP. Findings in the Zambian study also revealed that caregivers continuously perform physically demanding tasks of lifting, bathing and transferring the child, resulting in some caregivers saying that the strain can even make them suffer from headaches (Singogo et al 2015:3). Poor access to assistive devices such as hoists results in a lot of manual handling and physical input from caregivers. The overall lack of assistive devices makes it impossible for the child with mobility impairments to attend school, whereby the child stays at home needing full time care (Barlindhurg et al 2016:5).

The results from a qualitative study done with primary caregivers of children with CP in Malawi showed that the care of a CP child with incontinence problems often gives the caregiver a full time job of doing manual laundry throughout the day, thereby disrupting the caregiver from engaging in income generating activities such as farming (Barlindhurg et al 2016:5). This amount of hard work leads to poor health as revealed in the findings from a mixed method study conducted in Kenya with primary caregivers of children with motor impairments, loss of weight and being on chronic medication for a number of nonspecific physical discomforts. In the Kenyan study, researchers ended up giving most carers a provisional musculoskeletal diagnosis owing to passive and active movement restrictions (Geere et al 2012:386, 387).

Caregivers when asked to prioritise problems encountered in the fulfilment of their caregiving role listed spinal pain as the main concern (11 participants), shoulder pain (3 participants), lack of equipment (2 participants) and chores, which had only one participant listing it as a priority problem (Geere et al 2012:386). In this study, the task which was found to be most affected by musculoskeletal problems/ pain was child carrying and transfers. The results from the study by Geere et al (2012:389) however, failed to give a concrete association between caring for a child with CP and the poor health and well-being of the caregiver.

Physical burden can be in consideration of the amount of lifting and carrying which the caregivers do, ranging from picking to cuddle, transferring, and picking (Dalvand et al 2015: 454). Healthcare professionals often do not give sufficient education to families about CP, resulting in the families struggling to cope with the child (Olawale et al 2013: 161). Affected families thus felt that they could be in a better position to manage the

medical, postural and functional needs of the child better if they got more training from healthcare professionals (Olawale et al 2013:161).

- ***Emotional burden***

The role of being a primary caregiver for an individual with a disability can be emotionally stressful resulting in feelings of despair, guilt and resentment in some cases. Olawalale et al (2013:162) in their study in Ghana found that none of the caregivers in their study said that they were hopeless with the child's condition or ever contemplated terminating the life of the child.

This positive attitude could be linked with the findings from similar studies in Kenya and Malawi, whereby caregivers concealed their real feelings and chose rather to see caregiving as a blessing or a God given purpose which is yet to be revealed (Geere et al 2012:387; Barlindhurg et al 2016:5).

In a descriptive study aimed at establishing the well-being of caregivers in Zimbabwe, Dambi et al (2015:8) stated that less clinical distress was found among unemployed mothers, which was attributed to more bonding between the caregiver and the child, resulting in caregiving being seen as a blessing or calling while the employed caregivers have more responsibilities and roles to balance. This study also concluded that the caregivers suffered sleep deprivation; however, it is unclear how this was measured. Difficulty sleeping may be because of a crying child who has several discomforts or health problems which the child does not know how to communicate.

Furthermore, Dambi et al (2015:7) did not find any association between clinical stress of the caregiver and the child's age, severity of CP, caregiver age nor educational level and relationship between caregiver and child with CP. Another stressing factor for caregivers affecting their mental health is constant thoughts on what could have gone wrong with their child, though they try to conceal these troubling thoughts by seeing the child as a God given responsibility. They try to cope by hoping that one day the child will receive a miracle that will make him/her walk (Barlindhurg et al 2015:6).

Emotional issues, psychosocial issues and environmental factors were found to possibly contribute either negatively or positively to the caregiver's health and well-being (Geere et al 2012:387). In a qualitative study by Amakali and Small (2013:65, 66) to explore the lived experiences by parents caring for children with heart diseases in Namibia, it was found that the parents found themselves developing sympathetic feelings instead of being empathetic when their children are struggling with breathing or are exhausted. The parents feel guilty and get hopeless when they cannot access the food they feel is good for their child.

- ***Social burden***

While some families were supportive enough to take turns to provide full time/all day management of the child with a disability, other caregivers did not have any other family member assisting them in all day tasks such as doing exercises with the affected child, laundry and hospital visits for treatment (Barlindhurg et al 2016:5).

Caregivers have been found to spend less time with other community members since they spend most of their time doing laundry and taking care of the child with CP. Even though the families earn the respect of outsiders in their resilience and positive outlook, the burden of social participation restriction cannot be ignored (Barlindhurg et al 2016:4,5). Other factors brought forth from the qualitative study to describe challenges of caregivers for children with CP in Zambia include less time spent with community members, leading to feelings of being socially isolated and fear of being discriminated against since their community blames them for causing CP (Singogo et al 2015:3).

Contrary to other social burden findings, in their Zimbabwean study, Dambi et al (2015:5-8) concluded that caregivers had no disruption in their health and the quality of life in terms of usual activities, mobility and self-care. Some parents in a cross sectional descriptive study that aimed to investigate the socioeconomic challenges faced by parents of children with neurological dysfunctions in Nigeria also had no problems having neighbours who at times helped them to look after the child with CP while they attended to other duties and errands (Lawal et al 2014:62). Apparently, a

few caregivers had reported pain, discomfort, and depression with the passage of time but the research findings did not make it clear on the causes of these problems.

The respondents in the mixed method study in Kenya on the potential links between physical tasks and carers' health also strongly felt that a shared burden between parents of the child with CP does go a long way in improving the general well-being of the caregiver (Geere et al 2012:388).

Poverty has been found to increase burden both for caregivers who live in urban and rural areas; however, the rural areas are affected more since they have less access to formal services such as psychologist's interventions or assistance within the community from non-governmental organisations. Other obstacles that rural caregivers face include frequent transport costs to cities to access rehabilitation services (Wijesinghe et al 2015:91).

Some caregivers have found caregiving to be emotionally draining, possibly due to stigma towards disability, coupled with varying cultural beliefs that cerebral palsy is caused by the promiscuity of the mother or witchcraft (Singogo et al 2015:4). The feeling of being emotionally drained and helplessness can be related to constant care directed to any child with a permanently disabling ailment who is maximally dependent on care from an adult. In a Namibian study, parents caring for children with heart problems reported that they found it less fulfilling to engage in social relationship when they have constant thoughts about their child's medical problems taking more of their time (Amakali & Small 2012: 66). Parents in this study felt betrayed by their families who were not providing any form of social support. This finding describes a similar experience from the perspective of a rural caregiver for a child with CP in Malawi (Barlindhurg et al 2016:6).

- ***Financial burden***

In a Nigerian descriptive cross sectional study that aimed to investigate the socio-economic challenges faced by parents of children with neurological dysfunctions, it was found that at least 20% of the parents were earning an average of US\$60 per month, which is far below the US\$360 average income for other families .This could be linked to the disruption of business activities and higher costs of care related to

having a child with CP (Lawal et al 2014:64). Low income thus places the family in a lower social-economic class in the community.

A population based study was done using the Taiwan National Health Insurance database in Taiwan that aimed to determine the prevalence of cerebral palsy in the population group of children below the age of seven (7) years old and to also establish the association between socio-economic status and CP prevalence.

The results from this study revealed that there was an association between low income and higher prevalence of CP. It was also found that CP was more prevalent among the rural communities as compared to urban areas (Tseng, Lee, Chou, Sheu & Lee 2018:4).

Caregivers have been found to have lower educational attainment, thus lower chances of job opportunities (Brehault, Kohen, Raina, Walter, Russell, Swinton, O'Donnell & Rosenbaum 2004:188). This can possibly explain why some caregivers have suggested support in terms of extra income and food so that they may be better financially to provide care for the child with CP (Geere et al 2011:389).

The cost of living and expenditure has been found to increase when a family has a child with a disability. Some of the incurred expenses were transport to get medical assistance at tertiary hospitals far from where the family with the child with CP stay, purchase of assistive devices and at times it became necessary to employ a domestic worker to look after the other children (Lawal et al 2014:63). Furthermore, the continuous and unpredictable demands of caregiving were at times found to be contributory in making it impossible for caregivers to continue with their daily income generating activities.

Unfortunately, being unemployed further deepens the financial burden since healthcare costs and basic yet very important toiletries such as soap and nappies still need to be constantly provided. Caregivers in a cross-sectional descriptive study in Nigeria also indicated that the other siblings were being indirectly affected by the presence of the child with CP since now the family had to make budget cuts so as to accommodate the increased financial costs such as expensive medication and investigations of the child with neurological deficits (Lawal et al 2014:64).

Caregivers have also been found to have fear and worry about the future of the children with CP in their absence. Developmental changes such as puberty were some of the future worries that caregivers had (Barlindhurg et al 2016:5). In Namibia, the majority of caregivers for children with heart ailments were found to be female single parents who were often unemployed. These reported financial difficulties to provide an appropriate diet for their sick children. The poor diet coupled with low metabolism secondary to the heart condition often leads to failure to thrive among the children with heart conditions in Namibia (Amakali & Small 2013:67).

In a study to determine the effect of financial costs related to caregiving tasks on the caregiver burden in Canada, 36% of caregivers of patients with dementia also shared that caregiving is very expensive, while others also elaborated that the task of caregiving meant that they incur extra costs associated with caregiving and at times ending up spending some of their savings (Lai 2012:7). Caregiving regardless of the care recipient's age or diagnosis will result in a financial burden to the caregiver and his/her family.

- ***Health problems of the child***

In a hospital based prospective study to determine the clinical patterns, predisposing factors and associated co-morbidities among children with CP in India, the results showed that 55% had mental retardation, 45% had seizures, 26% had visual difficulties, 19% had hearing impairments and 47% had delayed development. Spastic CP was the most common being 81%, 12% hypotonic CP, 5% dystonic while mixed CP was the least common at 2%. Furthermore, researchers noted that seizures contributed to uncertainty to the prognosis of medical intervention (Gowda, Kumar, Shivappa, Srikanteswara, Shivananda, Mahadeviah, Govindraji & Ramaswamy 2015:112). High rate of comorbidity will then add to a higher burden of care since medication, rehabilitation and assistive devices are then a necessity.

From the findings in a nationwide survey in Japan on mental health of parents for children with disabilities, at least 51% of the children have been found to require

regular hospital visits (Yamaoka et al 2015:5). The most common subtype of CP with the presenting severe disabilities was Spastic CP (Dambi et al 2015:4).

Moreover, findings from a qualitative study in Malawi which aimed at gaining a better understanding of how families coped in caring for a child with CP and how they perceived rehabilitation services being offered, it was found that a delay by parents to bring the children with severe physical disabilities for continuous monitoring and treatment at the hospital usually leads to defaulting of medication for some days, thereby resulting in more seizures if the client is epileptic (Barlindhurg et al 2016:5). Similarly, children with CP have presented with the following health problems in a Kenyan study by Geere et al (2012:383) and in the Malawian qualitative study by Barlindhurg (2016:5):

- feeding and swallowing problems;
- verbal communication;
- mobility;
- spasms and
- regurgitation.

It was then stated that these problems add to the burden of care since the clients will be heavily dependent on a long-term rehabilitation program and may need regular doctors' follow-ups. The participants in a qualitative study done with primary caregivers of children with CP in Malawi noted that carers highly valued rehabilitation. They further strongly felt that rehabilitation had made a difference in what the children are able to do even though at times the most valued assistance may not have been provided (Barlindhurg et al 2016:5).

The child with severe CP in developing countries also lack mobility devices such as postural support wheelchairs. This then makes it impossible for them to attend school and this results in the risk of developing secondary complications such as fixed deformities and pressure sores from poor posture due to both lying and sitting (Barlindhurg et al 2016:4; Dambi et al 2015:6).

2.6 RELEVANCE OF STUDY ON CAREGIVING BURDEN IN NAMIBIA

The literature discussed in this chapter revealed that an informal caregiving model results in musculoskeletal, psychological and emotional problems for the caregiver involved (Barlindhurg et al 2016:5; Geere et al 2012:388). Informal caregivers have also been found to present with more emotional exhaustion and reduced personal accomplishment than professional caregivers (Lee & Singh 2010:40). The presence and impact of burnout of informal caregiving thus cannot be ignored. It is therefore important for researchers and practitioners to gather descriptive patterns of the factors related to emotional drain and quantify the percentage of informal caregivers affected in the area under study.

Findings from a study that was conducted in Italy on a single sample to determine the impact of care recipient factors, caregivers' factors and caregiving factors on the positive and negative impact of caregiving showed that only being a female and social restrictions contribute to a negative impact. Caregivers' quality of life and caregiving expenses predicted both negatively and positively on caregiving outcomes (Vellone, Fida, Cocchieri, Sili, Piras & Alvaro 2011:244).

Positive outcomes from informal caregiving include affection from care recipients, encouragement from the community and good relationships. Other benefits which result in positive experiences include the opportunity to do good deeds which is believed will be repaid positively in the future as widely taught in religious teachings (Gray, Hahn, Thongcharoenchupong & Thapsuwan 2016:10).

Annually family caregivers save the government healthcare systems \$25 billion in Canada and \$350 billion in America (Bastawrous 2013:434). To highlight the huge role played by family caregivers and to structure appropriate support programs, it is important to conduct both quantitative and qualitative studies so as to understand their challenges and experiences.

In a critical review discussion to analyse the definition of caregiver burden, it was suggested that future studies on caregiver burden need to adopt a mixed method approach so as to extensively get a full understanding of the concept of caregiver

burden (Bastawrous 2013:438). The study further suggested future studies to use stress and role theories as guiding frameworks.

2.7 CONCLUSION

In this chapter the researcher discussed cerebral palsy as a global problem. The prevalence, causes and signs and symptoms of cerebral palsy were discussed. The researcher further discussed caregiver burden in detail. Factors associated with burden of caregiver were reviewed globally, in Africa and in Namibia. The next chapter discusses the research design and methodology.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The previous chapter discussed the literature review. This chapter discusses the research design and methodology. A detailed description of the research setting, research design, methods and ethical considerations are addressed.

3.2 RESEARCH SETTING

Polit and Beck (2012:743) define a research setting as the actual site and circumstances in which data collection will take place. The research setting was at the out-patients departments of selected two public hospitals where the care recipients were being rehabilitated. The two public hospitals which were selected for this study are national referral hospitals. Most of the children with CP are referred to them for specialist services; therefore, it was easy to find a satisfactory number of the respondents for this study.

3.3 RESEARCH DESIGN

The researcher used a quantitative, non-experimental descriptive and cross sectional research design in the form of a survey. According to Polit and Beck (2017:164), a research design is the sequential techniques used by researchers in ensuring that their research yields accurate and easy to interpret evidence aimed at addressing a particular research question. The research design aims to provide the results which are credible (Athanasou et al 2012:81).

3.3.1 Quantitative design

Numerical or statistical data are presented through the use of quantitative research methods. In addition to other uses, quantitative methods are used to explain the

relationships and to generalise from a small sample to a larger population (Du Plooy-Cilliers et al 2014:14). The researcher aims to quantify data and make analytical generalisation of the results to all caregivers of children with CP.

3.3.2 Descriptive design

A descriptive design describes existing phenomenon through the use of numbers in characterising individuals or a group of people. Furthermore, the design measures factors of interest without manipulating the respondents. Numbers are used to describe entities (Athanasou et al 2012:88). The relationships between variables and the characteristics of events can be described by using descriptive statistics (Du Plooy-Cilliers et al 2014:75). In this study the researcher used descriptive statistics to describe variables that influence the burden of caregiving for children with CP by caregivers in Namibia. In this study the variables of interest are burden of caregiving, financial status of caregivers, psychological factors, social support and physical factors among the Namibian caregivers for children with CP.

3.3.3 Cross sectional design

Cross sectional design is defined as a type of study in which data are collected at one point in time (Polit & Beck 2017:168). In this study, a cross sectional study was done in the form of a survey. A survey can be defined as a process whereby a sample of the respondents is selected before a questionnaire is administered to them for specific research questions (Athanasou et al 2012:88). The respondents were purposively selected before the questionnaires were administered. This survey aimed to determine factors that influence burden of caregiving for children with CP in Namibia, and to describe the burden they are encountering. Variables to be described included physical factors, psychosocial factors, social factors and financial factors.

3.4 RESEARCH METHOD

Research methods are techniques used to put together a study and to collect and analyse data relevant to the research question (Polit & Beck 2012:13). The quantitative method was used.

3.4.1 Population

Population is the aggregate number of individuals or elements from which data are required (Du Plooy-Cilliers et al 2014:/.).

In this study, the target population was represented by all caregivers for children with CP in Namibia. The researcher, who was based in Windhoek, had direct access to caregivers for children with CP who were receiving occupational or physiotherapy rehabilitation at the two public hospitals under study (accessible population). A total number of one hundred and twenty (120) caregivers for children with CP were on the patient registers at the two hospitals. It was from this portion of the population that the sample was established for the study.

3.4.2 Sampling technique and sample

Sampling involves selecting a group of people, events, behaviours, or other elements from which to obtain information regarding a phenomenon in a way that best represents the population under study (Burns & Grove 2009:243; Brink et al 2012:132). It can either be random or non-random.

3.4.2.1 Sampling technique

In this study, the researcher used total population sampling to select the respondents for the study. Total population sampling can be defined as a type of purposive sampling that aims to examine an entire population which presents the same characteristics (Polit & Beck 2017:255). Polit and Beck (2017:255) list advantages of this sampling technique being that there is minimal chance of missing some information related to variables under study since all potential participants are invited to participate. Total population sampling included all members of the population under study, therefore, well detailed or exhausted data were expected, which makes it possible to make analytical generalisation to the rest of the population. The disadvantages in using this technique are that it is laborious and time consuming since the researcher needs to compile or access the full list of potential participants from the population. This technique was found to be best for the study since it would have a

smaller margin of error and the results obtained could be analytically generalised to the population under study in Namibia.

A sampling frame is a list of all elements of the population under study from which the sample is chosen (Brink et al 2012:132). Considering that there were already a total of one hundred and twenty (120) caregivers for children with CP that were on the physiotherapy and occupational therapy registers at the two public hospitals, the sampling frame was therefore the caregivers of all those who are listed on the registers. The caregivers for children with CP on the list were then all contacted and invited to participate in the study (Polit & Beck 2017:255).

3.4.2.2 Sample

A sample is a subset of a population (Polit & Beck 2012:742). One of the requirements of quantitative research is to draw a representative sample (Du Plooy-Cilliers et al 2014:135). Brink et al (2012:144) indicate that a sample should be calculated for each research problem since simply selecting a convenient number yields misleading results. The sample comprised of ninety one (91) primary caregivers of children with CP who met the inclusion criteria and who volunteered to participate to this study.

3.4.3 Eligibility criteria

Eligibility criteria are the standards defining the specific characteristics of the target population, by which people are chosen for inclusion in a study (Polit & Beck 2012:726).

3.4.3.1 Inclusion criteria

- The primary caregiver should have been informally providing caregiving services for a child with CP for a minimum of six (6) months before the study. Furthermore he/she was not being paid for services as a caregiver;
- Child under care should have a confirmed CP diagnosis by a paediatrician in their hospital inpatient folder or hospital outpatient card;

- Care recipient should be registered on a patient register of either occupational therapy or physiotherapy at the two public hospitals and

3.4.3.2 Exclusion criteria

- Caregivers whose care recipients were diagnosed as delayed developmental milestones or failure to thrive were excluded from the study.

3.5 DATA COLLECTION

Data collection is defined as the process of information gathering to address a research problem (Polit & Beck 2012:725). Du Plooy-Cilliers et al (2014:147) state that data collection is one of the crucial aspects of any research. The research question should guide the data collection method (Athanasou et al 2012:88).

3.5.1 Development of data collection instrument

A questionnaire is defined as a self-reporting document used to gather data (Polit & Beck 2017:741). It was used for collection of data for the present study.

The researcher developed a questionnaire comprising of questions relating to burden of caregiving for children with CP which was to be completed by all the respondents participating in the study. Furthermore, research objectives were considered. The data collection instrument (refer to Annexure 9) was developed through adaptation by the researcher using the Zarit Burden Interview (ZBI) instrument (refer to Annexure 8). The researcher applied for permission to adapt the ZBI from the author (refer Annexure 6) and permission was granted (refer to Annexure 7).

The ZBI is a data collection instrument which was developed by Stephen H. Zarit and it provides an in-depth assessment of both subjective and objective burden. It was found to be the best tool for use for this study since it has been validated in many different cultures and ethnic populations. The ZBI is the most commonly used data collection instrument in dementia caregiving research (Seng, Luo, Ng, Lim, Chiongh,

Goh & Yap 2010:759). The ZBI has been validated in English in a Sub-Saharan study with caregivers of stroke survivors attending an outpatient neurology clinic (Imarhiagebe, Asemota, Oripelaye, Akpekpe, Owolabi, Abidakun, Akemokwe, Ogundare, Azeez, & Osakue 2017:49).

The questionnaire was written in English language. The questions were unambiguous and they were clarified as the researcher used the services of an interpreter during data collection. Clarification was made by using the vocabulary easily understood by caregivers in Namibia. It consisted of close-ended and open-ended questions (refer to Annexure 9). The types of questions were a Likert scale and yes or no types of questions.

3.5.1.1 Characteristics of the data collection instrument

The questionnaire had thirty questions in total. The questions were four (4) open - ended questions and twenty-six (26) closed - ended questions (refer to Annexure 9). The researcher used an adapted ZBI questionnaire to collect data from caregivers who met the inclusion criteria. The questionnaire had four subsections:

- Section one (1) collected demographic details of the respondents. Demographic information collected information which included age, occupation, marital status, place of residence and level of education. It comprised of seven (7) closed - ended questions.
- Section two (2) focused on gathering data on factors influencing caregiver burden. Information gathered included severity of child's disability, living condition, physical health of the caregiver and spiritual belief relating to caregiving role. It consisted of five (5) closed - ended questions.
- Section three (3) sought to determine the caregiving burden as experienced by the respondents. The information gathered answered questions relating to the physical and psychological health of the caregiver as well as relations in the family with a child with CP. There were eight (8) closed - ended questions and one (1) open - ended question.
- Section four (4) gathered data on the challenges in the caregiving role. There were two (2) closed - ended questions and one (1) open - ended question.

- Section five (5) focused more on collecting data on strategies being used to lessen the caregiver burden. There were four (4) closed - ended questions and two (2) open - ended questions.

3.5.1.2 Pre-testing of the data collection instrument

The questionnaire which was adapted from the Zarit Burden Interview was pre-tested so as to evaluate if the quality of data/responses was providing factors associated with the burden of caregiving as well as to describe the burden and challenges being faced by caregivers for children with cerebral palsy.

Appointments were scheduled by the researcher with five (5) randomly selected respondents to take part in the pre-testing process. These respondents were not part of the main study since they might have responded differently after exposure to some of the questions during the pre-testing.

