THE BURDEN OF CARE AMONG CAREGIVERS OF FAMILY MEMBERS WHO SUFFERED SPINAL CORD INJURY IN THE NATIONAL SPINAL INJURY REFERRAL HOSPITAL

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A RESEARCH PROJECT PRESENTED IN PARTIAL FULFILMENT FOR THE AWARD OF MASTER OF MEDICINE, PSYCHIATR Y DEGREE, UNIVERSITY OF NAIROBI.

DECLARATION

I guarantee that this work has not been submitted in whole or in part for credit toward another degree or any other purpose at any other educational institution.

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LIST OF ABBREVIATIONS

ADLs – Activities of Daily Living

CBI – Care Burden Inventory Tool

Dr – Doctor

IQR – Inter Quintile Range

KNH – Kenyatta National Hospital

MMED – Masters in Medicine

NSIRH – National Spinal Injury Referral Hospital

QoL – Quality of Life

SCI – Spinal Cord Injury

SD – Standard Deviation

SPSS – Statistical Package for Social Sciences

WHO – World Health Organisation

ZBI – Zarit Burden Interview

DEFINITION OF TERMS

Paraplegia: After suffering a spinal cord injury, one or both legs, and sometimes the lower body, may experience a loss of mobility and feeling.

Quadriplegia: Loss of mobility and sensation in all four limbs or in all of the body below the neck in some cases.

Caregiver or Carers: Someone responsible for looking after another person who either is very young or critically ill and has a disability.

Socio-demographic characteristics: This pertains to the characteristics of a populace, encompassing factors like age, gender, educational attainment, financial status, marital situation, religious association, ethnicity, and related aspects.

Rehabilitation: The process of bringing someone back to their previous level of health or regular life after they have been injured or unwell.

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ABSTRACT

The term "burden of caregiving" refers to the difficulties that a caregiver faces on a variety of fronts, including the physical, the social, the mental, and the financial, when providing care for a family member who has suffered from a spinal cord injury. As the term of "burden of caregiving" explains, looking after a family member who has spinal cord injuries can be taxing in a number of different ways. There is an evident and pressing necessity to tackle the substantial caregiver burden, as the encountered challenges not only affect the post-treatment care of the patient but also have broader implications for the well-being of other family members, the caregiver, and the community as a whole. Despite the limited exploration of the caregiver burden's weight, it is apparent that there is a significant imperative to address this issue.

Study Objective – The objective of this study was to determine the level burden of caregiving of among family members with Patients with Spinal Injury in NSIRH and the sociodemographic characteristics of the caregivers and of the patients.

Method – The study was a quantitative method and the design was a descriptive cross-sectional study. A researcher designed socio-demographic questionnaire and a Zarit care burden interview was used. only those who gave informed consent and met the inclusion criteria were included in the study. The data was entered, cleaned and analysis done.

Study Site – The study was done in the National Spinal injury referral hospital which is located along rose avenue in Kilimani (Nairobi).

The study population comprised of the family members of the patients with spinal cord injury who have taken up the role of caregiving of the patient as they undergo rehabilitation as an outpatient or inpatient in the hospital.

Results – The study was carried out with the participation of 32 people, 29 of whom were hospital inpatients and 3 of whom were hospital outpatients who attended physiotherapy at the hospital.

The average burden score was 28.2, and the vast majority of caregivers were women 78.1% and were married. The majority of the patients were male accounting for 71.9% of the total, and the thoracic region was the most commonly injured level accounting for 65.6% of the total. Road traffic accidents are the leading cause of injury, accounting for 53.1% of all cases. Concerns about their ability to financially provide for themselves and their loved ones, fear, and uncertainty were common issues expressed by a significant number of those providing care for family members who had suffered spinal cord injuries. The high mean score that was scored in the financial domain as well as the self-criticism, fear, and uncertainty domain in the ZBI was a good demonstration of this point.

Conclusion and Recommendation – The individuals primarily responsible for the care of patients with spinal cord injuries indeed bear the weight of caregiving. The intensity of this caregiving burden is influenced by various sociodemographic factors, including age, educational level, gender, and other relevant factors.

Having support groups in various counties where carers can obtain moral help, training camps, and education forums that promote awareness of spinal cord injury and aftercare can help minimize the stress of providing care for someone with a spinal cord injury.

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CHAPTER 1: INTRODUCTION

1.1. Introduction

A spinal cord injury refers to any harm to the spinal cord resulting in lasting or temporary alterations in its typical motor, sensory, and autonomic functions. Various traumatic events can be responsible for causing spinal cord injuries. Varying according to the severity of injury, there are a variety of specialized terms that can be used to describe it. An injury to the cervical spine can cause quadriplegia, whereas damage to the thoracic and lumbar spines can lead to paraplegia. The results of a study that was conducted in KNH by Gichuhi,2007, the level of injury that occurs most frequently is C5. A spinal cord injury that affects only section of the thoracic or lumbar region can cause a condition known as paraparesis. It is possible to develop quadriplegia after suffering an incomplete injury to the cervical region of the spinal cord.

According to data provided by the World Health Organization (WHO) in 2013, somewhere in the range of 250,000 and 500,000 persons sustain injury to their spinal cords each and every year.

These injuries can be the aftermath of a wide scope of occurrences, such as falls from great heights, vehicle and motorbike accidents, attacks, gunshots, infections, malignant tumours, and benign tumours. According to a study that was carried out in KNH (Kinyanjui 2016), the most common cause was found to be road traffic accidents, which accounted for 55% of the cases. It is possible to lose some or all of the body's sensory and motor abilities below the area of the spinal cord injury, depending on the severity of the damage. When the damage is incomplete, the patients lose some functions but if the damage is complete, a patient loses all the motor and sensory function beneath the expanse of spinal cord affected These functions include the ability to breathe, regulate body temperature, walk, control bladder and bowel movements, and engage in sexual activity.

A severed spinal cord is a traumatic incident that not only changes the life of the victim but also the lives of his loved ones and the community at large. After having suffered damage to the spinal cord, patients frequently discover that their social as well as psychological life undergo substantial shifts as a result. As a direct consequence of this, it has an immediate effect on the patient's loved ones, who are forced to make adjustments to their daily routines in order to cope with the altered standard of living. In the event that a member of the family becomes ill or injured, the entire household is impacted; yet, in most cases, only one member of the family will take on the job of the primary carer. As a result, the person providing care must divide their attention between the newly acquired obligations, their own requirements, and those of the person in their life who has trauma to the spinal cord (Ma, 2014).

As a direct consequence of the abrupt and unanticipated nature of SCI, a member of the family is frequently thrust into the role of caregiver with little time or chance to prepare for or adjust to the new responsibilities. In addition, for a lot of people, this was the very first time that they had provided hospital-based care for a member of their family or a close friend (Rummana et al. 2020).

The aftercare of the patients and their carers is entwined in all elements of their lives, including their emotional lives, their physical lives, and their social lives. The carers are responsible for their loved ones' aftercare in all aspects of their lives.

1.2. Background

Individuals who have experienced damage to their spinal cord often lose the capacity to perform activities necessary for day-to-day living such as eating, dressing, walking, and working, which leaves them dependent, either partially or entirely, on the care they get from their medical professionals. The folks have no choice but to conform to the new standard of having someone assist them in their day-to-day life, which results in the requirement for carers (the carers ultimately wind up taking on the task of taking care of their loved ones as a result of an unavoidable circumstance).And thus they are not well prepared, and this puts them at danger of experiencing psychological impacts such as depression; as a result, they require assistance from friends to help them deal with the obstacles they face (Secinti et al,2020).

Caring for a loved one with a spinal cord injury is emotionally draining, according to a linked study, it can also be time-consuming, which may have a detrimental influence on the caregiver's ability to participate in social activities or maintain a career. The demands of caring for a loved one with a spinal cord injury can be overwhelming, some carers find that they are unable to maintain their paid employment, friendships, or attendance at social activities (Shiller & Strydom, 2017). This terrible event, which not only affects the life of the victim but also the lives of his family and the community at large, brings about change. The social and psychological lives of people who have suffered injuries to their spinal cord are dramatically impacted as a direct result of their injuries.

As a consequence of this, it has a direct punch on the lives of the patient's household, who are compelled to make some modifications in order to adapt to their new normal as a result of the circumstances. Although the effects are felt by the entire household, it is typically one member of the family who steps forward to be the primary carer for an ill or injured member of the family who lives in the home. As a result, the person providing care must divide their attention between the newly acquired obligations, their own requirements, and those of the person in their life who has a spinal cord injury (Ma, 2014).

The emotional, psychological, financial, and physical challenges that carers of victims with spinal cord damage encounter are numerous. This is due to the fact that the carers lack the requisite skills and expertise in dealing with victims who have spinal cord injuries. A weighty responsibility which the carers are expected to fulfil in the absence of any prior instruction or forewarning. According to Middleton et al. (2014), carers who are under an excessive amount of stress are more likely to experience physical and mental wellbeing issues, which can have a negative impact not just on their own well-being but also on their ability to provide adequate care to their patients. It can be difficult for them to meet both their own and another person's requirements, which can put a strain on their resources.

A study's findings showed that family carers of individuals with spinal cord injuries (SCI) endure both physical as well as financial strains as a result of their work. The growing number of responsibilities that family carers had to take on in order to provide adequate care for individua ls with spinal cord damage was a major contributor to the increased physical strain that carers in this study reported feeling. During the process of catering to the requirements of the people receiving care, the participants disclosed that they suffered from aches and fatigue in their bodies. Consistent with previous research, this study found that adults who take on caregiving responsibilities often find themselves in an unplanned job caring for the sick or disabled. This is a finding that oscilla tes with the findings of previous studies. Because the accident happened so quickly, it meant that I had to step into the role of carer without any prior preparation. This was noted to be connected to a deficiency in available options as well as an absence of preparation. This study indicated that participants in family caregiving roles encountered financial issues since they were unable to have time to work and make cash. This unanticipated and demanding duty of caring caused some level of strain on these family carers. All of these factors combined to make it difficult financially for carers, who often needed to borrow money just to get by. It was believed that the stress brought on by the financial load that carers experienced as an outcome of giving attention to those with SCI was the most worrisome and the most difficult for them to bear. This finding matches with Rodakowski et al. and Boschen, Tonack, and Gargaro, who came to the conclusion that family carers have financial challenges.

