

**SOCIAL SUPPORT, STRESS AND COPING STYLES OF CAREGIVERS OF CHILDREN  
WITH SICKLE CELL DISEASE. A STUDY OF MULAGO  
HOSPITAL KAMPALA DISTRICT –UGANDA**

**BY**

**NASSIWA SHAMIRAH**

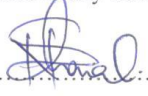
**2019-08-09443**

**A RESEARCH DISSERTATION SUBMITTED TO THE DIRECTORATE OF HIGHER  
DEGREES AND RESEARCH, IN PARTIAL FULFILLMENT FOR THE REQUIREMENTS  
FOR THE AWARD OF A MASTER’S DEGREE IN SOCIAL  
WORK AND SOCIAL ADMINISTRATION OF  
KAMPALA INTERNATIONAL  
UNIVERSITY**

**OCTOBER, 2023**

**Declaration**

I, Nassiwa Shamirah hereby declare that this research Dissertation is my work and has never been submitted to any institution of higher learning for any award.

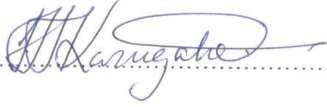
Signature:  ..... Date: 12<sup>th</sup> October 2023 .....

Nassiwa Shamirah

(Student)

**Approval**

I certify that the candidate has been under my supervision. The work presented is original and it is for the award of a Master's degree in Social Work and Social Administration.

Signature:  Date: 12/10/2023

Dr. Karugah Wilber.

(University Supervisor)

## **Dedication**

This piece of work is a dedication to all caregivers of patients with chronic illnesses particularly those taking care of children with sickle cell disease.

## **Acknowledgements**

Above all I am grateful to the Almighty for His grace and favor upon the completion of this thesis. My sincere thanks go to my supervisor, Dr. Karugahe Wilber for his technical assistance and tirelessly being at my disposal whenever called upon for guidance and advice. To my parents the late Sheikh Ismail Kezaala and Mrs. Nanyonga Fatuma for molding me up into the person I am today.

I am further indebted to all the staff of Mulago Hospital, particularly the sickle cell clinic, from where this study was carried. Thank you for your help. To all the respondents in the study thank you for your time and valuable responses. You made this study a success.

I also convey my most sincere thanks to all my lecturers; Professor Edward Bantu, Dr Tumukunde A. Dr. Edaku Charles, Dr.Kibuuka Muhammed and Dr. Kalema Kiweewa. To my colleagues in the College of Humanities and Social Sciences especially from the Department of Applied Psychology Dr.Nakalema Faith, Mr.Omuya Ronald, Ms.Nanyiti Florence, Ms.Christine Arinaitwe and Ms Among Sandra. Thank you for the encouragement you all gave me throughout the course of my study. My heartfelt gratitude goes to Mr. Mujuni J. Kitimbo for the support you have rendered throughout this study. May the Almighty Allah bless you always.

Last but not least to my lovely husband Mr. Kiggundu Abdunoor, to my children Hadijah, Habiiba, Habiibu, Husnah and Hanisha, my sisters Salma, Shamim, Swagia and brothers Salim and Umar. Without your love, it would have been hard to pull this far.

## Table of Contents

Declaration.....	i
Approval.....	<b>Error! Bookmark not defined.</b>
Dedication.....	iii
Acknowledgements.....	iv
Table of Contents.....	v
LIST OF FIGURES.....	x
ABSTRACT.....	xi
CHAPTER ONE.....	1
INTRODUCTION.....	1
1.0 Introductions.....	1
1.1 Background of the study.....	1
1.1.1 Historical perspective.....	1
1.1.2 Theoretical perspective.....	4
1.1.3 Conceptual perspective.....	5
1.1.4 Contextual perspective.....	6
1.2 Statement of the problem.....	6
1.3 Purpose of the study.....	7
1.4 Objectives of the study.....	7
1.5 Research questions.....	8
1.6 Research hypotheses.....	8
1.7 Scope of the study.....	8
1.7.1 Geographical scope.....	9
1.7.2 Content scope.....	9
1.7.3 Time scope.....	9

1.8 Significance of the study .....	10
CHAPTER TWO.....	12
LITERATURE REVIEW .....	12
2.0 Introduction .....	12
2.1 Theoretical review.....	12
2.2 Conceptual framework .....	19
2.3 Review of related literature.....	21
2.3.1 Relationship between social support and coping of caregivers of children with sickle cell disease .....	21
2.3.3 Relationship between stress and coping strategies of caregivers of children with sickle cell disease .....	29
2.3.4 Gender differences in coping among caregivers.....	31
2.6 Related studies .....	33
2.7 Identifying the gaps.....	38
CHAPTER THREE .....	40
METHODOLOGY .....	40
3.0 Introduction.....	40
3:1 Research design. ....	40
3:2 Target population. ....	40
3.3 Sample size .....	40
3.4 Sampling Procedure. ....	42
3.5 Research Instrument.....	42
3.7 Data quality control.....	42
3.7.1 Validity.....	42

3.7.2 Reliability of Research Instrument .....	43
3.7 Data Gathering Procedures .....	45
3.8 Data Analysis .....	46
3.8.1 Quantitative data analysis .....	46
Table 3.3: Mean range interpretation table .....	46
3.9 Limitations of the study .....	46
3.10 Ethical Considerations .....	47
CHAPTER FOUR.....	49
DATA PRESENTATION, ANALYSIS AND INTERPRETATION .....	49
4.0 Introduction.....	49
4.1 Demographic characteristics of the Respondents .....	49
4.2 Social support.....	51
4.3 Stress .....	53
CHAPTER FIVE .....	62
DISCUSSION, CONCLUSION AND RECOMMENDATIONS .....	62
5.0 Introduction.....	62
5.1 Discussion of findings.....	62
5.1.1 Relationship between social support and coping of care givers of children with sickle cell disease .....	62
5.1.2. Relationship between social support and stress among caregivers of children with sickle cell disease .....	63
5.1.3. Relationship between stress and coping strategies of caregivers of children with sickle cell disease .....	64



5.1.4. Significant gender difference in coping among care givers of children with Sickle cell disease .....	65
5.2 Conclusions .....	<b>65</b>
5.3. Recommendations .....	<b>67</b>
5.4 Contribution to Knowledge.....	<b>69</b>
5.5 Areas for further studies.....	<b>70</b>
REFERENCES .....	<b>71</b>
APPENDICES .....	<b>81</b>
APPENDIX 1: QUESTIONNAIRE .....	<b>81</b>

## LIST OF TABLES

Table 3.1: Summary of the population and sample size .....	41
Table 3.2: Reliability of research instrument.....	44
Table 4.1.3: Showing Education Level.....	51
Table 4.2: Social support .....	52
Table 4.3: Stress .....	54
Table 4.4: Coping strategies.....	56
Table 4.5 Objective One: Relationship between Social Support and Coping of care givers. ....	58
Table 4.6 Objective two: Relationship between Social Support and Stress among caregivers ....	59
Table 4.8 Objective four: Gender differences in coping among care givers. ....	61
Table 4.3: Stress .....	54
Table 4.4: Coping strategies.....	56
Table 4.5 Objective One: Relationship between Social Support and Coping of care givers.....	58
Table 4.6 Objective two: Relationship between Social Support and Stress among caregivers ....	59
Table 4.8 Objective four: Gender differences in coping among care givers. ....	61

## LIST OF FIGURES

Figure 2.2 provides a frame work relating the variables in the study: ..... 20

## ABSTRACT

The study was set to investigate the relationship between social support, stress and coping of caregivers of children with sickle cell disease of Mulago Hospital Kampala Uganda. The objectives of the study were: i) to establish whether there is a significant relationship between social support and coping of caregivers of children with sickle cell disease. ii) to examine whether there is a significant relationship between social support and stress among caregivers of children with sickle cell disease at Mulago hospital Kampala Uganda. iii) to examine whether there is a significant relationship between stress and coping among caregivers of children with sickle cell disease at Mulago hospital Kampala Uganda. iv) to examine whether there are significant gender differences among caregivers of children with sickle cell disease at Mulago hospital Kampala Uganda. The study was quantitative which used both correlational and causal comparative designs. The multi-dimensional scale of perceived social support, the perceived stress scale and the coping scale were the instruments used in data collection from 146 participants who consented to be part of the study. Eligible participants were randomly selected. Statistical Package for Social Sciences (SPSS) version 16. was used in data entry and analysis. Descriptive results indicated that majority of the respondents were female at 61.64 % compared to their male counterparts at 38.4 % , Social support was rated high with an average mean of 2.57. Results also indicated high levels of stress by an average mean of 2.78. Coping was also rated high with an average of 2.66. Pearson Linear Correlation coefficients revealed that social support had no significant relationship with problem focused coping with a sig value =.830>0.05 level of significance, also results indicated no significant relationship social support and emotional focused coping at sig value =.007 >0.05 and also no relationship between social support and avoidance focused coping at sig.value =.373 >0.05. Findings also indicated a positive significant relationship between social support and stress revealed by an r.value=.356\*\* and p.value=0.000. Results also indicated that stress has a significant relationship with problem focused coping with a sig.value=0.001< 0.005 level of significance, results further revealed that there is no significant relationship between stress and emotional focused coping by a sig.value=0.124>0.05 and finally stress having a significant correlation with Avoidance focused coping at sig.value=0.003<0.05 level of significance. Independent t-test results further revealed that there are no significant gender differences in engaging different coping styles. Hence implying that the levels of coping are almost the same among male and female caregivers. Conclusions were that social networks can provide the caregiver with mental and physical resources to aid in his or her capacity to deal with stress and make life easier for the patients being cared for. Hospital should encourage caregivers to seek social support from family, friends, and community

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.0 Introductions**

This Chapter gives details of the background of the study. It also covers the statement of the problem, purpose, objectives, research hypotheses, scope, significance of the study theoretical and conceptual frameworks.

Background of the study.

The background of the study looked at the historical, theoretical, conceptual and contextual perspectives;

#### **1.1.1 Historical perspective**

Chronic ailments or diseases are described by the World Health Organization as disorders requiring continuing care over years or decades, and they encompass a vast array of health concerns that extend beyond the usual definition of chronic illness. Heart disease, diabetes, cancer, asthma, chronic kidney disease, and sickle cell anemia are examples of chronic diseases. In addition, they include communicable disorders such as acquired immune deficiency virus and acquired immune deficiency syndrome. Chronic ailments include some mental disorders, such as depression and schizophrenia, as well as specific limitations and impairments that are not considered diseases, such as blindness and musculoskeletal disorders (WHO, 2016).

Chronic diseases need a complicated, protracted approach involving coordinated inputs from a large number of health specialists, access to necessary medications, and monitoring systems (Conrad and Shortell, 2016). Statistics from the National Centre for Health, Centers for disease control and Prevention (2013) suggest that about 13.3 million Americans, or more than 40 percent of the country's entire population, suffer from incurable and persistent chronic

illnesses. Approximately half of adults had a chronic illness, and 8% of children aged 5-7 were found to have activity limitations owing to at least one chronic disease or impairment (CDC, 2017).

East Africa suffers regionally significant non-communicable illnesses, such as rheumatic heart disease, sickle cell disease, and mental illness, in addition to the global non-communicable diseases with the highest priority (East Africa NCD Alliance, 2015). According to the World Health Organization, non-communicable illnesses account for 40 percent of fatalities in East Africa, and they are anticipated to surpass communicable diseases as the primary causes of death in sub-Saharan Africa, of which East Africa is a part.

According to the findings of a research done in eastern Uganda, a total of 1,210 fatalities among adults aged 30 and older were documented, of whom 50.7% were female. 53 percent of all fatalities were attributable to non-communicable illnesses, 8.2 percent to accidents, and 7 percent to maternal causes. Each year, cardiovascular illnesses accounted for the highest share of non-communicable disease mortality. Women reported greater rates of mortality than males. However, women's diabetes mortality was lower than men's in five of the seven investigated years (Davis *et al.*, 2021).

Sickle cell disease is one of the most common chronic illnesses mostly prevailing in children and young adults. According to the a Spanish Society of Pediatric Hematology and Encology (2019),Sickle cell disease also known as Sickle cell anemia is a hereditary blood disease which is transmitted by genes. The World Health Organization (2016) reported that 5% of the world's population carries the sickle cell genes responsible for causing sickle cell disease and each year alone about 300,000 of infants are born with major hemoglobin disorders

including more than 200,000 cases of sickle cell anemia in Africa. This implies that Africa alone has the greatest number of children born with sickle cell disease as compared to the rest of the world.

The WHO further asserts that in Africa up to 2% of the all children born are born with the condition. Countries in West Africa like specifically Ghana and Nigeria the frequency of the sickle cell trait is 15% to 30% where as in Uganda it shows marked tribal variations with the highest number reported among the Bamba tribe in the western part of the country (WHO, 2016).

According to the East African Medical Journal (2015) the frequency of the sickle cell trait in Uganda revealed variations between different tribal groups. 1-4 percent in the Karamajong, Banyankole and Bahim, 16-20% among the Bakiga, Basoga, Bagisu and Lugbara and highest numbers recorded at 40 Percent. Currently in Uganda approximately 25,000 babies are born with sickle cell disease each year. (East African Medical Journal, 2015).

Pediatric patients with Sickle Cell Disease require comprehensive care that involves the usual care of children in primary care and specialized multidisciplinary care ranging from nurses, haematologists, psychologists, social workers and other specialized departments. Taking care of someone with a long-term illness may be exceedingly difficult, especially in the last stages of the illness (Longman *et al.*, 2018). Among other things, the patient may no longer be able to take care of him or herself (hygiene, feeding, etc.). Caregiver diagnosis and management of patients' unpleasant symptoms (nausea/vomiting; diarrhea; pain; weariness; and weight loss) are also required. Health care workers are required to notice and diagnose problems, as well as adapt their life around the needs of an individual with a chronic disease (Chwalisz, 2018).

Studies on gender differences found that female caregivers report greater levels of both objective and subjective burden. Some studies concluded that caregiver burden is high among female caregivers. Others have found evidence in favour of greater levels of burden among women (Bivins M, 2013).

In a recent review of 42 studies on caregiver burden in schizophrenia, the majority of caregivers were mainly parents usually women followed by spouses and siblings of patients. Women either wives or sisters formed the greater part of caregiver of those with schizophrenia and their parents mostly mothers of patients and are usually elderly (Chan, 2011). The United States community survey noted that women constituted 82 percent of caregivers with 90 percent being mothers of patients, 70 percent of them over 60 years of age. (Collings S. 2015).