The respondents who volunteered to participate in the study were requested to sign the informed consent form (refer to Annexure 10) after the researcher had explained the purpose and significance of the study. They were informed about their right to participate and to withdraw from the study at any given time without any penalty. In order to maintain respondents' confidentiality, the respondents were asked not to write any identifying information on the questionnaires. Furthermore, the researcher did not share any information about the respondents. To ensure privacy the setting for data collection was in a private office at the occupational therapy department at one of the two public hospitals.

Twenty-five (25) minutes were allocated to complete the questionnaire. The respondents struggled to understand some of the words used such as 'overwhelmingly'. Two of the questions were noted as a repetition thus one was then omitted from the modified questionnaire. The use of an interpreter was noted as a necessity for the main data collection in order to clarify words which the respondents were struggling to understand. Afterwards the questionnaire was modified and translated into Oshiwambo language (refer Annexure 9a). The modified questionnaire was sent to the supervisor for approval (refer to Annexure 9).

The researcher filed and locked the completed pre-tested questionnaires and informed consent forms (refer to Annexures 9 and 10) in a lockable cabinet and the researcher was the only person with access to the cabinet. The cabinet is located at the occupational therapy department.

3.5.2 Data collection approach and method

The researcher used the quantitative approach for data collection. Researchers usually begin by identifying the type of data required for the study. Once data needs have been identified, the data collection methods are then chosen for all variables. In quantitative research, researchers collect data in an organised and controlled method (Polit & Beck 2017:266).

3.5.3 Data collection process

Data collection commenced after successful application for ethical approval to conduct study in Namibia was granted by Research and Ethics committee of the Department of Health Studies at the University of South Africa (UNISA) (refer to Annexure 1b) and research unit of the Ministry of Health and Social Services (refer to Annexure 3). Data were collected over a three (3) week period from the 16th of November 2017 to the 6th of December 2017.

The researcher telephonically contacted all potential respondents on the registers of both the physiotherapy and occupational therapy at the two public hospitals inviting them to participate in the study. Appointments were then scheduled for completion of the questionnaires with those respondents who had agreed to participate in the study at one of the public hospitals. Out of one hundred and twenty (120) who appeared on the patient register, a total of ninety-one (91) respondents volunteered and participated to this study and they were all listed on the registers.

Before data collection, the researcher explained to the respondents the purpose and significance of the study. Informed consent was also requested from the respondents (refer to Annexure 10). They were requested to sign and date the informed consent

form thus consenting to participate in the study. They were further informed that, participation in the study was voluntary and that they could withdraw at any time from participation without any penalty.

The researcher used the services of a colleague who spoke all native Namibian languages. This interpreter was introduced to the respondents and an indication of the reason of her presence in the study was explained. The interpreter signed a confidentiality binding contract (refer Annexure 11) with the researcher. The researcher ensured the privacy of the respondents by allowing them to complete or respond to the structured questionnaire in a private room at the two public hospitals, free from intrusion by outsiders. The respondents were asked not to put their identity on the questionnaire so that no one could link them to their responses. The respondents were also assured that their identity and information would not be shared with anyone in order to maintain confidentiality. They were further informed that the results from the research would be printed in a research thesis, and shared with the Namibian Ministry of Health and Social Services as well as publication in academic journals and or presented at academic conferences but their identity will not be revealed.

The questionnaire took an average of twenty minutes to complete. Ninety-one (91) questionnaires were completed from a possible one hundred and twenty (120) that are registered on the patient register. Collected data were then saved electronically via excel on a laptop and the data were password protected by the researcher. The questionnaires and the signed informed consent forms were locked in the researcher's personal cabinet and they were only accessible to the researcher throughout the data collection and analysis processes. As a token of appreciation for participating in the study, the respondents were each given fifty (N\$50) Namibian dollars after completion of the questionnaire so as to cover transport.

3.5.4 Data analysis

The purpose of data analysis is to convert and structure numerical data into meaningful data (Du-Plooy Cilliers et al 2014:211). Data obtained from open ended questions was quantified per response and frequency tables or graphs were used to present the results. For better clarity some of the responses from the respondents

were quoted and presented as obtained. Data which were collected from closed questions were descriptive and they were then forwarded for descriptive statistical analysis. Information obtained from the descriptive statistics was frequency and distribution for different demographic variables and the responses (Du Plooy-Cilliers et al 2014: 210-212).

The researcher used the services of a statistician for assistance in data analysis and presentation (refer to Annexure 14). Quantitative data analysis employs various techniques in converting the descriptive data into knowledge (Brink et al 2012: 179). The techniques employed for the study were:

- Data preparation - Data was edited, quantified then transformed into a presentable format (Muhammed & Yaakub 2013:4);
- Identification of variables for analysis which can be univariate, bivariate or multivariate was done. This study did multivariate analysis since there were more than two variables that influenced the burden of caregiving for children with CP in Namibia and
- Data were coded and entered into EPI info and analysis was done using SPSS version 24.0 of 2017. In that regard, the researcher used the services of a professional statistician.

Central tendency values such as average age of caregivers were calculated. Inferential statistics were used during the data analysis process to make inferences to the population under study at large, while descriptive statistics expressed as percentages were reported for each variable of interest (Brink et al 2012:180). A chi-square test was used to analyse the data collected and drawing conclusions from the data (Brink et al 2012:191) since the responses were independent from the respondents. Research data was presented in the form of different types of figures and tables.

3.6 VALIDITY AND RELIABILITY

3.6.1 Validity

Validity involves determining whether the research instrument measures what it is supposed to measure (Du Plooy-Cilliers et al 2014:254, 256). The following measures were done by the researcher to ensure the validity of the instrument:

3.6.1.1 Content validity

Content validity focused on evaluating whether the measurement being used included all elements of constructs being measured (Burns & Grove 2009: 335). In order to ensure content validity, eight (8) experts linked to the research and holistic management of children and caregivers of children with CP were used. The experts were the research supervisor, statistician, three masters' in public health lecturers, a clinical psychologist, a nurse and a medical social worker. The purpose of reviewing the content of the questionnaire was to improve the overall quality and representativeness of the scale items.

3.6.1.2 Construct validity

Construct validity looks at whether the tests are corresponding with the variables (Du Plooy-Cilliers et al 2014: 256). To ensure threats to construct validity, the researcher collected data after treatment sessions and encouraged the respondents not to feel pressured into responding to the questionnaire.

3.6.1.3 Criterion related validity

Criterion related validity determines the accuracy of the procedure when compared with another and its ability to predict the future (Du Plooy-Cilliers et al 2014: 256). To ensure criterion related validity, the results were compared with those collected using validated instruments such as the Zarit Burden Interview in a similar study in a developing country like Namibia.

3.6.1.4 External validity

External validity is the extent to which the research results can be generalised to the general population under different conditions, variations and settings (Polit & Beck 2017: 229). The results from the study will be analytically generalised to the Namibian population of caregivers for children with CP since the total population sampling technique was used, which is purposive.

3.6.1.5 Face validity

Face validity determines whether the design of the instrument and evaluation of it looks like what it was supposed to look like in relation to meeting research objectives (Du Plooy-Cilliers et al 2014: 256). To ensure good face validity in this study, the eight (8) experts being research supervisor, statistician and multidisciplinary experts in the rehabilitation of children with cerebral palsy (CP) and their caregivers judged the face validity of the instrument during the pre-testing of an instrument.

3.6.1.6 Internal validity

Internal validity refers to the conclusion that the outcome was caused by the independent variable (Polit & Beck 2017:223). To ensure internal validity, the researcher ensured that all feedback from experts was incorporated in the final instrument. The eight experts' being the research supervisor, statistician and multidisciplinary experts in the rehabilitation of children with cerebral palsy (CP) and their caregivers, who ensured that the research objectives were met and the questions in the questionnaire were addressed. Attrition bias was avoided by ensuring that data was collected at one point in time per respondent.

3.6.2 Reliability

Reliability refers to the reproducibility of a measured trait under study or study finding. When reliability is ensured, there is consistency in scores obtained if no variations

were done to study the respondents (Polit & Beck 2017: 303). To ensure reliability the following issues were addressed:

3.6.2.1 *Inter-rater*

This was the comparison of two observers or data collectors (Burns & Grove 2009: 333). To establish this in the study, the same instrument and structured method in the data collection were used for all the respondents.

3.6.2.2 *Test-retest*

This is the focus on ensuring that there is consistency in the results if the measurement is repeated with the same data collection instrument (Polit & Beck 2017: 304). This is difficult to establish in a cross sectional study since data were collected at different times with the same instrument but on different respondents.

3.6.2.3 *Internal consistency*

Internal consistency encompasses consistency of measuring the same construct with different items (Du Plooy-Cilliers et al 2014: 255). Data were collected through closed-ended and open-ended questions which enabled clarification of trait being measured thereby strengthening internal consistency.

3.7 ETHICAL CONSIDERATIONS

Ethical considerations refer to the steps followed in conducting the research to ensure that the rights of study participants are protected.

3.7.1 *Researcher- specific ethical considerations*

In order to obtain ethical clearance to conduct the research, the researcher submitted a research proposal to the Research and Ethics committee of the Department of Health Studies at the University of South Africa (UNISA). Ethical approval was granted

after the proposal was deemed to have met the stipulated ethical requirements (refer to Annexure 1b).

Permission to conduct the study with patients directly linked to the Ministry of Health and Social Services was granted by the permanent secretary of the Ministry of Health and Social Services, Namibia (refer to Annexure 3). Permission was also granted from the two public hospitals in Windhoek used for the study (Annexures 12 and 13). The permission granted by the hospital heads of the two hospitals also gave authorised access to patient registers at the occupational therapy and physiotherapy departments. Permission was also obtained from the author of the ZBI to adapt their data collection instrument (refer to Annexure 7).

3.7.2 Respondents' specific ethical considerations

Informed consent

The caregivers were fully informed of the aims of the study and procedures to be followed in collecting data. It was then clearly explained that information obtained was not going to be used against them or their child. Participation to the study was voluntary and the respondents were assured that they could withdraw from the study should they wish to without penalty, even if the consent form was signed (refer to Annexure 10).

Anonymity

In order to ensure anonymity, the researcher gave assurance that the respondents were not expected to record their names in the questionnaire. The researcher was also unable to match the identity of the respondents to the responses given (Du Plooy-Cilliers et al 2014:267).

Privacy

In order to ensure privacy, the researcher was not intrusive with the respondents' lives and ensured that their medical records and the information shared was kept strictly confidential during data collection.

Confidentiality

Assurance about the confidentiality of respondents entails that no information about the respondents will be publicly reported to third parties and data collected will not be accessible to other parties (Polit & Beck 2017: 147). In order to maintain confidentiality, all the completed questionnaires and informed consent forms (refer to Annexures 9 & 10) were kept in the researcher's personal cabinet which was only accessible to the researcher throughout the data collection and analysis process. Collected data was then saved electronically via excel on a laptop and was password protected by the researcher. A bilingual occupational therapy assistant who was used as an interpreter throughout the data collection process was requested to sign a confidentiality binding contract (refer Annexure 11). The researcher ensured that the respondents understood why the interpreter was present during the data collection process. They were further informed that the results from the research would be printed in a research thesis and shared with the Namibian Ministry of Health and Social Services as well as publication in academic journals and or presented at academic conferences but their identity will not be revealed.

3.8 CONCLUSION

In this chapter a comprehensive description of the research design and method was done. The description focused on the research setting, design, method and ethical considerations. The data collecting instrument was also described in detail. The next chapter is about the analysis, interpretation and presentation of the results.

CHAPTER 4

DATA ANALYSIS, PRESENTATION AND INTERPRETATIONS OF THE RESULTS

4.1 INTRODUCTION

Chapter 3 discussed the research design and the methodology. In this chapter data are analysed, interpreted and the results are presented. The researcher presented a description of data management and analysis. The presentation of the results is done under four main categories that are namely:

- Demographics of the caregivers for children with CP in Namibia;
- Description of the burden faced by caregivers (Factors influencing burden of caregiving);
- Challenges of caregiving for children with CP and
- Strategies to alleviate burden of caregiving.

The aim of this study was to investigate factors that influence the burden of caregiving on the caregivers of children with CP in Windhoek, Namibia.

The objectives of this study were:

- To determine the factors that influence the burden of caregiving on caregivers for children with CP in Namibia;
- To describe the burden of caregiving on caregivers for children with CP;
- To identify the challenges that are faced by caregivers in caring for children with CP and
- To identify strategies that lessen the burden of caregivers for children with CP

4.2 DATA MANAGEMENT AND ANALYSIS

The researcher together with the statistician (refer to Annexure 14) checked data for completeness, then edited the data, and lastly data were quantified then transformed into a presentable format (Muhammed & Yaakub 2013:4). Data were further cleaned and inconsistencies were corrected.

Data were coded and entered into EPI info and analysis was done using SPSS version 24.0.

Demographic details and burden characteristics were analysed using descriptive statistics. The type of data collected yielded the results in the format of frequencies and percentages since no actual figures such as exact age of caregivers was collected, instead age ranges were requested.

Bivariate analysis was used to describe the results of tests of association between potential factors and related caregiving variables of individual caregiver attributes and caregiving burden variables. Central tendency values such as the average age of caregivers were not calculated since only age ranges were captured. The highest number of the respondents was twenty-three (23) each from the age-group 25-29 and age group 35 plus years. Inferential statistics were used to make inferences to the population under study at large, while descriptive statistics expressed as percentages were reported for categorical variables (Brink et al 2012:180). A chi-square test was used to analyse the data collected and drawing conclusions from the data (Brink et al 2012:191) since responses were independent from the respondents. Responses from the open ended questions were quantitatively analysed. To clearly illustrate and give more detail on challenges and strategies, some of responses will be quoted and presented. The results were presented in the form of tables, bar graphs and pie charts.

4.3 RESEARCH RESULTS

4.3.1 Sample demographics

The demographic characteristics considered in this research included the age group, sex, marital status, and ethnic group, level of education, religion and fluency of languages spoken. Analysis was done from ninety-one (91) respondents.

A summary of demographic traits of the respondents for the study are summarised and each variable is discussed separately and sequentially in table 4.1 below.

Table 4.1 Demographic characteristics of caregivers (N=91)

Variables	Frequency (n)	Percentage (%)
Age group		
20-24	15	16.50%
25-29	23	25.30%
30-34	20	22%
35+	23	25.30%
Other	10	11%
Sex		
Female	89	97.80%
Male	2	2.20%
Marital status		
Married	31	34.10%
Single	53	58.20%
Divorced	2	2.20%
Other	5	5.50%
Ethnic group		
Oshiwambo	43	47.30%
Herero	13	14.30%
Damara>Nama	11	12.10%
Mixed race	9	9.90%
Caucasian	3	3.30%
Okavango	8	8.80%
Other	4	4.40%
Level of education		
Primary	18	19.80%
Grade 10	30	33%
Grade 12	23	25.30%
Tertiary	20	22%
Other (specify)		
Religion		
Christianity	88	97.80%
Muslim	0	0
African traditional	0	0
Other (specify)	2	2.20%

4.3.1.1 Age

From the data collected, there were 16.50% (n=15) respondents for the 20-24 age group, 25.30% (n=23) for the 25-29 year age group, 22% (n=20) for the 30-34 year age group, 25.30% (n=23) for the 35 and above age group, and 11% (n=10) stated their age as other. 'Other' age group might be referred to those respondents whom the researcher assumed that they were not willing to reveal their ages for personal reasons.

4.3.1.2 Sex

Ninety-seven-point eight percent 97.80% (n=89) of the respondents were female while only 2.20% (n=2) were males. The two males' category reveals that most males do not participate in caregiving for children with CP. Previous studies have revealed that predominantly female caregivers are the primary source of care regardless of the severity or nature of the disability (Pushpalatha & Shivakumara 2016:110; Fatudimu et al 2013:132). These studies therefore concur with the present study.

4.3.1.3 Marital status

In total, single women were 58.20% (n=53) whilst the married women were 34.10% (n=31). The researcher noted that most women were single and this could be due to the fact that those cohabitating were considered as single since they were not legally married. Two coma two percent (n=2) were divorced while 5.50% (n=5) stated their marital status as "other", which some explained as cohabitating for a long time. This trend is similar to the results from a study in Namibia that explained marital trends and patterns between 1992 and 2006 by Pazvakawambwa, Indongo and Kazembe (2013:6). In that study it showed that Namibian marriage system has undergone a gradual shift over the last fifteen (15) years with now the co-existence of the traditional framework type of marriage and cohabitation, and some individuals who choose to remain single until they are aged, for example into their late thirties. The study also found that the number of married individuals declined from 29.0% in 1992, 23.40% in 2000 to 20.40% in 2006.

4.3.1.4 Ethnic group

A greater proportion of respondents were from the Oshiwambo ethnic group 47.30% (n=43), followed by Herero 14.30% (n=13), then Damara>Nama 12.10% (n=11), mixed race 9.90% (n=9), Caucasian 3.30% (n=3), Okavango (Rukwangwali) 8.80% (n=8) then lastly other tribes which included Silozi (Zambezi region), foreign nationals and Tswana which totalled 4.40% (n=4). The distribution of the ethnic group tallies with the Namibia population census ethnic distribution results from 2011, in which results showed that 40.20% of the respondents were Oshiwambo speaking, the Herero speaking were 7.40%, Damara speaking were 7.30% and the Okavango speaking group was 10.70% (Namibia Statistics Agency 2013:43).

4.3.1.5 Level of education

According to the Namibian Ministry of Health and Social Services' *The Namibia Demographic and Health Survey* (2014:23), the level of education attended regardless of completion for the population was distributed as: 4.60% had no education, 19.60% had primary education, 65.70% had secondary education while 10.10% had more than secondary education. Furthermore, they concluded that the median years spent in formal school for the Namibian population was 8.9 years in urban areas. This trend is similar to the results from this study, whereby at least 19.80% (n=18) had completed primary education, 33% (n=30) had completed grade 10 education, 25.30% (n=23) had completed grade 12 and 22% (n=20) had completed tertiary education.

4.3.1.6 Religion

Ninety-seven-point eight percent 97.80% (n=89) of the caregivers in this study were Christians, while 2.20% (n=2) regarded their religion as other. This distribution of religious beliefs follows closely with the Namibian Ministry of Health and Social Services' *The Namibia Demographic and Health Survey* (2014:30), whereby 89.60% of the respondents were Christians, 1.10% had no religion while 9% gave their religion as other. This affirms that the Namibian population is largely Christian.

4.3.1.7 Languages spoken fluently

Table 4.2 Languages that respondents could speak fluently (N=91)

Language	Frequency (n)	Percentage (%)
English	87	95.60%
Afrikaans	36	39.60%
Other (Specify)	65	71.40%

Table 4.2 shows that in Namibia English and Afrikaans are the official languages while there are six (6) other possible languages the population can speak. This then explains the results from this study which had 95.60% (n=87) speaking English, 39.60% (n=36) speaking Afrikaans and 71.40% (n=65) speaking other languages. The respondents from this study revealed that on average more than one language is spoken fluently since they all responded to at least two (2) languages on the questionnaires (refer Table 4.2).

4.3.2 Factors influencing burden of care

4.3.2.1 Household living arrangements

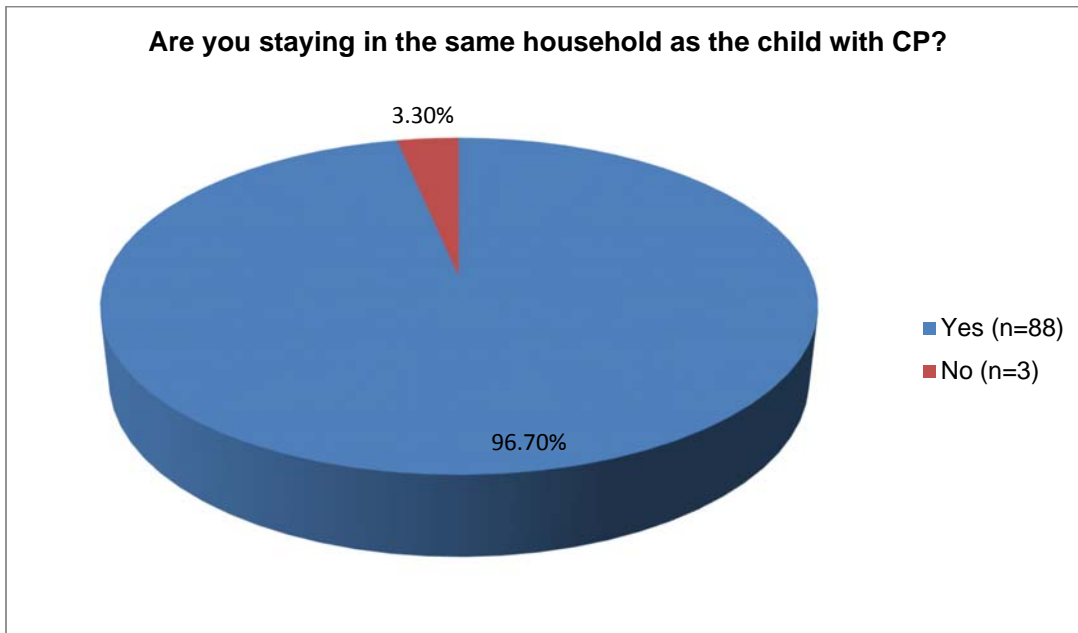


Figure 4.1 Results of household living arrangements of caregiver and care recipient (N=91)

The results from the study as shown in figure 4.1 revealed that 96.70% (n=88) of the caregivers lived in the same house as the care recipient, while 3.30% (n=3) were not staying in the same household as the child with CP. The researcher associated the

results with the Namibian Ministry of Health and Social Services' *The Namibia Demographic and Health Survey (2013:14)* which revealed that 31% of the Namibian population share one room for sleeping, 26% have two (2) rooms for sleeping and 43% use three (3) or more rooms.