As a result of the time spent taking care of their loved ones, especially quadriplegic family members who depend on them to carry out their daily basic activities like bathing, eating, toileting, turning in bed to prevent pressure sores, and moving around in the house and outside the house, the carer may experience physical exhaustion and have trouble sleeping as a result of the time spent caring for their loved ones. This is especially true for quadriplegic family members. This puts the carers at an increased likelihood of experiencing physical as well as mental health issues, which can result in a worse quality of life that is directly tied to their health (Nogueira, P.C. et al. 2012).

Few things have been done to assist patients with their aftercare once they have been discharged from the hospital. The majority of buildings and places are not quite accessible to patients who use wheelchairs, which contributes to the burden that is placed on their carers. Despite the devastating and dire changes that spinal cord injuries bring, little has been done to help patients. According to

(Graca et al. 2013), one of the primary factors that contributes to an increased load on carers is the accessibility of the surrounding environment.

The special difficulties of providing care for someone with SCI, in addition to the typical physical demands of the work of caregiving, may increase the risk of unfavorable outcomes for the caregiver. These consequences may include decreased life satisfaction, unhealthy lifestyle choices, and other similar issues. According to Arango et al. (2010), the prevalence of chronic diseases and overall poor health has increased.In an unavoidable circumstance, the carers are forced to take on the duty of providing care for their loved ones. Because of this, they are unprepared for the responsibility, and it puts them at risk of experiencing psychological repercussions such as depression. As a result, they need the support of their friends to help them deal with the difficult ies they face. (Secinti et al,2017)

The unexpected onset of SCI forced participants into the role of carer, which many of them were unprepared for but felt they had no choice but to assume as a result of the nature of the situatio n. Additionally, for many of the participants, it was the first time they had ever been required to provide care for a family member while they were hospitalized (Rummana et al 2020).

Recent study reveals that carers of individuals with spinal cord injuries may need to make certain adaptations to their lifestyles in order to properly care for their patients who have SCI-specific comorbidities, such as bladder and respiratory difficulties, as well as the management of pressure ulcers (Nogueira et al. 2012). This association is a strong predictor of carer outcomes such as load, according to MWM et al.2012. The amount of support provided by the carer for ADLs is proportional to how many of these challenges the care receiver has. It is possible for carers of persons with SCI and other neurologic disorders (such as TBI) to experience a variety of consequences as a result of their role as carers (Simpson & Jones, 2013). This is because people with SCI and other neurologic diseases encounter a variety of disabilities.

1.3. Statement of the Research Problems

A spinal cord injury is a draining condition that, contingent on the extent of the damage, can affect the motor and sensory functions of the upper limbs, lower limbs, and abdominal muscles. As a result, the affected individual may experience changes in the way their body functions. Because of these motor and sensory alterations, people who have suffered damage to their spinal cords require assistance in order to perform the tasks necessary for survival. When it comes to providing care for their loved ones, the closest relative is typically the one to step up and assume the role of a carer. A position that comes with its share of difficulties for the people providing care. When we talk about the "burden of care," what we mean to refer to are these different issues. Sixty-eight percent of those who provide care for Veterans reported experiencing a significant amount of mental stress as a result of their duty, and forty percent reported experiencing the same level of stress as a result of the physical responsibilities of caregiving. Furthermore, a relationship was observed between the hours dedicated to caregiving, the extent to which the care recipient's ability to perform Activities of Daily Living (ADL) was hindered, cohabitation with the care recipient, and marital status to the care recipient (Heejung et al., 2017). This correlation was evident in the association between the hours spent providing care and the impairment in the care recipient's ability to perform ADL.

The act of caring for an individual with a disability, such as a spinal cord injury (SCI), has been linked to significantly elevated levels of anxiety (88 percent), feelings of sadness (60 percent), and sleep disturbances (77 percent). According to the National Alliance for Caregiving, sixty percent of caregivers report reducing their time for exercise, maintaining a healthy diet, and attending medical and dental appointments due to their caregiving responsibilities (Family Carers of Veterans in the Year 2010). Research indicates that when only one family member assumes the role of primary caregiver following a spinal cord injury, it can negatively impact the patient's physical, emotional, and psychological well-being (Priebe, 2007). The failure of individuals to successfully juggle their responsibility of care with other duties, such as employment and family, has been identified as a primary contributor to the prevalence of a variety of issues in recent research. As a consequence of this disparity, people start to disregard their health, which invariably results in a condition that renders them unable to function normally.

As a result, the well-being of the carers is of the utmost significance when providing care for their family members who have spinal cord injuries because the level of care that is provided to their loved ones is directly correlated to the quality of care that the carers provide.

Those who have sustained a spinal cord injury in Kenya have only one public hospital option available to them for rehabilitation, and that option is the National Spinal Injury Referral Hospital (NSIRH). As indicated by the large number of persons in East Africa who suffered spinal cord injuries after independence and did benefit from the hospital's care, the hospital is also available to assist other countries in East Africa. This is evidenced by the fact that other countries in East Africa who have spinal cord injuries have undergone through rehabilitation in the hospital. The majority of studies concentrated on patients who had suffered spinal cord injuries; however, no local research has been conducted to evaluate caretakers of SCI sufferers. A study looking into the difficulties encountered by carers in the course of providing care for individuals who have spinal cord injuries would assist comprehend the fundamental issues and contribute to the development of solutions to solve those issues, which will, in turn, contribute to the protection of carers' well-being, which is of the utmost importance for the aftercare of SCI victims.

1.4. Justification of the study

Kenya suffers from a lack of information. on the challenges faced by the caregivers as a result of the responsibility they undertake to care for individuals with spinal cord injuries despite the upsurge in the number of victims who suffer from it over the years. Most studies emphasized the patient’s spinal cord injuries, their causes and forget the complication associated with the spinal cord damage which tend to make the patients co-dependent or fully dependent on their family members to carry on with their daily basic duties. Thus, the importance of the role of aftercare played by the carer of victims with spinal cord damage is usually overlooked. Caregivers of patients at the National Spinal Injury Referral Hospital have not been subjected to any published research on the challenges they experience providing care to their family members with spinal cord injuries. As a result, there is a dearth of data on the extent to which those caring for victims with spinal cord injuries bear in the caregiving process. It is, therefore, crucial to unearth the extent of the caregiving responsibility by carrying out the study on the burden of care among caregivers of family members who suffer spinal cord injury at National spinal injury hospital. Healthcare experts, with the input of SCI patients and caregivers, should develop an effective rehabilitation plan to educate caregivers about the patient's long-term treatment and care needs. Educated caregivers are better able to help patients regain their independence by recognizing cultural differences in their approach to treatment. Caregivers, meanwhile, should arm themselves with the knowledge to help those in their charge deal with adversity. Rather than reducing the total load, many common strategies actually add to it. Caregiver workload can be reduced through active intervention, which has been found to increase quality of care as well as caregiver health (Boschen et al., 2007). Consequently, motivating caregivers to adopt more physical methods by means of social connection and recreational activities is crucial.

The suggestions and recommendations from the study could be used to make treatment easier and help the hospital administration of NSIRH understand the level of burden of caregiving amongst the caregivers and could use the data findings to come up with policies for the hospital, that incorporate the caregivers in the rehabilitation program since it is the only public rehabilitation centre for the whole country and East Africa as a whole.

1.5. Significance of the Research

The results of the literature review make it quite clear that carers do, in fact, experience caregiving load. The findings and recommendations of this researchwill assist the hospital administration at NSIRH in formulating attempts to lessen that burden by coming up with various strategies to involve the carers in their rehabilitation program This study will also assist the Ministry of Health in learning more about the extent to which providing care places a burden on carers and in making plans for the future to reduce that strain through the formulation of policies at the ministry level. The results of this study's analysis can be compared with those obtained from another research, both those conducted locally and those conducted internationally. The research will also add to the pool of knowledge of literature.

1.6. Research Questions and Objective

1.6.1. Research Questions

This research will answer the following questions:

- RQ1: What is the level of caregiving burden among the caregivers for those with damage to their spinal cord?
- RQ2: What are the causes of the caregiving burden among caregivers of victims with spinal cord injuries?
- RQ3: What are the associations between socio-demographic characteristics and the burden of caregiving of the caregivers?

1.6.2. Broad Objectives

To determine the level of burden of caregiving among caregivers of family members who suffered Spinal Cord Injury at National Spinal Injury Referral Hospital.

1.6.3. Specific Objectives

- To assess the extent of caregiving burden experienced by family members caring for individuals with spinal cord injuries.
- To identify the factors contributing to the caregiving burden among family members caring for individuals with spinal cord injuries.
- To find out associations between the socio-demographic traits of the patient, caregivers and the burden of caregiving of the caregivers

CHAPTER 2: LITERATURE REVIEW

2.1. International Situation

There have been a number of studies carried out all over the world to investigate the carers and the pressures that come with providing care. A number of research have been conducted with the goal of investigating the correlations between the burden of care and the sociodemographic variables shared by carers and people who are afflicted with spinal cord injuries. The overwhelming majority of research conducted on a global scale demonstrates that carers have a lot on their plates. The degree of injury sustained by the patient and the gender of the person providing care are the two factors that are most important to consider. When it comes to the aftercare of individuals who have suffered a spinal cord injury, the health of the carers is of the utmost importance, and the quality of care that they provide is very susceptible to a variety of outside influences.

2.1.1. Global Situation on the Level of Burden of Care

A cross-sectional study conducted by Khazaeipour et al. in 2017 involved 163 individuals with spinal cord injuries (SCI) with the objective of assessing the burden experienced by caregivers and exploring the relationship between caregiver burden and the sociodemographic factors of both SCI patients and their caregivers. The study identified a notable burden among caregivers of SCI victims. The findings revealed varying degrees of caregiving strain, with 11.7% of respondents indicating little or very little burden, 43.6% reporting mild-to-moderate burden, 33.1% experiencing moderate-to-severe burden, and 11.7% reporting severe hardship in fulfilling caregiving responsibilities. The total burden score was documented as 38.9 ± 15.2.

As per the findings from a cross-sectional descriptive study involving 135 Iranian caregivers of individuals with spinal cord injuries, caregiving for someone with a spinal cord injury can pose various challenges in the primary caregiver's life. This study, conducted in Iran, aimed to explore the factors associated with the quality of life among caregivers of spinal cord injury victims. The results indicated that the severity of the injury significantly correlated with a diminished quality of life for caregivers, particularly in the case of quadriplegics who exhibited a higher dependence on caregivers, necessitating a higher level of care. In addition, it was discovered that the quality of life of the carers was lower than that which was reported for the population of Iran. Because of this, the carers experienced both physical exhaustion and sleep disruptions as a result of their work.