### **1.1.2 Theoretical perspective**

The social cognitive theory by Stajkovic & Kayla (2019) is recognized as one of the foremost research theory in study of human stress. The theory explains the concepts of human stress model as a reciprocal determination which emphasizes that behavior develops from constant interaction of people and their environment and that behavior affect people and their environment. (Stajkovic & Kayla, 2019).

The social cognitive theory will help this study in developing a plan that affects people, environment and behavior. This is because social cognitive theory possesses many valuable concepts that include self-efficacy, expectations, behavioral capability, reinforcement and observational learning (Stajkovic & Kayla 2019).



### **1.1.3 Conceptual perspective**

Social support has been defined in two perspectives; structural and the functional. Structurally social support refers to the existence and size of the support network and the extent the person is connected within in such a social network for example number of social ties and the nature of social exchanges between individuals. This includes relationships with family, friends and significant others). On the other hand the functional aspect of social support refers to the person's appraisal of the social support one is experiencing, the specific functions that members of a social network can provide such as emotional (re assurance ,empathy and affection), instrumental (material support and information giving) (Kent de Grey et al ,2018) . Social Support therefore has health promoting benefits by strengthening the individual's coping abilities and quality of life while facing stress life situations such as caring for those who are ill (Haugan & Erikson,2021). Social support is the provision of aid or solace to others in order to help them cope with a range of issues. It is derived from many interpersonal ties, including those with family, support groups, religious groups, and friends. Peer-to-peer exchange of personal, societal, or moral views promotes the social growth of an individual (Turner, 2018).

Stress refers to the harmful physical and emotional response that occurs when there is a poor match between environmental demands and the capacities, resources, or needs of an individual (LeBlanc, 2019). The WHO (2023), defines stress as a state of worry or mental tension caused by a difficult situation, a natural response that prompts one to address challenges and threats in one's life.

Felicia Maxon (2022), asserts that coping is the constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are perceived as exceeding the person's resources.

A general definition of the caregiver is a person who is responsible for providing care for another individual who has mental health issues, physical disability, or poor health due to disease or old age.

#### **1.1.4 Contextual perspective**

The study was carried out from Mulago Hospital, Kampala Uganda among the care givers of children with sickle cell disease. Mulago National Specialized Hospital, also known as Mulago National Referral Hospital, is a component of Mulago Hospital Complex, the teaching facility of Makerere University College of Health Sciences. It is the largest public hospital in Uganda. The patients with sickle cell disease still find it hard to access the hydroxyurea drug at Mulago hospital. The drug makes the blood cells bigger, helping them stay rounder and more flexible. Many of the 15,000 sickle cell patients across the country have to buy the medicine. According to Ministry of Health statistics, 245,000 babies are born annually with sickle cell disease in Uganda (Conrad, 2020).

#### **1.2 Statement of the problem**

Due to excessive and pathological effects of stress, depression and anxiety, it's important to identify the role of protective factors such as effective coping and social support among caregivers of children with sickle cell disease. In Uganda, a large number of care givers of children with sickle cell disease experience high levels of stress attributed to lack of adequate social support from their significant others like family and other relatives. The high levels of stress have been aggravated by poor financial situations where there is no enough money to attend to the incessant medical bills and proper feeding for children with sickle cell disease.

According to Koutsoumpa *et.al.* (2020), an estimated 35 percent of fatalities in Uganda are attributable to non-communicable chronic diseases inclusive of sickle cell disease, and this proportion is projected to increase in the future. Globally, carers suffer significant levels of strain, obstacles frequently associated with care giving activities, and negative effects on their own health. Caregiver stress also leads to increased financial costs to the person, family, and health care systems, making it a public health issue. The burden of care involves economic hardship, routine medications of the children such as folic acid which are not always available and the costs laboratory investigations which are often expensive, practical daily obstacles, and giving support for treatment with limited awareness of the patient's health state, which has caused many to experience elevated levels of stress because it is a full-time job (Najart et al 2023).

### **1.3 Purpose of the study**

The purpose of the study was to examine the effect of social support and stress on coping styles of care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.

### **1.4 Objectives of the study**

- i. To examine whether there is a significant relationship between social support on coping among care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.
- ii. To establish whether there is a significant relationship between social support and stress among caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.
- iii. To examine whether there is a significant relationship between stress on coping among caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.

- iv. To examine differences in gender and coping among caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.

### **1.5 Research questions**

- i. Is there a significant relationship between social support and coping of care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda?
- ii. Is there a significant relationship between social support and stress among caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda?
- iii. Is there a significant relationship between stress and coping strategies of caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda?
- iv. Are there significant gender differences in coping among care givers of children with Sickle cell disease in Mulago Hospital Kampala?

### **1.6 Research hypotheses**

- i. There is no significant relationship between social support and coping of care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.
- ii. There is no significant relationship between social support and stress among caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.
- iii. There is no significant relationship between stress and coping strategies of caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda.
- iv. There are no significant gender differences in coping strategies of caregivers of children with sickle cell disease in Mulago Hospital Kampala Uganda.

### **1.7 Scope of the study**

The scope of the study comprised of the geographical scope, content scope and time scope as indicated below;

### **1.7.1 Geographical scope**

The study was carried out from Mulago Hospital, Kampala Uganda among the care givers of children with sickle cell disease. Mulago Hospital was chosen given the fact that most children with sickle cell disease are highly referred and treated.

### **1.7.2 Content scope**

The study focused on effect of perceived social support and stress on coping strategies of care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda. Perceived social support was conceptualized in terms of support from the family, support from friends, support from community and support from peers. Stress was conceptualized in terms of behavioral stress, physical stress and psychological stress. Whereas coping strategies (dependent variable) was conceptualized in terms of problem focused, emotional and avoidance focused coping. The study also examined gender differences in coping styles of caregivers of children with sickle cell disease.

### **1.7.3 Time scope**

The study investigated the effect of social support and stress on coping strategies of caregivers of children with sickle cell disease at Mulago Hospital, Kampala Uganda, specifically covering the period of April 2016 to June 2023. However proposal writing took place between July to October 2022, data collection took place between November 2022, data analysis and writing of the research report took place between December 2022 and January 2023.

## **1.8 Significance of the study**

The findings would provide clarity on the existing information on social support, stress, and coping among care givers of children with sickle cell disease. Such knowledge can be of help to the communities since it will point at the importance of mental health to an individual.

The study would highlight different coping mechanisms which can be adopted by both home and hospital based care givers in handling stress generated as a result of taking care of children with sickle cell disease.

It is anticipated that the study would identify those facets of social assistance that are required by caregivers. These features may be stressed by the family of a child with sickle cell disease, as well as by responsible authorities, medical personnel, and peers.

This study also would also highlight the need for more effective and comprehensive metrics to aid caregivers in identifying needs and treatments. Providing care providers with interventions incorporating family and community support as well as knowledge on symptom management can be useful for lowering stress and enhancing the quality of life of care givers.

The study would draw the attention of relevant authorities to the variables affecting the Quality of Life for caregivers, particularly those caring for stroke or cancer patients. Quality of life (QoL) is described as "individuals' judgments of their place in life in relation to their objectives, aspirations, standards, and worries in the context of the culture and value systems in which they live. Included in health-related quality of life (HRQoL) are the physical and mental health perceptions of an individual. Examining Health-related quality of life (HRQoL) can reveal subgroups with poor physical or mental health, hence guiding policies or programs aimed at improving their health.

The study would help in the training of caregivers of patients with chronic illnesses in problem solving strategies to improve their social functioning and in the end decrease depression and emotional distress.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

This chapter presents a review of the literature on the relationship between Social Support, Stress and Coping of caregivers of patients with sickle cell disease. It will look, at the meaning of social support, perceived social support and stress, Perceived social support and Coping and Stress and Care giving.

#### **2.1 Theoretical review**

This research was predicated mostly on one particular theoretical framework known as the Transactional Stress Theory (Lazarus and Folkman, 2013). An individual would experience stress when the demands of his/her environment are greater than the resources he/she has available to meet those demands, as proposed by the Transactional Stress Theory. When confronted with a potential risk, the individual will conduct both primary and secondary analyses of the situation. Primary evaluation takes place when an individual assesses an interaction as potentially harmful, frightening, or challenging (Lazarus & Folkman, 2013). The person analyzes, or at least gives consideration to analyzing, the many coping techniques that are at his or her disposal in order to address the potential threat. The interaction between a person and his or her environment that either exceeds the person's capacity for coping with it or is so demanding that it has an adverse effect on the person's physical and mental health is referred to as stress. The individual does a mental assessment to determine whether or not they are capable of handling the situation. The individual will engage in cognitive and behavioral attempts in order



to control the physical and emotional demands that are in excess of the individual's capacity to manage the stressful event as a result of the response (Lazarus & Folkman, 2013).

When a person perceives a stressful situation as being more unpleasant or frightening, their response to the stress will be more negative. For instance, because of the demands of providing care, there may be an increase in the number of activities related to providing care that conflict with other commitments. The responsibilities of providing care may prohibit an individual from recharging their batteries through activities unrelated to care giving, getting proper rest, or participating in social activities. It is possible that insufficient care giving abilities to care for the patient and insufficient coping techniques to face difficulties in care giving could make the caregiver's stress level even higher (Lazarus & Folkman, 2013; Pearlin et al., 2019). Because of this, stress will eventually turn into a destructive cycle that feeds on itself (Pearlin *et al.*, 2019).

Understanding the dynamic and interactive process of caregiver stress has been made significantly easier by Lazarus and Folkman's (2013) proposal of the Transactional Stress Theory. Lazarus and Folkman's (2013) Transactional Stress Theory has been broadened by researchers in order to explain the prevalence of stress among caregivers of patients who have chronic health concerns. (Haley et al., 2017; Pearlin et al., 2019; ). The effects of stress on the provision of informal care have been the subject of investigation using a number of different models of the stress process (Zarit *et al.*, 2018).

Zarit and colleagues came up with the idea for the Caregiver Load Interview in 2018 so that they could investigate the effects of stress and burden on informal caregivers. The authors of the study by Zarit and colleagues distinguished between the objective and subjective challenges that come with providing physical care and the psychological impacts of doing so. Caregiver burden was described by Zarit et al. as the extent to which an event had an effect on the caregivers' mental, physical, social, and economical well-being (Zarit et al., 2018). The Zarit Load Interview (BDI) aimed to identify the factors that contributed to dementia caregivers' reports of feeling burdened by their work. The cognitive deficiencies, behavioral disorders, length of care received, and illness of the person receiving care were evaluated. The BDI was used to measure not just the evolution of perceived stress and load over time, but also the advantages of stress reduction programs that were designed to reduce the stress and burden felt by caregivers (Zarit *et al.*, 2018).

A comprehensive technique for analyzing the result among caregivers was proposed by Haley et al. (2017). Evaluation, coping reactions, and social support were shown to be crucial factors in determining the result of caregivers, according to a study that used a sample of 54 people who cared for seniors who had dementia (Haley et al., 2017). According to the findings of Haley and colleagues (2017), different styles of coping with stress and the availability of social support all had an effect on the final outcome (Haley et al., 2017). The stress and coping model has been shown to be a reliable instrument for assessing the effects of stress and coping among caregivers (Haley et al., 2017).

A theoretical model of agony was established by Vitaliano and colleagues (2017) in order to forecast the load that is placed on the wives of Alzheimer's disease patients. The model utilized the equation "Distress = Exposure to Stressors + Vulnerability divided by Psychological and Social Resources," which served as its foundation (p. 392). This approach demonstrated that the stressful nature of caring responsibilities was the source of the pain experienced by caregivers (Vitaliano et al., 2017). The reaction of the caregiver to the patient's physical, emotional, or cognitive limitations is what causes stress for the caregiver (Vitaliano et al., 2017). The physical, mental, and emotional responses of the caregiver to the responsibilities of providing care are what contribute to their vulnerability. The caregiver's resources include coping strategies, social supports, and life perspectives they've gained throughout the course of their work. As a result, the model showed that the burden of care giving was related to whether or not the experience of delivering care was seen as being good (Vitaliano et al., 2017).

The longitudinal effects of burden were investigated by Vitaliano et al. (2017) among 95 caregivers who provided long-term care to Alzheimer's disease patients at the beginning of the study as well as 15 to 18 months later. Between the ages of 15 and 18 months, there was a significant decline in the functioning of the people receiving care, as well as an increase in the amount of assistance provided by the caregiver with activities of daily life (Vitaliano et al., 2017). About one-third of those who provided care reported experiencing mild to severe feelings of depression or anxiety. The factors that evaluated the physical health and capacity for coping skills of caregivers remained the same. On the other hand, the mean scores on indices of outlook on life showed a drop (Vitaliano et al., 2017). According to the findings, the distress model is useful for estimating the amount of burden and stress that caregivers experience (Vitaliano et al.,

2017). Therefore, caregiver burden is the response to being exposed to stress, the level of effect that variables associated with vulnerability have, and the degree to which the caregiver assesses the available services as being helpful (Vitaliano et al., 2017). They came to the conclusion that chronic stress is a cause of the strain placed on caregivers. They also came to the conclusion that caregivers have varying reactions to the weight of the obligation of providing care (Vitaliano et al., 2017).

Within the context of their caregiver stress process theory, Pearlin et al. (2019) expanded upon the Transactional Stress Theory developed by Lazarus and Folkman (2013). According to the stress process hypothesis, caregiver stress builds up over time, with a number of antecedents contributing to both the stress process and the quality of life of the caregiver (Pearlin et al., 2019). In the field of study on care giving, one of the theories that has seen the most use is one that was established by Pearlin et al and titled the caregiver stress hypothesis. As a consequence, the caregiver stress hypothesis was chosen to serve as the conceptual underpinning for this investigation. The hypothesis suggested that the following five factors contributed significantly to the stress experienced by caregivers: They included history and the surrounding environment, the primary and secondary pressures, the secondary intra-psychic strains, and the outcome, or the caregiver's quality of life (Pearlin et al., 2019). However, the caregiver's method of dealing with stress and the social support resources available to them affected the result or quality of life of the caregiver (Pearlin et al., 2019).

The model of the stress process has always placed a significant emphasis on contextual and background factors (Pearlin et al., 2019). The background and context of the stress reaction included the caregiver's age, gender, ethnicity, educational background, socioeconomic standing,

as well as the amount of time they had been providing care and how long they expected to continue doing so (Pearlin et al., 2019). Researchers have investigated how a caregiver's quality of life is affected by the qualities of their background and the situation in which they work (Pearlin et al., 2019). The part that follows is a review of the relevant literature about the factors of background and context (Pearlin et al., 2019).