4.3.2.2 Spirituality of caregiver

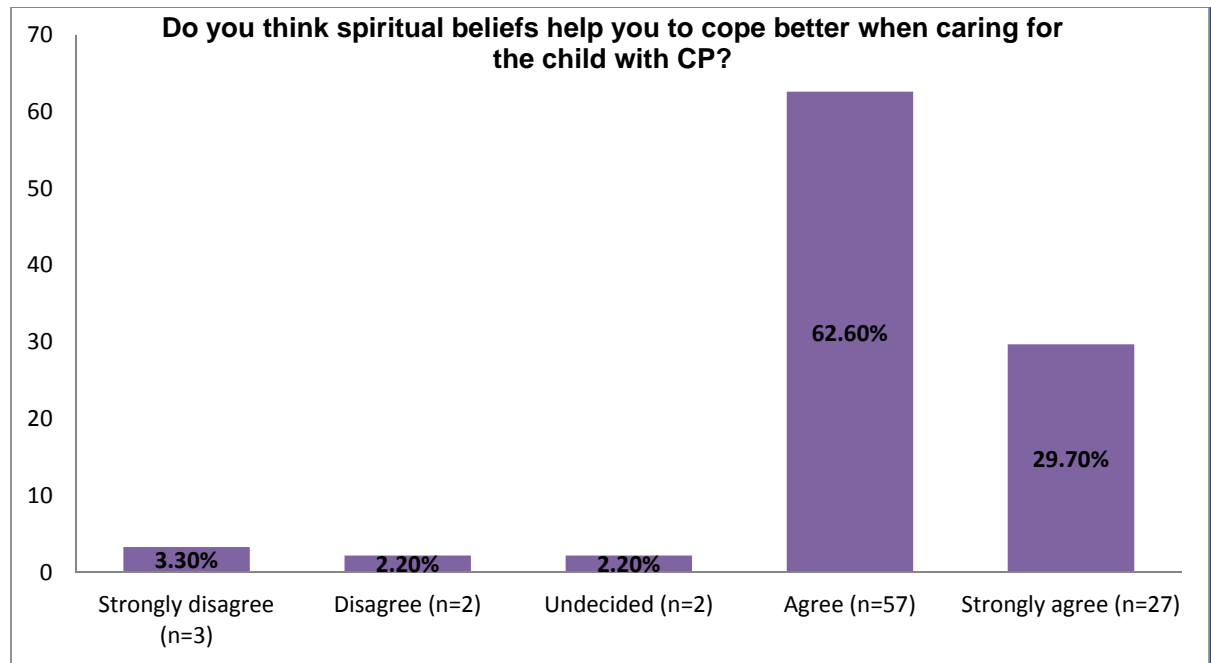


Figure 4.2 Influence of religion on caregiving (N=91)

Figure 4.2 shows that Namibians are generally spiritual people as indicated by the results that 29.70% (n=27) of the respondents and 62.60% (n=57) of the respondents either agreed strongly or agreed that they found their religious beliefs as having a positive influence in their coping mechanisms with the task of caregiving.

4.3.2.3 Physical health of caregiver

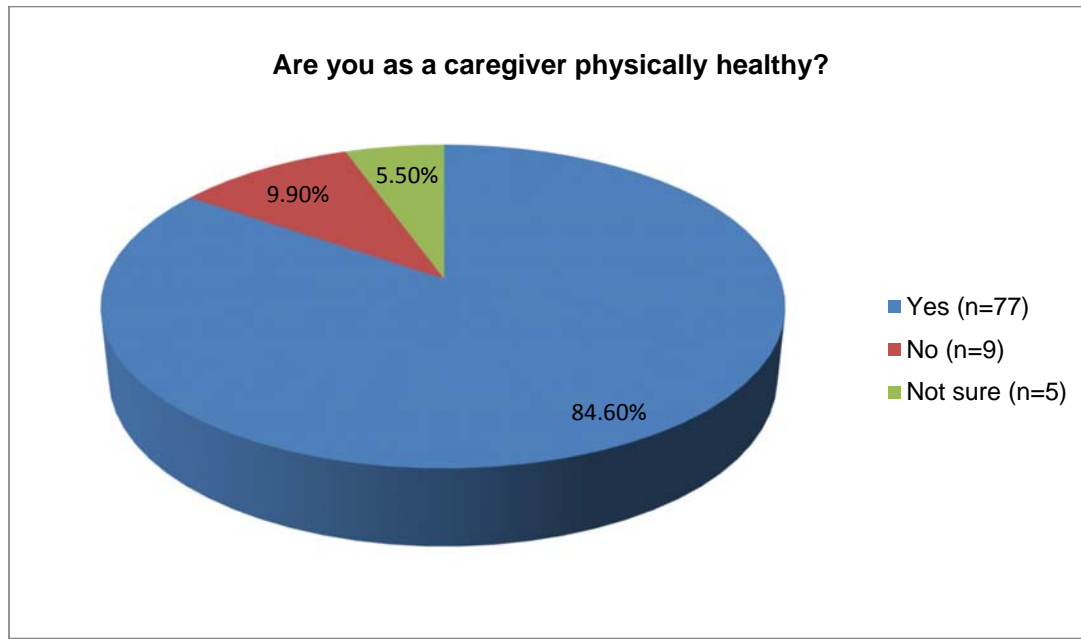


Figure 4.3 Physical health of caregivers (N=91)

When asked on whether they found themselves to be physically healthy, 84.60% (n=77) responded positively, 5.50% (n=5) were not sure, while 9.90% (n=9) said that they were not physically fit (refer to Figure 4.3). It was highly unlikely to have caregivers who are physically unfit since the study population mainly consisted of young people, with 63.74% (n=58) belonging to the age groups 20-24, 25-29 and 30-34 years. These results are comparable to the results from a descriptive study conducted in Harare, Zimbabwe, to compare the health-related quality of life between caregivers of children with CP and caregivers of children with minor health problems (Dambi, Chivambo, Chiwaridzo & Matare 2015:699). The results from this descriptive study revealed that caregivers of children with CP reported more problems with pain, discomfort and depression and they had a lower health related quality of life compared with caregivers of children with minor health problems.

4.3.2.4 Severity of disability of the child with CP

Table 4.3 Level of disability among care recipients (N=91)

Level of disability	Frequency (n)	Percentage of care recipients affected (%)
Both legs and arms affected	75	83.30%
Cannot talk (verbally communicate)	73	80.20%
Child struggles with mentally receiving, understanding, keeping or using any information given (cognitive ability) by others. Cognitive and perceptual ability.	58	68.20%
Child struggles to process or interpret information seen (perceptual skills)	57	69.50%
Child gets full assistance in bathing, dressing, toileting, feeding and other self-care activities.	87	97.80%

Table 4.3 presents the results when the respondents were requested to respond to questions relating to the type of disability which their care recipient had. The results show that a total of 83.30% (n=75) had both legs and arms affected. A total of 80.20% (n=73) were unable to communicate verbally, 68.20% (n=58) had cognitive problems, 69.50% (n=57) had perceptual problems, while 97.80% (n=89) care recipients needed maximum assistance with activities of daily living such as bathing, toileting or dressing. The level of severity of the CP determines the amount of input required by the caregiver in improving the quality of life of the child with CP. Children with more severe CP symptoms usually contribute to a poorer health-related quality of life for the caregiver (Dambi et al 2015:699,700).

In another study done in India to determine the effects of caregiving for children with CP on the caregivers' physical and mental health, it was found that there was an association between a poorer physical and mental health and a child with speech problems since they are unable to communicate their needs, resulting in the caregivers worrying a lot about their future (Ramita, Yadav, Singh & Sumalatha 2016:169). Unfortunately for this study this association was not specifically tested leaving room for further studies on this aspect in Namibia.

4.3.2.5 Other chronic conditions affecting child with CP

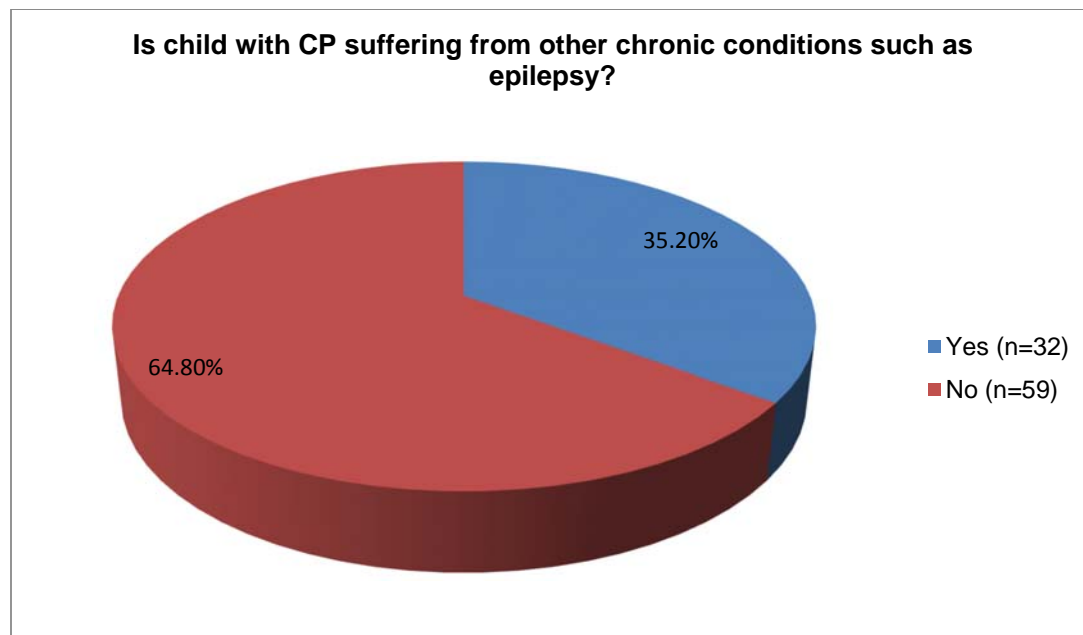


Figure 4.4 Presence of another chronic condition such as epilepsy by child with CP (N=91)

Thirty-five-point two percent (n=32) of the respondents were caring for children who had other chronic conditions such as epilepsy while 64.80% (n=59) respondents were caring for children with CP only (refer to Figure 4.4). These results support the results by Melo, Yamaguchi, Da Silva and Israel (2017:2) in their study which described the motor abilities and functioning of children and adolescents with cerebral palsy in an institution. It was found in that study that children and adolescents with CP had several impairments which contributed to higher costs of care and also maximal dependence on their caregivers for participating in activities of daily living.

4.3.2.6 Caregiver knowledge and understanding of CP

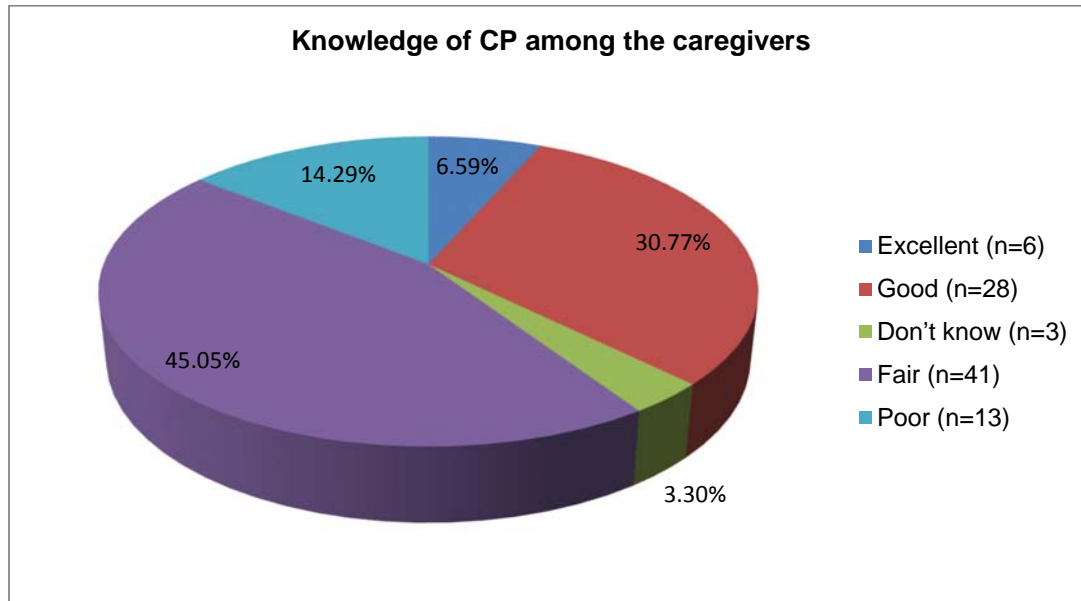


Figure 4.5 Knowledge of CP among caregivers (N=91)

Figure 4.5 reveals how the ninety-one (N=91) of the respondents rated their knowledge and understanding of CP. Caregivers who had good knowledge of CP were 30.77% (n=28), whilst 45.05% (n=41) had fair knowledge of CP, 14.29% (n=13) had poor knowledge, 3.30% (n=3) did not know how knowledgeable they were of CP and 6.59% (n=6) had excellent knowledge on CP. This high level of knowledge among the caregivers can be related to their attendance of the annual CP workshops which are conducted by therapists from the two public hospitals in Windhoek. This could be comparable to the results from a cross sectional comparative study which was done in Zimbabwe to find the differences in the knowledge levels among caregivers who have previously attended a CP workshop and those who had not. The results showed that the respondents who had attended a CP workshop before were more knowledgeable on the aetiology, symptoms and home-based therapy programs (Dambi, Mandizvidza, Chiwaridzo, Nhunzvi & Tadyanemhandu 2016:170).

4.3.2.7 Social and community support for caring for the child with CP

The caregivers included in the study had different experiences regarding the perceived social and community support in the role of caregiving. A frequency table about their responses is presented below:

Table 4.4 Results of social and community support (N=91)

Description of community/social support	Frequency (n)	Percentage (%)
They do not care	29/91	$29/91 \times 100 = 29.70\%$
They show no understanding of my child's CP	51/91	$51/91 \times 100 = 56\%$
I feel discriminated	43/91	$43/91 \times 100 = 47.30\%$
They do include me in all activities	23/91	$23/91 \times 100 = 25.30\%$
They offer to help with activities to do with caring for the child with CP	36/91	$36/91 \times 100 = 39.60\%$

Table 4.4 shows that 56.0% (n=51) of caregivers felt that the communities in which they live do not understand cerebral palsy as a medical condition, 47.30% (n=43) felt discriminated and 29.70% (n=29) felt that the community did not care about them. There were 25.30% (n=23) caregivers who felt that they were included in all the community activities, and 39.60% (n=36) felt that the community offered to help with activities of caring for the child with CP. The different perspectives from the caregivers may be related to the level of knowledge of the caregiver on CP which can directly affect their self-esteem, age of caregiver, ethnicity or the level of financial independence of the caregiver.

A further study in the future can be conducted to explore more on the varying community and social support as experienced by Namibian caregivers. The results indicated the need for community awareness so that the community can be more aware of the importance of social support for the caregiver for a child with CP so as to prevent psychological healthcare problems. This observation is comparable to the findings from the Zambian study on the experiences of caregivers for children with CP, whereby the importance of community and social support was recommended (Chiluba & Moyo 2017: 7).

4.3.2.8 Perceptions of caregivers on active involvement in medical management of child with CP

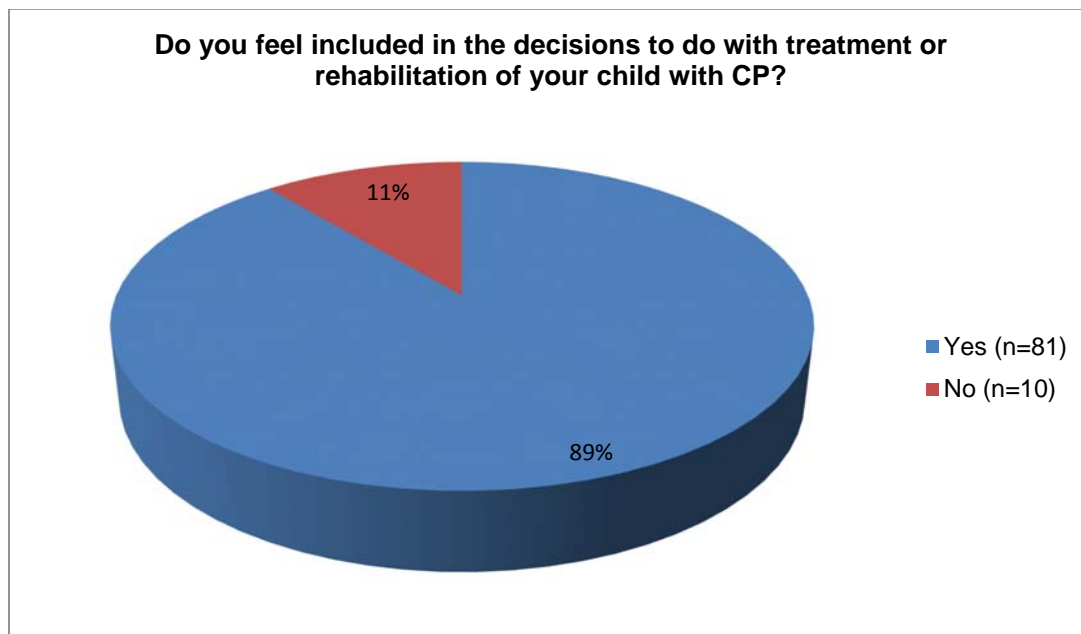


Figure 4.6 Do caregivers feel included in the medical treatment or rehabilitation of the child with CP? (N=91)

Figure 4.6 shows a descriptive summary of the responses from caregivers when they were asked if they felt included in the medical treatment or rehabilitation of their child with CP.

The results indicated that 89% (n=81) of the caregivers felt being actively involved in the medical treatment or rehabilitation of their child with CP, while 11% (n=10) felt that they were not actively involved in the medical treatment or rehabilitation of their child with CP. These results indicate that Namibia is implementing the WHO Framework on

integrating people-centred healthcare services very well considering the high number of caregivers who felt included in the overall care of the child with CP.

4.3.3 Description of the burden faced by caregivers

4.3.3.1 Caregiving as physically straining

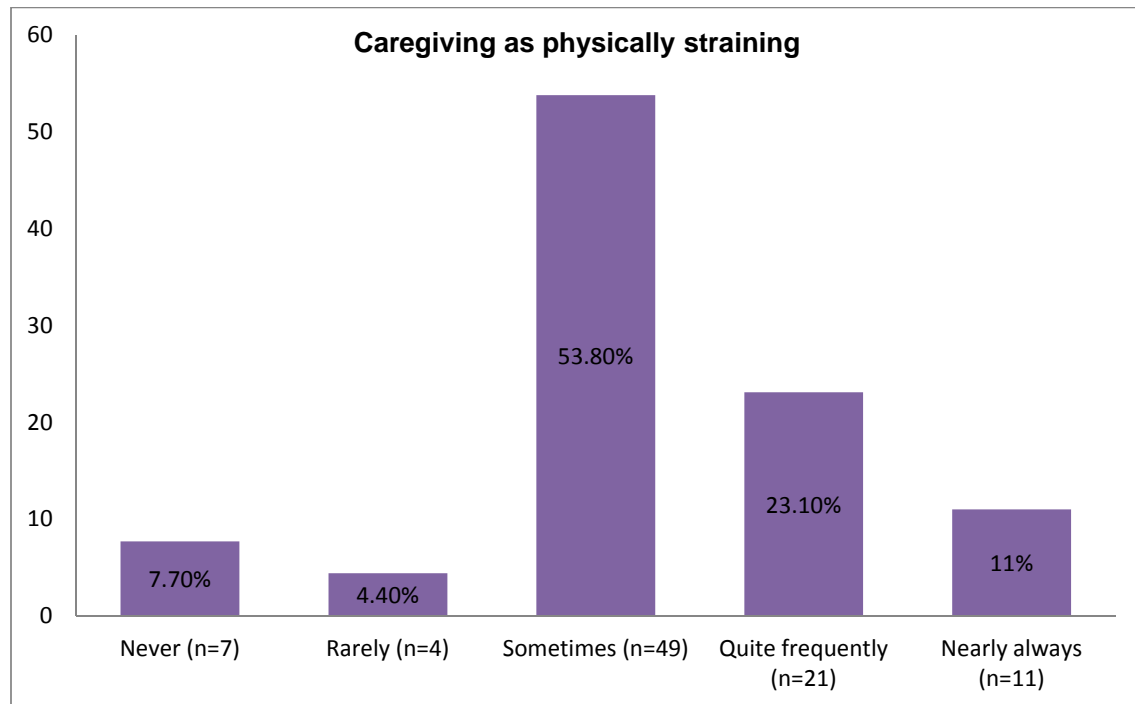


Figure 4.7 Caregiving and physical strain (N=91)

Figure 4.7 shows that 53.80% (n=49) of the respondents sometimes find caregiving stressful, 23.10% (n=21) quite frequently, 11.0% (n=10) nearly always, 4.40% (n=4) rarely, while 7.70% (n=7) never find this task of their lives stressful, tiring or exhausting. This could impact the caregiver's physical health resulting in poorer health than the caregivers of similar age whose children are not disabled. This conclusion is comparable to a previous study in Zimbabwe to determine the health related quality of life for caregivers for children with CP compared to caregivers for children with minor health problems, which concluded that poorer health was related to caring for a child with CP (Dambi et al 2015:700).

4.3.3.2 Caregiving with relation to balance of caregivers' roles

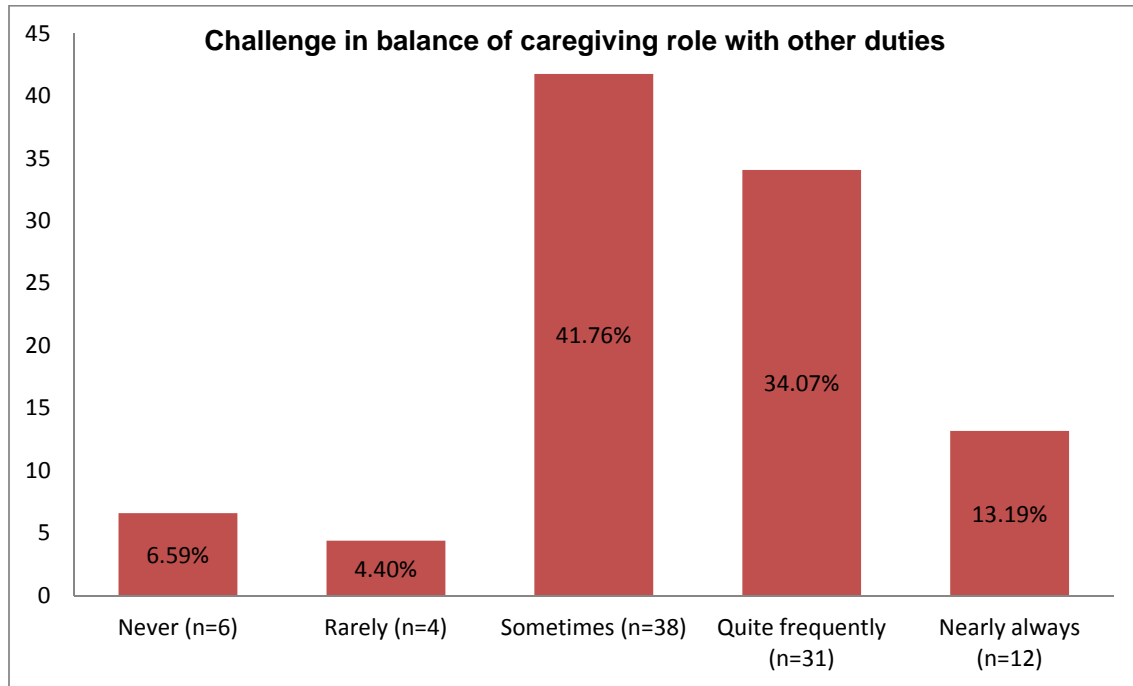


Figure 4.8 Challenge in balance of caregiving role with other duties (N=91)

Similarly, caregivers when asked if they found it difficult to balance their caregiving role, other family duties and their formal job, 41.76% (n=38) sometimes struggled, 34.07% (n=31) quite frequently, 13.19% (n=12) nearly always while 4.40% (n=4) rarely and 6.59% (n=6) never struggled to balance their roles (refer to Figure 4.8). Struggling to balance the caregiving role, other family duties and jobs was a uniform pattern for all caregivers regardless of level of education, age or religion.