Carmina et al. (2017) administered a study with 75 relativ3s of victims who had spinal cord injuries to learn about the care burden, perseverance, and life satisfaction of these individuals. They found that "all caregivers experienced varying levels of burden," with 52% expressing a mild-to-moderate burden, 43% experiencing a moderate-to-severe burden, and 5% indicating a severe burden. None of the caregivers reported feeling little or no burden at the time of the assessment. "Dependence" and "the future of the injured" were the two items that caused the carers the most concern. Only 15% of the sample had low resilience, and 7% had extremely low resilience, but the overall resilience of the sample as a whole was medium to high (mean = 141.93, SD = 23.44). The topics "what their lives mean to them" and "carers' independence" received the highest number of votes. The results indicated a level of life satisfaction that ranged from moderate to high (mean = 36.6, standard deviation = 6). These scores have nothing to do with the individuals' identities or the severity of their injuries. Interview scores were negatively correlated with Zarit Burden's scores on the Resilience Scale (r = -.370, P =.001) and the Life Satisfaction Checklist (r = -.412, P.001).

The outcome of a study that was conducted out in Nepal on 71 carers with the purpose of determining the amount of primary carer load and the relation between carer burden and sociodemographic characteristics of spinal cord injury patients and their carers revealed that the mean carer burden score was 46.28 12.05. The majority of people (63.4%), followed by those who reported severe burden (18.3%), those who reported mild to moderate burden (11.3%), and those who reported little or no hardship (7.0%). The most common sources of anxiety for carers were "what the future holds for patients" (3.07 1.22) and "what should be done more for patients" (3.04 1.01) (Sinha et al 2022).

A cross-sectional study conducted at Dhulikhel Hospital and Spinal Injury Rehabilitation Centre in Nepal aimed to investigate factors influencing depressed mood in persons with traumatic spinal cord injury (TSCI) and the perceived burden of caregivers in a country with a low per capita income. The study demonstrated a high prevalence of depressed mood among individuals with TSCI and a significant burden of caregiving among their caregivers. The individuals diagnosed with TSCI had a mean age of 34.8 (11.0) years, and their caregivers had an average age of 33.6 (12.3) years. The majority of TSCI patients were paraplegic (73.7%), with 67.4% being male. Among the caregivers, the majority were female (61.1% of all caregivers). Depression was observed in 68% of individuals with TSCI, and 91.6% of caregivers reported feeling burdened by their responsibilities (Adhikari SP et al., 2020).

A cross-sectional study was done in Turkey with a total of one hundred family carers of people with SCI in order to evaluate the burdensomeness experienced by these individuals. According to the result of the research, one of the most important factors in lowering the level of sadness that carers experience is receiving aid from other members of the same family as well as wellwishers. (Secinti et al., 2017).

100 primary carers of people with spinal cord injuries participated in the study. The mean burden score for caregivers is 45.3, with a standard deviation of 11. Twenty percent of the carers in the sample experienced severe burden, whereas forty percent experienced mild to moderate strain, and the remaining forty percent experienced moderate to severe burden. (Thelakkadan et al 2020).

According to the findings of a cross-sectional study carried out in Fiji, the strain of providing care for a patient who has a spinal cord injury is a contributor to the psychological discomfort that carers experience. The research was conducted on thirty primary carers of stroke victims in order to investigate the psychological response of the carers as well as the load that they carry. The findings showed that the psychological well-being of the carer was negatively impacted by the experiences of providing care to another person. The results of the study showed that the participants had significant temporal dependence (Gajraj 2011).

2.1.2. Global Situation on the Causes of Burden

A Cross sectional study for primary carers of 71 patients, used Zarit burden interview to access on the different domains of burden of care. The total mean burden score was 46.28 with a standard deviation of 12.05. The individual ZBI components' mean values ranged anywhere from 1.10 to 3.07, on average. After going through and examining each component of the scale it was concluded that the items pertaining to self-criticism, dread, and doubt had the highest mean burden ratings. Carers were more concerned about the patients' futures (3.07+/- 1.22), what could be done for the patients (2.79 ± 1.26), and what should be done more for the patients (3.04 ± 1.01). On the other hand, the mean burden score for the questions that dealt with the weariness of caregivers, patient dependence, and financial concerns was high. I feel overwhelmed by caring for my patient and juggling my other responsibilities (2.31 1.30), and my income is insufficie nt to cover patient care and other expenses (2.77 1.14), all of which have occurred since my patient became ill (2.68 1.19) (Sinha et al 2022).

In a cross-sectional study encompassing 55 family caregivers for individuals with spinal cord injuries (SCI), the primary objectives were to determine the caregiver burden (CB) for those caring for individuals with SCI and to explore the psychological consequences of assuming the role of a caregiver. The category that received the highest score in this study was time-dependent load, attributed to the necessity of providing assistance in the day-to-day activities of individuals with spinal cord injuries. The substantial hours spent on caregiving emerged as predictors of burden, leading to potential social isolation. Financial constraints resulting from this situation were also identified as predictors of developing burden (Maitan et al., 2018).

Similarly, another cross-sectional study involving 30 primary caregivers of individuals with Spinal Cord Injury in Fiji aimed to investigate the psychological responses of caregivers and evaluate the challenges associated with caregiving for SCI patients living in the community. The participants demonstrated elevated levels of both time-dependent and development-related burden. The overall Caregiver Burden Interview (CBI) score had a standard deviation of 21.39, with a mean score of 47.6 (Gajraj et al., 2011).

In order to assess the stress placed on caregivers, a descriptive cross-sectional study was undertaken in Iran utilizing the Zarit caregiver burden questionnaire with 163 people with SCI and their caretakers who had been admitted for outpatient therapy. Most carers mentioned having limited resources due to lack of money. This was a cross-sectional descriptive research.

Seventy-five carers of loved ones with spinal cord injuries participated in a cross-sectional study, and their experiences of burden were linked mostly to future uncertainty, insecurity in providing care, and the injured person's dependence. This difficulty was linked mostly to worry about the future, anxiety about providing care, and the afflicted family member's dependence.

Researchers in Nepal conducted a cross-sectional study at the Dhulikhel Hospital and Spinal Injury Rehabilitation Centre to examine the factors that contribute to depression after traumatic spinal cord injury (TSCI) and the perceived stress this causes for caregivers in a country with a low GDP per capita. It was observed that the financial load was the greatest (71.5%), followed by the responsibility burden (22.2%), and then the time burden (6.3%) (S P Adhikari et al., 2020). Sixty-eight percent of people carrying the burden of TSCI (traumatic spinal cord injury) and 91.6% of caregivers reported feeling depressed.

The aim of this cross-sectional study of 105 caregivers done in Penshawar,Nepal was to quantify the emotional and social demands placed on those who take care of people with spinal cord injuries. The study's results showed that providing care for people with spinal cord injuries placed a heavy emotional and mental burden on carers.(SZA Shah,2017)

2.1.3. Global Situation on Sociodemographic Characteristics of Caregivers and their Patients.

The objective of this cross-sectional study was to investigate the quality of life (QoL) and the related risk factors among caregivers of individuals with spinal cord injuries (SCI) in Iran, with a particular focus on the Brain and Spinal Injury Repair Research Center of Tehran (BASIR). 75 were women (55.0%), 60 were men (45%), 95 were married (70.4%), 40 were single (30%), 76 were unemployed (56.3%), and 42 had completed post-secondary education (31.1%). Caregivers' ages ranged from 18 to 60 years on average. One hundred eleven (82.2%) of the affected people were paraplegic, while 24 (17.8%) were quadriplegic. Parents (24%), spouses (23%), siblings (32%), children (15%), and other relatives (6%) make up the largest group of caregivers for people with SCI. According to a group of researchers (Farajazadeh et al. 2021).

The stress on primary carers was statistically substantially associated with a number of sociodemographic characteristics, including marital status (P = 0.009), activities of daily living (P = 0.038), monthly family income (P = 0.023), and the amount of time spent caring for patients (P = 0.028). According to the results of the research, primary carers carry a heavy overload of care, which is mostly caused by anxiety and ambiguity regarding the prognosis of the patient, the dependency of the patient, carer tiredness, and financial concerns. There was a correlation between the load placed on primary carers and a number of sociodemographic characteristics of both patients and their carers (P. Sinha et al 2022).

In a cross-sectional study conducted at the Hutlike Hospital and Spinal Injury Rehabilitation Center in Nepal, depressed mood among individuals with traumatic spinal cord injury (TSCI) was found to be significantly associated with gender, education, lesion type, and time since the injury. The study also identified factors linked to increased caregiver burden, including the TSCI patient's occupation, level of education, severity of injury, length of care, and degree of depression. Financial burden was reported as the greatest load (71.5%), followed by the burden of responsibility (22.2%), and finally, the burden of time (6.3%) (Adhikari et al., 2020).

Another cross-sectional study involving 163 SCI patients, conducted by Khazaeipour et al. in 2017, aimed to assess the burden of caregiving and the relationship between caregiving and sociodemographic factors of SCI patients and their caregivers. The study revealed a correlation between the severity of the injury (P=0.010) and the caregiver burden score, as well as between the occupational status of SCI patients and their caregiving responsibilities (P=0.041).

Positive correlations were found between caregivers' age (r=0.350, P<0.001), the number of years they have been providing care (r=0.253, P<0.001), and the time period of providing care (r=0.176, P=0.025) with the caregiver burden score. Additionally, the burden was inversely proportional to the caregiver's level of education (r=-0.235, P=0.002).

In a cross-sectional study involving 59 caregivers of individuals with traumatic spinal cord injuries, the objective was to identify potential factors associated with Health-Related Quality of Life (HRQoL) in this population. The study examined the relationship between HRQoL and variables such as gender, age, the presence of comorbidities, and characteristics of caregiving. The data revealed that women, with an average age of 44.8, constituted the majority of caretakers for individuals with spinal cord injuries, according to a 2016 study by Nogueira et al.