The study had a hypothesis that socio-demographic factors, previous caring experiences, and the structure of caregiver networks were background and contextual sources of stress (Pearlin et al., 2019). Background and context are predecessors to the stress process, which might have an effect on the result or quality of life of the carer (Emanuel et al., 2020; Haley et al., 2017 & Pearlin et al., 2019).

The history and context both covered topics that played an important role in determining the outcome for caregivers (Pearlin et al., 2019). The background and context factors of the caregiver stress process theory that were investigated for the purpose of this study included the caregiver's age, the length of time they have been providing care, the type of recipient's disability, the caregiver's economic burden, the resources provided by their family and their social network, as well as the caregiver's utilization of those resources (Pearlin et al., 2019).

The social cognitive theory as stated by Stajkovic & Kayla (2019), explains the theoretical frame work that guided the study. The theory emphasises that behaviours develops from constant interaction of people and their environment and that ensures behaviours affecting these people and their environment (Stajkovic & Kayla, 2019).

The social cognitive theory will be used to guide in developing a plan that affects people, environment and human behaviour at work. It will also help in providing knowledge about the recommended behaviour and the skills necessary to continue and discovering positive role models and recognizing positive changes in others for observational learning. Other authors like Han Seyle proposed General Adoption Syndrome (GAS) theory in relation to social cognitive theory as a means of conceptualizing stress and considered stress to be the body response to threatening situations (Buchmann, 2015).

General Adoption Syndrome (GAS) by Han (2003), stated that stress results when people perceive a situation as threatening and are unable to cope. It is believed that stress triggers cerebral cortex and limbic system to carry messages to the hypothalamus. When the messages reach anterior hypothalamus, the Automatic Nervous System is aroused this controls the heart, lungs, stomach, blood vessels and glands (Palmer and Dryden, 2015). The ANS is made up of both Sympathetic Nervous System and Parasympathetic Nervous System. The SNS aids in relaxation and helps to restore a person to state of equilibrium. In a stressful situation the SNS prepares the body for action by increasing the strength of skeletal muscle, heart rate, sugar and fat levels, respiration, mental activity, while reducing blood clotting time, intestinal movement and tears (Casale & Wild, 2012).

The SNS also allows the bladder to relax, pupils to dilate and most blood vessels to constrict. During the stress response, the pituitary thyroid and adrenal glands are activated. The pituitary gland releases adrenocorticotrophic hormone which activates adrenal cortex in order to increase arterial blood pressure. The pituitary gland then releases thyroxin which is a thyroid stimulating

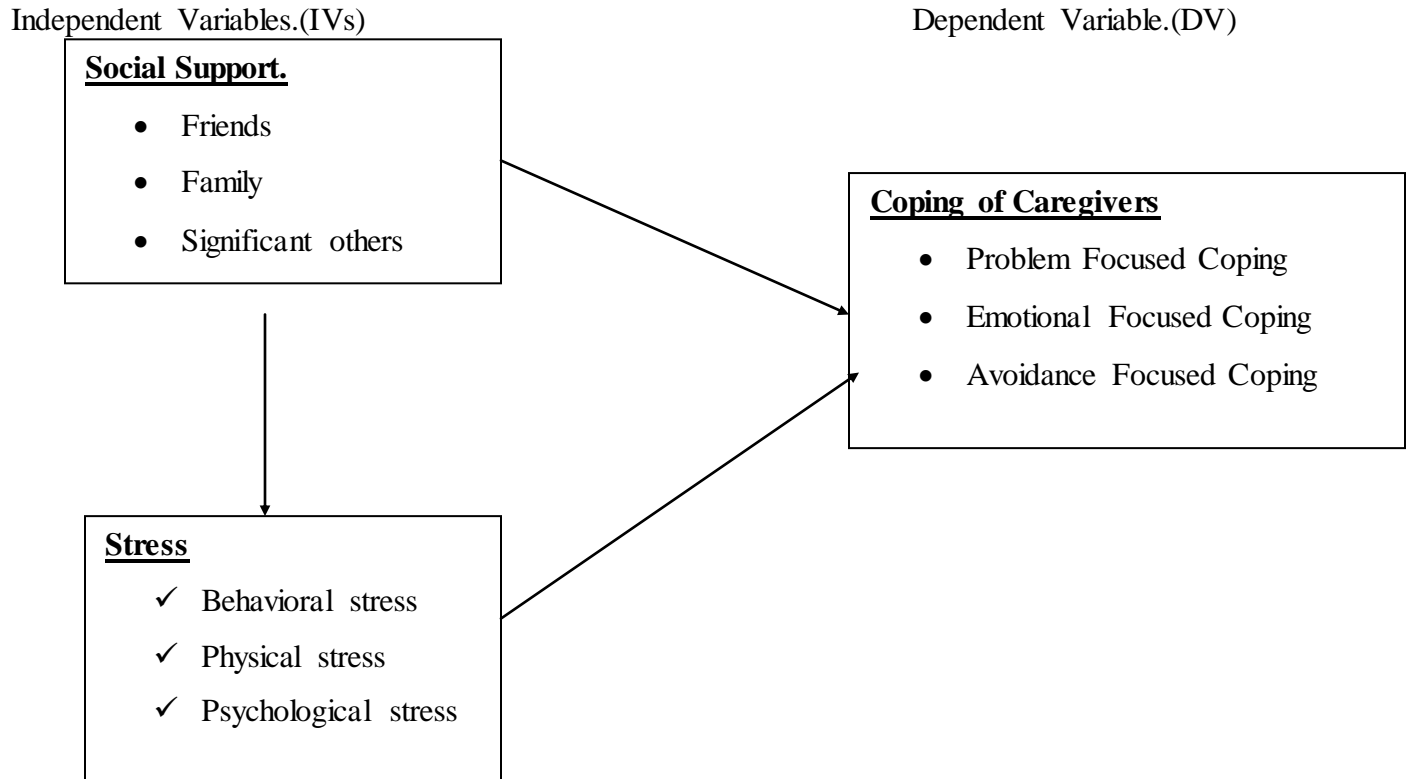
hormone. Thyroxin increases metabolic rate, respiration, heart rate, blood pressure, and intestinal motility. Too much thyroxin and over activity of the thyroid gland can lead to anxiety attacks, the adrenal gland produces adrenaline and noradrenalin, which is released into the blood supply. The adrenal gland increases heart rate and pressure in which blood leaves the heart, dilates gastroinstin activity which leads to person to feel as if they have “butterflies” in their stomach (Chwalisz, 2018).

A person’s instinctive impulse draws from energy reserves and puts it immediately at their disposal to either defend one’s self (fight) or to run away (flight). The activation of the SNS and adrenal glands allows for hormones such as cortisol, adrenaline (flight), and noradrenalin (fight) to provide instant energy to take appropriate action (Lazarus & Folkman, 2013). In the resistance stage, stress is on the verge of being resolved. Homeostasis begins resorting balance and a period of recovery and renewal takes place. The exhaustion stage occurs if stress has continued for some time. When this happens, the body’s ability to resist is lost and all energy supply is gone. The exhaustion stage may be referred to as adrenal fatigue, mala adaptation, and dysfunction. If stress is not resolved by this point, overload and burnout may occur (Cohen, 2014).

## **2.2 Conceptual framework**

Figure 1: A conceptual framework of the study showing the relationship between Perceived Social Support, Stress and Coping of Caregivers.

**Figure 2.2 provides a frame work relating the variables in the study:**



**Source:** Adopted from Glozah (2013) and modified by the researcher, 2023

The conceptual framework in figure 1 illustrates that the independent variables (Social Support and stress) affect coping of caregivers (dependent variable). Social Support was conceptualized in terms of support from the family, support from friends, support from significant others i.e. community and support from peers. Stress was conceptualized in terms of behavioral stress, physical stress and psychological stress. Whereas coping strategies (dependent variable) was conceptualized in terms of problem focused, emotional focused and avoidance focused coping. Social support has a direct impact on coping strategies of caregivers whereas stress may be a mediating variable between social support and coping of caregivers.



## **2.3 Review of related literature**

The review of related literature was presented following the study objectives;

### **2.3.1 Relationship between social support and coping of caregivers of children with sickle cell disease**

Phillips-Salimi *et al* (2013) found that perceived social support was positively associated with caregiver coping among parents of children with SCD. The study added that parents who reported higher levels of social support had lower levels of caregiver burden and were more likely to use positive coping strategies such as seeking social support and problem-solving. Vitaliano *et al* (2013) found that perceived social support was positively associated with caregiver coping among parents of children with chronic illnesses. The study found that parents who reported higher levels of social support were more likely to use positive coping strategies and less likely to use negative coping strategies such as denial or avoidance.

The social network provides the caregiver with mental and physical resources to aid in his or her capacity to deal with stress and make life easier for the person being cared for. When talking about "functional social support," it is referred to as the real availability of people who can meet a certain demand. In addition to this, it includes the provision of emotional assistance in the form of attentiveness, trust, and regard. The degree to which the support is helpful as well as the level of difficulty the caregiver faces in acquiring it are both aspects that make up its character (Cohen, 2014). Ohaeri and colleagues (2016) found that perceived social support was negatively associated with caregiver distress among parents of children with SCD. The study found that parents who reported higher levels of social support had lower levels of depression, anxiety, and stress.

The supportive resources can be mental (for example, nurturing), physical (for example, financial assistance), informational (for example, guidance), or social (for example, companionship) in nature (e.g., sense of belonging). One's perception of the availability of assistance, the amount of help actually received, or the level of social network integration are all valid ways to assess one's level of social support.

Social support reduces the adverse psychological impact of exposure to stressful life events and on-going life strains which in turn reduces someone's exposure to psychological problems (Fadzil, 2013). When caregivers believe that they would receive social support as needed, they would spend less time worrying about stressful events; therefore they would have less experience depression and anxiety hence not experience symptoms of hopelessness (Lazarus & Folkman, 2013) and additionally knowing that there are people to talk to when you are in trouble makes the urban adolescents feel relaxed and comfortable as reported by (Cohen, 2014). Perceived social support has been reported as a protective factor for caregivers who experience mental stress care giving.

The social capital developed as a result of friendship is of particular significance to an individual's well-being because it allows repeated access to social support (Glover and Parry, 2018). In relation to this point research has suggested that friendship ties are more beneficial in terms of emotional aid and companionship (Glover & Parry, 2015).

Chandra & Batada (2016) noted that members of one's own family and friends, as well as administrators, counselors, psychologists, caregivers, coaches, and classmates can all be good

sources of social support. Help in the form of emotional, instrumental, informational, and evaluative support are all components of social support, which are also provided through transactional interactions between individuals. A community's churches and other gathering places often provide social services as well. In addition, caregivers pointed to the importance of family, peer interactions, community involvement, and school as sources of social support. According to the findings, the social support received from members of one's own family and from friends is the most valuable form of social support, surpassing that received from other types of social support (Chandra & Batada, 2016).

The negative psychological effects of being exposed to stressful life events and ongoing life pressures can be mitigated by the provision of social support (Fadzil, 2013). People who have the expectation that they will get social support when they need it are less likely to spend time worrying about stressful events, and as a result, they are less likely to experience depression and anxiety (Lazarus & Folkman, 2013). Furthermore, perceived social support has been reported as a protective factor for caregivers who experience mental stress while providing home-based care for a loved one (Cohen, 2014).

It is anticipated that both stress and the perception of social support can safeguard mental health in two different ways: directly, through the advantages of having social ties, and indirectly, by acting as a buffer against the effects of stressful situations. The idea of social support is multifaceted and generally refers to the emotional, instrumental, or informational assistance that is received from other people. For instance, providing encouragement, assisting

with housekeeping, or informing someone of a job opportunity are all examples of social support.

Marissa.C (2019), argued that it is possible that the demand for stress reduction networks of caregivers will increase as a result of the increasing challenges associated with providing care to patients suffering from chronic diseases, in particular cancer. This demand may be greatest with regard to the socio-emotional aspects of support. Caregivers who believe that such assistance is easily accessible and readily available may make use of it to repair links with family and friends that may have been severed as a result of the patient's illness.

According to the findings of a number of studies, one of the factors that acts as a mediator between psychological symptoms and freedom and quality of life is perceived social support. The discomfort that is caused for caregivers might be affected differently depending on the type of social interaction that is taking place (negative support, daily emotional support, etc.). The presence or absence of informal caring is dependent upon a number of distinct types of social support (Gaugler, 2015).

Kim et al. (2016) found that the majority of caregivers received assistance from their employers (77 percent) or from their peers (85 percent). However, none of the caregivers reported using child care services, and only a small percentage (1 percent) desired to use such services. According to these findings, caregivers are more likely to receive aid in the workplace, which is to their advantage. Caregivers who have children may benefit greatly from finding or

offering child care services in the community, as well as from encouraging caregivers to receive support from other family members and friends, close friends or child care.

Positive adjustment in the provision of care for chronically sick patients is frequently associated with the availability of social support and dependable individuals (Walker, 2017). On the other side, there is a higher association between lack of support and high levels of emotional discomfort or affective disorders (Nijboer and others, 2018). The mental health of carers often improves within the first year following a diagnosis, when they perceive an increase in social support. Schumacher and colleagues (1993) argue that social support modifies both the patient's functional status and the caregiver's sadness. When caregivers believed they received social support, the association between the patient's degree of functioning and their suffering was substantially smaller (Li & Zhang, 2014).

Raffaelli et al. (2012) found that having a higher level of perceived social support was connected with having lower levels of stress. In addition, support from various sources like family, friends, and significant others demonstrated that family support played a unique role in buffering the negative impacts of stress on Mexican teenagers, such as hopelessness, sadness, and anxiety (Raffaelli et al, 2012).

According to Chwalisz (2018), having support can help sever the connection between an event that could be stressful and the body's response to that event. Intervening between the experience of stress and the beginning of the negative consequence by breaking the link between the two and, respectively, providing support at this time. As a result, having social support can assist in reducing or eliminating the emotional response, lowering the physical process, or

modifying the maladaptive behavioral responses to stress that are displayed by carers (Chwalisz, 2018).

The health and well-being of the caregiver is significantly impacted by the presence of social support. There were certain impacts that were unique to caregivers that were observed across a variety of conditions (Monahan & Hooker, 2017). Miller et al. (2016) conducted research to determine the factors that lead to the caregiver's suffering. One of these factors was the amount of social support that was easily accessible.

According to Miller et al. (2016), "the caregiver is a precondition for possibly effective long-term social support (Folkman et al., 2016). The number of people who lived outside of the caregiver's household and with whom the caregiver had interacted in the previous four weeks was used as a metric to determine the caregiver's level of social support (Miller et al., 2016). Visits from friends or family members, as well as more casual meetings with neighbors, are considered to be forms of social aid (Miller et al., 2016).