4.3.3.3 Effect of caring for CP child on family relations

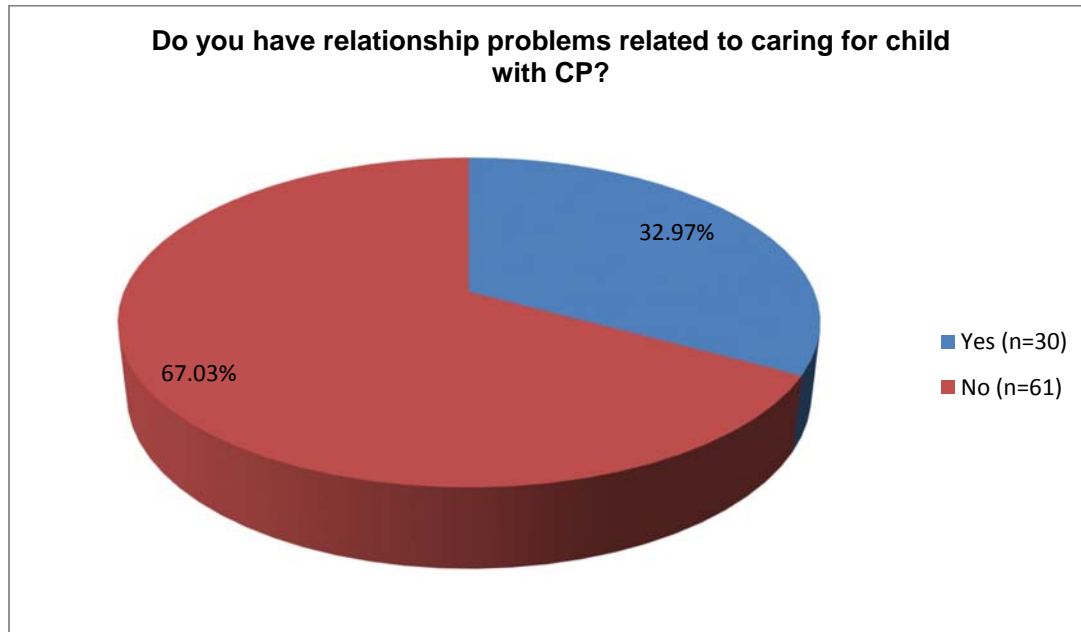


Figure 4.9 Proportion of caregivers with relationship challenges with family (N=91)

- ***Relationship challenges***

Relations between caregiver and their family was challenging for 32.97% (n=30) of the respondents while 67.03% (n=61) had no problems with other family members or friends that they could relate to in caring for a child with CP (refer Figure 4.9). Factors influencing the difficult relations included financial strains, stigmatisation of the child with CP and poor communication. The discussion that follows below (refer Figure 4.10 and Table 4.5) relates to the 32.96% (n=30) respondents who indicated that they had relationship problems with other people as a result of having a child with CP.

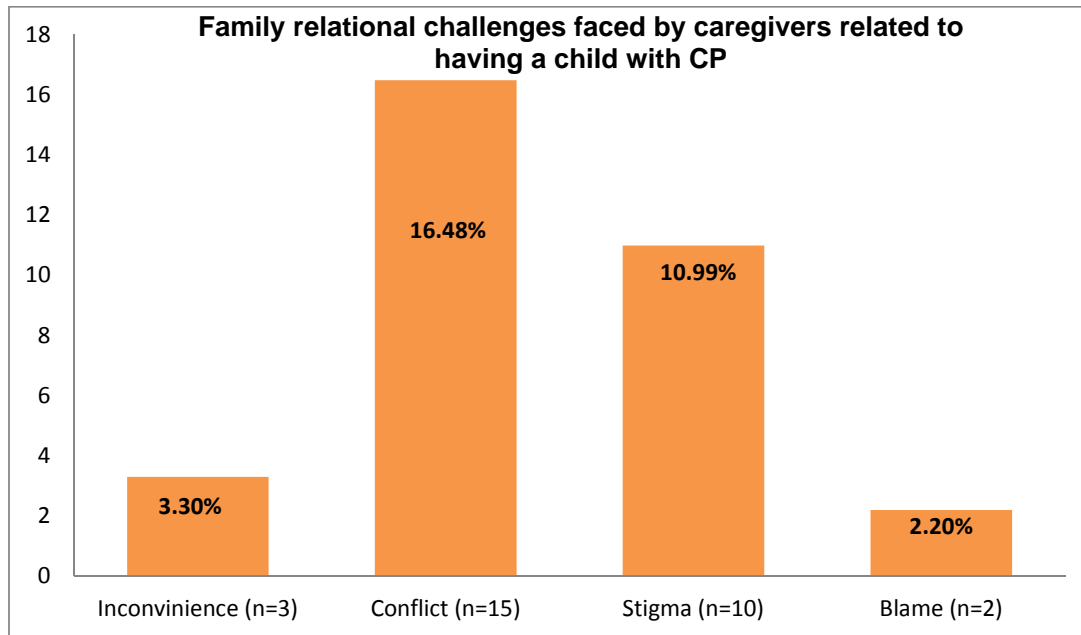


Figure 4.10 Family relational challenges faced by caregivers related to having a child with CP (N=91)

The categories of challenges (refer to Figure 4.10 and Table 4.5) listed from the responses which were given for open ended questions were:

- Inconvenience
- Conflict
- Stigma
- Blame

The researcher read the responses of each questionnaire then counted how many caregivers gave responses under each category. The total for each category was then calculated as a fraction from the ninety-one (91) possible respondents to get the percentage per category. The researcher noted that this study is quantitative hence analysis will be quantitative not qualitative. This explanation is illustrated sequentially (refer to Table 4.5) and the discussion of this table follows below it:

Table 4.5 Effect of caregiving on family relationships (N=91)

Category	Calculation according to fraction: (N=91)	Percentage (%)
Inconvenience	3/91	$3/91 \times 100 = 3.3$
Conflict	15/91	$15/91 \times 100 = 16.48$
Stigma	10/91	$10/91 \times 100 = 10.99$
Blame	2/91	$2/91 \times 100 = 2.2$

It should be noted that the explanation of the previous paragraph is illustrated also in tables 4.6 and 4.7.

- ***Inconvenience***

As shown in table 4.5 there were 3.30% (n=3) caregivers whose responses mentioned that the child required full time care therefore when they go for family functions they cannot help out with chores and at the same time they hardly get individual time to go and run errands. Family members could not help always since they also had other things to do. Frequent hospitalisations were found to be another challenge since it hindered the primary caregiver from keeping a formal job so they ended up relying on other family members which always resulted in conflict.

- ***Conflict***

This category was the leading causal factor for relationship challenges since a total of 16.48% (n=15) caregivers' responses had conflict either with a spouse, their parents, paternal grandparents of care recipient or with other family members or friends. Refusal of responsibility for the child by biological fathers and also issues of blame on the biological members created tension within families. Stress and irritability also came up as a contributing factor to family tensions since the caregiver becomes impatient and rude. Financial dependence and family gossip were other causes for the family relationship problems. Family conflict between the caregiver and the biological father of the child with CP or with the extended family was also found in a Zambian study describing challenges for caregivers for children with CP (Singogo et al 2015:4).

- **Stigma**

Stigma from other family members was a cause for relationship tension for 10.99% (n=10) of those caregivers who had relationship problems. Caregivers in the current study experienced both concepts of 'felt' and 'enacted' stigma (Gray 2002:73). For some caregivers, their immediate family members understood cerebral palsy as a medical condition with its accompanying signs and symptoms; however, they felt that the community and other extended family members labelled their child with CP since they did not understand the condition. Caregivers felt isolated by people who did not want to be associated with the child, whom they feared brought bad luck on them. At times families gossiped about the caregiver and the child with CP, thereby creating further tension and eliciting anger from the caregiver. A direct result of 'felt' stigma in the study was the lack of social and financial support from the family and friends.

- **Blame**

Blame was found to be a cause for relationship misunderstandings in 2.20% (n=2) of those caregivers who had relationship problems directly related to caregiving for a child with CP. An issue brought up by one of the caregivers was how the paternal family of her child with CP felt that she had been unfaithful to their relative hence having a child with a disability was her punishment. This experience is similar to a previous study whereby biological mothers of the children with CP were openly blamed by their partners and extended families for infidelity which resulted in them giving birth to a child with CP (Olawale et al 2013:161).

4.3.3.4 Musculoskeletal ailments related to caregiving duties

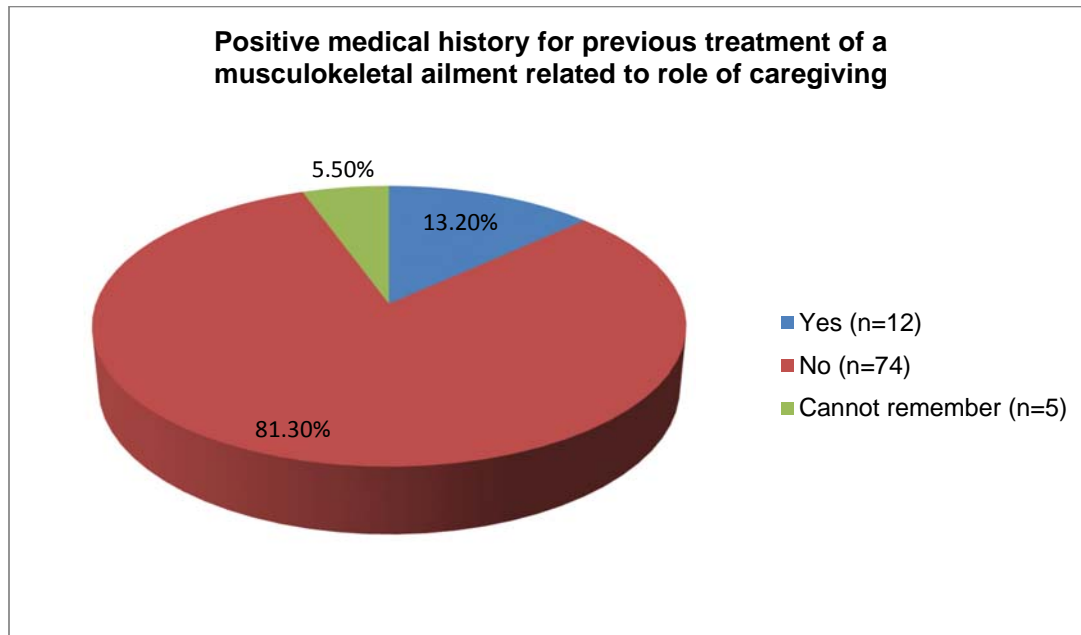


Figure 4.11 Positive history by caregiver for previous treatment of a musculoskeletal ailment related to role of caregiving (N=91)

In response to the question of musculoskeletal problems related to the role of caregiving, Figure 4.11 shows that 13.20% (n=12) of the caregivers had previously been treated for a physical ailment which they could directly link to caregiving, 81.3% (n=74) responded that they had never been treated of musculoskeletal problems, while 5.50% (n=5) of the respondents could not remember being ill or being treated of a physical ailment they could relate to caregiving. It is highly likely that those who cannot remember may not have had a serious musculoskeletal complaint previously since pain and discomfort may not be easily forgotten. A low percentage of 13.20% (n=12) of caregivers with a positive musculoskeletal ailment indicated that caregiving tasks have no effect on the physical health of the caregiver in Namibia. It may therefore be of interest to conduct a follow - up study to find out if the age and weight of the child with CP had an influence on the caregiver having a musculoskeletal medical history.

4.3.3.5 Physical and mental health of caregiver

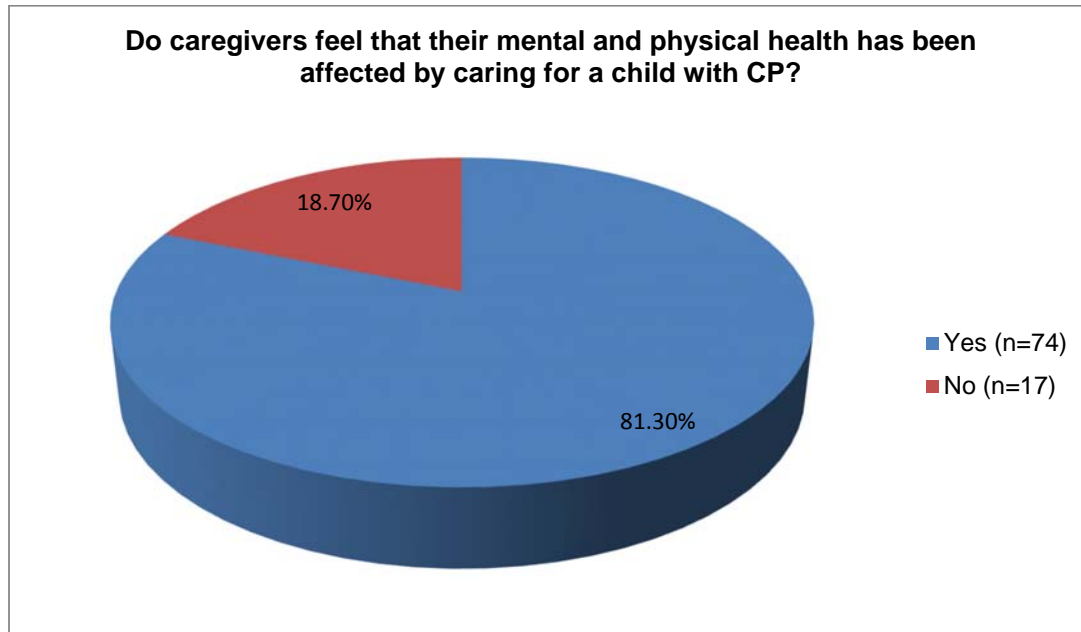


Figure 4.12 Do caregivers feel that their mental and physical health has been affected by caring for a child with CP? (N=91)

In figure 4.12 the results revealed that 81.30% (n=74) of the respondents' physical and mental health had been affected by their role of caring for the child with CP (refer to Figure 4.12). A total of 18.70% (n=17) did not find their task of caregiving as causing a decline in their physical and mental health. The results from this study are inconsistent with results from a descriptive study conducted in India which aimed to find if the mental and physical health of caregivers had been affected by having a child with a disability. The results from that study showed that caregivers' physical and mental health were moderately affected by their role of caregiving (Ramita et al 2016: 169) as opposed to 81.30% (n=74) of caregivers for this study who shared that their physical and mental health had been affected.

4.3.3.6 Effect of caregiving role on caregivers' sleeping routine and pattern

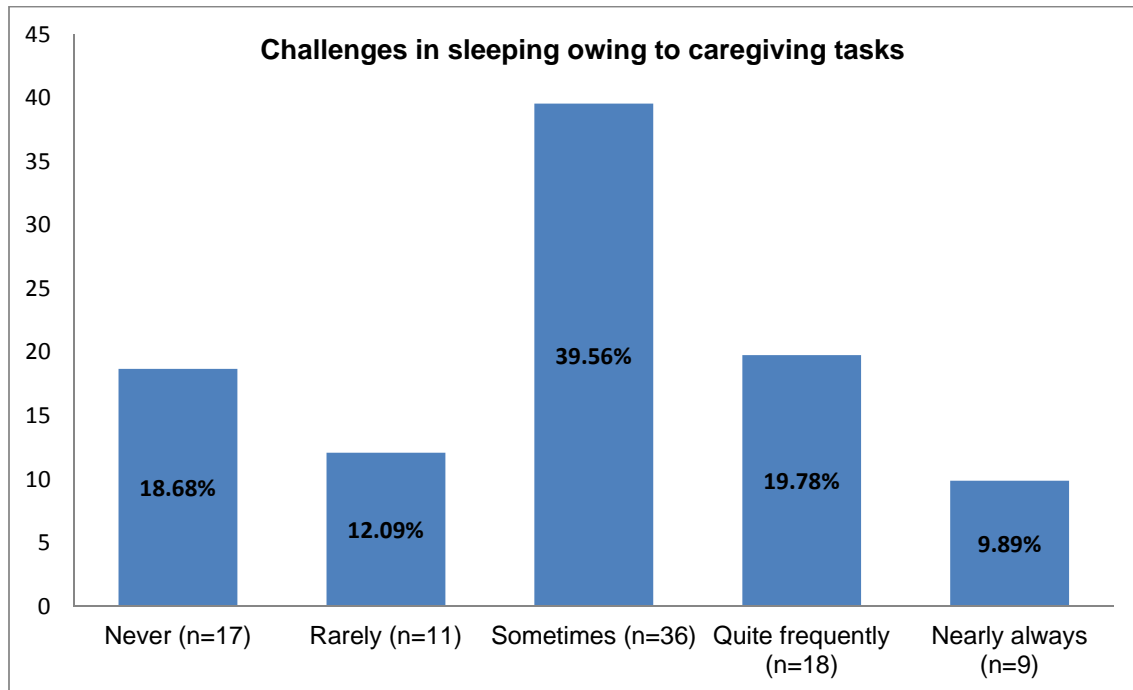


Figure 4.13 Challenges in sleeping owing to caregiving tasks (N=91)

As indicated in figure 4.13, 39.60% (n=36) sometimes struggled to sleep, 12.10% (n=11) rarely struggled, 18.70% (n=17) never struggled, 19.80% (n=18) quite frequently struggled to sleep, while 9.90% (n=9) nearly always struggled to sleep. Factors that may have contributed to challenges in finding sleep for caregivers related to the task of caregiving in the current study could be various night tasks of caregiving for the child with CP such as positioning, other chronic illnesses of the child and caregiver psychological stress. This interpretation can be supported from the results from a cross sectional study conducted in India to determine sleep disorders among children with CP and their association with sleep disorders among primary caregivers. The results from that study in India revealed that sleep disorders among caregivers were related to sharing a bed with a child with CP and it was also related to positive medical history of seizures by the child with CP (Adiga, Gupta, Khanna, Taly & Thennarasu 2014:474).

4.3.3.7 Effect of caregiving role on ability of caregiver to have free time

Table 4.6 Do the caregivers have enough time for themselves away from the caregiving role? (N=91)

Do you have enough time for yourself away from caregiving role?		
Response	Frequency (N=91)	Percentage (%)
Yes	18/91	19.80%
No	73/91	80.20%

Table 4.6 above shows how caregivers' ability to have a social life was affected by the role of caregiving. About 80.20% (n=73) of the caregivers pointed out that they did not have any free time from their caregiving role, while 18.80% (n=18) still could enjoy some quality individual time from their caregiving role. This lack of social life could be a contributing factor to the psychological effects the caregiving role has on the caregiver as shown in Figure 12 below.

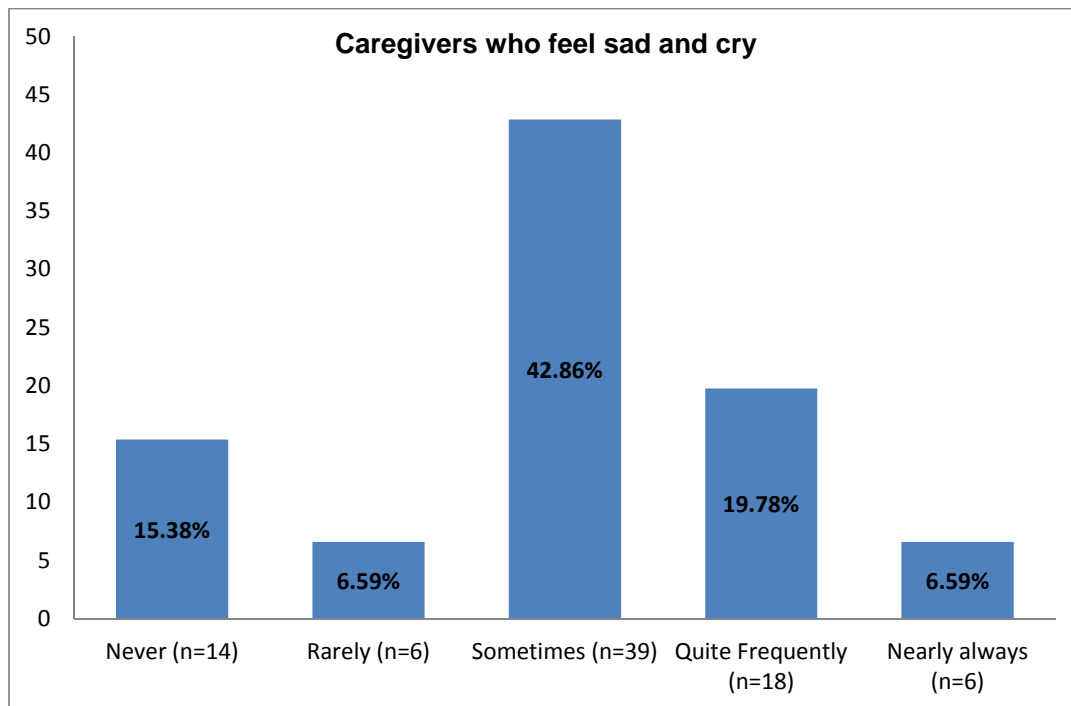


Figure 4.14 Caregivers who feel sad and cry (N=91)

The decrease in the physical and mental health among those who reported being sad and cried 19.80% (n=18) quite frequently, 42.90% (n=39) who sometimes got sad and cried, 6.60% (n=6) of them indicated nearly always, 15.40% (n=14) were never sad, 6.60% (n=6) said they rarely cried and 15.40% (n=14) never felt sad and did not cry (refer to Figure 4.14). This then contributes not only to a decline in the quality of life of the caregiver but also indirectly affects the child with CP. This is comparable to the results of a study in Ghana which aimed at identifying and describing the psychological impact of CP on families from an African perspective. The study found loss of joy in families and that 50% of families are now choosing to consult traditional healers to find help (Olawale et al 2013: 161).