In a study conducted in China that focused on 150 caregivers and their patients with spinal cord injuries, individuals were discharged from the Second and Third Affiliated Hospitals of Nanchang University. This research aimed to investigate the burden of care on caregivers and explore their coping mechanisms. The participants had an average age of 43.23, with a predominant male representation (115 out of 150, or 76.7%). The causes of spinal cord injuries varied, with 65 cases resulting from traffic accidents (43.3%), 52 cases from falls (34.7%), 15 cases related to falls (10%), 10 cases from heavy injuries (6.7%), and 8 cases from other causes (5.3%). The majority of injuries occurred in the cervical region (102 out of 150, or 68%), followed by the thoracic spinal cord (17.3%) and the lumbar spinal cord (12.0%).

Four of the instances involved injury to two or more segments of the spinal cord, which accounts for the remaining 2.7%. In 93 out of the 150 instances, or 62%, the patient had incomplete paralysis, while in 57 out of the 150 cases, or 38%, the patient had entire paralysis. 103 patients had health insurance, which is a 68.7% coverage rate, whereas 47 patients did not have health insurance, which was a 31.3% coverage rate.

The vast majority of carers were female (120 out of 150, or 80%), and 88.7% of them (133 out of 150) had an education that was equivalent to or lower than that of junior high school. The overwhelming preponderance of male patients is reflected in the fact that the majority of carers were also female spouses (117 out of 150). The majority of carers (134 out of 150, or 89.3%) said that they did not practise any religion, while only 16 carers (10.7%) stated that they belonged to an organised religion. Ten percent of the people providing care for others were themselves afflicted with chronic conditions. According to Hai-ping Ma et al. (2014), the mean number of days of care supplied was 50.17 8.00, and 90% of carers were satisfied with the care they gave, despite the fact that 80% of them reported that their own health had deteriorated since being a primary carer.

According to the findings of a cross-sectional study conducted in Fiji, the provision of care for patients with spinal cord injuries contributes to the psychological distress experienced by caregivers. The study focused on thirty primary caregivers of stroke victims, aiming to explore the psychological responses of caregivers and the burden they carry. The majority of participants were female (n=20), of Fijian ethnic background (n=18), married (n=18), and primarily spouses (n=13). Participant ages ranged from 21 to 70 years, with an average age of 39.2 years (standard deviation = 14.1). The individuals receiving care ranged from 21 to 65 years old, with a mean age of 38.5 years (standard deviation = 12.4). Most care recipients were male (n=26), experiencing paraplegia (n=18), and had sustained complete injuries (n=23) (Gajraj, 2011).

2.2. Regional Trend

This research aimed to examine the impact of patient and carer characteristics on the burden and its dimensions, as well as to provide evidence of the CBI's factor structure and internal consistenc y among the caregivers of disabled people who participated in the study. The research was done in a randomly chosen rural area in Egypt called Minia. It included 260 family carers of disabled patients. The vast majority of the individuals providing care were either female (87.7%), married (80.7%), or uneducated (58%). The average age of carers was 43.6 years old with a standard deviation of 12.8 years, and only 14% of them were employed. The majority of the participants are the impaired person's parents (62.6%), and the length of time spent providing care ranged from one year to forty years, with the mean being 14.3 years and the standard deviation being 9.9 years. There were 90 people in the sample, and 37 percent of them claimed that their economic situatio n had gotten worse. The age range of those receiving care was between 31.7 and 18.8 years old, with 73.3% of them being male. 141 (or 58%) of the total 243 people receiving care had some sort of physical impairment. The average score on the CBI for the carers was 48.9 with a standard deviation of 17.9. The time-dependent load scored the most out of the five different aspects of burden, with a total of 13.1 out of 5, followed by the physical burden, which scored 9.9 out of 4.9. The highest values were given for the developmental load (9.1 4.8) and the social burden (8.9 4.1), while the emotional burden (7.9 4.2) received the lowest scores. Carers older than 60 years old showed a considerably larger reliance burden in both time and physical labour (13.4 4.5 and 15.5 6.5, respectively), in comparison to younger age groups. Carers with less education reported higher levels of overall load in all of its characteristics, with the exception of emotional stress. Additionally, there was a correlation between low family income and greater burden scores.

Caring for male patients was substantially related with higher social burden (9.3 4.2), compared to caring for female patients (7.9 3.7), among the demographic variables of care recipients associated with the burden of care. The kind of disability was found to have a strong association with the scores of the caregiver's overall burden as well as its five components; those who cared for patients with mixed impairments had higher scores in both the total CBI and all of its dimensions. The findings of the study indicated that carers experience varying degrees of stress depending not only on their own features but also on those of the individuals for whom they provided care.(E.R. Ghazawy et al 2020)

An additional study that was very similar to it was conducted in the Cape Town Area on twenty caregivers in order to try to get a better understanding of the stress that is felt by family members who take care of people who have physical disabilities. This study was exploratory and descriptive in nature. It was discovered that the caregivers faced multiple challenges, such as problems with their physical health, feelings of personal isolation, problems with their finances (including the cost of acquiring devices, personal care, and specialized transport), unemployment, and some of them even lost their paid employment as a result of the time-consuming responsibility of taking care of a family member. (Shiller & Strydom, 2018).

The results of a qualitative descriptive study conducted in Ghana, involving ten family members and researchers at the neurosurgical units of the Komfo Anokye Teaching Hospital, revealed that family caregivers of individuals with spinal cord injuries often assumed their roles without adequate preparation. Despite this lack of preparation, these caregivers were tasked with responsibilities related to both basic activities for daily living and instrumental activities for daily living. As they get more active in caregiving responsibilities, family caregivers feel both physical and financial constraints. This is because the time spent on caring tasks prevents them from engaging in any activities that contribute to economic growth. The primary coping mechanisms employed by family caregivers of individuals diagnosed with spinal cord injuries (SCI) include seeking support from other family members and friends, along with drawing on hope and religious traditions. These findings support the recommendation that family carers undergo extensive training before taking on the responsibilities of caregiving. It is essential to have social support mechanisms in place for family carers of those who have SCI in order to lessen the financial load that comes along with providing care (Rumana et al.2017).

2.3. Local trend

There is a paucity of information that is readily available to the general public concerning the challenges that come with providing care to individuals who have suffered spinal cord injuries. In addition, there has been no research conducted on the hardship of providing care for others. Studies are conducted on people who have suffered spinal cord injuries, but not on the people who care for them.

According to the results of a research that was conducted by Kinyanjui (2016) on 49 patients who were brought to KNH with spinal cord injuries over the course of six months, spinal cord injuries are among the most prevalent injuries that are received as a result of trauma and are responsible for a large amount of morbidity and death. According to the findings of the study, males were more likely to be impacted than females, with a male-to-female ratio of 15.3:1. In addition, the affected males belonged to their economically productive age group, with a mean age of 37.5 years. Accidents involving motor vehicles were the leading cause of injury, accounting for 55% of all cases, followed by falls from a height, which accounted for 37% of all cases. The cervical spine is the part of the spine that suffers the greatest injuries on a regular basis. After three months from the moment of injury, the mortality rate was 40.8% for the entire period. It was discovered that 44.8% of people had acquired bedsores.

The majority of individuals wounded in road traffic accidents were male, and around 55% of the injuries sustained were to the head, according to study conducted by Gichuhi in 2007 at KNH. The thoracic region was hit the worst, followed by the cervical area.

2.4. Variables

Independent variables: The chosen sociodemographic features, comprising age, gender, marital status, educational level, occupation, level of injury, and duration of injury.

Dependent variable: Burden of caregiving

Moderating Factors: financial, social physical, and emotional challenges.

2.4.1. Conceptual Framework

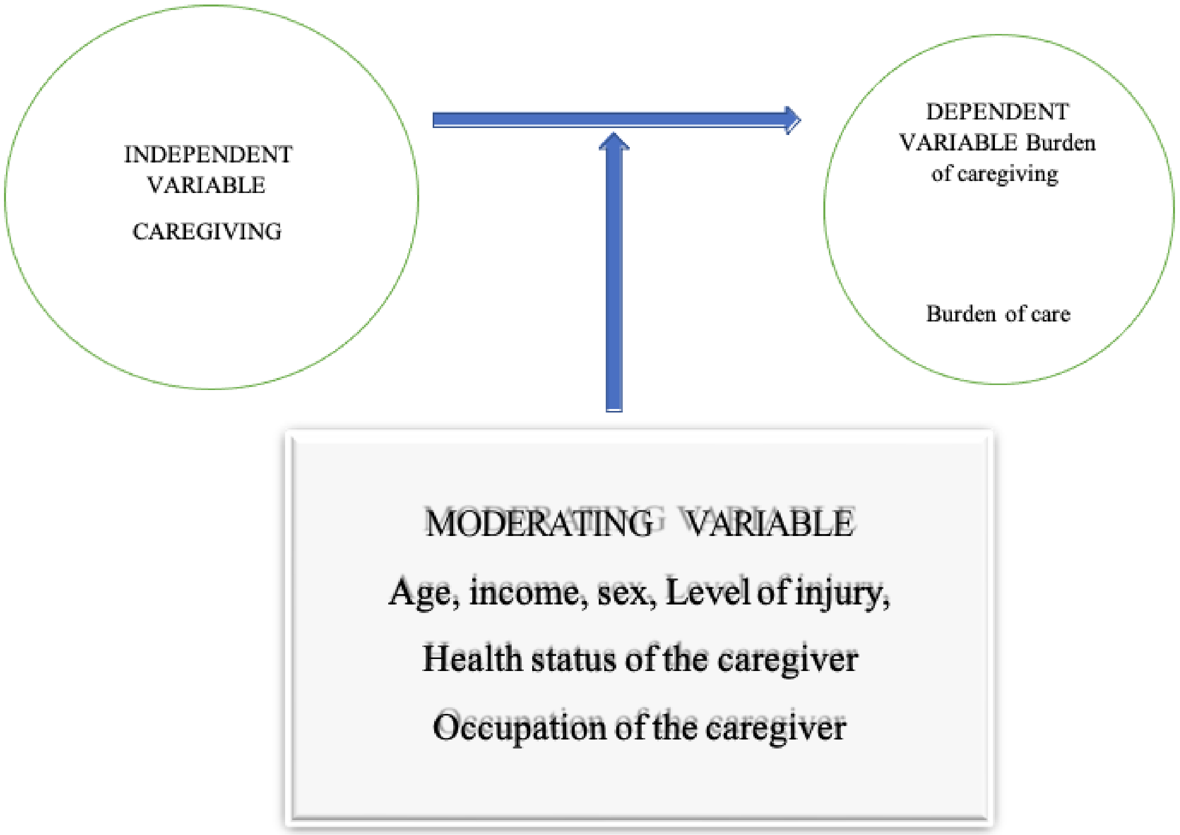

Figure 1: Conceptual Framework

CHAPTER 3: METHODOLOGY

3.1. Study Design

This research's main goal was to access the level of strain (physical, emotional, social, and financial problems) faced by the caregivers that care for patients with damage to the spinal cord in NSIRH.