The social network is able to provide psychological support, educational opportunities, and incentives for ethical behavior (Chang et al., 2016). There was a correlation between the caregiver's perceptions of the availability of social support and a reduction in stress and depression, and there was a correlation between participation in social activities and an increase in the caregiver's level of life satisfaction (Chang et al., 2016). However, social networks can also be a source of additional stress for caregivers if the caregiver believes the network is able to provide assistance but the network is unable to do so, resulting in conflict within the network (Chang et al., 2016).

Liu *et al.*, (2011) conducted a prospective correlational study with 103 family caregivers in order to investigate the association between self-rated problem solving, psychological distress, and social support among informal carers of stroke victims. The study was conducted with 103 family caregivers. They made the discovery that the caregivers' views of social support and physical health were affected by the caregivers' confidence in their ability to solve problems (Liu *et al.*, 2011).

### **2.3.2 Relationship between social support and stress among caregivers of children with sickle cell disease**

Simoes and colleagues (2019) found that perceived social support was negatively associated with caregiver stress and burnout among parents of children with SCD. The study found that parents who reported higher levels of social support had lower levels of stress and burnout and were more likely to use positive coping strategies. Therefore perceived social support is an important factor in mitigating stress among caregivers of children with SCD. Higher levels of social support are associated with lower levels of stress, stress-related symptoms, and burnout. Furthermore, caregivers who perceive high levels of social support are better able to manage the demands of caring for a child with SCD and are more likely to use positive coping strategies.

Miller.*et.al* (2010) assert that informal and formal support share the ability to provide concrete aid and assist in evaluating problems, to help in formulating and implementing plans of action, to give feedback and to affirm a person's capacity to deal with the situation. Social relationships are believed to enhance the feelings of self-worth, self-esteem and a sense of wellbeing resulting from feeling value by meaningful others and to aid in resolution of

designated problems or losses. Daniel and colleagues (2018) who found that perceived social support was positively associated with quality of life among caregivers of children with SCD. The study found that caregivers who reported higher levels of social support had better physical, emotional, and social functioning.

Lower perceived social support from family not friend predicted greater perceived stress. The family is the major source of support for caregivers particularly from parents and grandparent (White.et.al 2004). Research conducted by Broadly *et al* (2017), revealed that both quantitative and qualitative studies found self-stigmatizing caregivers use social withdrawal to cope with judgmental reactions from the public and from family and therefore less likely to seek support even when it's available. Further research revealed that caregivers who reported greater affiliate stigma, perceived social support from the family to be lower and this is associated with higher perceived stress (Perlick *et al.*, 2014).

Stress is the body's physiological and psychological response to danger or threat. There was a negative correlation between anxiety, stress, and depression according to Nahid and Sarkis (2014), showing that college students with low levels of social support suffer from higher levels of anxiety, stress, and sadness. For students, this is tremendously instructional since it stresses the need of social support by reducing their psychological distress. Similar findings were made by Glozah (2013), who found that students who have a sense of social support are less likely to suffer from mental health issues. Male students reported higher levels of academic stress, whereas female students reported higher levels of depression. This was also proven (Glozah, 2013). According to Glozah (2013), there is no evidence that social support has an impact on students' mental health.



### **2.3.3 Relationship between stress and coping strategies of caregivers of children with sickle cell disease**

Thomas and colleagues (2017) found that caregivers of children with SCD who used positive coping strategies, such as seeking social support and engaging in leisure activities, reported lower levels of stress and greater psychological well-being. The study also found that caregivers who used avoidance coping strategies, such as denial and substance use, reported higher levels of stress and poorer psychological well-being.

Ayodeji. A, Jude .U.Ohaeri, Olumide, and Andrew.T.Olagunju (2020) who found that caregivers of children with SCD reported using a variety of coping strategies, including problem-focused coping, emotion-focused coping, and religious coping. The study also found that caregivers who used more problem-focused coping strategies reported lower levels of stress and greater psychological well-being. Robinson *et al.* (2019) found that caregivers who reported higher levels of stress were less likely to engage in self-care activities or seek social support. Another study found that caregivers who reported using more positive coping strategies reported lower levels of stress.

Osuorah and colleagues (2013) found that problem-focused coping strategies were associated with lower levels of stress among caregivers of children with SCD. The study found that caregivers who used problem-focused coping strategies, such as seeking information about the disease and engaging in self-care activities, reported lower levels of stress.

The Implications for interventions: Given the negative impacts of caregiver stress on their physical and mental health, as well as the well-being of the children they care for, it is important to develop interventions that promote effective coping strategies among caregivers. Some

interventions that have been successful in this regard include psycho-education programs, mindfulness-based interventions, and family-based interventions that promote communication and problem-solving skills (Stollon *et al.*, 2018).

The provision of care for members of the family who are chronically ill, particularly those who struggle with mental health issues, can be a cause of stress for other families. The source of stress is both anxiety-inducing and financially burdensome for the family. Techniques for managing stress are an absolute necessity for families who are taking care of relatives who are dealing with ongoing mental health issues. Patients who need their families' support more than ever, could be negatively affected by the family's exposure to stressful situations and ineffective coping techniques (Billings *et al.*, 2020).

Caregiver stress can lead to multiple negative outcomes including declines in physical health, increased mental health concerns, and overall decreased quality of life. Caregiver stress also leads to increased financial costs to the person, family, and health care systems, making it a public health issue. Recognizing caregiver stress is the initial step to identifying those in need of support and to providing quality care. Fortunately, caregiver stress can be prevented or reduced using a culturally competent multidimensional approach to addressing social determinants of health and unmet physical, psychological, and social/emotional needs of caregivers (Buchmann, 2015).

While caring for a loved one can be very rewarding, it also involves many stressors. And since care giving is often a long-term challenge, the emotional impact can snowball over time. One may face years or even decades of care giving responsibilities. If the stress of care giving is

left unchecked, it can take a toll on caregiver's health, relationships, and state of mind, eventually leading to burnout, a state of emotional, mental, and physical exhaustion. And when one gets to that point, both the caregiver and the person being cared of suffer. Learning to recognize the signs of caregiver stress and burnout is important, so the caregiver can take immediate action to prevent things from becoming worse and start improving the situation for both the caregiver and the person cared for (Casale & Wild, 2012).

There are a number of factors that can play a role in caregiver stress syndrome. For some caregivers, the constant demands of caring for a person who has a serious illness can result in burnout. For others, the lack of boundaries between their roles as a caregiver and a spouse, child, or other loved one can be challenging. Still other caregivers put unrealistic expectations on themselves, thinking that they can do it all and refusing to ask for help. This may often be because they don't want to be a burden on anyone else. Other caregivers are simply frustrated by the overwhelming needs of their loved one, or the financial and other resources needed to care for someone with a long-term illness or disability (Chang *et al.*, 2016).

#### **2.3.4 Gender differences in coping among caregivers**

Robinson *et al* (2020) argued that given the differences in coping strategies and experiences of stress between male and female caregivers, interventions should take gender into account when developing programs to support caregivers of children with sickle cell disease. For example, interventions could be tailored to address the specific coping strategies that are more commonly used by male and female caregivers, or to address the emotional distress experienced by female caregivers.

Nwogu *et al* (2015) found that female caregivers of children with sickle cell disease are more likely to use emotion-focused coping strategies, such as seeking social support and using positive thinking, while male caregivers are more likely to use problem-focused coping strategies, such as problem-solving and seeking information. Additionally, female caregivers have been found to experience higher levels of emotional distress and burden than male caregivers.

Caregiver health and well-being can be moderated and mediated by coping. Coexisting is a term used to describe a person's mental and behavioral efforts to deal with the stressors of a difficult circumstance (Pearlin *et al.*, 2019). Care giving outcomes are influenced by both caregiver self-efficacy and caregiver distress evaluations in dealing with the circumstance (Folkman *et al.*, 2016).

Coping mechanisms and the availability of the use of social support services were linked to caregivers' stress and quality of life, according to the study. The most important stress mediators were coping mechanisms (Haley *et al.*, 2017). Individual caregivers were in charge of their own coping mechanisms, including their own behaviors and practices (Haley *et al.*, 2017). The three key components of coping are regulating the circumstances causing stress, controlling the interpretation of the event to reduce the perceived threat, and managing the stress symptoms arising from the perceived stressful scenario (Pearlin *et al.*, 2019).

Robinson *et al* (2020) noted that caregivers of children with sickle cell disease experience significant stressors, including frequent hospitalizations, managing pain, and balancing caregiving with other responsibilities. Effective coping strategies, such as seeking social support,

engaging in self-care activities, and using positive thinking and problem-solving skills, can help caregivers manage their stress and improve their mental and physical health.

According to Robinson *et al* (2020), given the differences in coping strategies and experiences of stress between male and female caregivers, interventions should take gender into account when developing programs to support caregivers of children with sickle cell disease. For example, interventions could be tailored to address the specific coping strategies that are more commonly used by male and female caregivers, or to address the emotional distress experienced by female caregivers.

## **2.6 Related studies**

Given *et al.* (2014) found that among 152 caregivers for cancer patients, caregiver children between the ages of 45 and 54 exhibited greater depressive symptoms, whereas caregivers between the ages of 35 and 44 reported a significant sense of abandonment. These findings were based on the findings of caregivers for cancer patients between the ages of 35 and 44. They suggested that female adult child caregivers reported a greater amount of difficulty connected with providing care than did caregivers who provided care for their spouses.

The length of time that a caregiver is required to provide care is one indicator of how persistent caregiver stress is (Pearlin *et al.*, 2019). In their study of 80 caregivers, Dorfman *et al.* (2016) came to the conclusion that the duration of time spent providing care had no association with the amount of burden or strain experienced. Caregivers reported higher levels of stress and burden at the beginning of their obligations as caregivers; however, they reported lower levels of stress and burden as time went on (Dorfman *et al.*, 2016).

Smith et al. (2015) carried out a study to determine the levels of stress experienced by caregivers of Alzheimer's disease patients over time. The levels of stress experienced by 310 caregivers at the beginning of the study were compared to the levels of stress experienced by 213 carers one year after the study began. As the needs of the people receiving care increased over time, the caregivers reported feeling an increase in stress and a reduction in their quality of life. Aronson (2017) conducted research on the quality of life of a sample of 345 people who cared for people with multiple sclerosis (MS). They came to the conclusion that longer periods of care giving, worsening symptoms in the care recipient, and a lack of symptom stability in MS care recipients were all related with a decline in quality of life (Aronson, 2017). In conclusion, the research that was looked at provided support for the caregiver stress notion (Pearlin et al., 2019). There is a connection between some qualities of caregivers and the quality of life of caregivers, and this connection may have an adverse effect on caregivers' quality of life (Given et al., 2014).

The caregiver experiences stress due to the specific nature of the care recipient's disability (Pearlin et al., 2019). According to the findings of the research, the adverse effects of providing care might take on a variety of forms. For example, Monteko (2018) conducted an investigation into the relationship between the health of the caretaker and the degree of impairment experienced by the person being cared for by the caretaker, using a group of fifty elderly women whose spouses suffered from dementia. During the preliminary stages of the symptoms, Monteko found that the disruption of the caretakers' life plans caused them to feel angry and disappointed. However, once the carers established a routine, they experienced a decrease in discomfort, despite the increasing demand for their services.

Based on a sample of 392 senior caregivers and 427 senior non-caregivers, Schulz and Beach (2018) made the observation that a combination of bereavement, extended anguish, and health issues raised the chance of health problems and mortality for the elder caregiver. In addition, the results of the measurements showed that older spouse caregivers who struggled with mental or emotional stress in addition to a disability reported the highest levels of caregiver distress (Schulz & Beach, 2018). Caregivers of elderly people who did not identify any health problems, mental or emotional strain, or other sources of difficulty reported the least amount of suffering (Schulz & Beach, 2018). The majority of disabled people's partners who reported experiencing mental or emotional strain as a result of providing care had mortality risks that were much higher than those of people who did not provide care (Schulz & Beach, 2018).

While caring for people with chronic health conditions, caregivers face a significant financial burden (Lai, 2012). In a study of 2,661 caregivers of people with life-threatening illnesses, Covinsky et al. (2014) explored the financial toll that severe disease takes on those who provide care. Covinsky et al. found that nearly a third of people receiving care needed a lot of aid from a caregiver. A family member usually has to give up their job or make significant changes to their social and environmental circumstances in order to care for a family member. Caregivers who lost their whole family's savings or their primary source of income were around one-third of the total.

Emanuel et al. (2020) studied the influence of economic hardship on caretakers in a sample of 988 terminally ill patients and 893 caregivers. Having trouble with money can lead to physical, social, and emotional stress, according to research by Emanuel et al (Emanuel et al., 2020). There was an additional emotional and financial burden on family caregivers when

elderly, low-income patients with a severe chronic disease were not responding to medical treatments (for example, incontinence, physical mobility) (Emanuel et al, 2020).

According to Pearlin et al. (2019), caregivers' family and social support networks may have a significant impact on their outcomes (Pearlin et al., 2019). The quality of life of a carer can be influenced by the caregiver's social support network and the caregiver's coping style. All the caregiver's connections are in a network, whereas social support provides partial or entire assistance to the caregiver. In some cases, social support might provide a specific kind of help to the carer.

An examination of the impact of the social network on the caregivers of Parkinson's patients by Miller et al. (2016) included 54 married PD patients. Caregivers' anxiety had no connection to the size of their social network, according to the study's findings. Some researchers believe that the absence of meaningful link between stress and social network among PD patient caretakers may be due to the limitations of the metrics used in their study (Miller et al., 2016). They observed that the number of persons the caregiver interacted with was used as a measurement in their study. In order to participate in the social network, caregivers and their networks were not need to have any significant social ties (Miller et al., 2016).

Caregiver support services, according to the stress hypothesis, will have a positive impact on caregivers' well-being (Pearlin et al., 2019). Caregiver perceptions of their roles as caregivers differ from person to person, even though they are performing the same tasks in a similar way (Montgomery & Kosloski, 2019). An intervention program designed to meet the individual needs of caregivers at various points in their caring journey was the most effective and efficient, according to researchers (Harding et al., 2011).



Care giving is characterized by a high level of stress, which has been linked to a variety of undesirable outcomes, both directly and indirectly (Pearlin et al., 2019). In order to secure the safety and well-being of the care recipient, caregivers are subject to a number of primary stresses (Pearlin et al., 2019). Stressors secondary to caring are those that originate from the caregiver's emotional and psychological well-being as a result of their role as a caregiver. Secondary stress may happen if the primary caregiver and a family member disagree about the quality of care the care recipient received from the primary caregiver, for example.