4.4 CHALLENGES OF CAREGIVING BURDEN

4.4.1 Social life challenges

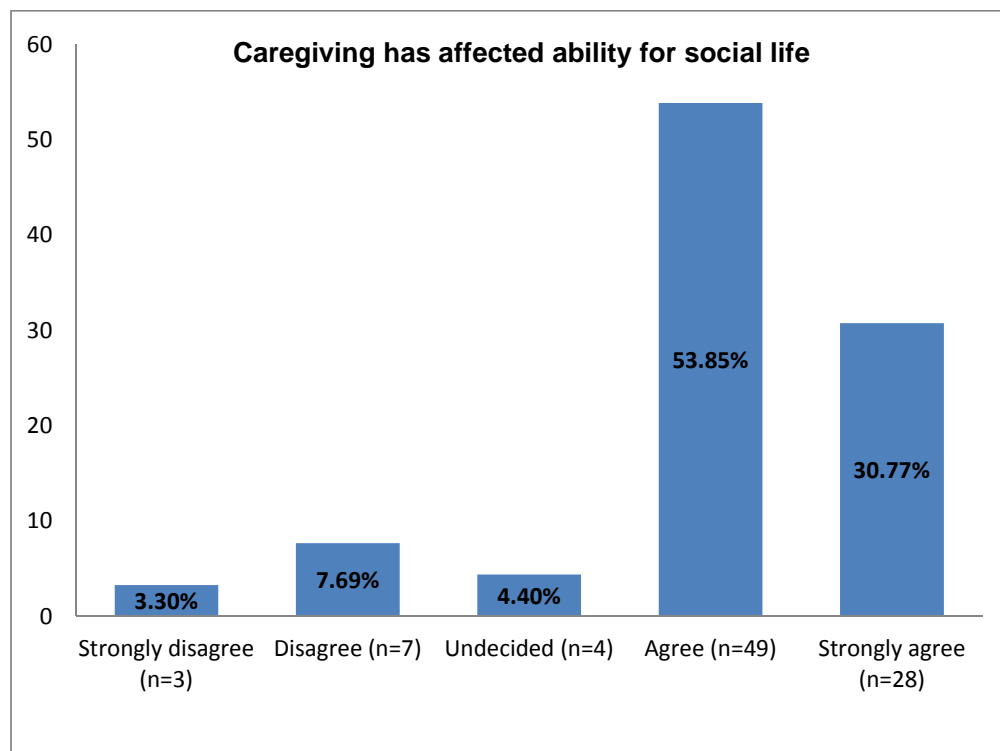


Figure 4.15 Effect on social life of caregiving role (N=91)

Figure 4.15 revealed the results of the responses from caregivers when they were responding to the question on whether or not they feel that their social life has been affected by caring for their child with CP.

Caregivers who strongly agreed to social life being affected were 30.80% (n=28), 53.80% (n=49) agreed, 4.40% (n=4) were undecided, 7.70% (n=7) disagreed that their social life had been affected, while 3.30% (n=3) strongly disagreed that their social life had been affected by caring for the child with CP. Some of the caregivers indicated that they no longer have a social life since they have to give full time care and attention to the child with CP. The researcher’s interpretation of the results is that caregivers are unable to partake in social activities since their caregiving demands are a daily routine without a break. This observation is comparable to the findings from a mixed research study design which was conducted in Zambia to determine the experiences and challenges among caregivers for children with CP. Findings from that study showed that more than half of the caregivers needed assistance in caring for the child with CP so that they could be able to do other duties (Chiluba & Moyo 2017:5).

4.4.2 Financial challenges

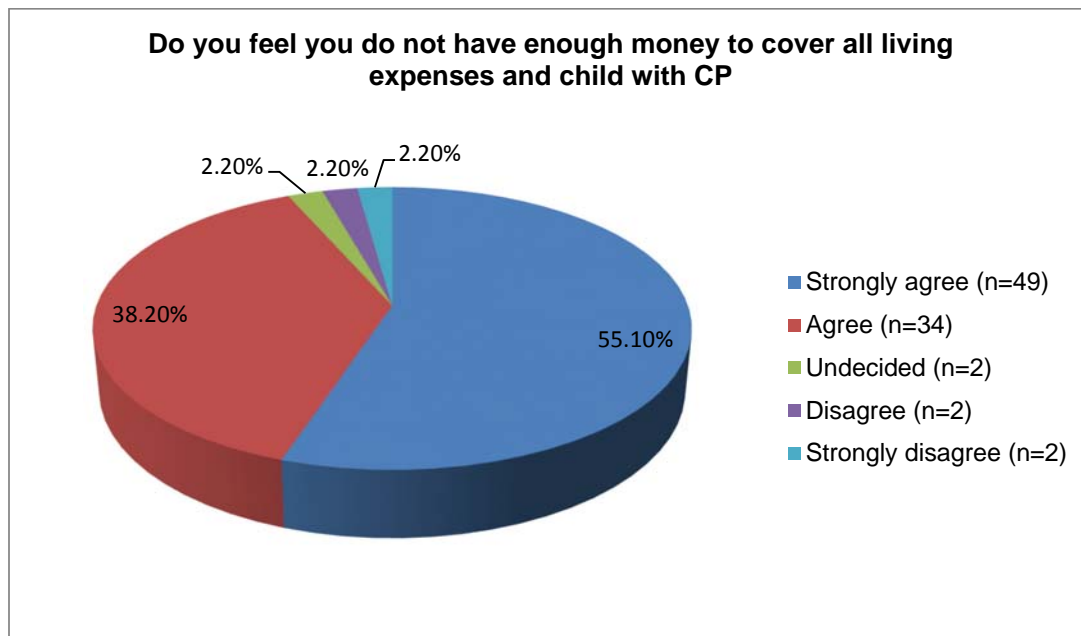


Figure 4.16 Financial strain for caregiver’s related to child with CP (N=91)

Figure 4.16 shows that 55.10% (n=49) and 38.20% (n=34) of the respondents either strongly agreed or agreed respectively that they do not have enough money or the financial capability to cover the costs related to the care of the child with CP and also their other living expenses.

The other results showed that 2.20% (n=2) were undecided, 2.20% (n=2) disagreed while 2.20% (n=2) strongly disagreed that they did not have enough money to sufficiently cover all the costs related to the care of a child with CP. For those who disagreed to not having enough money or who were undecided, there was an assumption by the researcher that they were reluctant to disclose their financial status. The results from the 2013 Demographic and Health Survey from the MOHSS, Namibia, found unemployment prevalence as 43.20% in urban areas generally and 41.20% in Khomas region specifically (The Namibia Demographic and Health Survey 2013:15). This high unemployment rate thus poses a huge risk for financial dependency, as well as desperation and strains on the caregivers for children with CP and their families.

4.4.3 Perceived challenges as explained by caregivers

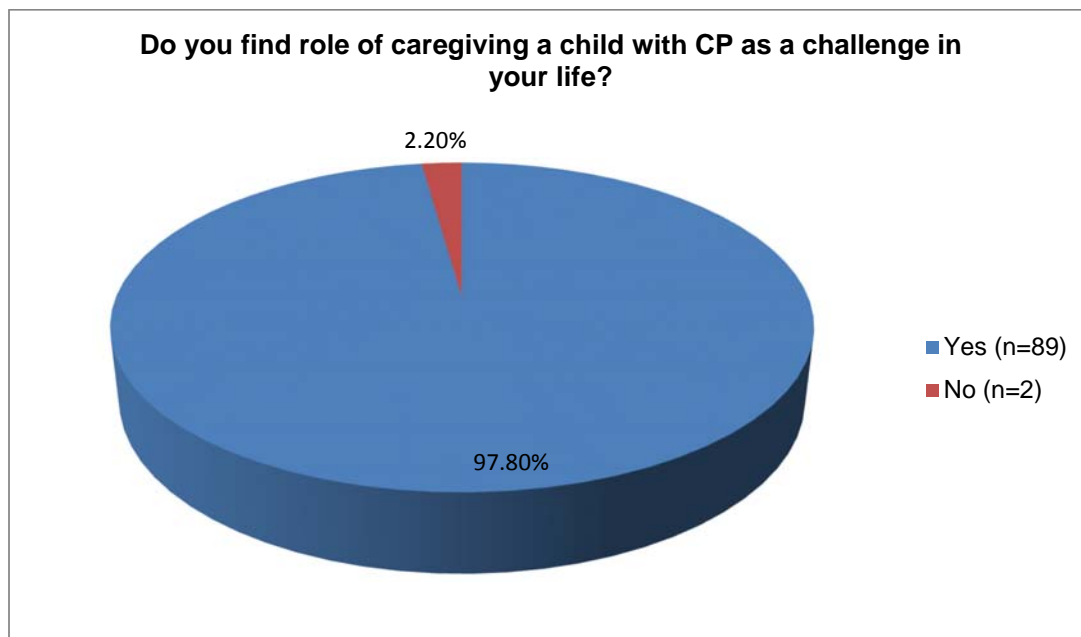


Figure 4.17 Do you find the role of caregiving a child with CP as a challenge in your life? (N=91)

The respondents explained in their own words how caring for a child with CP has been a challenge for them.

After reading through each questionnaire and noting the responses, at least 97.80% (n=89) of caregivers agreed that a child with CP was bringing a lot of challenges in their life while the remaining 2.20% (n=2) had accepted their situation and no longer associated their role as bringing challenges in their life (refer to Figure 4.17). Those who had accepted the situation were probably now more experienced in their caregiving role, which would be comparative to the results from a study conducted to determine the effects of caregiving for children with CP on the physical and mental health of caregivers in India (Ramita et al 2016:170). The total for each category was then calculated as a fraction from the ninety-one (91) possible respondents to get the percentage per category. It was mentioned that the researcher noted that this study is quantitative hence the analysis is quantitative and not qualitative. This explanation is illustrated sequentially (refer to table 4.7) and the discussion followed.

Categories of challenges with day to day tasks of caregiving that came up from the caregivers were:

- High financial costs and overall impact to the caregivers and their family;
- Community issues;
- General ill health of the child with CP and
- Twenty-four (24) hour /daily management difficulties.

Table 4.7 Caregivers’ perceived challenges in caring for children with CP (N=91)

Category	Calculation according to fraction (N=91)	Percentage (%)
High financial cost	40/91	40/91 x 100 = 43.96%
Community issues	12/91	12/91 x 100 = 13.19%
General ill health of the child with CP	7/91	7/91 x 100 = 7.69%
Twenty-four (24) hour /daily management difficulties	20/91	20/91 x 100 = 21.99%

4.4.3.1 High financial cost and overall impact to the caregiver and their family

The results as indicated in table 4.7 show that a total of 43.96% (n=40) caregivers in their responses revealed financial costs as a challenging factor with their task of caregiving for a child with CP.

Some of the demands requiring finances included buying formula milk, buying disposable diapers and ensuring that the child has the necessary food which they are able to consume such as potatoes, yoghurt and butternut. This result is comparative to the results from a study on the psychological impact of cerebral palsy on families in Accra Ghana that found that 88.50% of families were having financial challenges related to the care of a child with CP (Olawale et al 2013: 162)

“I do not have enough money to buy the milk, nappies and come to hospital many times”

Frequent transport fare costs were also reported since the child needed to come for medical and rehabilitation follow-ups. Caregivers also shared that it was difficult to balance caring for the child in addition to balancing their other roles such as job requirements or caring for the other children. One caregiver shared:

“I have 4 children in total. The total cost of looking after them is made more by this child. He should have been off nappies and milk now if he was normal. My other children are my helpers, which at times is unfair but unfortunately that’s our life.”

4.4.3.2 Community issues

The responses from the caregivers as reflected in table 4.6 show that a total of 13.19% (n=12) of caregivers indicated different community issues that added to their burden of caregiving. These, though not exhaustive included lack/absent moral and financial support from biological fathers of the children with CP as one caregiver shared:

“The father runs away from his house when he gets paid to avoid paying for the child’s upkeep”

With regards to dealing with different issues in the community which are secondary to individuals without full understanding and knowledge on CP, one caregiver indicated that:

“My biological father is not supportive of the child, and neighbours always gossip about my child. Last week I beat up some lady who was stigmatising my child. I get very angry when people say bad things about my child. They provoke me.”

4.4.3.3 General ill health of the child with CP

At least 7.69% (n=7) of caregivers as reflected in table 4.7 shared how their child's CP ill health makes them feel helpless, stressed and anxious. Only one (1) respondent shared that she at times considered suicide.

“He gets seizures which are serious at least after every 6 months. He then needs to stay in hospital.”

“My life and the life of the child does not change. It remains the same, no expectations of anything new. The child's condition does not get better.”

4.4.3.4 Twenty-four (24) hour /daily management difficulties

The need for twenty-four (24) hour care was mentioned by 21.99% (n=20) of the caregivers as shown in table 4.6. Responses listed different aspects of the full time care they needed to provide for the child with CP. Activities done during the twenty-four hours included assistance with daily activities such as feeding, lifting, transferring, assisting with mobility, acting as playmates and protecting the children with CP. One of the respondents shared:

“Spending all the time caring for her. No relief”

The researcher noted that upon commenting on the challenges, 2.20% (n=2) of caregivers' responses indicated that their children had multiple disabilities and more than one child had a physical disability; this led to a high child-minder turnover to assist them with caring for the child. Feeding challenges specifically swallowing and

generally taking long to eat were mentioned in the responses by 4.4% (n=4) of the respondents.

4.5 STRATEGIES TO ALLEVIATE THE BURDEN OF CAREGIVING

4.5.1 Suggested support methods by caregivers

Table 4.8 Suggested support methods by caregivers (N=91)

Suggested support strategy	Frequency (n = 91)	Percentage (%)
Financial assistance	42/91	$42/91 \times 100 = 46.15\%$
Specialised care schools or day-care centres	32/91	$32/91 \times 100 = 35.16\%$
Caregiver support groups	25/91	$25/91 \times 100 = 27.47\%$
Improved medical care	22/91	$22/91 \times 100 = 24.18\%$
Employment	2/91	$2/91 \times 100 = 2.20\%$
Flexible working hours	2/91	$2/91 \times 100 = 2.20\%$

The researcher did a manual reading and counting of responses from the open ended responses in order to indicate and discuss the results. Table 4.8 above shows the support which is needed by the caregivers in caring for a child with CP, namely:

- Financial support;
- Specialised care schools/day-care centres;
- Paid employment;
- Flexible working hours;
- Caregiver support groups and
- Medical care.

A discussion of the results in table 4.8 follows in the next four sections.

4.5.1.1 Financial support

The results as indicated in table 4.8 reveal that financial support was listed by 46.15% (n=42) of the caregivers as a support mechanism through which their caregiving burden can be reduced.

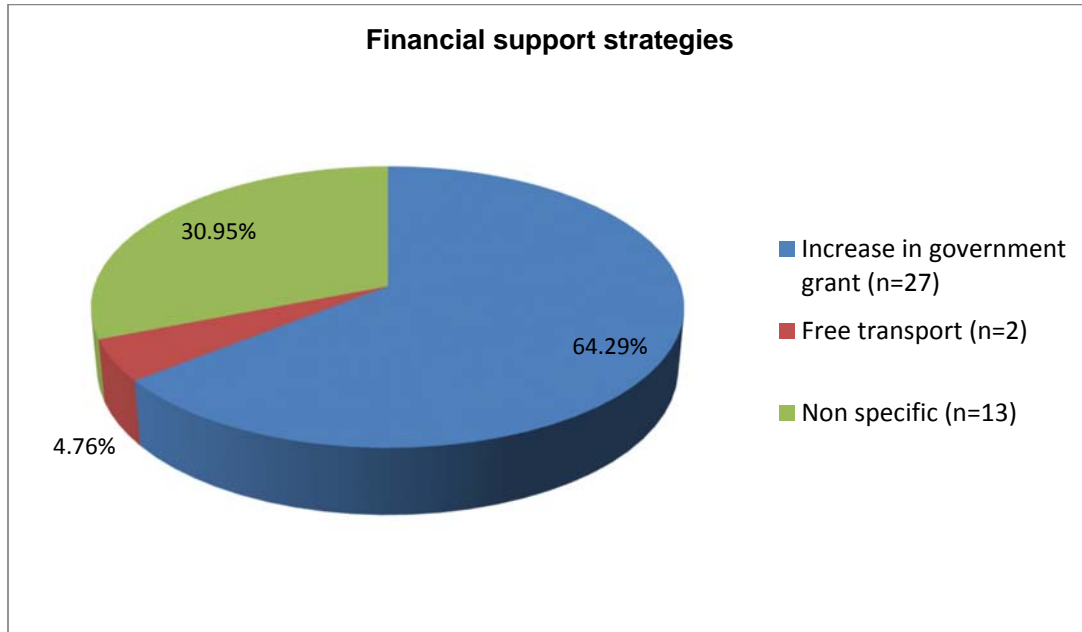


Figure 4.18 Suggested financial support strategies by caregivers (N=42)

Figure 4.18 is a graphical presentation of strategies that were suggested by caregivers that would lessen financial challenges of caregiving. An increase in the government monthly grant for children with disabilities was suggested as an important policy change by 64.29% (n=27) of the caregivers. At least 4.76% (n=2) of the respondents also suggested that there should be free and available wheelchair accessible public transport in Windhoek so that the caregivers do not struggle when they travel with the child. Though they suggested financial support as a strategy to lessen caregiver burden, 30.95% (n=13) were not specific on the type of financial support they preferred. These results are similar to the findings from a qualitative study aimed at understanding the challenges experienced by mothers of children with cerebral palsy in Zambia, where caregivers were struggling more in the rural areas to financially cover all their expenses such as transport and assistive devices for their child (Singogo, Rhoda & Mweshi 2015:4).

4.5.1.2 Specialised care schools/day-care centres

The responses from respondents as indicated in table 4.8 show that 35.16% (n=32) of the respondents suggested that there should be specialised day-care centres and schools so that children with CP can attend school during the day.

Closely related to that, 2.20% (n=2) of the respondents suggested that companies should be given incentives if they allowed parents of children with CP to have flexible working hours. At least 2.20% (n=2) of the respondents needed support in the form of paid employment so that they could be in a position to provide for themselves and the child with CP.

4.5.1.3 Caregiver support groups

As shown in table 4.8 above, 27.47% (n=25) of the caregivers suggested support for caregivers in the form of basic commodities such as nappies, food and also the facilitation of regular caregiver support networks where different topics can be discussed. The demand for nappies and food is significant since the caregivers are unable to fully financially provide for their children as single mothers (single mothers constitute 53.20% as shown in Table 4.1). The results on the need and importance of community support are comparable to a study conducted at a teaching hospital in Lusaka Zambia to determine the experiences of caring for a child with CP where caregivers indicated that they needed more home and community based therapy from the physiotherapists (Chiluba & Moyo 2017:5).

4.5.1.4 Medical care

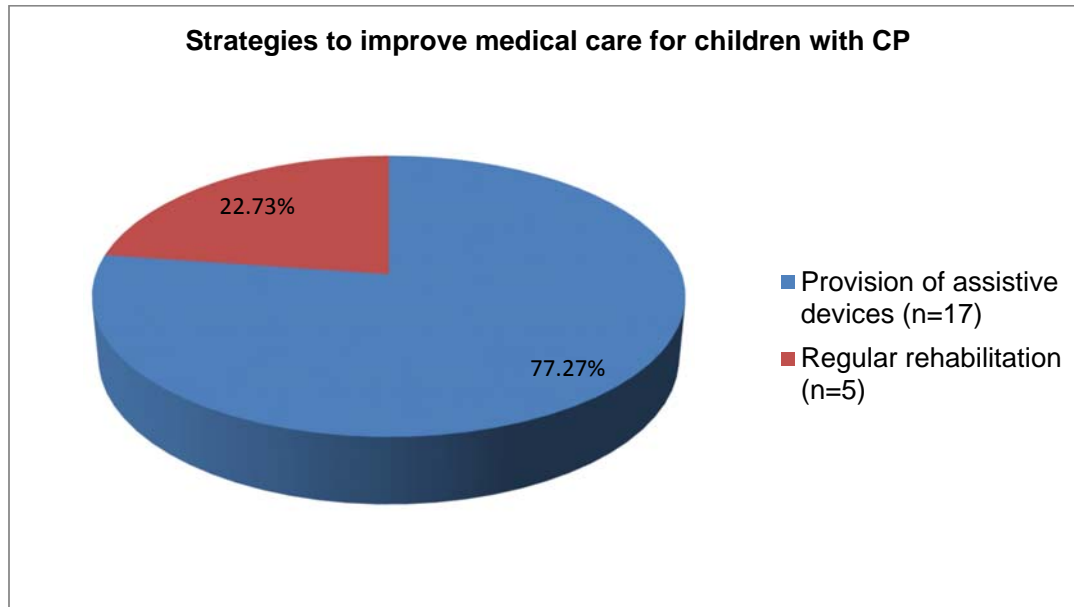


Figure 4.19 Suggested strategies to improve healthcare of children with CP (N=22)

Table 4.8 also showed that 24.18% (n=22) of the ninety one (91) respondents who participated in this study suggested an improved overall health care for children with CP as a support strategy that would ease their burden of care.

Figure 4.19 shows that of those respondents who indicated need for improving healthcare, 77.27% (n=17) were in need of assistive devices such as wheelchairs and standing frames while 22.73% (n=5) of the respondents also suggested regular rehabilitation input and provision of rehabilitation at home. The results of this study concurs with a qualitative study conducted in Malawi with primary caregivers of children with CP it was noted that mobility was a common healthcare problem for children with CP and the caregivers highly valued rehabilitation (Barlindhurg et al 2016:4).

4.5.3 Inclusion of caregivers in recreational activities to help in the role of caregiving

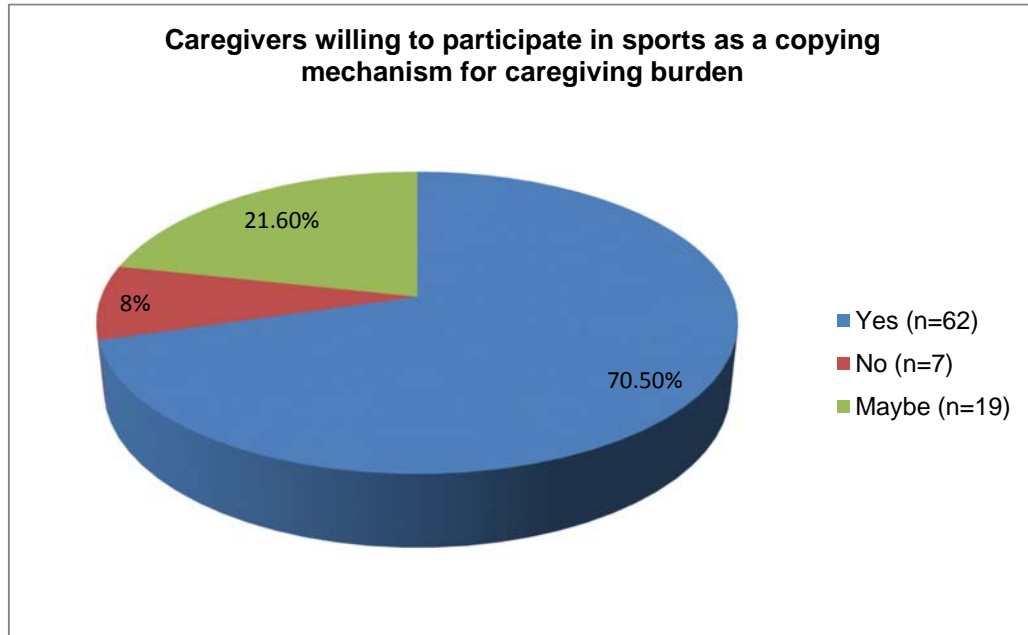


Figure 4.20 Interest in recreational sport as a coping strategy (N=91)

Caregivers who indicated interest in participating in sport as a recreational strategy to deal with the caregiving burden were 70.50% (n=62); 21.60% (n=19) were doubtful on whether they would participate or not, while 8% (n=7) did not want to participate (refer Figure 4.20). A high interest in recreational sport could be that caregivers are searching for an activity that can help release anxiety and the continuous pressure associated with their role of caregiving. This can be supported by the results from a large scale study with students in the USA which revealed that physical activity contributed to an improved quality of life with widespread physical, cognitive, social and spiritual domains (Gill, Hammond, Reifsteck, Jehu, Williams, Adams, Lange, Becofsky, Rodriguez & Shang, 2013:S32).