This was accomplished by conducting a cross-sectional descriptive study in the National Spinal Injury Referral Hospital.

3.2. Area of Study

The research was done at the National Spinal Injury Referral Hospital, which can be found in Nairobi on 0.6149 hectares of land at the crossroads of Lenana Road and Rose avenue. It was first established in 1944 as the Amani Chastine Home, and its primary mission was to offer medical care to injured veterans who had served in World War II. It was rebranded as the National Spinal Injury Hospital soon after Kenya gained its independence, and it continues to be the only rehabilitation centre in Kenya that receives funding from the public sector. There are currently 35 beds available, and they are reserved for male and female patients of varying ages. It is staffed by medical professionals who are experts in a variety of subjects. has psychiatrists, psychologists, plastic surgeons, general surgeons, orthopaedic surgeons, physicians and general surgeons. Patients not only from Kenya but also from other East and Central African nations are able to make use of the service. The majority of the patients hail from Kenya. Patients who have suffered a spinal cord injury are required to stay in the hospital for a minimum of three months in order to receive treatment. This treatment has the primary goal of preventing secondary complications (bedsores, DVT), promoting neuro recovery, and following injury with the goal of improving patients' independence in activities of daily living, helping accept a new lifestyle, and facilitating community reintegration. Patients who have suffered a spinal cord injury are admitted to the hospital. The National Spinal Injury Referral Hospital is responsible for a variety of medical services, some of which are detailed here:

- Spinal, medical, and surgical therapies, which may include spinal, plastic, and general operations;
- Physical and occupational therapy (rehabilitation services);
- Spinal health education for the purpose of prevention. On occasion, awareness-raising campaigns are organised in an effort to educate people about the myriad of risk factors that can contribute to spinal cord injuries.

- Services provided by laboratories
- Radiological services
- Services relating to both mental health and social welfare.

3.3. Study Population

The male and female primary carers of family members who suffered from a spinal cord injury and were undergoing rehabilitation at National Spinal Injury Referral Hospital as either inpatients or outpatients will make up the study population. The individuals providing care were at least 18 years old and were competent to provide their permission after receiving all relevant information. The facility has an average of 35 patients who are admitted as inpatients and 15 patients to 20 patients who visit the outpatient physiotherapy clinic every day from Monday to Friday. Patients that seek treatment at NSIRH include those who have suffered spinal injuries in addition to other orthopaedic disorders.

3.3.1. Inclusion Criteria

Participants had to be at least 18 years old and be carers for patients who suffered from spinal cord injuries to be included in the study. Those participants who provided their informed consent.

3.3.2. Exclusion criteria

Participants in the study were not allowed to take part if they were less than 18 years old, if they were paid carers, if they refused to provide their consent, or if their patients suffered from an orthopedic ailment other than a spinal cord injury. The study also excluded carers whose patients did not have a spinal cord injury.

3.4. Sample size

The census technique was used for the research, and as a result, the sample size of 32 caregivers included all of those caregivers of patients with spinal cord injuries who provided their agreement to participate in the study and met the inclusion criteria.

3.5. Sampling Method

The census technique was used for the research, and each and every carer who satisfied the inclusion criteria and took care of a patient during the course of the study took part in it. The carers of patients who were suffering from spinal cord injuries and were undergoing the rehabilitation programme at the National Spinal Injury Referral Hospital were the ones who were approached. Other carers included those who did accompany their family members who had spinal cord injuries to the physiotherapy outpatient clinic and those whose patients came for appointments after being discharged from the hospital.

3.6. Recruitment

After receiving authorization from the ethical committees at KNH/UON, a request for authorisation to collect data was presented to the Ethical Committee of the National Spinal Injury Referral Hospital. This was done after the National Spinal Injury Referral Hospital received consent from the KNH/UON Ethical committee. The management of the institutio n, as well as the physiotherapist at the physiotherapy outpatient department, psychologist and social worker at the mental health and social department, and the ward in-charges, were provided with an explanation of the study's general information, as well as its objectives and methods. The researcher was present at the physiotherapy outpatient section from Monday through Friday, 8:00 AM until 5:00 PM, and she was given a room there. The physiotherap y clinic is only open during the daylight hours of Monday through Friday.

The participant was then directed to the where the researcher was and received a thorough overview of the research, provided that both they and their caregiver expressed a willingness to participate. Those meeting the specified criteria for the study were subsequently invited to sign the consent form. Individuals who were unwilling to participate or did not meet the researcher's criteria were thanked and offered appropriate counseling. Participants who chose not to join or did not fulfill the requirements were acknowledged and permitted to proceed with their plans for the day. Interviews with study participants involved the utilization of a socio-demographic questionnaire, developed by the researchers, to investigate the socio-demographic characteristics of both the patient and the caregiver. Additionally, a Zarit Burden Interview was conducted to evaluate the caregiving burden among the caregivers.

3.7. Data collection

The socio-demographic questionnaire the researcher devised was used to collect data over the course of fifteen to twenty minutes for each responder, and then it was followed up with an interview with Zarit Burden.

3.8. Study Instruments

3.8.1. Socio-Demographic Questionnaire

The researcher utilized a questionnaire they had prepared, designed to capture the socio-demographic details of both the caregiver and the patient with spinal cord injury (including age, gender, marital status, education level, religion, residence, employment status, kinship between the patient and the caregiver, as well as the level and duration of spinal cord injury). This instrument was employed for the purpose of data collection.

3.8.2. Zarit burden interview

When it comes to measuring subjective stress as well as perceived social, physical, financial, and emotional pressures, a ZBI-22 scale is a tool that has been shown to be reliable and accurate. The responses were rated on a Likert scale from 0 (never) to 4 (almost usually), with 0 meaning never, 1 meaning seldom, 2 meaning sometimes, 3 meaning frequently, and 4 meaning almost always. The overall burden score might have been anywhere from 0 to 88. When the entire ZBI score went up, it showed that there was a comparable rise in the burden that was placed on the caretakers. The burden levels of caregivers were categorized as (a) little or no burden (total score = 0–20), (b) mild to moderate burden (total score = 21–40), (c) moderate to severe burden (total score = 41–60), and (d) severe burden (total score = 61–88), based on the total Zarit burden interview scores.

3.9. Quality Assurance

Throughout the study, the researcher consistently adhered to research ethics. The principal researcher took responsibility for conveying comprehensive information about the study, including its aim, objective, data gathering procedures, as well as the associated benefits and risks. Furthermore, she played a key role in the administration of questionnaires to the participants. In order for the provided data to be deemed valid for research, consent forms were signed by the participants. To maintain anonymity and ensure participant confidentiality, the questionnaires were assigned numbers for data entry, omitting any personal details. The completed questionnaires were securely stored in encrypted computers and the physical copies were immediately destroyed. For added security, an encrypted code was applied during both data entry and analysis on the software. To prevent any potential influence of the care recipient on the caregivers' responses, interviews were conducted in a secluded area inaccessible to the person with spinal cord injury, both during and after the data collection and analysis phases.

3.10. Statistical Analysis Plan

Prior to entry into the Microsoft Excel spreadsheet for the year 2020, a meticulous examination of the data was conducted to ensure its comprehensiveness and accuracy. Subsequently, the data was exported to version 26 of SPSS. For categorical data, participant characteristics were analyzed and presented as frequencies and percentages, while continuous data were analyzed using means and standard deviations. The Zarit Caregivers Burden Interview was employed to assess the caregiving burden, categorizing scores as either indicative of a burden or no burden, with the severity determined by the scores. Following this, the information was summarized using frequencies and percentages. Correlations between socio-demographic characteristics and the difficulty of caregiving were explored using Pearson chi-square tests, Pearson correction, and independent t-tests. A significance level of $p < 0.05$ was set, with any p-value below this threshold considered indicative of statistical significance.

3.11. Ethical consideration

Upon obtaining ethical approval from the appropriate departments, the data collection process commenced. Participants in the study were explicitly notified that their involvement was entirely voluntary. Importantly, they were assured that choosing not to participate or withdrawing from the research project at any point would neither result in punishment nor victimization. Informed consent can be obtained from all potential participants once a thorough explanation of the study's process, goals, and significance are provided. No one will be aware of anything the participants share with the researcher. The care recipient will be kept in a different room throughout the interviews to reduce the possibility of their presence influencing the responses. Caregiver participants will be notified that they will not personally profit from their involvement but that their input will help the government and the Ministry of Health (MOH) develop policies and measures to ease the strain of caregiving. The participants will be made aware that they will neither receive monetary compensation nor special treatment for their time and cooperation during the study. It will be made clear to participants that completing the permission document is the only way their willingness to participate in the study can be officially recorded.

3.12. Benefits of the Study

This study will offer NSIRH administration insights to leverage in formulating policies designed to alleviate the challenges caregivers face when offering care to persons with spinal cord injuries and their families. This study's findings will also be of benefit to NSIRH's mental and social services departments, which wil be in a better position to collaborate with patients' caregivers to lessen the caregiving load for everyone involved.

The outcome of this study will also help the Ministry of Health, to be aware of the burden of caregiving among caregivers and use the findings to create policy and make changes on existing policies that wil make caregivers' jobs easier.

3.13. Study Strength and Limitation

The fact that this study is the first of its kind to assess the amount of burden associated with caring among carers of family members suffering from spinal cord injuries in National Spinal Injury Referral Hospital is one of the strengths of the study. This research was limited in that it was carried out within the confines of a hospital, which means that the findings cannot be extrapolated to the population as a whole outside of the hospital. The hospital in which the study was carried out is the only public facility that is dedicated to the rehabilitation of persons who have suffered damage to their spinal cords. Despite this, the hospital's capacity is far lower than the number of people who require its assistance.