Giving assistance with a wide range of daily duties entails a lot of observable and objective pressures (Pearlin et al., 2019). Caregivers may endure significant stress due to the care recipient's inability to perform daily tasks. Primary stressors can become more acute with time (Dorfman et al., 2016). Physical limitations of care recipients have an impact on the daily schedules and emotional functioning of caregivers. As soon as a patient was diagnosed, and at various times for the next 52 weeks, data was collected. Findings showed that caregiver discomfort was linked to a variety of symptoms experienced by care recipients and demographic variables such as age, employment status, and household income for the caregiver (Given et al., 2014).

Stress, burden, and schedule disturbances were the most common concerns of caregivers at both the time of diagnosis and the time of death (Given et al., 2014). Caring for someone with a serious medical condition, on the other hand, put a strain on the caregiver's personal and professional life (Given et al., 2014). 40 cancer caregivers and 40 dementia caregivers were evaluated by Haley et al. (2015) for their stress levels and coping mechanisms. Caregivers' high levels of unfavorable assessments of care recipients' abilities to meet their own needs and their lack of social involvement were linked to low levels of life satisfaction (Haley et al., 2015).

Giving care to those who require extensive attention has been linked to severe stress and load, according to Emanuel and co-authors (2020) (Emanuel and Colleagues, 2020).

Stressors that arise from the responsibilities of both the caregiver and care recipient are known as secondary stressors (Pearlin et al., 2019).

Resurrecting historical family conflicts between the caregiver and non-caring family members can lead to secondary stressors, such as role tension and emotional stress. As an example, disagreements among family members over the patient's level of impairment or the quality and amount of care provided by other family members may be a source of role tension. When the caregiver does not feel appreciated or recognized for the care they provide, it can cause conflict (Pearlin et al., 2019).

Role conflict may arise as a result of having to care for a loved one while still working to support yourself. Hired caregivers, according to this research, may experience sentiments of hopelessness, helplessness, wrath, and frustration. As a result of their client's disability and the difficulties in obtaining affordable and trustworthy care, hired carers had a tough time establishing a healthy work-life balance (Duxbury et al., 2011).

## **2.7 Identifying the gaps**

The majority of research conducted focused on the requirements of caregivers providing care to patients. As Uganda begins an epidemiological transition with an increased burden of non-communicable diseases and as caring for the needs of people with other chronic illnesses becomes commonplace, more research will be required to understand the specific challenges associated with the management of cancer, diabetes, chronic kidney disease, and stroke, as well

as the needs of caregivers in communities and rural areas ( Komuhangi *et al.*, 2022). More research is therefore required to investigate the psychosocial factors surrounding palliative care and also recognition of the role played by informal care givers in the management of other chronic illnesses.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.0 Introduction**

This chapter covers the research design, target population, sample size, sampling procedure, data source, research instruments, validity and reliability, data collection procedure, data analysis, limitations and ethical considerations.

#### **3:1 Research design.**

The study was quantitative in nature and employed descriptive, correlational and causal comparative designs. For descriptive statistics means and standard deviations were used and for inferential statistics a correlational and causal comparative design were used to determine the relationship between variables and compare two independent samples respectively. The quantitative approach was used because it studies phenomena using numerical data and statistical, analytical computing tools and data could be collected data from a large sample of respondents at same time (Adeyoyin, 2020).

#### **3:2 Target population.**

The target population included 230 respondents; these included 200 Informal caregivers of children with sickle cell disease and 30 formal caregivers at Mulago hospital Kampala District Uganda (Ministry of Health, 2020). The population was chosen because was likely to provide the right information that was relevant to the study.

#### **3.3 Sample size**

The study used Slovene's formula to calculate the sample size of the respondents. Slovene's formula:

$$n = \frac{n}{1 + N(\alpha)^2}$$

Where:  $n$  = sample size;

$N$  = target population, and

$\alpha$  = 0.05 level of significance

$$n = \frac{230}{1 + 230(0.05)^2}$$

$$n = \frac{230}{1 + 230 (0.0025)}$$

$$n = \frac{230}{1.575}$$

$$n = 146$$

Out of 30 formal caregivers at Mulago Hospital and 200 informal caregivers, the study used a sample size of 19 formal caregivers at Mulago Hospital and 127 Informal caregivers respectively.

**Table 3.1: Summary of the population and sample size**

Population Category	Target population	Sample size
Formal Caregivers.(Doctors & Nurses).	30	19
Informal caregivers. (Relatives & Friends).	200	127
TOTAL	230	146

### **3.4 Sampling Procedure.**

Snowball sampling method was used because it was easier to get respondents/participants through a chain referral and was the easiest way to find samples and quick to find subjects as they come from reliable sources.

### **3.5 Research Instrument**

This study used questionnaires to achieve objective one, two and three of this study. The questionnaires were closed ended and they were distributed among the care givers of children with sickle cell disease at Mulago Hospital, Kampala Uganda. A four point Likert scale was used to determine the responses and the opinions of the respondents in regard to the study sub themes. Four point Likert scale included: 1=strongly disagree; 2=disagree; 3=agree; and 4=strongly disagree. The researcher preferred to use a questionnaire because it is fast, covers a big number of respondents in a short time and it is cheap.

### **3.7 Data quality control**

This section had two sub-sections, on validity and the other on reliability.

#### **3.7.1 Validity**

To ensure content validity of the questionnaire to be used in the study, the researcher discussed the items in the instrument with the supervisor. Advice was given by the supervisor to help the researcher determine the validity of the research instrument. The advice included but not limited to suggestions, clarifications and other inputs. These suggestions were used in making necessary changes.

A four point scale was opted for indicating very relevant (VR), quite relevant (QR), somehow relevant (SHR) and not relevant (NR). The content validity ratio was calculated.

According to Amin (2015), the content validity index (CVI) of  $\geq 0.7$  is valid; an argument for accepting any instrument falling therein.  $(CVI) = \frac{\text{Number of good questions}}{\text{Total number of questions}}$

For this research, the CVI of at least 0.7 was adequate. This was calculated from the list of questionnaires in the appendices. In these questionnaires, there are 51 valid (good/relevant) questions.

Hence,  $(CVI) = \frac{\text{Number of good questions}}{\text{Total number of questions}} = \frac{35}{40} = 0.88 > 0.7$ . This clearly shows that the questionnaires to be used for data collection are valid.

### **3.7.2 Reliability of Research Instrument**

Reliability is a measure of the degree to which a research instrument yields consistent results after repeated trials (Mugenda & Mugenda, 2016). Kothari (2016) recommended a test – retest method to be used by administering the same instrument twice on the same sample group of the subject at different times to test reliability of the instrument. The researcher determined the reliability by first administering the instrument to a sample of respondents that was involved in the study. The researcher administered the same instrument to the same sample group of the subject for the second time. Test-retest or stability testing, according to Amin (2015), shows that results from a test administered once are the same or nearly the same when the test is given again at a later date (retest). When computing the alpha co-efficiency of reliability, Cronbach's alpha equations were used to determine the internal consistency of the questionnaire items.

Also, Pearson's Product Moment's Correlation Coefficient (r) was used to determine the reliability coefficient stability of the data collection instrument. A coefficient of 0.7 for questionnaires was considered high enough for the instrument to be deemed reliable (Neuman,

2015). Pearson's Product Moment Correlation Coefficient is one of the best-known measures of association for determining the relationship between dependents and independent variables. i.e.

$$r_{xy} = \frac{n\sum xy - \sum x \sum y}{\sqrt{[n\sum x^2 - (\sum x)^2][n\sum y^2 - (\sum y)^2]}}$$

Where  $r_{xy}$  = Pearson's Product Moment Correlation Coefficient

$\sum x$  = sum of scores in x distribution

$\sum y$  = sum of scores in y distribution

$\sum x^2$  = sum of squared scores in x distribution

$\sum y^2$  = sum of squared scores in y distribution

$\sum xy$  = sum of the product of point x and y scores

n = the number of point x and y scores Kerlinger (2019).

A coefficient ( $r_{xy}$ ) of 0.7 for questionnaires and 0.8 for interview schedules was considered adequate enough for the instrument to be deemed reliable (Neuman, 2018). This was obtained from the data collected. Also, the researcher considered, the CVI of at least 0.7 as adequate for this research

**Table 3.2: Reliability of research instrument**

<b>Construct variable</b>	<b>Cronbach's Alpha</b>	<b>No. of items</b>
Perceived social support	0.92	12
Stress	0.85	10
Coping strategies	0.78	13
<b>Mean</b>	<b>0.85</b>	



The mean for reliability test was established at 0.85 and therefore the internal consistency (reliability) of the instrument was confirmed.

### **3.7 Data Gathering Procedures**

#### **Before the administration of the questionnaires**

The researcher received an introduction letter from the Directorate of Higher Degrees and Research at Kampala International University to use when requesting authorization from hospitals in the Kampala district to conduct the study. An approval letter from the research ethical committee of Mulago hospital was obtained and consent from suggested respondents was also sought. Formal and informal caregivers of the study's confidentiality and privacy was assured throughout the data collection exercise. The researcher explained to the various stakeholders in the area of study of the purpose and significance of the study. The identified respondents were given questionnaires to fill.

#### **During the administration of the questionnaires**

After providing their answers, the respondents were asked not to sign the questionnaires. The three-day window following the distribution date of the surveys was stressed by the researcher. Finally, the completeness of all returned surveys was reviewed.

#### **After the administration of the questionnaires**

The Statistical Package for Social Sciences version 16. (SPSS) was used to code, and statistically analyze the data.

### 3.8 Data Analysis

#### 3.8.1 Quantitative data analysis

Different data analyses and statistical techniques were used namely: Data on profile of Respondents was analyzed using simple frequencies and percentage distributions. Means and standard deviations were used to determine the extent of perceived social support, stress and coping strategies. Pearson's Linear Correlation coefficient was used to analyze hypothesis 1, 2 and 3. The independent t-test was used to test hypothesis 4.. An item analysis helped to identify the strengths and weaknesses of respondents in terms of perceived social support, stress and coping strategies from which conclusions were derived. The statistical package which was used for analysis of data in this study was SPSS version 16.0. The following numerical values and response modes were used to interpret the means;

**Table 3.3: Mean range interpretation table**

Mean range	Response mode	Interpretation
3.26-4.00	Strongly agree	Very high
2.51-3.25	Agree	High
1.76-2.50	Disagree	Low
1.00-1.75	Strongly disagree	Very low

### 3.9 Limitations of the study

Testing: In terms of time spent administering the questionnaires, comprehension of the items on the surveys, and justifications provided to the respondents, research assistants were used.

Attrition/Mortality: Not all questionnaires were returned as neither completely answered nor even retrieved back due to circumstances on the part of the respondents such as travel, sickness, hospitalization and refusal/withdrawal to participate. In anticipation to this, the researcher reserved more respondents by exceeding the minimum sample size. The respondents were requested not to leave any item in the questionnaires unanswered and closely followed up as to some key informants were revealed in detail the gaps and deficiencies that could affect its success; this could affect the content validity of the first research question.

The research environments classified as uncontrolled settings where extraneous variables influenced on data gathered such as comments from other respondents, stress, and motivation on the part of the respondents while on the process of answering the questionnaires.

The study design which was used also limited a wide range of areas of study and so findings are basically limited to Mulago Hospital, Kampala Uganda.

### **3.10 Ethical Considerations**

Ethics are standards for proper conducts that differentiate between acceptable and unacceptable behavior. The contents of the research instruments were first discussed with subject matter experts before questionnaires were given out to the participants to fill in for the study. The aim of this was to make sure the content of the research instrument is appropriate for the study.

Verbal consent was obtained from the respondents who were willing to participate in the study and they were assured of confidentiality. Respondents would free to quit if they were no longer interested in participating in the study since it was voluntary to participate in the study.

Verbal or written informed consent was obtained from every research participant. Each participant was made aware that the information they shared would be used in this report.

Participants were made aware that participation was wholly voluntary and that they could stop participating at any time.

Confidentiality was maintained through the removal of names and identifying information from the data.

## CHAPTER FOUR

### DATA PRESENTATION, ANALYSIS AND INTERPRETATION

#### 4.0 Introduction

This chapter presented, analyzed and interpreted data collected from the field. Data analysis and interpretation was based on the research objectives. Below are the data presentations and analysis of research findings;

#### 4.1 Demographic characteristics of the Respondents

The study showed the profile information of respondents as to gender, age and level of education.

**Table 4.1.1: Showing sex of respondents**

<b>Item</b>	<b>Description</b>	<b>Frequency</b>	<b>Percentage (%)</b>
<b>Sex</b>	Male	56	38.4
	Female	90	61.6
<b>Total</b>		<b>146</b>	<b>100.0</b>

Source: Primary Data, 2023

Table 4.1.1 above indicates the gender of respondents where majority of them were female with a dominance of (61.6 percent) compared to their counterparts the male with (38.4 percent). Therefore, this implied that majority of caregivers at Mulago Hospital are female compared to female.

**Table 4.1.2: Showing the Age of Respondents**

<b>Item</b>	<b>Description</b>	<b>Frequency</b>	<b>Percentage (%)</b>
	20-25 years	19	13.0
	26-30 years	42	28.8
<b>Age group</b>	31-35 years	44	30.1
	36-40 years	24	16.4
	41 and above years	17	11.6
	<b>Total</b>	<b>146</b>	<b>100.0</b>

**Source: Primary Data, 2023**

Table 4.1.2 above indicates that majority of the responds were between the age of 31-35 years with 30.1 percent, 26-30 with 28.8 percent, 36-40 with 16.4 percent, 20-25 with 13.0 percent and 40 and above with 11.6 percent . This implies that majority of the caregivers at Mulago Hospital are mature in regards to age.

**Table 4.1.3: Showing Education Level**

Item	Description	Frequency	Percentage (%)
	Certificate	37	25.3
	Diploma	52	36.0
<b>Education Level</b>	Degree	31	21.2
	Masters	26	17.5
	PHD	0	0
	<b>Total</b>	<b>146</b>	<b>100.0</b>

**Source: Primary Data, 2023**

Table 4.1.3 above indicates that majority of respondents were diploma holders with 36.0 percent, certificate holders with 25.3 percent, degree holders with 21.2 percent, masters with 17.5 percent and no PhD holder. This implies that majority of respondents were educated enough and were able to interpret the questionnaire and answer it.