4.6 MULTIVARIATE CHI-SQUARE TESTS OF ASSOCIATION

Table 4.9 Relationships between demographic variables and caregiver burden

Variable	Age group	Sex	Marital status	Ethnic group	Level of education	Religion
Do you find caregiving as physically straining/tiring/exhausting?	$X^2=18.015$ $p=0.323$	$X^2=5.551$ $p=0.235$	$X^2=14.025$ $p=0.299$	$X^2=17.786$ $p=0.813$	$X^2=13.025$ $p=0.367$	$X^2=1.712$ $p=0.789$
Do you at times feel overworked by trying to balance your caregiving role, other family duties and your job?	$X^2=11.755$ $p=0.761$	$X^2=0.680$ $p=0.954$	$X^2=9.949$ $p=0.620$	$X^2=19.442$ $p=0.728$	$X^2=6.745$ $p=0.874$	$X^2=2.799$ $p=0.592$
Does having the child with CP in your family negatively affect relationships between yourself and other family members?	$X^2=2.486$ $p=0.647$	$X^2=0.863$ $p=0.353$	$X^2=2.700$ $p=0.440$	$X^2=2.776$ $p=0.836$	$X^2=0.743$ $p=0.863$	$X^2=4.773$ $p=0.029^*$
Have you been treated for any physical health problem that you can relate to your task of caregiving for the CP child? (For example backache)	$X^2=11.567$ $p=0.172$	$X^2=0.470$ $p=0.791$	$X^2=3.628$ $p=0.727$	$X^2=8.958$ $p=0.707$	$X^2=6.612$ $p=0.358$	$X^2=0.476$ $p=0.788$
Do you feel like your physical and mental health has been affected by caring for your child with CP?	$X^2=7.767$ $p=0.100$	$X^2=0.470$ $p=0.493$	$X^2=1.694$ $p=0.638$	$X^2=3.069$ $p=0.800$	$X^2=5.185$ $p=0.159$	$X^2=0.476$ $p=0.490$
Do you at times feel generally sad with your caregiving task and cry?	$X^2=20.299$ $p=0.207$	$X^2=0.727$ $p=0.605$	$X^2=21.868$ $p=0.039^*$	$X^2=19.919$ $p=0.701$	$X^2=17.137$ $p=0.145$	$X^2=2.453$ $p=0.653$
Do you at times struggle to sleep as a result of your role in caring for the child with CP?	$X^2=14.626$ $p=0.552$	$X^2=0.4921$ $p=0.296$	$X^2=15.027$ $p=0.240$	$X^2=23.557$ $p=0.487$	$X^2=13.471$ $p=0.336$	$X^2=3.219$ $p=0.522$

Variable	Age group	Sex	Marital status	Ethnic group	Level of education	Religion
Do you have enough time for yourself away from your caregiving role to the child?	$\chi^2=3.318$ $p=0.506$	$\chi^2=1.177$ $p=0.278$	$\chi^2=3.660$ $p=0.301$	$\chi^2=4.4868$ $p=0.561$	$\chi^2=0.677$ $p=0.879$	$\chi^2=0.511$ $p=0.475$
Do you feel like the child with CP has affected your ability to have a social life?	$\chi^2=16.881$ $p=0.393$	$\chi^2=1.753$ $p=0.781$	$\chi^2=10.519$ $p=0.570$	$\chi^2=23.962$ $p=0.464$	$\chi^2=14.594$ $p=0.264$	$\chi^2=14.939$ $p=0.050$
Do you feel like you do not have enough money to sufficiently take care of the child with CP in addition to your other living expenses?	$\chi^2=13.186$ $p=0.659$	$\chi^2=0.222$ $p=0.994$	$\chi^2=11.993$ $p=0.446$	$\chi^2=43.393$ $p=0.009^*$	$\chi^2=12.977$ $p=0.371$	$\chi^2=21.645$ $P<0.001$

Table 4.9 revealed that there were no significant associations between caregiver burden against age group, sex or level of education (all **p values > 0.05**). However, there was a significant relationship between marital status and caregiver generally feeling sad with their task making them cry (**p value = 0.039**).

Table 4.10 Association between marital status and caregiver feeling sad and crying? (N=91)

		Do you at times feel generally sad with your caregiving task and cry?				
Marital Status	Responses	Never	Rarely	Sometimes	Quite frequently	Nearly Always
	Married	22.60%(n=7)	3.2%(n=1)	51.6%(n=16)	16.1%(n=5)	6.5%(n=2)
	Single	11.30%(n=6)	5.7%(n=3)	41.5%(n=22)	18.9%(n=10)	22.6% (n=12)
	Divorced	50%(n=1)			50%(n=1)	
	Other		40%(n=2)	20%(n=1)	40%(n=2)	

Table 4.10 reveals association between marital status of caregiver and generally feeling sad and crying.

At least 22.6% (n=12) of single caregivers nearly always felt sad and cried compared to 6.5% (n=2) married caregivers. Similarly 22.60% (n=7) married caregivers never felt sad and cried while 11.30% (n=6) single caregivers never felt sad and cried (refer to Table 4.10).

A significant association was also found between ethnic group of the caregiver and the inability to have enough money to sufficiently cover all other living expenses in addition to the child with CP (**p value = 0.009**). Regardless of the ethnic group, all caregivers indicated that they either agreed strongly or just agreed with the statement “Do you feel like you do not have enough money to sufficiently take care of the child with CP in addition to your other living expenses?”

Religion was found to be significantly associated with:

- negative relationships within the family secondary to having a child with CP, and
- Inability to have enough money to sufficiently cover all living expenses in addition to caring for the child with CP (**p values were 0.029 and <0.001 respectively**).

Table 4.11 Relationships between caregiver burden and individual caregiver attributes (N=91)

Variable	Are you staying in the same household as the child with CP?	Do you think your spiritual beliefs help you to cope better when caring for your child?	Would you describe yourself as physically healthy/fit?	Does your child have other chronic medical problems such as epilepsy?	How would you rate your knowledge and understanding of Cerebral palsy?
Do you find caregiving as physically straining/tiring/exhausting?	$X^2=9.861$ $p=0.043^*$	$X^2=18.645$ $p=0.287$	$X^2=6.366$ $p=0.606$	$X^2=3.048$ $p=0.550$	$X^2=33.755$ $p=0.006^{**}$
Do you at times feel overworked by trying to balance your caregiving role, other family duties and your job?	$X^2=10.793$ $p=0.029^*$	$X^2=18.516$ $p=0.295$	$X^2=7.322$ $p=0.502$	$X^2=2.911$ $p=0.573$	$X^2=26.573$ $p=0.460$
Does having the child with CP in your family negatively affect relationships between yourself and other family members?	$X^2=1.309$ $p=0.253$	$X^2=3.278$ $p=0.512$	$X^2=3.052$ $p=0.217$	$X^2=2.838$ $p=0.92$	$X^2=3.961$ $p=0.411$
Have you been treated for any physical health problem that you can relate to your task of caregiving for the CP child? (For example backache)	$X^2=4.867$ $p=0.088$	$X^2=2.594$ $p=0.957$	$X^2=17.285$ $p=0.020^*$	$X^2=6.269$ $p=0.440$	$X^2=8.797$ $p=0.360$
Do you feel like your physical and mental health has been affected by caring for your child with CP?	$X^2=13.504$ $P<0.001^*$	$X^2=5.015$ $p=0.286$	$X^2=0.093$ $p=0.955$	$X^2=0.303$ $p=0.582$	$X^2=13.512$ $p=0.090$

Variable	2.1 Are you staying in the same household as the child with CP?	2.2 Do you think your spiritual beliefs help you to cope better when caring for your child?	2.3 Would you describe yourself as physically healthy/fit?	2.5 Does your child have other chronic medical problems such as epilepsy?	5.2 How would you rate your knowledge and understanding of Cerebral palsy?
Do you at times feel generally sad with your caregiving task and cry?	$X^2=11.088$ $p=0.026^*$	$X^2=13.954$ $p=0.602$	$X^2=9.072$ $p=0.336$	$X^2=6.652$ $p=0.155$	$X^2=20.068$ $p=0.217$
Do you at times struggle to sleep as a result of your role in caring for the child with CP?	$X^2=7.13$ $p=0.129$	$X^2=21.582$ $p=0.157$	$X^2=5.695$ $p=0.681$	$X^2=1.047$ $p=0.903$	$X^2=11.768$ $p=0.786$
Do you have enough time for yourself away from your caregiving role to the child?	$X^2=12.581$ $P<0.001$	$X^2=10.135$ $p=0.038^*$	$X^2=0.038$ $p=0.981$	$X^2=0.330$ $p=0.856$	$X^2=5.635$ $p=0.228$
Do you feel like the child with CP has affected your ability to have a social life?	$X^2=32.746$ $P<0.001$	$X^2=16.966$ $p=0.388$	$X^2=7.943$ $p=0.439$	$X^2=3.195$ $p=0.526$	$X^2=33.080$ $p=0.070$
Do you feel like you do not have enough money to sufficiently take care of the child with CP in addition to your other living expenses?	$X^2=13.776$ $p=0.080$	$X^2=21.642$ $p=0.155$	$X^2=9.658$ $p=0.290$	$X^2=5.165$ $p=0.271$	$X^2=49.317$ $P<0.001$

The results in table 4.11 revealed that staying with a child with CP in the same household was found to be highly significant with all characteristics of caregiver burden except affecting family relations, affecting physical health, sleeping problems or not having enough money for living expenses in addition to caring for the child with CP (p values are presented in Table 4.11). This finding was possibly caused by an endless circle of care without a reasonable break (p = 0,029).

Table 4.12 Association between age group of caregiver and lack of sleep (N=91)

		Do you at times struggle to sleep as a result of your role in caring for the child with CP?				
Age group (years)	Responses	Never	Rarely	Sometimes	Frequently	Nearly Always
	20-24(n=15)	6.70% (n=1)	13.30% (n=2)	26.79%(n=4)	33.30% (n=5)	20% (n=3)
	25-29(n=23)	8.70% (n=2)	13% (n=3)	47.80% (n=9)	21.70% (n=5)	8.70% (n=2)
	30-34(n=20)	25% (n=5)	10% (n=2)	45% (n=9)	5%(n=1)	15%(n=3)
	35+(n=23)	26.10% (n=6)	13% (n=3)	34.8% (n=8)	26.10% (n=6)	
	Other(n=10)	30% (n=3)	10% (n=1)	40% (n=4)	10% (n=1)	10% (n=10)

Table 4.12 shows the association between age group of caregiver and the extend to which they struggle to sleep. At least 33.30% (n=5) from the 20-24 year age group, 21,70% (n=5) from the 25-29 year age group, 26.10% (n=6) from 35+ age group frequently struggled to sleep. There was no significant association between the age group of the carer and lack of sleep, though the 20-24 year age group had a higher percentage in the 33.30%(n=5) for frequent lack of sleep and 20%(n=3) for always struggling to sleep. This can be explained by maturity levels and still adjusting not only to first child but also emotional immaturity in coping with having a child with CP.

Spiritual beliefs had no association relating to caregiver burden with this sample of participants (all **p values > 0.05**). There was a significant relationship between the health status of the caregiver and a positive history for having been treated for a physical health problem related to caregiving (**p value= 0.02**).

The results from this study are comparable to the findings from a study that was conducted in rural Bangladesh with regards to understanding the lives of caregivers for children with CP. It was found that there was a significant relationship between families with a child with CP and low family functioning abilities (physical, emotional,

social and cognitive), poor family relationships, lots of worry and poor communication (Zuurmond, Mahmud, Polack & Evans 2015:11).

A detailed significance on the positive relationship between having been treated for a physical ailment related to caregiving and whether the caregiver was physically fit is presented graphically in Figure 4.19 below:

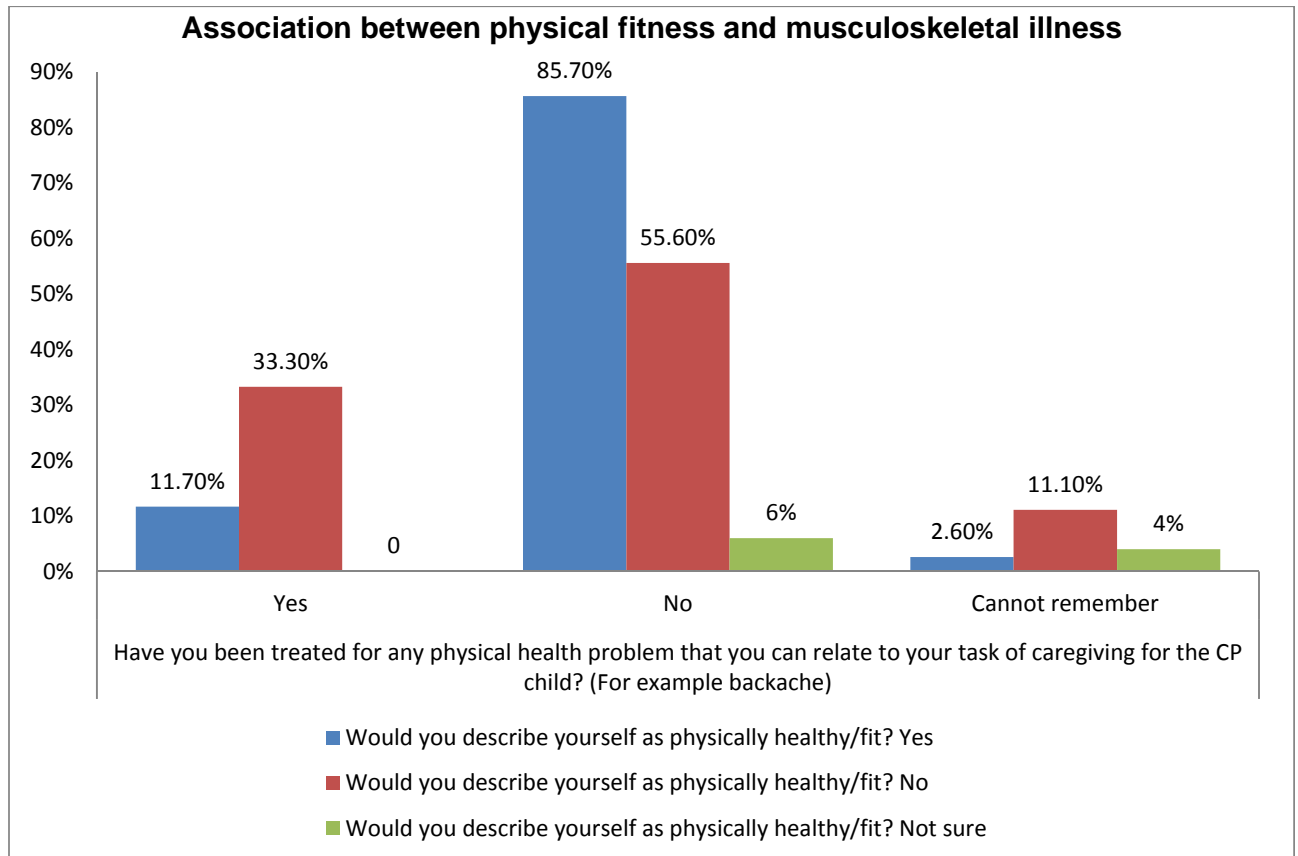


Figure 4.21 Graphical presentation of the association between physical fitness and musculoskeletal illness (N=91)

Figure 4.21 shows that the presence of other chronic conditions such as epilepsy was found to be non-significant in influencing any of the descriptive traits of caregiver burden in Namibia (all **p values > 0.05**). However, knowledge and understanding of cerebral palsy was found to be significant in its relationship with caregiving as physically tiring (p value = 0.006), child with CP affecting the ability for social life (p value = 0.07) and inability for caregivers finding enough money to cover all living costs, including the child with CP (p value < 0.001).

4.7 CONCLUSION

In Chapter 4 the results were analysed, interpreted and presented. The service of the statistician was used in the data analysis. The results were presented under the following main subheadings:

- Demographics of the caregivers for children with CP in Namibia;
- Strategies to alleviate caregiving burden;
- Description of the burden faced by caregivers and
- Challenges of caregiving for children with CP.

Chapter 5, which is the conclusion of the study, discussed the research results, limitations and recommendations of the study.

CHAPTER 5

DISCUSSION OF THE RESULTS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

In this last chapter, a discussion of the results is presented. The researcher starts by summarising and discussing the study results, which is followed by the recommendations for caregivers, policymakers, clinicians and suggestions for future research. Lastly limitations of the study are stated. The chapter ends with concluding remarks of the study.

5.2 SUMMARY OF THE RESEARCH RESULTS

The purpose of the study was to investigate factors that influence the burden of caregiving among caregivers of children with cerebral palsy in Namibia. The objectives of this study were:

- To determine factors that influence the burden of caregiving on caregivers for children with CP in Namibia;
- To describe the burden of caregiving on caregivers for children with CP;
- To identify the challenges that Namibian caregivers encounter in caring for children with CP and
- To identify strategies that lessen the burden of caregivers for children with CP.

The data were collected from caregivers whose children with CP were receiving occupational therapy and physiotherapy at two public hospitals in Windhoek. An adapted questionnaire from the ZBI was used to collect data. Generally, the results of the study showed that the marital status of caregivers, staying in the same household with a child with CP, caregivers' knowledge of CP and not having enough money were factors that influenced the burden of caregiving for caregivers of children with CP in Namibia.

Caregiving for a child with CP was described as an inconvenience that brought conflict within families, and resulted in blame and stigma of the caregiver. Common challenges among the caregivers were high financial costs, community issues, 24-hour care and general ill health of the child with CP. Strategies for easing burden were financial support, specialised schools for children with CP, caregiver support groups and improved medical care. The following paragraphs outline the results from the study.

5.2.1 Factors associated with caregiving burden for children with CP in Namibia

In this study, marital status was found to have a significant relationship with a higher burden of care among caregivers for children with CP. This was also similar to a study that determined the factors associated with caregiver burden among caregivers for children with CP in Sri Lanka. The results found that low spousal support resulted in higher burden of care (Wijesinghe et al 2015:90). The results of this study indicated that 58.2% (n=53) of the caregivers were single parents, who also indicated that they lacked enough partner support. It is also important to note that in this study 97.8% (n= 89) of the caregivers were female (refer Table 4.1). This further correlates with the results from the study conducted to determine the factors linked with caregiver burden among caregivers in Sri Lanka (Wijesinghe et al 2015:90), which found that being a female and having low income is more associated with higher burden of care for children with CP.

There was a significant association between staying in the same household as a child with CP and feelings of sadness and crying. This can be explained by the feeling of hopelessness by some caregivers or it can be linked to lack of partner and social support. Caregiving has been linked with depression among the caregivers of patients with dementia in a study to investigate factors contributing to caregiver burden in Hunan province in China, thus the respondents in this study were also asked if they felt generally sad with their caregiving task and cry (Wang et al 2014:994). At least 42.9% (n=39) indicated that they sometimes cried, 19.8% (n=18) indicated that they cried quite frequently and 15.4% (n=14) indicated that they cried nearly always (refer to Figure 4.12).

While in developed countries the caregiver is driven by personal beliefs, family expectations and generational role models to provide informal caregiving services to a family member, for the caregivers in Namibia the caregiver has got no choice or any other option since this is viewed as their primary responsibility.

The issue of stigma and blame is prevalent in the Namibian community according to the study findings which makes this study significant since it has highlighted areas that need to be intervened in order to strengthen informal caregiving services in Namibia. These areas are central topics for public awareness campaigns which are CP causes, its symptoms and support services that are available for affected families. Additionally, the community needs to be educated on strategies that can be implemented in the prevention of CP, such as encouraging women to give birth at the hospital.

Health care professionals also need to understand the cultural context of the caregivers they work with. This will assist in identifying the 'cry for help' patterns, thereby ensuring that the caregivers are always in good health, thus in a good position to provide optimal care to the children with CP. This will be the ability to understand the source of strain and personal coping strategies. It is also of importance to understand the social and community support available for the caregiver.

5.2.2 Challenges with caregiving for children with CP

The caregivers indicated that one of their main challenges was the twenty-four (24) hour care of the child with CP, which include doing different tasks such as feeding, positioning, playing with the child, changing diapers and any other self-care and grooming tasks. These tasks by Namibian caregivers are similar to those by Brazilian caregivers in an institution with children and adolescents with CP (Melo et al 2017:4). Most of the Brazilian children with CP spent most of their time in bed, needed assistance with sphincter control, lacked fine movement control and needed maximal assistance with all daily tasks including dressing and feeding. This result has shown that full time care for a child with CP is not only isolated to Namibia but it is a characteristic for each child with CP who has multiple impairments.

This study has brought to the attention of the researcher the amount of dependence of the child with CP; however, it does not give detailed levels of impairments that the

child has according to a standardised measurement format such as the Gross Motor Function Classification System Expanded and Revised (GMFCS-E&R).

Lack of assistive devices such as a wheelchair also came up under the medical care challenges. This lack of wheelchairs was found as a complete barrier for those children since they are unable to sit upright to engage and or participate in different activities (Bray et al 2014:9). Caregivers whose children do not have wheelchairs constantly have to provide a supportive environment. Children without assistive devices are at an increased probability of developing secondary complications such as contractures, breathing and feeding problems. These then increase the amount of care, thereby increasing the burden for caregivers which according to the findings in this study, the caregivers were actually unaware that it is a contributing factor to their burden.