Figure flow chart showing the flow of how the data procedure:

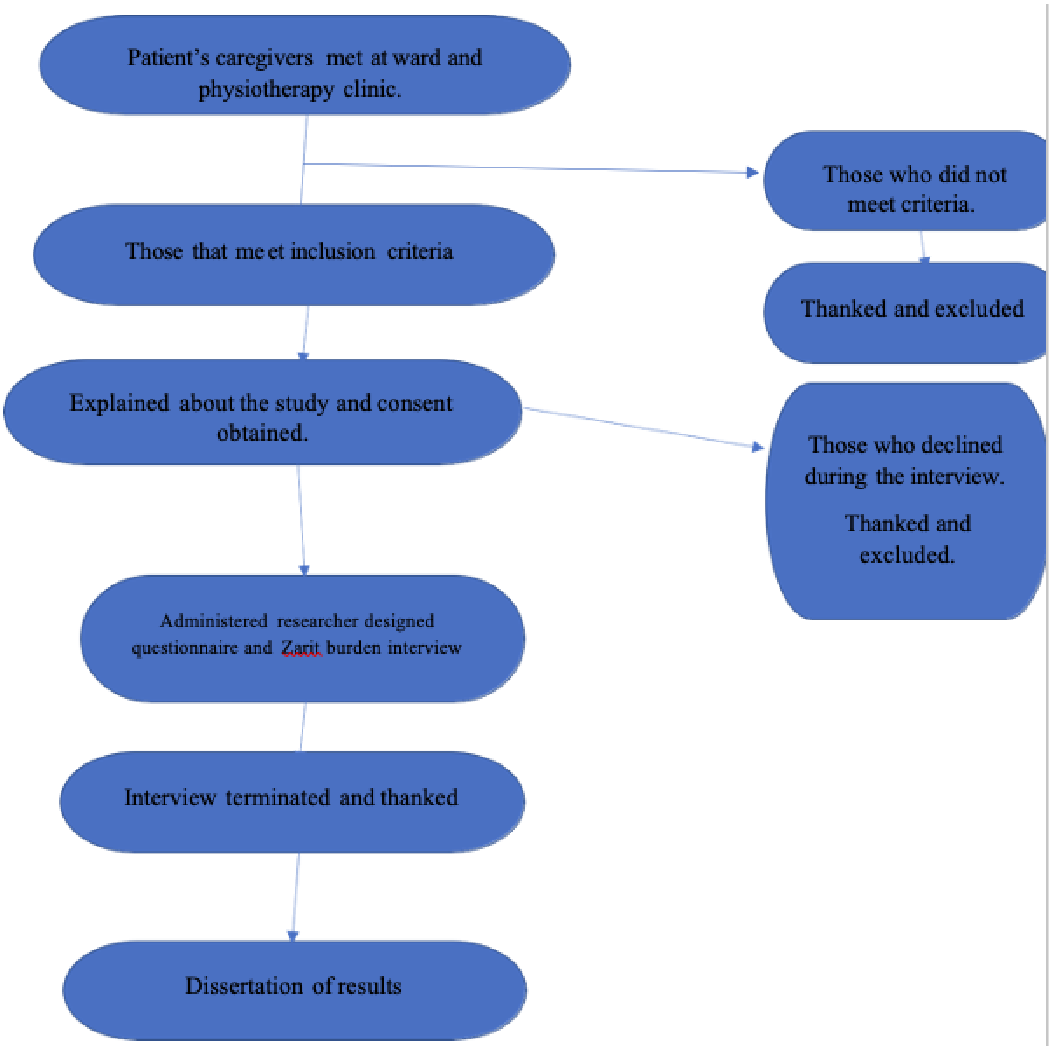

Figure 2: Study Flow Chart

CHAPTER 4: RESULTS AND DATA ANALYSIS

4.1. Introduction

This section presents data analysis. Tables, charts, and graphs, as well as an interpretation of the study's conclusions, have been used to convey the results. A total of 32 participants agreed to take part in the research; 29 of them were caregivers whose patients were inpatients at the hospital, while the other 3 caregivers were from a physiotherapy clinic as they had accompanied their relatives for physiotherapy. The collection of data was done in accordance with the study's broad objective, which was to establish the level of burden of caregiving experienced by caregivers of family members who were treated at the National Spinal Injury Referral Hospital for injuries to the spinal cord. The findings are provided in accordance with the particular aims of the research.

4.2. Demographic Characteristics

4.2.1. Caregivers

Age: The vast majority of the individuals providing care were female (78.1%), and their average age was below 40 years old (31.3%). The average age of the carers was 46.5 years, with a standard deviation of 11.4 years; the age of the caregiver who was the youngest was 21.0 years old, and the age of the caregiver who was the eldest was 73.0 years old. The median age was 44.5 years old with an interquartile range of 37.5 to 54.0 years.

Sex: There were a total of 25 female participants, making up 78.1% of the total, while there were only 7 male participants, making up 21.9% of the total.

Level of Education: 53% of the caregivers had attained a level of education equivalent to or higher than that of a tertiary institution, and 31% of the caregivers had completed the requirements of an institution of secondary education.9.3%reported have gone to primary level and 6.3%(n=2) having not gone to school.

Marital Status: The vast majority of the individuals providing care were married (90.6%; n = 29), whereas only 6.3%; n = 2 were single.one of the caregiver had lost a spouse via sudden illness.

Kinship: Parents made up 25% of the population, while spouses made up 34.4% of the total.15.6% of the population were children and siblings (n = 5).

Table 1: Demographic Characteristics of the Caregivers

	Frequency *(n=32)*	**Percent**
Age in years		
<40	10	31.3
40 – 49	9	28.1
50 – 59	9	28.1
≥60	4	12.5
Sex		
Male	7	21.9
Female	25	78.1
Education		
Informal	2	6.3
Primary	3	9.4
Secondary	10	31.3
Tertiary	17	53.1
Marital status		
Married	29	90.6
Single	2	6.3
Widow	1	3.1
Kinship		
Parents	8	25.0
Sibling	5	15.6
Child	5	15.6
Spouse	11	34.4
Other	3	9.4

4.2.2. Patients

Age: 46.9% of the patients were younger than 40 years old, making up the majority of the patient population. The average age of the patients was 42.9 years old, with a standard deviatio n of 15.5 years; the age of the youngest patient was 16.0 years old, while the age of the oldest patient was 72.0 years old. The median age was 40 years old (interquartile range: 33.5 – 55.5) Sex: The proportion of male patients to total patients was 71.9 percent (n = 23), whereas the proportion of female patients to total patients was 28.1 percent (n = 9).

Marital status: 50% of the persons were single and had never been married (n=16), whereas 43.8% of the people were married and had n=14.

The level of injury: 65.6% of the patients had the majority at the thoracic level, while only 18.8% of patients did so at the lumbar level, and only 15.6% of patients did so at the cervical level.

Duration of Injury: The vast majority of the patients had been suffering from the injuries for somewhere between one and two years. Those who had the ailment for one year made up 43.8% of the total, while those who had it for two years made up 37.5%. 10 years was the longest duration of time that was documented (n=1).

Table 2: Demographic Characteristics of the Patients

	Frequency *(n=32)*	**Percent**
Age in years		
	15	46.9
40 – 49	6	18.8
	6	18.8
≥60	5	15.6
Sex		
<40		
50 – 59		
Male	23	71.9
Female	9	28.1
Marital status of patient		
Married	14	43.8
Single	16	50.0
Widowed	2	6.3
Level of injury		
Cervical	5	15.6
Thoracic	21	65.6
Lumbar	6	18.8
Duration of injury (years)		
1	14	43.8
2	12	37.5
3	3	9.4

7	1	3.1
9	1	3.1

10	1	3.1

4.3. Burden of Caregiving Among the Caregivers

The research aimed to determine the burden of caregiving among the caregivers of family members with spinal cord injury. A score of 20 and above was considered as having a higher burden of care, while those below as having low or no burden of care. The mean score was 28.2 (SD 8.0), where the lowest score was 13, and the highest was 44. The median score was 29.0 (IQR 24.0 – 34.0).

Table 3: Burden of Caregiving

	Frequency *(n=32)*	**Percent**
Burden	26	81.3
No burden	6	18.8

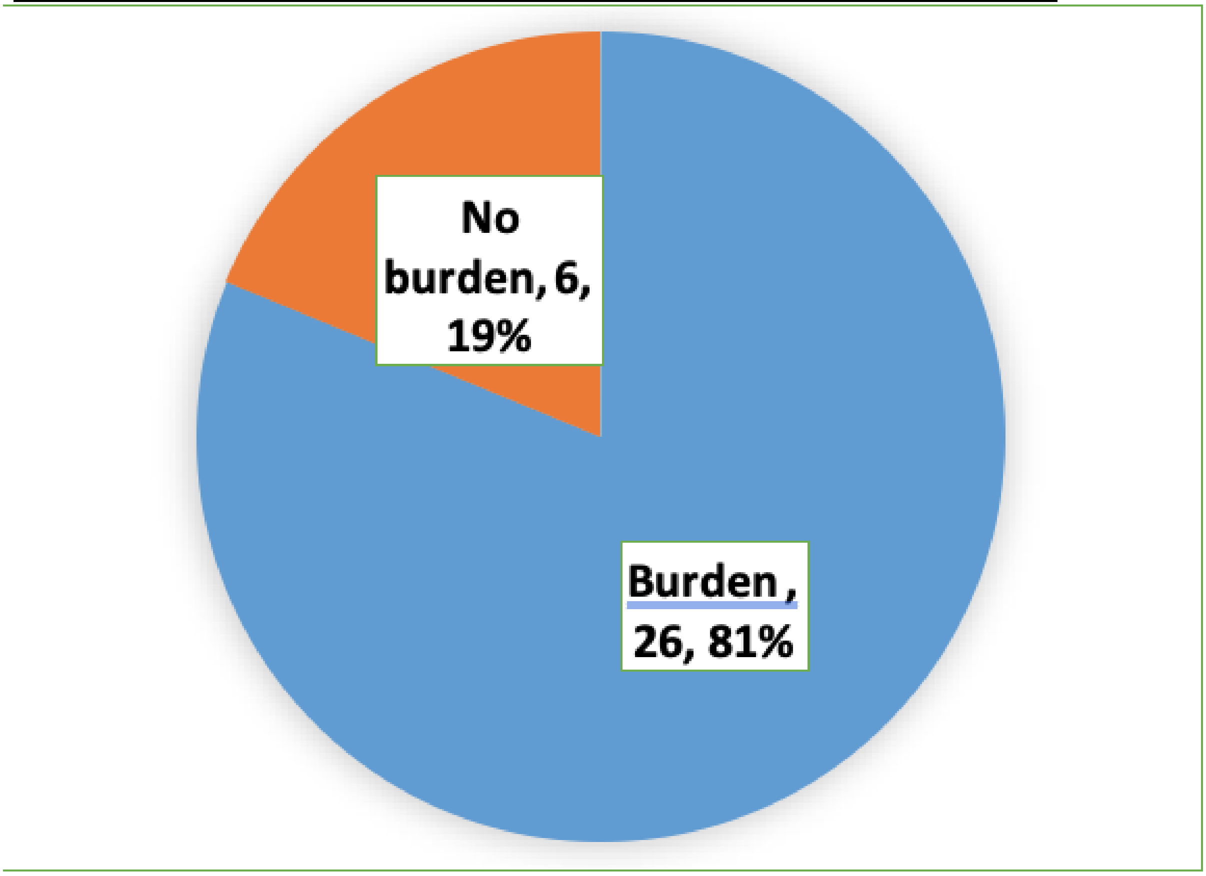

Figure 3: Percentage of Burden of Caregiving

Table 4.5 demonstrates that of the 81.3%(n=26) who reported burden of care,80.8%(n=21) were women, and 19.2%(n=5) were male. Whereas the 18.8% who reported no burden 4were women and 2 were men.