#### **4.2 Social support**

The first independent variable in this study was social support, for which the researcher wanted the respondents to rate the extent to which they agree or disagree with each question. The questions on social support were based on the four Likert scale and the responses were analyzed using SPSS version 16. and summarized using means as indicated in table 4.2;

**Table 4.2: Social support**

<b>Items on Social support</b>	<b>Mean</b>	<b>Interpretation</b>	<b>Rank</b>
<b>Social support</b>			
There is a special person who is around when I am in need	3.46	Very high	1
There is a special person with whom I can share my joys and sorrows	3.15	High	2
My family really tries to help me	3.11	High	3
I get emotional help and support I need from my family	2.95	High	4
I have a special person who is a real source of comfort for me	2.73	High	5
My friends really try to help me	2.72	High	6
I can count on my friends when things go wrong	2.66	High	7
I can talk about my problems with my family	2.43	Low	8
I have a friend with whom I share my joys and sorrows	2.24	Low	9
There is a special person in my life who cares about my feelings	2.15	Low	10
My family is willing to help me make decisions	1.73	Very low	11
I can talk about my problems with my friends	1.45	Very low	12
<b>Average mean</b>	<b>2.57</b>	<b>High</b>	

**Source:** Primary Data, 2023

**Key for interpretation of means**

<b>Mean range</b>	<b>Response range</b>	<b>Interpretation</b>
3.26 - 4.00	Strongly agree	Very high
2.51 - 3.25	Agree	High
1.76 - 2.50	Disagree	Low
1.00 - 1.75	Strongly disagree	Very low

With respect to social support, this aspect was rated high on average and this is indicated by the average mean of 2.57, hence implying that there is increased risk of depression and other stresses



in the absence of social support, as well as the buffering effects of social support on hospital and caregivers. Still results indicate that the highest rated items of social support were; there is a special person who is around when I am in need (mean=3.46), there is a special person with whom I can share my joys and sorrows (mean=3.15); my family really tries to help me (mean=3.11); i get emotional help and support I need from my family (mean=2.95); I have a special person who is a real source of comfort for me (mean=2.73); My friends really try to help me (mean=2.72); I can count on my friends when things go wrong (mean=2.66). The following items under social support were rated low and these are; I can talk about my problems with my family (mean=2.43); I have a friend with whom I share my joys and sorrows (mean=2.24), there is a special person in my life who cares about my feelings (mean=2.15). The following items were rated very low; my family is willing to help me make decisions (mean=1.73), I can talk about my problems with my friends (mean=1.45).

### **4.3 Stress**

The second independent variable in this study was stress, for which the researcher wanted the respondents to rate the extent to which they agree or disagree with each question. The questions on stress were based on the four Likert scale and the responses were analyzed using SPSS and summarized using means as indicated in table 4.3;

**Table 4.3: Stress**

<b>Items on Stress</b>	<b>Mean</b>	<b>Interpretation</b>	<b>Rank</b>
In the last month, you have been upset because of something that happened unexpectedly	3.38	Very high	1
In the last month, you have felt that you were unable to control the important things in my life	3.20	High	2
In the last month, you have felt nervous and stressed	2.94	High	3
In the last month, you have felt confident about your ability to handle your personal problems	2.90	High	4
In the last month you have felt that things were going your way	2.69	High	5
In the last month, you found out that you could not cope up with all the things that you had to do	2.62	High	6
In the last month, you have been able to control irritations in your life	2.50	High	7
In the last month, you have felt that you were on top of things	2.41	Low	8
In the last month, you have been angered because of the things that were outside of your control	2.38	Low	9
You have always felt that difficulties were piling up so high that you could not overcome them	1.65	Very low	10
<b>Average mean</b>	<b>2.78</b>	<b>High</b>	

**Source: Primary data, 2023**

#### **Key for interpretation of means**

<b>Mean range</b>	<b>Response range</b>	<b>Interpretation</b>
3.26 - 4.00	Strongly agree	Very high
2.51 - 3.25	Agree	High
1.76 - 2.50	Disagree	Low
1.00 - 1.75	Strongly disagree	Very low

Results in table 4.3 revealed that the level of stress was high and this was indicated by the average mean of 2.78, implying that majority of caregivers are affected with stress as reflected in their emotional response that occurs while in the hospital. Still results indicate that the highest rated items were; in the last month, you have been upset because of something that happened unexpectedly (mean=3.38), in the last month, you have felt that you were unable to control the important things in my life (mean=3.20), in the last month, you have felt nervous and stressed (mean=2.94), in the last month, you have felt confident about your ability to handle your personal problems (mean=2.90), in the last month you have felt that things were going your way (mean=2.69), in the last month, you found out that you could not cope up with all the things that you had to do (mean=2.62), in the last month, you have been able to control irritations in your life (mean=2.50).

The following items were rated low; in the last month, you have felt that you were on top of things (mean=2.41), in the last month, you have been angered because of the things that were outside of your control (mean=2.38); one item was rated very low; you have always felt that difficulties were piling up so high that you could not overcome them (mean=1.65). Hence implying that Emotion-focused coping includes a wide range of strategies that are directed toward managing one's emotional response to the problem. Some examples are avoidance, withdrawal, expressing emotion, and the use of substances such as alcohol or food. As might be expected, avoidance strategies are often associated with poor outcomes, but other emotion-focused strategies, such as expressing emotion through journals or writing, may be associated with positive outcomes.

**Table 4.4: Coping strategies**

<b>Variables</b>	<b>Mean</b>	<b>Interpretation</b>	<b>Rank</b>
<b>Items on Coping strategies</b>			
When dealing with a problem, i spend time trying to understand what happened	3.66	Very high	1
When dealing with a problem I try to see the positive side of the situation	3.52	Very high	2
When dealing with a problem I try to step back from the problem and think about it from a different point of view	3.31	Very high	3
When dealing with a problem I consider several alternatives of handling the problem	2.85	High	4
When dealing with the problem I try to see the humor in it	2.79	High	5
When dealing with a problem I think about what it might say about the bigger life style changes I need to make.	2.71	High	6
When dealing with a problem I often wait it out and see if it doesn't take care of itself	2.66	High	7
When dealing with a problem I often try to remember that the problem is not as serious as it seems	2.60	High	8
When dealing with a problem I often use exercise, hobbies or meditation to help me get through a tough time	2.47	Low	9
When dealing with a problem I make jokes about it to try to make light of it.	2.40	Low	10
When dealing with a problem I make compromises	2.35	Low	11
When dealing with a problem I take steps to take better care of myself and family for the future	1.89	Very low	12
When dealing with a problem I work on making things better for the future changing my habits, such as diet, exercise budgeting and staying in closer touch with people I care about	1.37	Very low	13
<b>Average mean</b>	<b>2.66</b>	<b>High</b>	

**Source: Primary data, 2023**

<b>Mean range</b>	<b>Response range</b>	<b>Interpretation</b>
3.26 - 4.00	strongly agree	Very high
2.51 - 3.25	Agree	High
1.76 - 2.50	Disagree	Low
1.00 - 1.75	Strongly disagree	Very low

With respect to coping strategies, this aspect was rated high and this was indicated by the average mean of 2.66, hence implying that caregivers have tried to manage crises, conditions, and demands that are appraised as distressing while at the hospital. Still results indicate that the highest rated items on coping strategies were; when dealing with a problem, i spend time trying to understand what happened (mean=3.66), when dealing with a problem I try to see the positive side of the situation (mean=3.52); when dealing with a problem I try to step back from the problem and think about it from a different point of view (mean=3.31); when dealing with a problem I consider several alternatives of handling the problem (mean=2.85); when dealing with the problem I try to see the humor in it (mean=2.79); when dealing with a problem I think about what it might say about the bigger life style changes I need to make (mean=2.71); When dealing with a problem I often wait it out and see if it doesn't take care of itself (mean=2.66), when dealing with a problem I often try to remember that the problem is not as serious as it seems (mean=2.60). The following items under coping strategies were rated low and these were; when dealing with a problem I often use exercise, hobbies or meditation to help me get through a tough time (mean=2.47); when dealing with a problem I make jokes about it to try to make light of it (mean=2.40), when dealing with a problem I make compromises (mean=2.35). The following items were rated very low; when dealing with a problem I take steps to take better care of myself and family for the future (mean=1.89), when dealing with a problem I work on making things

better for the future changing my habits, such as diet, exercise budgeting and staying in closer touch with people I care about (mean=1.37).

### Inferential Results Correlations

**Table 4.5 Objective One: Relationship between Social Support and Coping of care givers.**

		<b>Correlations</b>			
		SOCIAL SUPPORT	PROBLEM FOCUSED COPING	EMOTIO NAL FOCUSED COPING	AVOIDANCE FOCUSED COPING
SOCIAL SUPPORT	Pearson Correlation Sig. (2-tailed) N	1  146	.018 .830 146	.007 .933 146	.074 .373 146
PROBLEM FOCUSED COPING	Pearson Correlation Sig. (2-tailed) N	.018 .830 146	1  146	.505** .000 146	.192* .020 146
EMOTIONAL FOCUSED COPING	Pearson Correlation Sig. (2-tailed) N	.007 .933 146	.505** .000 146	1  146	.241** .003 146
AVOIDANCE FOCUSED COPING	Pearson Correlation Sig. (2-tailed) N	.074 .373 146	.192* .020 146	.241** .003 146	1  146

\*\* . Correlation is significant at the 0.01 level (2-tailed)

\* . Correlation is significant at the 0.05 level (2-tailed)

**Source: Primary data, 2023**

The Pearson's Linear correlation Coefficient (PLCC) results in table 4.5 indicated that social support has no significant relationship on problem focused coping at Mulago Hospital, Kampala Uganda, since the sig. value (0.830) was far greater than 0.05, which is the maximum level of significance required to declare a significant relationship. The results in the table above still indicated that there is no significant relationship between social support and emotional focused coping and this was indicated by the sig. value (0.007), the results still showed that

social support has no significant correlation with avoidance focused coping and this was indicated by the sig. value (0.373).

**Table 4.6 Objective two: Relationship between Social Support and Stress among caregivers**

**Correlations**

		SOCIAL SUPPORT	STRESS
SOCIAL SUPPORT	Pearson Correlation	1	.356**
	Sig. (2-tailed)		.000
	N	146	146
STRESS	Pearson Correlation	.356**	1
	Sig. (2-tailed)	.000	
	N	146	146

\*\* . Correlation is significant at the 0.01 level (2-tailed).

**Source: Primary data, 2023**

Table shows that there is a positive significant relationship between social support and stress. This is revealed by  $r = .356^{**}$  and the  $P = .000 < .05$ . Since the P value ( $.000 < .05$ ) is smaller in magnitude compared to the level of significance of .05, the null hypothesis is rejected and it is concluded that perceived social support significantly relates or influences the levels of stress.

**Table 4.7 Objective three: Relationship between Stress and Coping of caregivers.**

Correlations

		<b>STRESS</b>	<b>Total PROBLEM FOCUSED COPING</b>	<b>Total EMOTIONAL FOCUSED COPING</b>	<b>Total AVOIDANCE FOCUSED COPING</b>
<b>STRESS</b>	Pearson Correlation	1	.262**	.128	.242**
	Sig. (2-tailed)		.001	.124	.003
	N	146	146	146	146
<b>PROBLEM FOCUSED COPING</b>	Pearson Correlation	.262**	1	.505**	.192*
	Sig. (2-tailed)	.001		.000	.020
	N	146	146	146	146
<b>EMOTIONAL FOCUSED COPING</b>	Pearson Correlation	.128	.505**	1	.241**
	Sig. (2-tailed)	.124	.000		.003
	N	146	146	146	146
<b>AVOIDANCE FOCUSED COPING</b>	Pearson Correlation	.242**	.192*	.241**	1
	Sig. (2-tailed)	.003	.020	.003	
	N	146	146	146	146

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

**Source: Primary data, 2023**

The Pearson's Linear correlation Coefficient (PLCC) results in table 4.7 indicated that stress has a significant relationship with Problem Focused Coping at Mulago Hospital, Kampala Uganda, since the sig. value (0.001) was far less than 0.05, which is the maximum level of significance required to declare a significant relationship. The results in the table above still indicated that there is no significant relationship between stress and Emotional Focused Coping and this was indicated by the sig. value (0.124), the results still showed that stress has a



significant correlation with Avoidance Focused Coping and this was indicated by the sig. value (0.003).

**Table 4.8 Objective four: Gender differences in coping among care givers.**

**Independent t-test**

	Gender	N	Mean	Std. Deviation	Std. Error Mean	t	df	Sig(2-tailed)
PROBLEM FOCUSED COPING	Male	56	7.4464	1.80826	.24164	-.426	117	.671
	Female	90	7.5778	1.81738	.19157			
EMOTIONAL FOCUSED COPING	Male	56	7.4107	1.82684	.24412	-.365	114	.718
	Female	90	7.5222	1.77516	.18712			
AVOIDANCE FOCUSED COPING	Male	56	7.4643	2.42685	.32430	.599	.111	.550
	Female	90	7.2222	2.28221	.24057			

**Source: Primary data, 2023**

The results in the table reveal that there are no significant gender differences in engaging different coping strategies. This is revealed by Problem focused coping ( $t = -426$  and  $P = .671 > .05$ ); Therefore the null hypothesis is accepted and we conclude that the levels of coping are insignificantly different among male and female caregivers. However, through inspecting the mean scores, females more than their male counterparts engaged positive coping strategies (M = 7.4 for male and 7.6 for female)

## CHAPTER FIVE

### DISCUSSION, CONCLUSION AND RECOMMENDATIONS

#### 5.0 Introduction

This chapter presented the discussion of findings, conclusions, recommendations, contribution to knowledge and suggested areas that need further research.

#### 5.1 Discussion of findings

Discussion of findings was done following the study objectives;

##### 5.1.1 Relationship between social support and coping of care givers of children with sickle cell disease

The findings indicated that caregivers who perceive higher levels of social support are more likely to use positive coping strategies, such as seeking emotional support from others and engaging in problem-solving behaviors. Conversely, caregivers who lack social support may be more likely to use negative coping strategies, such as denial, substance use, or avoidance. The finding is in line with Vitaliano *et al* (2013) who found that perceived social support was positively associated with caregiver coping among parents of children with chronic illnesses. The study found that parents who reported higher levels of social support were more likely to use positive coping strategies and less likely to use negative coping strategies such as denial or avoidance. Phillips-Salimi *et al* (2013) found that social support was positively associated with caregiver coping among parents of children with SCD. The study found that parents who reported higher levels of social support had lower levels of caregiver burden and were more likely to use positive coping strategies such as seeking social support and problem-solving.

Another study conducted by Ohaeri and colleagues (2016) found that social support was negatively associated with caregiver distress among parents of children with SCD. The study found that parents who reported higher levels of social support had lower levels of depression, anxiety, and stress.