Previous studies have found that knowledge and understanding of the child's diagnosis had an influence on the overall care of the patient and that it influences their health seeking behaviour (Soo & Tan 2014:134). With reference to this study, some knowledge about CP by the caregivers was poor for 14.4% (n=13), fair for 45.6% (n=41) and 3.3% (n=3) of the respondents were not sure (refer to Figure 4.17). The 'fair' as represented by 45.6% (n=41) can possibly give the Namibian health professionals a good picture since it can mean that they are engaging the caregivers in the management of the health of the child with CP so they might end up with fair knowledge of the child's medical condition.

Caregivers shared that they have a huge financial challenge in getting their child with CP get a good quality of life.

Costs were directly for consumables such as nappies and they were also indirectly caused by the unemployment status of the caregiver who could not look for jobs since they have to give the child for full time care. Low income, staying in rural areas, being a male and the child with CP having several deficits have previously been found to be directly related to higher burden of care among caregivers for children with CP in Sri Lanka (Wijesinghe et al 2015:8). This explains the different policies that aim to alleviate poverty for these families through the provision of government grants to help cover the costs for the family since families with a child with a disability are financially vulnerable. In the Namibian context, it is sad to note that caregivers with children with

CP are relying on the government's social grant of N\$250 per month, which is hardly enough to cover the costs of care for a child with CP in a month.

Partner and community support was found lacking in this study. This explains the significant relationship between those with poor physical health and history of having been treated for a physical ailment. This conclusion can be supported by a previous study which was conducted in China to investigate caregiver burden and factors associated with different types of burden in caring for patients with dementia. The results from that study showed that caregivers had good nuclear family support, yet they lacked extended family support, thereby resulting in them complaining of musculoskeletal problems (Wang et al 2014:994). Furthermore, 96.7% (n=88) of caregivers in this study were cohabitating with a child with CP (refer Figure 4.1). This can also support the result that caregivers did not have enough time for themselves because they are always attending to their caregiving role. This finding is comparable to the results from a study on the determinants of objective and subjective burden in China, where they associated dementia related financial burden, age of caregiver and cohabitating with care recipient as variables associated with social burden problems (Wang et al 2014:994).

For the Namibian context, neglect of centres and no/poor support for caregivers with CP is a cause for concern. In Windhoek, the only centre for children with CP where parents could leave them during the day while working is Oponganda. This centre has since closed down due to lack of funding. It is important to highlight that this centre had on average nine (9) children with profound CP who needed maximal assistance in their daily activities. The staff member who looked after the children had no formal training to improve the quality of care of the children with CP.

For some caregivers, the biological fathers of the children with CP were not providing any financial support. Traditional beliefs such as accusing the caregiver of being a witch or accusing them of having engaged in taboo practices during pregnancy clearly showed a picture of a community that is stigmatising and isolating the caregiver.

The general ill health of the child with CP was also found to be a challenge and contributing factor to the burden of caregiving. The results from this study showed no

significant association between the presence of other comorbidities as related to caregiver burden; however, previous studies have found this association as significant (Wijesinghe et al 2015:90). Possibly not enough information was collected through the data collection instrument that could have shown this association.

Considering the result from the question asked to the respondents; “Do you at times struggle to sleep as a result of your role in caring for the child with CP?” responses were as follows: always 9.9% (n=9), frequently 19.8% (n=18) and sometimes 39.6% (n=36) (refer to Figure 4.11). Thus, sleep disturbances may not only be for the caregiver but for the extended family in situations whereby dwelling is a single room. This is similar to the living conditions for caregivers in a study with caregivers for patients with dementia in China (Wang et al 2014:993).

5.2.3 Strategies for lessening burden of caregiving for children with CP

Caregivers in this study described their role as an endless routine that they do, making it impossible for them to have time for themselves due to their caregiving duties. Resultantly, 81.3% (n= 74) of the caregivers as per the results of this study felt that their physical and mental health had been affected by their role of caregiving (refer to Figure 4.10). Caregivers suggested that the government should introduce specialised day-care centres so that they can get relief from their caregiving role and also become more financially productive in order to provide an income for their families.

These strategies have been highlighted as beneficial in an Italian study that determined the relationship between well-being and burden of caregiving for people with severe neuro-motor and cognitive disorders. The results from that study revealed that addressing psychosocial, social, relational and personal well-being issues would cause optimal functioning and reduction in caregiver’s burden (Fianco, Sartori, Negri, Lorini, Valle & Delle-Fave 2015:52).

Caregivers also suggested need for financial assistance, food aid and free housing to be made available by the government. Coping mechanisms for caregivers in this study can be related to their social and community challenges since 56.0% (n=51) of caregivers felt that the community in which they live does not understand cerebral palsy as a medical condition, 47.3% (n=43) of the respondents felt discriminated and 29.7% (n=29) of them felt that the community did not care (refer to table 4.7). However,

there is a need to conduct a more in-depth mixed design to get a better understanding of how the community and social circumstances influence caregiver burden coping strategies. This hypothesis is related to the results from a previous study in India that aimed to find the difference between stress, burden and the coping mechanisms of caregivers for children with cerebral palsy and autism. One of the findings was that parents with children with CP were more dependent on the circumstances rather than conditions of the child (Pushpalatha & Shivakumara 2016:114).

5.3 RECOMMENDATIONS

Based on the results of this study, the researcher proposes the following recommendations:

5.3.1 Caregivers

- Support groups that meet at regular intervals so as to provide a platform where learning can occur so as to better equip caregivers with ideas for the execution of their important role;
- Awareness among caregivers on ways to prevent psychological, musculoskeletal and social problems associated with their role and
- Examples of topics that may be discussed at support groups include lifting techniques, different treatment options available for children with CP, correct twenty-four (24) hour positioning for children with CP and low cost aids and assistive devices fabrication for therapeutic home programs.

5.3.2 Health care professionals

- Refer caregivers as soon as possible when they identify health risks of caregiving on the well-being of the caregiver;
- Educate caregivers on evidence based home based care programmes, the importance of correct positioning strategies and social support services available at their disposal to help with the task of caregiving and

- Prescribe all assistive devices that are available that will give more independence to the child with CP and decrease the physical burden through unnecessary manual lifting and carrying children over long periods and distances.

5.3.3 Policymakers

- Revision of social grants so that the grants can meet the needs of the children with CP and improve their overall quality of life and
- Revision of the housing policy so that families with children with disabilities can be prioritised in receiving subsidised or free housing from the government.

5.3.4 Future research

- A similar nationwide research can be carried out and the results can be compared to the results from this study;
- An additional topic focusing on physical burden of care can be carried out;
- A follow up study can be done to get a more detailed picture on the financial costs and financial burden indicators for caring for a child with CP. Similarly, to raise more awareness on the significance of informal caregiving, a study to determine replacement costs for unpaid caregiving work for children with CP can also be done;
- A research need was also identified in the area of special schools. Future research should explore the Namibian policy, as well as the social and individual traits that act as barriers to accessing formal education for children with CP and
- Qualitative research can also be done to find out the cultural beliefs and community attitude towards children with CP and their families.

5.4 CONTRIBUTIONS OF THE STUDY

The following are expected contributions of the study:

- From the results of this study, health care professionals can be informed about the challenges that caregivers encounter so that they may ensure that home programs for children with CP are relevant;

- The results from the study can be used to inform health policy developers in improving health policies so as to promote informal caregiving, which not only improves the quality of life of the children with CP but reduces government expenditure through continued hospitalisation of sick children from preventable ailments;
- The results from this study are also expected to be used in raising awareness among communities on issues around CP so that the communities can be more supportive of families of children with disabilities and
- The study has also shown research gaps which provide a foundation for future research in this area.

5.5 LIMITATIONS OF THE STUDY

The limitations of the study are the following:

- Generalisation of the results will be impossible since data was only collected from caregivers whose children with CP were receiving occupational therapy and physiotherapy at two public hospitals in Windhoek;
- Diagnosis of CP was given either by the paediatrician or a medical officer. From the child with CP's clinical notes, it was different from one child to another's diagnostic test and examinations done, thus this could have led to bias.

5.6 CONCLUDING REMARKS

The researcher carried out this study with the intention to determine factors influencing burden of caregiving for caregivers of children with CP in Namibia. The results showed that being single and staying in the same household with a child with CP was significantly related to higher burden of care for children with CP. Thus, major results of this study supported some of the results from the literature, thereby indicating that there is still some work to be done in order to contribute in improving the plight of informal caregivers for children with CP. The Namibian setting has highlighted that caregiver burden of care is more psychosocial since results have not provided enough evidence to relate it to musculoskeletal ailments. Based on these results, the researcher proposed some recommendations that could contribute to the lessening of

the burden of caregivers for children with CP and indirectly improve the health and well-being of the care-recipients. The study presented the results that showed that the burden experienced by caregivers of children with CP should be addressed so as to improve the quality of care for children with CP.

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ANNEXURES

**ANNEXURE 1: APPLICATION LETTER FOR ETHICAL APPROVAL FROM
RESEARCH AND ETHICS COMMITTEE OF THE DEPARTMENT OF HEALTH
STUDIES, UNIVERSITY OF SOUTH AFRICA (UNISA)**

ANNEXURE 1

Request for ethical approval from UNISA research ethics committee

Box 50309

Bachbrecht

Windhoek

Namibia

12 October 2016

The Chairperson

Ethical Approval Committee

Colleges of Health Sciences

University of South Africa

South Africa

Dear Sir/Madam

RE: REQUEST FOR ETHICAL APPROVAL TO CONDUCT RESEARCH STUDY IN WINDHOEK, NAMIBIA

I hereby request for permission to conduct a study focusing on the caregivers of children with cerebral palsy (CP).

My name is Hellena Makura and I am a research student pursuing a master in public health (MPH) at the University of South Africa (UNISA) (student number is 50781774). I am currently employed by Windhoek Central Hospital as an Occupational Therapist.

The title of my study is:

- **Factors influencing caregiving for parents of children with cerebral palsy (CP) in Windhoek**

The purpose of the study is to investigate factors that influence burden of caregiving for children with CP in Namibia. The significance of the study will be to inform policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of

children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers.

For more information you may contact myself or my supervisor Dr KA Maboe, a senior lecturer in the department of health studies and her contacts details are: email maboeka@unisa.ac.za or 0027 12 4292393 telephonically

I will be looking forward to a favourable response.

Yours faithfully



Hellena Makura (Ms)

(0815907275/ 50781774@mylife.unisa.ac.za)

**ANNEXURE 1B: ETHICAL APPROVAL LETTER FROM RESEARCH AND
ETHICS COMMITTEE OF THE DEPARTMENT OF HEALTH STUDIES,
UNIVERSITY OF SOUTH AFRICA (UNISA)**

ANNEXURE 1B



**RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)**

1 March 2017

Dear MS H Makura

Decision: Ethics Approval

HS HDC/648/2017

MS H Makura

Student: 5078-177-4

Supervisor: Dr KA Maboe

Qualification: D Litt et Phil

Joint Supervisor: -

Name: MS H Makura

Proposal: Factors influencing the burden of caregivers of children with Cerebral Palsy in Namibia.

Qualification: MPCHS94

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted for the duration of the research period as indicated in your application.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 1 March 2017.

The proposed research may now commence with the proviso that:

- 1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*
- 2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*



Open Rubric

University of South Africa
Pretorius Street, Muckleneuk Ridge, City of Tzaneke
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
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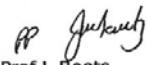
3) The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.

4) [Stipulate any reporting requirements if applicable].

Note:

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,


Prof L Roets
CHAIRPERSON
roetsl@unisa.ac.za


Prof MM Moleki
ACADEMIC CHAIRPERSON
molekmm@unisa.ac.za

**ANNEXURE 2: REQUEST FOR ETHICAL APPROVAL TO CONDUCT A
STUDY IN NAMIBIA**

Request for permission to conduct study in Namibia

Box 50309

Bachbrecht

Windhoek

Namibia

3 July 2017

The Chairperson

Ethical Approval Committee

Ministry of Health and Social Services

Namibia

Dear Sir/Madam

RE: REQUEST FOR ETHICAL APPROVAL TO CONDUCT RESEARCH STUDY IN WINDHOEK, NAMIBIA

I hereby request for permission to conduct a study focusing on the caregivers of children with cerebral palsy (CP).

My name is Hellena Makura and I am a research student pursuing a master in public health (MPH) at the University of South Africa (UNISA) (student number is 50781774). I am currently employed by Windhoek Central Hospital as an Occupational Therapist.

The title of my study is:

- **Factors influencing caregiving for parents of children with cerebral palsy (CP) in Windhoek**

The purpose of the study is to investigate factors that influence burden of caregiving for children with CP in Namibia. The significance of the study will be to inform policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers.

Kindly refer to an Ethical Clearance certificate from UNISA as attached.

For more information you may contact myself or my supervisor Dr KA Maboe, a senior lecturer in the department of health studies and her contacts details are: email maboeka@unisa.ac.za or 0027 12 4292393 telephonically.

I will be looking forward to a favourable response.

Yours faithfully

A handwritten signature in black ink, consisting of a stylized monogram followed by the name 'kura'.

Hellena Makura (Ms)

(0815907275/ 50781774@mylife.unisa.ac.za)

**ANNEXURE 3: ETHICAL APPROVAL LETTER FROM RESEARCH UNIT OF
NAMIBIAN MINISTRY OF HEALTH AND SOCIAL SERVICES**

ANNEXURE 3



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 2032150
Fax: 061 - 222558
Email: shimenghipangelwa71@gmail.com

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3 HK
Enquiries: Mr. J. Nghipangelwa

Date: 21 September 2017

Ms. Hellena Makure-Kumire
P.O. Box 50309
Bachbrecht
Windhoek
Namibia

Dear Ms. Kumire

Re: factor influencing the burden of caregiving for children with Cerebral Palsy in Namibia.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
 - 3.1 The data to be collected must only be used for academic purposes;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects' should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
 - 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
 - 3.5 Preliminary findings to be submitted upon completion of the study;

3.6 Final report to be submitted upon completion of the study;

3.7 Separate permission should be sought from the Ministry of Health and Social Services for publication of the findings.

Yours sincerely,



Andreas Mwoombola (Dr.)
Permanent Secretary



**ANNEXURE 4: REQUEST FOR PERMISSION TO CONDUCT THE STUDY AT
PUBLIC HOSPITAL 1**

Annexure 4

Request for permission to conduct the study in Namibia

Box 50309

Bachbrecht

Windhoek

Namibia

25 September 2017

Medical Superintendent

Katutura Intermediate Hospital

Ministry of Health and Social Services

Namibia

Dear Doctor

RE: REQUEST TO CONDUCT RESEARCH STUDY AT OCCUPATIONAL THERAPY AND PHYSIOTHERAPY DEPARTMENTS

My name is Hellena Makura and I am a research student pursuing a master in public health (MPH) degree at the University of South Africa (UNISA) (student number is 50781774). I am currently employed by Windhoek Central Hospital as an Occupational Therapist.

I hereby request for permission to conduct a study focusing on the caregivers of children with cerebral palsy (CP).

The title of my study is:

- **Factors influencing the burden of caregiving for children with Cerebral Palsy by caregivers in Namibia**

The purpose of the study is to investigate factors that influence burden of caregiving for children with CP by caregivers in Namibia. The significance of the study will be to inform policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers

Kindly refer to an Ethical Clearance certificate from UNISA department of Health Studies and ethical clearance from the office of the permanent secretary of MOHSS as attached.

For more information you may contact myself or my supervisor Dr KA Maboe, a senior lecturer of the department of health studies at UNISA and her contacts details are: email maboeka@unisa.ac.za or 0027 12 4292393 telephonically.

I am looking forward to a favourable response.

Yours faithfully

A handwritten signature in black ink, appearing to read 'H. Makura-Kumire', with a stylized initial 'H' inside a square box.

Hellena Makura-Kumire (Ms)

(0815907275/ 50781774@mylife.unisa.ac.za)

**ANNEXURE 5: REQUEST FOR PERMISSION TO CONDUCT THE STUDY AT
PUBLIC HOSPITAL 2**

Request for permission to conduct the study in Namibia

Box 50309

Bachbrecht

Windhoek

Namibia

25 September 2017

Medical Superintendent

Windhoek Central Hospital

Ministry of Health and Social Services

Namibia

Dear Dr Uirab

RE: REQUEST TO CONDUCT RESEARCH STUDY AT OCCUPATIONAL THERAPY AND PHYSIOTHERAPY DEPARTMENTS

My name is Hellena Makura and I am a research student pursuing a master in public health (MPH) degree at the University of South Africa (UNISA) (student number is 50781774). I am currently employed by Windhoek Central Hospital as an Occupational Therapist.

I hereby request for permission to conduct a study focusing on the caregivers of children with cerebral palsy (CP).

The title of my study is:

- **Factors influencing the burden of caregiving for children with Cerebral Palsy by caregivers in Namibia**

The purpose of the study is to investigate factors that influence burden of caregiving for children with CP by caregivers in Namibia. The significance of the study will be to inform policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers.

Kindly refer to an Ethical Clearance certificate from UNISA department of Health Studies and ethical clearance from the office of the permanent secretary of MOHSS as attached.

For more information you may contact myself or my supervisor Dr KA Maboe, a senior lecturer of the department of health studies at UNISA and her contacts details are: email maboeka@unisa.ac.za or 0027 12 4292393 telephonically.

I am looking forward to a favourable response.

Yours faithfully

A handwritten signature in black ink, appearing to read 'H Makura'.

Hellena Makura-Kumire (Ms)

(0815907275/ 50781774@mylife.unisa.ac.za)

**ANNEXURE 6: REQUEST FOR PERMISSION TO ADAPT ZARIT BURDEN
INTERVIEW QUESTIONNAIRE**

Annexure 6

Request for permission to adapt Zarit Burden Interview

Box 50309

Bachbrecht

Windhoek

Namibia

12 October 2016

Dear Prof Steve Zarit

**RE: REQUEST FOR PERMISSION TO ADAPT ZARIT BURDEN INTERVIEW
TOOL TO CONDUCT RESEARCH STUDY IN WINDHOEK, NAMIBIA**

My name is Hellena Makura and I am a research student pursuing a master in public health (MPH) at the University of South Africa (UNISA) (student number is 50781774). I am currently employed by Windhoek Central Hospital as an Occupational Therapist.

I am kindly asking for permission to adapt your 21 item version of the Zarit Burden Interview so that it can be more relevant for use in our setting.

The title of my study is:

- **Factors influencing caregiving for parents of children with cerebral palsy (CP) in Windhoek**

The purpose of the study is to investigate factors that influence burden of caregiving for children with CP in Namibia. The significance of the study will be to inform policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers.

Ethical approval has been granted by UNISA. Kindly refer as attached.

I am doing this research under the supervision of Dr Kefiloe Maboe, a Senior Lecturer in the Department of Health Studies. Her contact details are maboeka@unisa.ac.za via email or telephonically 0027 12 4292393.

If approved study will be conducted from February 2017 and expected to be completed in December of 2017.

Kindly refer to an Ethical Clearance certificate from UNISA as attached.

For more information you may contact myself or my supervisor Dr KA Maboe, a senior lecturer in the department of health studies and her contacts details are: email maboeka@unisa.ac.za or 0027 12 4292393 telephonically.

I will be looking forward to a favourable response.

Yours faithfully



Hellena Makura (Ms)

(0815907275/ 50781774@mylife.unisa.ac.za)

**ANNEXURE 7: APPROVAL FOR USE OF ZARIT BURDEN INTERVIEW
QUESTIONNAIRE**

ANNEXURE 7: APPROVAL LETTER FOR USE OF ZARIT BURDEN INTERVIEW



User agreement
Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
PROVIDE™
27 rue de la Villette
69003 Lyon
France
Telephone: +33 (0)4 72 13 65 75
Fax: +33 (0)4 72 13 66 82

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

Section 1.01 Identification of the User

User Name	Hellena Makura
Legal Form	Student
Address	24 Bethe Street Pioneers Park Windhoek namibia Box 50309 Bachbrecht Windhoek Namibia
Country	Namibia
Email address	50781774@mylife.unisa.ac.za
Telephone number	00264815907275

Section 1.02 Identification of the Questionnaire

Zarit Burden Interview_UserAgreement_March2016_5.0

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Title	Zarit Burden Interview (ZBI)
Author(s)	Zarit Steven H
Owner	Zarit Steven H and Zarit Judy M
Copyright	Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit
Original bibliographic references	<p>ZBI-22</p> <p>Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. <i>Gerontologist</i>. 1980;20(6):649-55</p> <p>Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985</p> <p>Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990</p> <p>ZBI-12</p> <p>Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. <i>Gerontologist</i>. 2001 Oct;41(5):652-7 (PubMed Abstract)</p>

Article 2. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of Use	Clinical project or study
Title	Factors influencing the burden of caregivers of children with Cerebral Palsy in Namibia
Type of research	Other
Other	Cross sectional descriptive study
Number of patients expected	120
Start	03/2017
End	06/2018
Mode of administration	Paper administration

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred

Acting in the Owner's name, MRT transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")

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(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, free of charge, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing MRT of the same beforehand by the signature of a Translation Agreement indicating the terms of it and to providing a copy of the translation thus obtained as soon as possible to MRT.

The User acknowledges and accepts that it is not entitled to amend, modify, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without MRT's prior specific written consent.

(b) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.

- Use in a publication or on a website with unrestricted access:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a protected version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: <https://eprovide.mapi-trust.org/>
- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

- Use for dissemination:

- On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a clean version of the Questionnaire, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.

The User undertakes to also respect the following special obligations:

- to indicate the name and copyright notice of the Owner
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- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

- On promotional / marketing documents

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In the case of publication on promotional/marketing documents, the User undertakes to respect the following special obligations:

- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
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- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

For any other use not defined herein, please contact MRT for the specific conditions of use and access fees (if applicable).