Table 4: Sex Distribution in Association with the Burden of Caregiving

Gender	Burden n=26 and %	No Burden n=6 and %
Female	21(80.8%	4(66.7%)
Male	5(19.2%)	2(33.3%)

Table 5: Burden of Caregiving

Level of burden	**Frequency** *(n=32)*	**Percent**
No /little burden	6	18.75
Mild -Moderate	23	71.88
Moderate -Severe	3	9.37
Severe burden	0	0

Level of burden: The score on the ZBI was used to measure the level of load imposed. Those who scored less than 20 were placed in the category of having no , little burden whereas those who scored between 21 and 40 were placed in the category of having a mild to moderate burden, and they made up 71.88% (n = 23) of the caregivers.9.37% of respondents fell into the moderate-to-severe burden category, with scores ranging from 41-60.There was no severe load recorded because none of the caregivers scored higher than 60 percent.

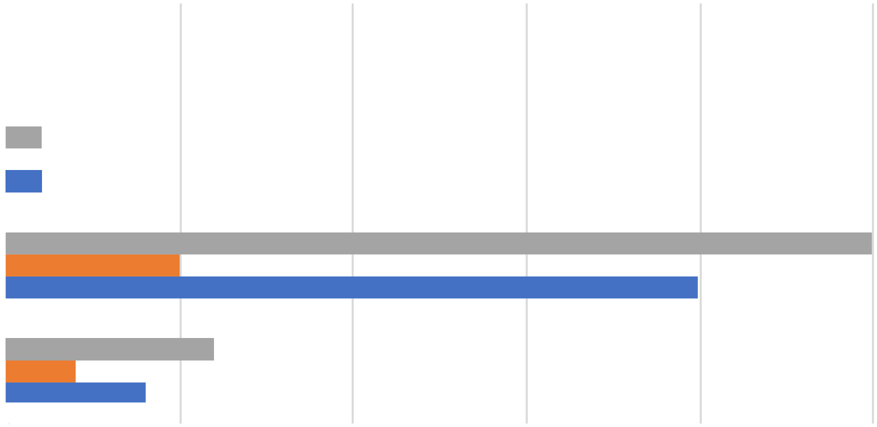

Figure 4: Sex Distribution in Association to the Levels of Burden

4.4. Causes of Caregiving Burden

The study sought to assess causes of the caregiving burden among the caregivers of family members with spinal cord injuries.

Means and standard deviations were calculated for each of domain.

Overall, among the five domains, the financial burden domain had the highest mean score of 2.47+/- the self-criticism, fear, and uncertainty-related burden domain had the second highest mean score of 2.13+/-0.56 while the negative emotional burden domain had the lowest mean score of 0.63+/-0.55. (Table 7)

Each domain contained different questions whose individual mean score was also calculated: **Negative emotion domain** - question 4'do you feel embarrassed over your relative behaviour?' scored the highest mean score of 0.94+/-0.55 while question 13 "Do you feel uncomfortable about having friends over because of your relative? Scored the lowest mean score with 0.37+/- 0.75.

Exhaustion burden-question 17 had the highest score with 1.31+/_1.20'Do you feel you have lost control of your life since your relative's il ness 'while question 18 scored the lowest 0.75+/- 0.92 'Do you wish you could leave the care of your relative to someone else'

Financial burden–question 15 mean score 2.47+/- 1.19' Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?'

Patient's dependency and demand for care-related burden--question 8 scored the highes t of 1.66 +/-1.15 'Do you feel your relative is dependent on you?' question 14 the lowest at 1.34+/-1.143.' Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?'

Personal family and social life-related burden-question 2 had the highest score of 1.03+/0.86. 'Do you feel that because of the time spent with your relative that you don't have enough time for yourself?' question 6 had the lowest at 0.50+/-0.67.' Do you feel that your relatives currently affect your relationship with other family members or friends in a negative way?'

Self-criticism, fear, and uncertainty-related burden- question 20 had the highest score of 2.62 +/-0.94 .'Do you feel you should be doing more for your relative?' with question 19 scoring the lowest 1.34+/- 1.43. Do you feel uncertain about to do about what to do about relatives?

Table 6: Causes of Caregiving Domains

Domain	**Mean ± SD**
Negative emotion burden	0.63 ± 0.55
Exhaustion burden	1.14 ± 0.90
Personal family and social-life-related burden dependency and demand for care-related burden criticism, fear, and uncertainty-related burden	0.79 ± 0.41Patient's 1.52 ± 0.61Self- 2.13 ± 0.56
Financial	2.47 ± 1.19

Item	**Negative emotion burden**	**Mean ± SD**
4	Do you feel embarrassed over your relative behaviour?	0.94 ± 1.05
5	Do you feel angry when you are around your relatives?	0.41 ± 0.88

Table 7: Causes of Caregiving Burden Per Item

9	Do you feel strained when you are around your relative?	0.78 ± 0.98
13	Do you feel uncomfortable about having friends over because of your relative?	0.37 ± 0.75
	Exhaustion burden	
16	Do you feel that you will be unable to take care of your relative much longer?	1.25 ± 1.32
17	Do you feel you have lost control of your life since your relative’s illness?	1.31 ± 1.20
18	Do you wish you could leave the care of your relative to someone else?	0.75 ± 0.92
	Personal family and social-life related burden	
2	Do you feel that because of the time spent with your relative that you don’t have enough time for yourself?	1.03 ± 0.86
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	1.00 ± 1.14
6	Do you feel that your relatives currently affect your relationship with other family members or friends in a negative way?	0.50 ± 0.67
10	Do you feel your health has suffered because of your involvement with your relative?	0.59 ± 0.84
11	Do you feel you don’t have as much privacy as you would like because of your relative?	0.75 ± 0.76
12	Do you feel that your social life has suffered because you are caring for your relative?	0.84 ± 0.88
	Patients dependency and demand for care-related burden	
1	Do you feel that your relative asks for more help than he/she needs?	1.56 ± 0.95
8	Do you feel your relative is dependent on you?	1.66 ± 1.15
14	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	1.34 ± 1.43
	Self-criticism, fear, and uncertainty-related burden	
7	Are you afraid what the future holds for your relative?	2.03 ± 0.97
19	Do you feel uncertain about to do about what to do aboutrelatives?	1.34 ± 1.04
20	Do you feel you should be doing more for your relative?	2.62 ± 0.94
21	Do you feel you could do a better job in caring for your relative?	2.16 ± 0.81
22	Overall, how burdened do you feel in caring for your relative?	2.50 ± 1.30
	Financial	
15	Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?	2.47 ± 1.19

4.5. Association Between Socio-Demographic Traits and Burden of Caregiving

The study sought to find out relation between socio-demographic traits and the burden of caregiving.

The results on Table 4.9 shows that there was no socio-demographic characteristic that was found to be statistically associated with burden of care, however it can be also be noted that those aged above 45.0 years were 2.3 times the odds of having a higher burden of care, also females were 2.1 times more at odds of having a higher burden than males. Participants with the level of education at Secondary and below were 2.0 times the odds of having higher burden of care than those with Tertiary.

The results in Table 9show that there is not much difference that is statistically significa nt between the mean score of the caregivers who were aged more than 45yrs and less 45 years in relation to the burden of care.

Less than 45years had a mean score of 29 +/-7.5 whereas those caregivers who were more than 45years had 26.5+/-8.3.

Table 8: Association Between Socio-Demographic Traits and Burden of Caregiving

	Burden, *n=26*	**No Burden,** *n=6*	**OR (95% CI)**	**p-value**
Age of caregiver, *n (%)*				
≤45	12 (46.2)	4 (66.7)	Reference	
>45	14 (53.8)	2 (33.3)	2.3 (0.4 – 15.1)	0.373
Marital status of caregiver, *n (%)*				
Married	23 (88.5)	6 (100.0)	-	-
Single/Widowed	3 (11.5)	0 (0.0)		
Gender of caregiver, *n (%)*				
Male	5 (19.2)	2 (33.3)	Reference	
Female	21 (80.8)	4 (66.7)	2.1 (0.3 – 14.9)	0.458
Caregiver education, *n (%)*				
Secondary and below	13 (50.0)	2 (33.3)	2.0 (0.3 – 12.9)	0.461
Tertiary	13 (50.0)	4 (66.7)	Reference	

Table 9: Association Between Socio-Demographic Traits and Burden of Caregiving

Age of caregiver	**N**	**Mean ± SD**	**p-value**

≤45	16	26.5 ± 8.3	0.230
>45	16	29.9 ± 7.5	
Marital status of caregiver			
Married	29	28.1 ± 8.2	0.862
Single/Widowed	3	29.0 ± 7.6	
Gender of caregiver			
Male	7	28.3 ± 10.3	0.981
Female	25	28.2 ± 7.5	
Caregiver education			
Secondary and below	15	29.7 ± 7.8	0.323
Tertiary	17	26.9 ± 8.2	

CHAPTER 5: DISCUSSION

5.1. Introduction

In this chapter, we will discuss the findings of the study, coming to a conclusion about those findings, and then offering a recommendation based on those findings.

5.2. Discussion

The results of this investigation indicate, the most prevalent cause of injury is a motor vehicle accident, which accounted for 53.1% of all reported injuries. On the other hand, stab wounds and gunshot injuries accounted for 3% of all reported injuries. Most fatalities were due road accidents, accounting for 55% of the cases that were analysed, according to a retrospective study that was carried out at KNH and published in 2007 by Gichuhi.