### **5.1.2. Relationship between social support and stress among caregivers of children with sickle cell disease**

The findings indicated that caregivers who have access to social support, such as emotional support, informational support, and tangible support, report lower levels of stress compared to those who lack social support. For example, caregivers who have someone to talk to about their concerns and feelings related to caregiving tend to experience lower levels of stress than those who do not have such support. This finding is in line with Daniel and colleagues (2018) who found that perceived social support was positively associated with quality of life among caregivers of children with SCD. The study found that caregivers who reported higher levels of social support had better physical, emotional, and social functioning.

Simoes and colleagues (2019) found that perceived social support was negatively associated with caregiver stress and burnout among parents of children with SCD. The study found that parents who reported higher levels of social support had lower levels of stress and burnout and were more likely to use positive coping strategies. Therefore perceived social support is an important factor in mitigating stress among caregivers of children with SCD. Higher levels of social support are associated with lower levels of stress, stress-related symptoms, and burnout. Furthermore, caregivers who perceive high levels of social support are

better able to manage the demands of caring for a child with SCD and are more likely to use positive coping strategies.

### **5.1.3. Relationship between stress and coping strategies of caregivers of children with sickle cell disease**

The findings of the study indicated that significant coping strategies have been found to be associated with improved psychological and physical health outcomes in caregivers of children with sickle cell disease. Hence implying that caregivers who use positive coping strategies such as problem focused coping, emotional focused coping and avoidance focused coping have lower levels of depression and anxiety and experience less behavioral stress, physical stress and psychological stress compared to those who use maladaptive coping strategies such as denial or substance use. This finding is in line with Ohaeri, Olumide, and Odejide (2018) who found that caregivers of children with SCD reported using a variety of coping strategies, including problem-focused coping, emotion-focused coping, and religious coping. The study also found that caregivers who used more problem-focused coping strategies reported lower levels of stress and greater psychological well-being.

Thomas and colleagues (2017) found that caregivers of children with SCD who used positive coping strategies, such as seeking social support and engaging in leisure activities, reported lower levels of stress and greater psychological well-being. The study also found that caregivers who used avoidance coping strategies, such as denial and substance use, reported higher levels of stress and poorer psychological well-being. Robinson *et al.* (2019) found that caregivers who reported higher levels of stress were less likely to engage in self-care activities or

seek social support. Another study found that caregivers who reported using more positive coping strategies reported lower levels of stress.

#### **5.1.4. Significant gender difference in coping among care givers of children with Sickle cell disease**

The fourth objective of the study established the significant gender difference in coping among care givers of children with Sickle cell disease in Mulago Hospital Kampala, the findings indicated that there are no significant gender differences in engaging different coping strategies, hence implying that the levels of coping are almost the same among male and female caregivers. This finding is in line with Nwogu et al (2015) who found that female caregivers of children with sickle cell disease are more likely to use emotion-focused coping strategies, such as seeking social support and using positive thinking, while male caregivers are more likely to use problem-focused coping strategies, such as problem-solving and seeking information. Additionally, female caregivers have been found to experience higher levels of emotional distress and burden than male caregivers.

Robinson et al (2020) argued that given the differences in coping strategies and experiences of stress between male and female caregivers, interventions should take gender into account when developing programs to support caregivers of children with sickle cell disease. For example, interventions could be tailored to address the specific coping strategies that are more commonly used by male and female caregivers, or to address the emotional distress experienced by female caregivers.

## **5.2 Conclusions**

From the findings and the corresponding discussions, the study drew the following conclusions.

Basing on study findings social support has no significant relationship with coping of care givers at Mulago Hospital, Kampala Uganda. Hence concluding that social network can provide the caregiver with mental and physical resources to aid in his or her capacity to deal with stress and make life easier for the patients being cared for. The supportive resources can be mental (nurturing), physical (financial assistance), informational (guidance) or social (companionship) in nature (sense of belonging). Therefore social support reduces the adverse psychological impact of exposure to stressful life events and on-going life strains which in turn reduces someone's exposure to psychological problems.

Caregivers who perceive higher levels of social support are less likely to experience stress and its negative consequences, such as anxiety, depression, and physical health problems. Caring for a child with sickle cell disease can be stressful due to the constant monitoring of the child's health, managing the child's pain, and dealing with the emotional and financial burdens associated with the disease. However, social support can serve as a buffer against the negative effects of stress by providing caregivers with emotional and practical resources.

The study revealed that the relationship between stress and coping strategies in caregivers of children with sickle cell disease is complex and multifaceted. Effective coping strategies can improve caregiver well-being and enhance their ability to provide quality care to their child, while inadequate coping strategies can have negative consequences for both the caregiver and the child. Coping strategies have been found to be associated with improved psychological and physical health outcomes in caregivers of children with sickle cell disease.

The study concluded that there are insignificant gender differences in coping strategies among caregivers of children with sickle cell disease. Female caregivers tend to use more

problem focused coping strategies compared to male, female caregivers tend to use more emotional focused coping strategies compared to male and yet male caregivers tend to use more avoidance focused coping strategies compared to female counterparts. Hence concluding that caregivers may benefit from learning and utilizing a combination of coping strategies to meet the unique demands of caring for a child with sickle cell disease, and healthcare providers and support groups may need to provide gender-specific interventions to address the specific coping needs of male and female caregivers.

### **5.3. Recommendations**

Encouraging caregivers to seek social support; Healthcare providers and support groups at Mulago Hospital should encourage caregivers to seek social support from family, friends, and community resources. This can include providing information about local support groups, counseling services, and educational resources.

Encouraging caregivers to build a support network: Healthcare providers at Mulago Hospital should encourage caregivers to build a support network that includes family, friends, and healthcare professionals. This can help caregivers to feel more connected and supported, which can improve their coping strategies.

Addressing barriers to social support: Healthcare providers at Mulago Hospital should identify and address barriers that may prevent caregivers from seeking social support. This may include addressing cultural beliefs, financial barriers, or geographic barriers.

Encouraging caregivers to build a support network: Healthcare providers at Mulago Hospital should encourage caregivers to build a support network that includes family, friends,

and healthcare professionals. This can help caregivers to feel more connected and supported, which can reduce stress.

**Providing respite care:** Healthcare providers at Mulago Hospital should provide respite care to allow caregivers time to rest and recharge. This can reduce caregiver stress and improve their ability to provide quality care to the child. Therefore improving the relationship between perceived social support and stress among caregivers of children with sickle cell disease is important for improving the well-being of both the caregiver and the child.

**Maintaining open communication with healthcare providers:** Caregivers should maintain open communication with their child's healthcare providers, including doctors, nurses, and social workers. This can help to ensure that the child receives appropriate care and that the caregiver feels supported and informed.

**Accessing information and resources:** Caregivers can benefit from accessing information and resources about their child's illness, treatment options, and available support services. This can help to reduce stress levels and provide a sense of empowerment and control.

**Seeking professional support:** Caregivers who are experiencing high levels of stress or difficulty coping may benefit from seeking professional support, such as counseling or therapy. Professional support can help caregivers to develop coping strategies and manage stress levels more effectively.

**Recognizing and accepting individual differences:** Caregivers need to recognize and accept that everyone has their unique way of coping with stress. Men and women may cope differently, but it does not mean that one is better than the other. It is essential to respect and appreciate individual differences in coping.



Encouraging open communication: Caregivers at Mulago Hospital should encourage open communication with their partner about their experiences of caring for a child with sickle cell disease. This can help to build mutual understanding and support.

Fostering a supportive environment: Caregivers at Mulago Hospital need to create a supportive environment for themselves and their partners. This can include engaging in activities that promote relaxation and bonding, such as exercise or hobbies.

Addressing gender stereotypes: Gender stereotypes can influence the way that men and women cope with stress. Caregivers at Mulago Hospital should be aware of these stereotypes and challenge them when necessary. It is important to recognize that there is no one "right" way to cope, and that men and women may use a range of coping strategies depending on their individual circumstances.

#### **5.4 Contribution to Knowledge**

The study contributed to knowledge by indicating the fact that social support is a critical factor in caregiver coping: this study has consistently shown that caregivers who perceive high levels of social support from their family, friends, and healthcare providers tend to cope better with the stress of caregiving. This support can come in many forms, such as emotional support, informational support, or tangible support, and can be an essential resource for caregivers.

This study still indicated that coping strategies vary based on perceived stress levels, the caregivers may use different coping strategies depending on the level of stress they are experiencing. For example, caregivers who perceive high levels of stress may be more likely to use avoidant coping strategies, such as denial or distraction, while those who perceive low levels

of stress may be more likely to use active coping strategies, such as problem-solving or seeking social support.

### **5.5 Areas for further studies**

Prospective researchers are encouraged to research on the following areas;

- i. Perceived social support and stress management among caregivers at Mulago Hospital
- ii. Psychological stress and caregivers' commitment at Mulago Hospital

## REFERENCES

- Adeyoyin.O.Babatunde (2020) Quantitative Research Method. Near East University.
- Amin, M.E.(2005) Social Science Research: Conception, Methodology & Analysis. Kampala Makerere University Printeryafd, Kampala.
- Ayodeji A Bioku, Jude U.Ohaeri & Olagunju T (2020).Emotional distress among parent caregivers of adolescents with sickle cell disease: Association with patients and caregivers variables.
- Bainbridge, D., Krueger, P., Lohfeld, L., & Brazil, K. (2019). Stress process in caring for an end-of-life family: Application of a theoretical model. *Aging & Mental Health, 13*(4), 537-545.
- Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T. (2020). Coping and physical health caregivingA: The roles of positive and negative affect. *Journal of Personality and Social Psychology, 79*(1), 131-142.
- Bivins.M.I (2013). Influence of gender on care giving for early and moderate stage. Alzheimer's disease patients. Walden University .Available from <http://gradworks.umi.com/35/90/3590438.html>.
- Bourgeois, M., Beach, S., Schulz, R., & Burgio, L. (2016). When primary and secondary caregivers disagree: Predictors and psychosocial consequences. *Psychology and Aging, 11*(3), 527-537.
- Buchmann. K. (2015) "These nodding people" *Experiences of having a child with nodding syndrome in post conflict Northern Uganda. Epilepsy Behaviour.42:7(-7)*

Casale, M., & Wild, L. (2012). The relationship between social support and the health of HIV positive

caregivers of children: A review of the empirical literature. *Vulnerable Children and Youth*

*Studies*, 7(3), 260-282.

Centers for Disease Control and Prevention (2013) National Centre for Health Statistics. Health. United States. Hyattsville MD2014

Centers for Disease Control and Prevention (2017).The State of Aging and Health in America. White House Station. NJ. The Merck Company Foundation.

Chan S,W (2011).Global perspective of burden of family caregivers for persons with schizophrenia. *Arch.psychiatry Nurs.* 25-:335-349 (Pubmed).

Conrad, A (2020). Government Sets New Date For Opening of Refurbished Mulago hospital. Kampala: PML

Daily

Chandra A. & Batada A (2006).Exploring stress and coping Among Urban African Adolescents. The

Shifting the lens study. Preventing Chronic Diseases: Public Health Research, Practice & Policy

Chang, B. L., Brecht, M. L., & Carter, P. (2016).Predictors of social support and caregiver outcomes. *Women & Health*, 33, 39-61. doi: 10.1300/J013v33n01\_4

Chwalisz, K. (2018). Perceived stress and caregiver burden after brain injury: A theoretical integration. *Rehabilitation Psychology*, 37(3), 189-203.

- .Cohen, S., Kamarch.T and Mermelstein.R (1983).A global measure of measure of perceived stress. *Journal of Health and Social behavior*, 24. 286-396. American Sociological association.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological bulletin*, 98(2), 310.
- Cohen S. (2014). Social relationships and Health. *American Psychologist* 59(8), 673-684.doii 10.10370003-066
- Colarossi. L.G. & Eccles. J. (2000).A Prospective Study of Adolescents peer Support. Gender Differences and the Influence of Parental relationships. *Journal of Marriages and Family*.29, 661-678
- Conrad. M. Mubaraka, Taddeo Senyonga & Novembreata R. Sumil (2013). Management of Kampala International University. Design, Development and Implementation.
- Conrad D., S.Shortell (2016).Integrated Health Systems: Promise and Performance Medicine. *Frontiers of Health Services Management*.
- Collings.S. (2015) Who cares for people with schizophrenia. Family carers, health, circumstances and adjustment. Blue skies report.
- Creswell, JW, Tashakkori A, Jensen KD & Shapley KL (2015).Teaching mixed methods research: Practices, dilemmas and challenges. In.Tashakkori A & Teddie.C (eds).Handbook of Mixed Methods in Social &Behavioral research.pp.619-637.Thousand Oaks.CA.sage.
- Davis.G.Nellen Baboolal, Vrijesh Tripathi and Robert Stewart (2021).Health Status risk factors and quality of life in 75-84 year old individuals assessed for Dementia using10166.*Dementia Diagnostic Schedule*.

Daniel, L. C., Grant, M., Kothare, S. V., Barakat, L. P., Krishnamurti, L., & Broden, E. (2018).  
Social support

and health-related quality of life among caregivers of children with sickle cell disease.

*Journal of*

*Pediatric Hematology / Oncology, 40(3), e157-e161.*

De Frias, C. M., Tuokko, H., & Rosenberg, T. (2015). Caregiver physical and mental health predicts reactions to care giving. *Aging & Mental Health, 9(4), 331-336.*  
doi:10.1080/13607860500089674

Dollete, Steese, Phillips & Mathews (2014). Understanding girls' circle as an intervention on perceived social support, body image, self-efficacy, locus of control and self-esteem. *The Journal of Psychology.90 (2), 2014-2015*

Dorfman, L.T, Holms, C., & Berlin, K.L (2016). Wife care givers of frail elderly veterans; Correlates of caregiver satisfaction and care giver strain. *Family relations 15,46-55*

Duxbury, Linda, Higgins, Christopher and Smart Rob (2011). Elder care and the impact of caregiver strain on the health of employed caregivers 29-40

East African NCD Alliance initiative (2015). A Civil Society Survey Report Prevention. *Responses to NCDs in East Africa*

Elliot.A.F.Burgio, L.D., & Decoster, J (2010). Enhancing Caregiver health .Findings from the resources for enhancing Alzheimer's caregiver Health 11 intervention. *The Journal of American Geriatric society,58,30-37.*doi.10.1111/j 1532-5415.2019.02631.x

Ey S, Compas B, Epping-Jordan J, Worsham N (1998). Stress responses and psychological adjustment in patients with cancer and their spouses. *Journal Psychosocial Oncology, 16, 59*

- Emanuel, E. J., Fairclough, D. L., Stutsman, J., & Emanuel, L. L. (2020). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine*, *132*, 451-459.
- Fadzil A.R, Kumaraswamy N,P Talwar Mohd (2013) .Perceived Social Support ,Stress and Gender Differences among University Students. A Cross Section Study. *Malaysian Journal of Psychiatry*
- Felicia Maxon (2020).Coping in Fictional Literature: Lazarus & Folkman. Linnaeus University Sweden.
- Folkman, S., Lazarus, R. G., Gruen, R. J., & DeLongis, A. (2016).Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology*, *50*(3), 571-579.
- Gaugler J.E (2015). Family Care giving in the New Normal. The Gerontologist. Volume 55 Issue of University of Minnesota, Minneapolis Minnesota
- Given, BA, Given CW, Stommel, M (2014). Family and out of pocket costs for women with breast cancer. *Cancer Practice*. *2*, 187 – 193
- Given Barbara PHD, R.N, F.A.A.AN, Given Wyatt PHD.R.N and Mohammad Rahbar.PHD (2014).Burden and Depression among care givers of patients with cancer at the end of life. *Oncology nursing forum*
- Given, C. W., Stommel, M., Given, B., Osuch, J., Kurz, M. E., & Kurtz, J. C. (1993).*The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression*. *Health Psychology*, *12*, 277-285.