Article 3. Term

MRT transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. Territories and Languages

MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Questionnaire	Language
ZBI-22	English for South Africa

Article 6. Price and Payment Terms

The User undertakes in relation to MRT to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

ROYALTY FEES*	Commercial users	Cost per study	1 000 €
		Cost per language	500 €
	Funded academic research	Cost per study	Free
		Cost per language	Free
	Not funded academic users	Cost per study	Free
		Cost per language	Free

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DISTRIBUTION FEES*	Commercial users	Cost per study	1 000 €
		Cost per language	500 €
	Funded academic research	Cost per study	300 €
		Cost per language	50 €
	Not funded academic users	Cost per study	Free
		Cost per language	Free

Agreed and acknowledged by

Hellena Makura

22-Sep-2016

ANNEXURE 8: ZARIT BURDEN INTERVIEW TOOL

ANNEXURE 8

ZARIT BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
2. Do you feel that because of the time you spend with your relative you don't have enough time for yourself?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
3. Do you feel stressed about caring for your relative and trying to meet other responsibilities for your family or work?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
4. Do you feel embarrassed because of your relative's behaviour?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
7. Are you afraid about what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
8. Do you feel your relative is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always
10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

17. Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

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ANNEXURE 9: QUESTIONNAIRE (ENGLISH)

ANNEXURE 9
RESEARCH QUESTIONNAIRE

Please take between fifteen (15) to twenty minutes (20) to answer the following questions which relate to your task of caring for your child with cerebral palsy. You may answer the questions as best as they apply to your situation not how it should be. Your identity, that of **the child and your responses will be kept confidential as stated in the informed consent form.**

Kindly answer the following questions with an X to your answer:

1. Section one (1): Demographic data

1.1 Age group

1.20-24	2.25-29	3.30-34	4.35+	5.Other (specify)

1.2 Sex

1.Male	2.Female	3.Other

1.3 Marital status:

1.Married	2.Single	3.Divorced	4.Other

1.4 Ethnic group:

1.Oshiwambo	
2.Herero	
3.Damara>Nama	
4.Mixed race	
5.Caucasian	
6.Okavango	

7.Other	
---------	--

1.5 Level of education

1.Primary	2.Grade 10	3.Grade 12	4.Tertiary	5.Other (specify)

1.6 Languages spoken fluently

1.English	2.Afrikaans	3.Other (specify)

1.7 Religion

1.Christianity	2.Muslim	3.African traditional	4.Other (specify)

2. Section two (2): Factors influencing caregivers' burden

Kindly answer the following questions with an X to your answer:

2.1 Are you staying in the same household as the child with CP?

1.Yes	2.No

2.2 Do you think your spiritual beliefs help you to cope better when caring for your child?

1.Strongly disagree	2.Disagree	3.Undecided	4.Agree	5.Strongly agree

2.3 Would you describe yourself as physically healthy/fit?

1.Yes	2.No	3.Not sure

2.4 How disabled is your child?

	1.Yes	2.No
Both legs and arms affected		
Cannot talk(verbally communicate)		
Child struggles with mentally receiving, understanding, keeping or using any information given (cognitive ability) by others. Cognitive and perceptual deficits		
Child struggles to process or interpret information seen (perceptual skills)		
Child gets full assistance in bathing, dressing, toileting, feeding and other self-care activities.		

2.5 Does your child have other chronic medical problems such as epilepsy?

1.Yes (specify)	2.No

3. Section three (3): Description of caregiver burden

3.1 Do you find caregiving as physically straining/tiring/exhausting?

1.Never	2.Rarely	3.Sometimes	4.Quite frequently	5.Nearly always

3.2 Do you at times feel overworked by trying to balance your caregiving role, other family duties and your job?

1.Never	2.Rarely	3.Sometimes	4.Quite frequently	5.Nearly always

3.3 Does having the child with CP in your family negatively affect relationships between yourself and other family members?

1.Yes	2.No

If your answer is yes kindly explain how a child with CP affect relationships in your family.....

3.4 Have you been treated for any physical health problem that you can relate to your task of caregiving for the CP child? (For example backache)

1.Yes	2.No	3.Cannot remember

3.5 Do you feel like your physical and mental health has been affected by caring for your child with CP?

1.Yes	2.No

3.6 Do you at times feel generally sad with your caregiving task and cry?

1.Never	2.Rarely	3.Sometimes	4.Quite frequently	5.Nearly always

3.7 Do you at times struggle to sleep as a result of your role in caring for the child with CP?

1.Never	2.Rarely	3.Sometimes	4.Frequently	5.Always

3.9 Do you have enough time for yourself away from your caregiving role to the child?

1.Yes	2.No
-------	------

--	--

4. Section four (4): Challenges with caregiving burden

4.1 Do you feel like the child with CP has affected your ability to have a social life?

1.Strongly disagree	2.Disagree	3.Undecided	4.Agree	5.Strongly agree

4.2 Do you feel like you do not have enough money to sufficiently take care of the child with CP in addition to your other living expenses?

1.Strongly disagree	2.Disagree	3.Undecided	4.Agree	5.Strongly agree

4.3 Explain in your own words how caring for a child with CP has been a challenge to you?

.....
.....
.....
.....

5. Section 5: Strategies to alleviate burden of caregiving

5.1 In what ways can you be supported to better care for the child with CP? Please explain

.....
.....
.....
.....

5.2 How would you rate your knowledge and understanding of Cerebral palsy?

1.Excellent	2.Good	3.Don't know	4.Fair	5.Poor

5.3 How best can you describe your social and community support system for caring for your child? Mark all applicable

1.They do not care	
2. They show no understanding of my child's CP?	
3.I feel discriminated	
4.They do include me in all activities	
5.They offer to help with activities to do with caring for the child with CP.	

5.4 Do you feel included in the decisions to do with treatment or rehabilitation of your child?

1.Yes	2.No

5.5 Would you like to be included in recreational activities such as sports or crafts to help you relax and copy better in your role of caregiving?

1.Yes	2.No	3.Maybe

5.6 What further support would you need in caregiving for your child with CP?

.....

.....

.....

Thank you for participating in the study! We value your input in efforts to improve the health and well-being of caregivers of children with cerebral palsy in Namibia!

ANNEXURE 9a: QUESTIONNAIRE (OSHIWAMBO)

9a QUESTIONNAIRE (OSHIWAMBO)

OMAPULAAPULO GEGONGELO LYOMAUYELELE

Longitha uulethembo wominute omulongo nantano (15) sigo ominute omilongo mbali (20) wu yamukule omapulo taga landula kombinga yankene ho sile onuulema gwoye (omunuumvo wombanda) oshimpwiyu. Yamukula omapulo komukalo ngoka wu wete gwe ku opalela monkalo yoye nomunuumvo ihe hakwaashoka aantu yi itaala nenge haya ningi. Omaukwatya nuuthemba weni nomunuumvo osho wo omayakulo to ka gandja otaga kala ga gamenwa pwaa na ngoka e na uuthemba okutseya mpoka ga za ngaashi sha hololwa mofooloma yegano.

Ngashingeyi yamukula omapulo taga landula mokutula okakombo (X) mokakololo keyamukulo lyomondjila:

1. Omauyelele gopamiyalu (Demographic data)

1.1 Owu li poomvula dhinipo?

1. 20-24	2. 25-29	3. 30-34	4. 35+	5. Yilwe (tumbula)

1.2 Uukwashikekookantu

1. Omulumentu	2. Omukiintu	3. Gulwe

1.3 Ondjokana:

1. A hokanwa	2. Ina hokanwa	3. A hengwa/ngana	4. Yilwe

1.4 Omuhoko: Omuwambo/Omuherero/OmuDamara/OmuNama/ okwa za momihoko dha yoolokathana/ OmuAraba/ Omukavango/ gulwe

1.	Omuwambo	
2.	Omuherero	

3.	OmuDamara/ OmuNama	
4.	Okwa za momihoko dha yoolokathana	
5.	OmuAraba	
6.	Omukavango	
7.	Gulwe	

1.5 Ondondo yuulongelwe / uulongelwe

1.Okwa mona elongo lyopetameko	2.Okwa mana ondondo 10	3.Okwa mana ondondo 12	4.Okwa mona elongo konima yondondo 12 hol.UNAM, VTC	5.Yilwe (tumbula)

1.6 Omalaka ngoka ho popi nawa

1.Oshiingilisa	2.OshiAfrikaans	3.Galwe (tumbula)

1.7 Eitaalo/ uukwaitaalo

1.Omukriste	2.OmuMuslim	3.Okwi itaala momithigululwakalo dhoshiAfrika	4.Galwe (tumbula)

2. linima mbyoka yi na emwethemo enene mesiloshimpwiyu lyokanona haka:

**Ngashingeyi yamukula omapulo taga landula mokutula okakombo (X)
mokololo keyamukulo lyomondjila:**

2.1 okanona/ omunuulema nguka ohamu zi megumbo limwe naye?

1.Eeno	2.Aawe

2.2 Sho wa tala eitaalo lyoye otali kwathele tuu opo wu taambe ko onkalo ndjika yokusila omunuulema nguka oshimpwiyu?

1.Ite tsu kumwe nasho	2.Aawe	3.Kandi shi nawa	4.Eeno	5.Osho lela

2.3 Ngoye mwene owu na uukolele wokoluntu ndishi?

1.Eeno	2.Aawe	3. Kandi shi shi nawa

2.4 Okanona hono ho sile oshimpwiyu oke na uulema wunipo?

1.Oke na uulema komaako nomagulu		
2.Ihaka popi (omupulupulu)		
3.Oke na uulema womadhilaadhilo hol. Iha taamba ko nokulongitha uyelele ngaashi wa gandjwa, oha dhimbwa mbala nosho tuu		
4.Oke na uupyakadhi mokutaamba nokuuvako iinima yontumba meendelelo ngaashi sha tumbiwa (omunyengwi)		
5. Oka pumbwa eyambidhidho aluhe ngele tashi ya okukoshwa, okuzalekwa, okulongitha okandjugo, okulya nayilwe mbyoka ka li ke na okukala take yi ningi kokene mokwiisila oshimpwiyu.		

2.5 Kakele kuulema, okanona haka oke na uuvu wule we ka konena hol. Oshintona?

1.Eeno	2.Aawe

3. linakugwanithwa yomusilishipwiyu

3.1 Oshinakugwanithwa shika shesiloshimpwiyu lyomunuulema oshi li ngiini moku shi talela monkalo yesiku kehe hol, oshilolodhi?

1.Nandonando	2.Haaluhe	3.Ethimbo limwe	4.Olwindji	5.Konyalo kehe ethimbo

3.2 Ope na poompito dhimwe ho uvu wa ndumbalelwa uunene nowa lolodhwa kiinakugwanithwa yesiloshimpwiyu lyokanona, iimpwiyu yegumbo osho wo kiilongo yoye?

1.Nandonando	2.Haaluhe	3.Ethimbo limwe	4.Olwindji	5.Konyalo kehe ethimbo

3.3 Okukala wu na okanona ke na uulema ohashi vulu okuteyapo nenge okushunitha pevi ekwatathano pokati koye naapambeke yoye?

1.Eeno	2.Aawe

Ngele osho, hokolola nkene oshinima/okanona haka ke eta omalunduluko momakwatathano pokati koye naapambeke yoye.

.....

3.4 Owa pangelwe nale shi na sha nuunkundi wolutu ngaashi we ehamene nando ombunda e to pangwa mpono pamwe wa zi po nuunongo mokukwathela okanona koye haka?

1.Eeno	2.Aawe	3.Ite dhimbulukwa

3.5 Esiloshimpwiyu lyokanona haka owu wete pamwe lya guma uukolele woye wokolutu nenge wopamadhilaadhilo?

1.Eeno	2.Aawe

3.6 Ope na poompito mpono ho kala wu uvutile nayi oshinakugwanithwa shika e to iyadha nokuli to lili?

1.Nandonando	2.Haaluhe	3.Ethimbo limwe	4.Olwindji	5.Konyalo kehe ethimbo

3.7 Ope na poompito dhimwe mpono ho iyadha ito kotha nokuli omolwonkalo ndjika yokusila omunuulema nguka oshimpwiyu?

1.Nandonando	2.Haaluhe	3.Ethimbo limwe	4.Olwindji	5.Konyalo kehe ethimbo

3.9 Oho mono tuu we ethimbo lya gwana okuninga sha shilwe shopaumwene kashi shi okutonatela/okusila oshimpwiyu okanona hoka?

1.Eeno	2.Aawe

4. Omashongo ga holoka molwuunakugwanithwa yesiloshimpwiyu lyomunuulema

4.1 Sho wa tala oshinakugwanithwa lyokusila okanona haka oshimpwiyu osha guma onkalo yoye yopankalathano?

1.Nandonando	2.Aawe	3.Kandi shi wo nawa	4.Eeno	5.Osho lela

4.2 Owu uvite waa na iimaliwa ya gwana mokusila okanona haka oshimpwiyu nawa kwa gwedhwa oompumbwe dhoye dhopaumwene?

1.Nandonando	2.Aawe	3.Kandi shi wo nawa	4.Eeno	5.Osho lela

4.3 Niitya yoye mwene, hokolola nkene okusila oshimpwiyu okanona ke na uulema sha kala eshongo enene kungoye?

.....

.....

.....

.....

5. Omikalo dhokuhwepopeka iinakugwanithwa yaasilishimpwiyu

5.1 Eyambidhidho lini wa pumbwa mokusila omunuulema goye oshimpwiyu? Fatulula.

.....

.....

.....

.....

5.2 Sho to tala uunongo nontseyo yoye kombinga yuulema wokoluntu oyi li ngiini?

1.Dhingi	2.Nawa	3.Kandi shi wo nawa	4.Hwepo	5.Oyi li pevi noonkondo

5.3 Paku shi talela komayambidhidho gopankalathano aantu yomomudhingoloko oye li ngiini ngele tashi ya kesiloshimpwiyu lyokanona haka? Tenda kofi mbyoka yi li mondjila.

1. Kaye na ko nasha	
2. Otaa ulike yaa na ko euveko lyasha kombinga yokanona ke na uulema	
3. kehe moshinima/ Ondi uvite inandi halika	
4. nyangadhalwa omwa kwatelelwa aalumentu	
5. ohaya kwatha miinyangadhalwa yi na sha nesiloshimpwiyu lyomunuulema nguka.	

5.4 Owu uvite tuu wa pitikwa wu kuthe ombinga mookuninga omatokolo ge na sha nepango osho wo ehungomwenyo lyokanona koye?

1.Eeno	2.Aawe

5.5 Owa hala / owu na ohokwe yokukutha ombinga miinima ya nika omainyanyudho ngaashi omaudhano nenge okweetapo iihongonwa yontumba mokuthuwapo ngoye wi igilile iinakugwanithwa yi na sha nesiloshimpwiyu lyokanona?

1.Eeno	2.Aawe	3.Otashi vulika

5.6 Omayambidhidho genipo to pumbwa mokusila omunuulema goye oshimpwiyu monakwiiwa?

.....
.....
.....

Tangi sho wa li wa kutha ombinga momapekaapeko ngaka. Ekuthombinga lyoye olya simana mokuhwepopaleka uundjolowele nonkalonawa yaatekuli naasilishimpwiyu yaanona ye na uulema moNamibia!

ANNEXURE 10: INFORMED CONSENT FORM

ANNEXURE 10

INFORMED CONSENT FORM

My name is Hellena Makura-Kumire. I am a Master of public Health student at the Department of health studies at the University Of South Africa (UNISA).I am an Occupational therapist at Windhoek central hospital.

The title of my study is: **Factors influencing the burden of caregiving for children with Cerebral Palsy in Namibia**

The main aim of the study is to investigate factors that influence burden of caregiving for children with cerebral palsy (CP) in Namibia.The study has been approved by the Research and Ethics Committee of the Department of Health Studies of the University of South Africa (UNISA).

I hereby request your participation to this study. Your participation will be the completion of a questionnaire that will take about fifteen (15) minutes. No names will be used on the questionnaire and the information will be kept in a safe place by the researcher for confidentiality. Third party individuals such as statistician for the study will sign a legally binding confidentiality form where they commit not to disclose any information related to the research to other people.

Your participation in this study is totally voluntary, and you can withdraw from participating at any time. Your participation will be valuable to my study and will contribute towards informing policymakers, clinicians and social services on the medical, social, psychological and financial challenges faced by caregivers for children with CP. Raising awareness on this important issue will better inform holistic multidisciplinary management of children with CP and pave way for community strategies that aim to improve life of children with CP and their caregivers.

You are kindly requested, if you agree to participate, to sign the consent form to confirm that you are willing to participate in this study. Furthermore kindly know that this study will be distributed by presentation at national and international journals and by publication in accredited journals.

If you have any question concerning the study, or your participation in the study, please feel free to contact the researcher Hellena Makura-Kumire on

0815907275/0612033142 or via email to 50781774@mylifeunisa.ac.za or supervisor Dr KA Maboe 0027 12 429 2393,Maboeka@unisa.ac.za or Chairperson of the University of South Africa, Department of Health Studies Research and Ethics Committee Prof. E Maritz maritje@unisa.ac.za.

The researcher

I have discussed the benefits and obligations involved in this research with the respondents and in my opinion, the respondents understand this information.

Researcher's signature

Date

The respondents

I hereby give informed consent to voluntarily participate in the above research study. I agree to complete a questionnaire. I have read the information leaflet and understood that my participation is voluntary and that I may refuse to participate or withdraw from the study at any time.

Respondent's signature

Date

**ANNEXURE 11: CONFIDENTIALITY BINDING
CONTRACT**

ANNEXURE 11

CONFIDENTIALITY BINDING CONTRACT

Research title - **Factors influencing the burden of caregivers of children with Cerebral Palsy in Namibia**

I, _____, the _____ (specific job description, interpreter/statistician (delete inapplicable)) have been contracted to provide my services for the above mentioned study.

I hereby agree and bind myself to the following contractual obligations:

1. I shall keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (WhatsApp, screenshots, USB) with anyone other than the *Researcher(s)*.
2. I shall keep all research information in the form of questionnaires secure while it is in my possession.
3. I shall return all research information in the form of questionnaires to the *Researcher(s)* when I have completed the research tasks.
4. After consulting with the *Researcher (and conclusion of study)*, I shall delete all research information stored on computer hard drive regarding this research project that is not returnable to the *Researcher(s)*

Statistician

(Full Name)

(Signature)

(Date)

Interpreter

(Full Name)

(Signature)

(Date)

Researcher

(Full Name)

(Signature)

(Date)

**ANNEXURE 12: APPROVAL LETTER TO CONDUCT
STUDY AT PUBLIC HOSPITAL 1**

ANNEXURE 12



Republic of Namibia

Ministry of Health and Social Services

Private Bag 13215
WINDHOEK
Namibia

Intermediate Hospital Katutura
Independence Avenue
WINDHOEK

Telephone (061) 203 4004/5
Telefax (061) 222706

Enquiries: Ms. F.M. Shiweda

Date: 26 September 2017

OFFICE OF THE CHIEF MEDICAL OFFICER

Ms. Hellena Makure-Kumire
P. O. Box 50309
Bachbrecht
Windhoek, Namibia

Dear Ms. Hellena Makure-Kumire


**RE: FACTOR INFLUENCING THE BURDEN OF CAREGIVING FOR CHILDREN WITH
CEREBRAL PALSY IN NAMIBIA**

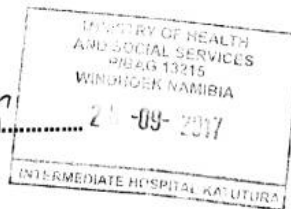
The above mentioned subject refers:

This office hereby grants you permission to do research factors influencing the burden of caregiving for children with Cerebral Palsy in Namibia at Intermediate Hospital Katutura, Khomas Region.

Thank you

Yours in health


.....
DR. F. M. SHIWEDA
CHIEF MEDICAL OFFICER



**ANNEXURE 13: APPROVAL TO CONDUCT STUDY AT
PUBLIC HOSPITAL 2**



REPUBLIC OF NAMIBIA
Ministry of Health and Social Services

Private Bag 13215 Windhoek Namibia	Harvey Street	Tel. No: (061) 203 3024 Fax No: (061) 222886
Enquiries: Ms. Iipinge	Ref.	Date : 27 September 2017

OFFICE OF THE MEDICAL SUPERINTENDENT
WINDHOEK CENTRAL HOSPITAL

Ms.Hellena Makura-Kumire
0815907275

Dear Ms Kumire

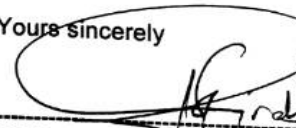
RE: PERMISSION TO CONDUCT A RESEARCH STUDY ON WHICH FACTORS INFLUENCING THE BURDEN OF CAREGIVING FOR CHILDREN WITH CEREBRAL PALSY SEEN AT OCCUPATIONAL THERAPY AND PHYSIOTHERAPY, WINDHOEK CENTRAL HOSPITAL.

Kindly be informed that permission has been granted for you to conduct a research on the above mentioned subject:

- 1.1 Patients /clients information should be kept confidential at all times
- 1.2 The purpose for research is only for your study purposes as you have requested and it does not include any remuneration.

Thank you for your kind gesture.

Yours sincerely


DR.D .I.UIRAB
CHIEF MEDICAL SUPERINTENDENT



ANNEXURE 14: LETTER FROM STATISTICIAN

ANNEXURE 14

LETTER FROM STATISTICIAN

P. O Box 40933
Ausspannplatz
Windhoek,
Namibia
+264813791830

11 April 2018

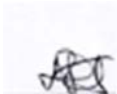
The Examination Committee
Department of Health Studies
UNISA

Dear Prof. K.A Maboe

RE: MASTERS IN PUBLIC HEALTH DISSERTATION: MS HELLENA MAKURA

This letter serves to confirm, that I, Dr. Lillian Pazvakawambwa assisted Ms. Hellena Makura, in the analysis of data on the “**Factors influencing the burden of caregivers of children with Cerebral Palsy in Namibia**”. The Data Analysis process involved the capturing of data from the 91 filled questionnaires using IBM SPSS Statistics version 24, classification and coding of the data provided. After successful data capture checks were done to ensure completeness and data quality and thereafter produced general descriptive and chi- squared tests of association to establish factors influencing the burden of caregivers of children with cerebral palsy in Namibia.

Sincerely yours



Dr. L. Pazvakawambwa

ANNEXURE 15: LETTER FROM LANGUAGE EDITOR

ANNEXURE 15

ACET Consultancy
Aneyasha Communication, Editing and Training
Box 50453 Bachbrecht, Windhoek, Namibia
Cell: +264814218613
Email: mlambons@yahoo.co.uk / nelsonmlambo@icloud.com

9 May 2018

To whom it may concern

LANGUAGE EDITING – HELENA MAKURA

This letter serves to confirm that a MASTER OF PUBLIC HEALTH entitled FACTORS INFLUENCING THE BURDEN OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN NAMIBIA by Helena Makura was submitted to me for language editing.

The thesis was professionally edited and track changes and suggestions were made in the document (except references), which if followed by Ms Makura, will result in a thesis with a high standard of English.

Yours faithfully



Dr N. Mlambo

PhD in English

M.A. in Intercultural Communication

M.A. in English

B. A. Special Honours in English – First class

B. A. English & Linguistics

ACET Consultancy
Aneyasha Communication, Editing & Training
Box 95509 Soweto, Windhoek, Namibia
Cell: (+264) 814218613 or 0814234235
Email: mlambons@yahoo.co.uk
nelsonmlambo@icloud.com

ANNEXURE 16: LETTER FROM TECHNICAL EDITOR

ANNEXURE 16: TECHNICAL EDITOR'S LETTER



To Whom It May Concern

Re: Technical Editing

This letter serves to inform you that the Master thesis for Ms Hellena Makura, title: **FACTORS INFLUENCING THE BURDEN OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN NAMIBIA**, was technically edited and formatted.

Regards

Rinnie Matlou

.....