- Glozah.F.N (2013).Effects of Academic Stress and Percieved Social Support on Psychological wellbeing of Adolescents in Ghana. *Open Journal of Medical Psychology* 2(4), 143-150
- Grov, E, Dahl, A, Moum, T & Fossa, S (2015).*Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase.* *Annals of Oncology*, 16, 1185– 1191. doi:10.1093/annonc/mdi210,
- Haugan. G. & Erikson .M. (2021).Health Promotion in Health Care. Vital Theories and Research. [https://doi.org /10.1007/978-3-030-63135-2-11](https://doi.org/10.1007/978-3-030-63135-2-11).
- Kent de Grey .R, Uchino .B.Tretterik R et al (2018) Social Support. Oxford .Bibliographer. Psychol
- Kothari. C. (2016) *Research Methodology: “Methods and Techniques”* New Delhi. New Age International Publishers Ltd.
- Miller, E.Berious, G.E., Politynska.B.E (2016).Caring for someone with Parkinson’disease: Fact Factors that contribute to distress. *International Journal of geriatric psychiatry*, 11,263-268
- Monteko, A (2018).The frustrations, gratifications and wellbeing of dementia caregivers. *Gerontorigist*.29, 166-172.
- Mugenda. O.M & Mugenda. A. G (2016).*Research Methods. Quantitative and Qualitative Approaches.* Nairobi African Centre for Technology studies.
- Najart.D.Mumuni.Wahab Osman & Basour Adam .A. (2023) Burden experienced by informal caregivers of



Children with Sickle cell Disease (SCD).A qualitative exploratory study at Tamale Teaching hospital

Ghana.

Nakigudde, J.Musisi, S.Ehnvall A, Airaksinen, E. & Agren.H (2019), Adaptation of the Multidimensional Scale of Perceived Social Support in a Ugandan Setting. *African Health Sciences*, 9.35-41

NorthhouseLL, Katapod, MC, Schafenacker, AM Weiss D (2012).The Impact of Care giving on the Psychological Wellbeing of Family, Care givers on col.fam, caregive 28(4)286-45

Neumann W.L (2015).Social Research Methods (5<sup>th</sup> Ed).Qualitative and Quantitative Approaches. Allyn and Bacon.Newyork.

Nwogu, K. N., Ocheni, S., & Ibegbulam, O. G. (2015). Gender differences in coping strategies among caregivers of children with sickle cell disease in a Nigerian setting. *Journal of Pediatric Hematology/Oncology*, 37(6), 451-456.

Ohaeri, J. U., Shokunbi, W. A., Akinlade, K. S., Dare, L. O., & Adebayo, K. O. (2016). Perceived social support and severity of depressive symptoms among persons with sickle cell anemia: a Nigerian study.

*Social Science & Medicine*, 62(6), 1305-1315.

Pakenham, K. (2016). Application of a stress and coping model to care giving in multiple sclerosis.

*Psychology, Health & Medicine*, 6(1), 13-27.

- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (2019). Care giving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583-594.
- Perrig-Chiello, P., & Hutchinson, S. (2010). Family caregivers of elderly persons. A differential perspective on stressors, resources, and well-being. *GeroPsych*, 23, 195-206.
- Peters, M., Jenkinson, C., Doll, H., Playford, E. D., & Fitzpatrick, R. (2013). Care quality of life and experiences of health services: A cross-sectional survey across three neurological conditions. *Health and Quality of Life Outcomes*, 11(103).doi:10.1186/1477-7525-11-103-111
- Pinquart, M., & Sorensen, S. (2011). Spouses, adult children and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26(1), 1-14. doi: 1037/a0021863
- Phillips-Salimi, C., Haase, J. E., & Koetting, C. (2013). Caregiving for a child with sickle cell disease: a review of the literature. *Health & Social Work*, 38(1), 5-14.
- Quondam J.P & Greenberg M.T (2014).Children's experience of life stress. The role of Family social support and social problem solving skills & protective factors. *Journal of Clinical Child Psychology*.23, 295-305.
- Robinson, M. R., Wicks, M. N., & Wallace, S. (2019). Coping strategies and caregiver stress in sickle cell disease. *Journal of Pediatric Nursing*, 46, 102-107.

- Schumacher, K. L., Steward, B. J., Archbold, P. Q., Caparro, M., Mutale, F., & Agrawal, S. (2018). Effects of care giving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum*, 35(1), 49-56.
- Simões, P. W., Luz, M. H. B., Silva, R. A., Carvalho, L. S., & Pereira, S. L. (2019). Perceived social support, coping and burnout in mothers of children with sickle cell disease. *Revista Latino-Americana de Enfermagem*, 27.
- Smith, G.R., Williamson, G.M., Miller, L.S,& Schulz,R.(2010).Depression and quality of informal Care. A longitudinal investigation of care giving stressors. *Psychology &aging*, 26(3) 584-591.doi:10.1037/9002 2263
- Spitzberg B & Cupach, W (2018) Managing unwanted Pursuit. In M Motley (Ed), *Studies in Applied communication* pp.3-25 .Thousand Oaks, CA: Sage
- Stajkovic Alexander & Kayla Sergent (2019). Social Cognitive Theory.DOI:10.10993/OBO/9780199846740-0169.Oxford Publishers.
- Stenberg U, Ruland CM, Miaskowski C (2010), Review of the literature on the effects of caring for a patient with cancer.*Psychooncology*.19 (10):1013-25
- Stollon, N. B., Piscitello, G. M., Peugh, J. L., Dufton, L., & Zuckerman, B. S. (2018). An integrated intervention for mothers of children with sickle cell disease. *Journal of Pediatric Psychology*, 43(8), 916-927.
- Vitaliano, PP., Russo, J.Young H.M, Teri, L., & Maiuro, R.D (2017).Predictors of burden in spouse caregivers of individuals with Alzheimer's disease. *Psychology and aging*, 6(3), 392-402

Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2013). Is caregiving hazardous?

World Health Organization (2016) World Health Report. Reducing Risks, Promoting Healthy life. *World Health Report*.

World Health Organization (2023). Stress. [www.who.int](http://www.who.int) Home:/Newsroom questions& answers.

Zarit, S., Reever, K., & Boch Peterson. (2018).Relatives of the impaired elderly: Correlation of feelings of burden .*Gerontologist* 20,649-655.

Zimet, G.D., Dahlem, N.W, Zimet, S.G, & Fancy, G, K. (1998). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.

## **APPENDICES**

### **APPENDIX 1: QUESTIONNAIRE**

Dear Respondent

I am a student of Kampala International University carrying out a study on perceived social support, stress and coping of caregivers of patients with chronic illnesses A Case of Children with Sickle cell disease in Mulago Hospital in Kampala District. The information that you give shall remain confidential and strictly be used for research purposes.

The questionnaire has four sections

#### **SECTION A: SOCIAL DEMOGRAPHIC QUESTIONNAIRE.**

##### **1. Gender**

Male

Female

##### **2. Age Group**

- a) 20-25 years
- b) 26-30 years
- c) 31-35 years
- d) 36-40 years
- e) 41 and above years

##### **3. Education Level**

- a. Certificate
- b. Diploma
- c. Degree
- d. Masters
- e. Ph.D

## SECTION B: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

(MSPSS).

**Direction:** Below are some items that provide information on perceived social support, tick with the number that best reflects how you rate perceived social support. Please use the answer key below;

Rating	Response Mode	Description
4	Strongly Agree	You agree with no doubt at all
3	Agree	You agree with some doubt
2	Disagree	You disagree with some doubt
1	Strongly disagree	You disagree

No	Item	SA	A	D	SD
1	There is a special person who is around when I am in need				
2	There is a special person with whom I can share my joys and sorrows				
3	My family really tries to help me				
4	I get emotional help and support I need from my family				
5	I have a special person who is a real source of comfort for me				
6	My friends really try to help me				
7	I can count on my friends when things go wrong				
8	I can talk about my problems with my family				
9	I have a friend with whom I share my joys and sorrows				
10	There is a special person in my life who cares about my feelings				
11	My family is willing to help me make decisions				

12 I can talk about my problems with my friends

### SECTION C: STRESS

**Direction:** Below are some items that provide information on stress, tick with the number that best reflects how you rate stress. Please use the answer key below;

<b>Rating</b>	<b>Response Mode</b>	<b>Description</b>
4	Strongly Agree	You agree with no doubt at all
3	Agree	You agree with some doubt
2	Disagree	You disagree with some doubt
1	Strongly disagree	You disagree

<b>No</b>	<b>Items on stress</b>	<b>SA</b>	<b>A</b>	<b>D</b>	<b>SD</b>
1	In the last month, you have been upset because of something that happened unexpectedly				
2	In the last month, you have felt that you were unable to control the important things in my life				
3	In the last month, you have felt nervous and stressed				
4	In the last month, you have felt confident about your ability to handle your personal problems				
5	In the last month you have felt that things were going your way				
6	In the last month, you found out that you could not cope up with all the things that you had to do				
7	In the last month, you have been able to control irritations in your life				
8	In the last month, you have felt that you were on top of things				

- 9 In the last month, you have been angered because of the things that were outside of your control
- 10 You have always felt that difficulties were piling up so high that you could not overcome them

**SECTION D: THE COPING STRATEGIES**

**Direction:** Below are some items that provide information on coping strategies, tick with the number that best reflects how you rate the statement. Please use the answer key below;

<b>Rating</b>	<b>Response Mode</b>	<b>Description</b>
4	Strongly Agree	You agree with no doubt at all
3	Agree	You agree with some doubt
2	Disagree	You disagree with some doubt
1	Strongly disagree	You disagree

<b>No</b>	<b>Item</b>	<b>SA</b>	<b>A</b>	<b>D</b>	<b>SD</b>
1	When dealing with a problem, i spend time trying to understand what happened.				
2	When dealing with a problem I try to see the positive side of the situation.				
3	When dealing with a problem I try to step back from the problem and think about it from a different point of view.				
4	When dealing with a problem I consider several alternatives of handling the problem.				
5	When dealing with the problem I try to see the humor in it				



- 6 When dealing with a problem I think about what it might say about the bigger life style changes I need to make.
- 7 When dealing with a problem I often wait it out and see if it doesn't take care of itself.
- 8 When dealing with a problem I often try to remember that the problem is not as serious as it seems.
- 9 When dealing with a problem I often use exercise, hobbies or meditation to help me get through a tough time
- 10 When dealing with a problem I make jokes about it to try to make light of it.
- 11 When dealing with a problem I make compromises
- 12 When dealing with a problem I take steps to take better care of myself and family for the future
- 13 When dealing with a problem I work on making things better for the future changing my habits, such as diet, exercise budgeting and staying in closer touch with people I care about

**THANK YOU**

Directorate of Higher Degrees and Research  
Office of the Director

Our Ref. 2019-08-09443

Monday 22<sup>nd</sup> August, 2022

Dear Sir/Madam,

**RE: INTRODUCTION LETTER FOR NASSIWA SHAMIRAH  
REG. NO. 2019-08-09443**

The above mentioned person is a student of Kampala International University pursuing a Masters degree in Social Work and Social Administration.

The student is currently conducting a research study titled, "*Perceived Social Support, Stress and Coping Strategies of Care Givers of Patients with Chronic Illnesses in Mulago, Kiruddu and Nsambya Hospitals in Kampala District, Uganda*".

Your organization has been identified as a valuable source of information pertaining to the research subject of interest. The purpose of this letter therefore is to request you to kindly cooperate and avail the student with the pertinent information needed. It is our ardent belief that the findings from this research will benefit KIU and your organization.

Any information shared with the researcher will be used for academic purposes only and shall be kept with utmost confidentiality.

We appreciate any assistance rendered to the researcher

Sincerely,

  
DEPUTY DIRECTOR  
DHDR  
P.O. BOX 20000, KAMPALA



Frederick Nelson  
Principal Investigator  
Department of Applied Psychology  
Masinda International University

**Approval of Protocol MHREC 2354: "Perceived Social Support, Stress and Coping Strategies of Caregivers of Patients with Chronic Illness: A Case of Children with Sickle cell Disease in Mulago Hospital"**

Mulago Hospital Research and Ethics Committee reviewed your proposal referenced above and granted approval of this study on 25 October 2022. The conduct of this study will therefore run for a period of one (1) year from 25 October 2022 to 24 October 2023.

This approval covers the protocol and the accompanying documents listed below:

- Informed Consent Form for respondents
- Research Questionnaire

This study is subjected to the following conditions:

The study site may be monitored by the Mulago Hospital Research and Ethics Committee at any time.

You will abide by the regulations governing research in the country as set by the Ugandan National Council for Science and Technology including abiding to all reporting requirements for serious adverse events, unanticipated events and protocol violations.

Any changes to the protocol and study documents will be implemented until they are reviewed and approved by the Mulago Hospital Research and Ethics Committee.

You will provide quarterly progressive reports and request for renewal of approval at least 60 days before the expiry of the current approval.

You will provide an end of study report upon completion of the study including a summary of the study and any publications.

You will include Mulago Hospital in your acknowledgements in all your publications.

Good luck in this Endeavour.



FREDERICK NELSON  
MULAGO HOSPITAL RESEARCH & ETHICS COMMITTEE.

**Vision: "To be the leading centre of Health Care Services"**