According to the findings of one study (Parajuli 2020), road traffic accidents were responsible for 78% of spinal cord injury cases in eastern Nepal, whereas falls from trees, hills, or buildings were responsible for 22% of spinal cord injuries. There are similarities in these two studies with a difference in their percentages which could be attributed to the poor infrastructures where new roads are constructed and old roads not repaired in eastern Nepal leading to high incidences of road traffic accidents.

5.2.1. Burden of Care

According to the findings of the study, carers do, in fact, feel the stress of providing care for their loved ones, albeit to varying degrees depending on the individual. The standard deviation for the caregiver burden score was 8, while the mean score was 28.2. In addition, the results of this research showed that the majority of participants 71.88% reported experiencing a load that was mild to moderate, while 18.75% reported suffering no or very little stress, and none reported a burden that was severe. According to the findings of a study that was conducted in Iran by Khazaeipour et al, the majority of caregivers suffered mild to moderate strain, with 43.6% of them reporting such, and 11.7% reporting severe hardship.

In a parallel study conducted in China, closely resembling our own, Hai-Ping Ma et al. revealed that a substantial 88% of primary caregivers experienced a moderate-to-severe burden. Moreover, the mean score they obtained on the Zarit Caregiver Burden Interview (22-Q) was 52.9 ± 11.6, significantly higher than the mean score obtained in our study. This striking disparity can be attributed to the social and cultural norms that are prevalent on the respective continents, as well as the prevalence of conventional models of family organization. Social support, which varies greatly from country to country, is an additional component that can significantly ease the burden of caregiving. In the context of social support, "effective training" refers to the process of preparing caregivers for this position "providing educational and occupational opportunities" as well as "possible financial supports" are also examples of social support.

According to the outcome of a research conducted in Nepal in 2022, caregivers do feel the weight of their responsibilities.63.4% of participants reported moderate-severe load, 18.3% reported severe burden, and 7% reported no or little burden (P.sinha et al 2022), despite the fact that in our study there was no report of severe burden.

Approximately 38% of patients had a full spinal cord injury. Roughly ,34% that is one-third of those providing care to patients were the patients' own spouses. The age of the caregiver was 42.9 years, with a standard deviation of 1.2 years. The majority of caregivers (44%) reported having a moderate amount of hardship. (Gopal et al 2017). The outcome of the research are comparable to those of our study, in which the average age of the caregiver was 46.5 years, the majority of caregivers (71.88%) reported having a moderate burden, and 34% of caregivers were spouses.

It is possible that the disparities in the different levels of burden that have been reported can be linked to the differences in the number of quadriplegics that have been reported in the various studies. When compared to quadriplegics, paraplegics are only partially reliant on their caretakers, while quadriplegics are wholly dependent on those who assist them. Thus, studies with a sizeable number of quadriplegics will report sever burden.

5.2.2. Causes of Burden

According to the results of this research, the financial strain was rated as the most burdensome. This may be ascribed to the financial duties that they have to cater for, such as the medical expenses owing to the hospital appointments and physiotherapy, medical aids (special mattress to prevent pressure sore, special stockings to prevent deep venous thrombosis, feeding aids, diapers), basic needs (food, clothing, and shelter), all of which are occurring in the midst of the current economic crisis. In addition, this might be attributed to the fact that they are unable to find work. The internal criticism, anxiety, and unpredictability domain also recorded a high score; this may be because to the sudden adoption of their position of caregiving, for which they were not prepared and for which they have no training in the aftercare of the spinal cord injuries. (Kafle et al, 2019) and other research came to the same conclusions, indicating that patients and members of their families frequently have to visit a number of different medical facilities before they can choose the one that most adequately satisfies their requirements.

The country as a whole suffers from a severe lack of trauma centres and treatment facilities, as well as a shortage of qualified healthcare staff, which exacerbates the problem. As a consequence of this, patients and members of their families carry heavier burdens, not only in terms of their physical health but also in terms of their mental well-being and their financial situation. The burden of financial responsibility was mentioned in this study. According to the findings of a study that was conducted in Nepal, 72.0% of primary caregivers were facing some type of financial trouble, which accounts for 91.0% of caregiver burdens (Adhikari.2017). This study was carried out to investigate the burdens that primary caregivers face. According to Robinson et al. (2009), the most powerful and consistent predictors of the various physical and psychological outcomes that were taken into consideration here were the absence of adequate long-term care services and the presence of financial issues. Both of these factors were shown to be present.

A great number of additional studies came to quite similar conclusions regarding the financial difficulties. (P. Sinha et al. 2020) showed that among the reasons of burden that were reported in this study, the ones that seemed to create the most concern were associated to finances, as well as self-criticism, fear, and uncertainty concerns. Additionally, this study found that the ones that seemed to give the most concern were linked to reasons of burden that were reported in other studies. These concerns have also been uncovered and documented in previous research carried out in Nepal. According to the findings of the research that was conducted in Nepal, seventy-two percent of primary caregivers were going through some kind of financial problem, which accounts for ninety-one percent of the responsibilities that are placed on caregivers (Adhikari.2017). Other studies that were quite comparable to this one did demonstrate a time-dependent burden in addition to a developmental burden; however, the instrument that was used to quantify caregiver stress was different in those other research (Patrizia Maitan et al 2018).

The varying political, cultural, and social economic circumstances of the nations in which the research was carried out are likely to blame for the disparities in the scores obtained for the various categories of burden-causing factors that were reported.

5.2.3. Socio-Demographic Characteristics

This study revealed that the majority of participants were women, constituting 78.1%, and the average age of caregivers was 46.5 years. Similar patterns were observed in studies conducted in other countries such as Nepal and Iran, where the majority of caregivers were women, often married. However, certain studies also noted that parents formed the larger portion of caregivers (Ghazawy et al., 2020). The predominant presence of female caregivers (aged 18–70) in this study reflects historical gender roles within families and society. Typically, wives and mothers assume the responsibility of caring for family members with spinal cord injuries, while husbands or fathers are more focused on work, income generation, and are generally less directly involved in the caregiving for individuals with SCI.

While this study did not find a statistically significant relationship between caregivers' gender and the burden of care, it did reveal that being female increased the odds of experiencing a high burden level by 2.1 times. Nevertheless, consistent with many similar studies, our findings indicate that older caregivers, aged over 45, face a higher burden, with 2.3 times the odds. This could be attributed to their overall ability, energy levels, and potentially lower adaptability to the new caregiving role compared to younger individuals. Elder caregivers may also contend with medical conditions, whether directly related to aging or not, contributing to an increased care burden that demands attention and care.

In terms of sociodemographic characteristics, this study did not find any statistically significant associations, but it did observe that females were more likely to experience the burden of care, and caregivers aged over 45 were prone to caregiving burden. A similar study in Turkey (Secinti et al., 2017) reported that caregiver age, sex, educational level, and physical health did not significantly predict the burden of care.

The majority of caregivers in this study were literate, with many having tertiary or secondary education. Those with higher educational levels (tertiary education) were less likely to experience the burden of care, potentially due to improved knowledge about SCI individuals, their needs, and coping strategies.

Research by Gerhart et al. indicated that as people with SCI age, they may require more physical support from caregivers. Spouses who were caregivers reported higher levels of somatic depression, depressive mood, anger, and resentment than those who were not caregivers. Schulz et al. observed high levels of depression and burden in caregivers of people with SCI.

This study revealed that thoracic injuries were the most common, followed by lumbar and cervical injuries, consistent with findings from Nogueira et al. (2012). Caregivers experienced high levels of both time and development burden. Despite the majority of caregivers being under 40 and literate, age and educational level did not significantly impact caregiver pressures, according to A. Conti et al. (2021).

The amount of physical secondary issues in care recipients was found to be proportionally related to the strain experienced by family caregivers of people with SCI. Caregivers with lower education levels, care recipients with tetraplegia and incomplete injuries, and those providing support for a longer period reported higher levels of burden. Psychological status of care recipients did not contribute significantly to caregiver strain in this investigation (P. Sinha et al). Younger and better-educated caregivers had less burden, possibly due to a better understanding of patient requirements and the ability to develop coping mechanisms. Completeness of SCI significantly influenced caregiver burden, with employment status and education of caregivers also found to be significantly associated with caregiver burden (Gopal et al., 2017).

Caregiver stress was found to be proportional to the severity of the injury and the duration of caregiving. Early caregivers may have initially held an optimistic outlook on patient recoveries, but as they realized the permanence of the damage, frustration and burden increased. Additionally, caregivers' physical and mental abilities tend to decline with age.

5.3. Conclusion

The purpose of this study was to investigate whether or not carers of patients with spinal cord injuries experience challenges as a result of the caregiving responsibilities they have for loved ones who have experienced spinal cord injuries. The term "burden of care" refers to the physical, emotional, social, and financial obstacles that individuals face on a daily basis as a result of providing assistance to family members in the performance of life's activities. In addition, the purpose of the study was to investigate the socio-demographic features of the patients as well as the caregivers for those patients, and how those factors contributed to the difficulty of providing care for those patients. The findings of our research showed that the majority of people had a mild to moderate burden. The main features of the caregiver's burden were things like self-criticism, fear, and worry about the future of the patient, as well as financial concerns. There are certain socio-demographic variables, such as education level, gender, and age, that did contribute to the stress that caregivers carried.

Therefore, the findings of the study indicated that caregivers do face difficulties in providing care for a loved one who has a spinal cord injury. If the stress associated with providing care is not addressed, it may have a detrimental effect on the caregiver's physical and mental health, as well as their social life, financial situation, and quality of life in general, ultimately leading to poor quality of life for both the caregiver and the patient aftercare.

5.4. Recommendation

The study has shed light on the elements that do influence the difficulty of caregiving. The findings could be used by the Ministry of Health to formulate policies and for future planning, particularly on issues that pertain to patients with spinal cord injuries and their caregivers. It is possible that the load could be lessened by addressing the need for counselling, training, and education on spinal cord injuries, as well as by raising awareness about the difficulty of providing care.

Have a similar study done in the community set up to be able to have a wider scope of the situation

5.5. Study Closure Plan

The study's associated digital and paper copies were clearly labelled and filed away according to their respective categories.

5.6. Study Dissemination Plan

The study's results were shared with the medical research department at Kenyatta National Hospital and the university library for future use. A scholarly journal will eventually publish the results of this investigation.

STUDY TIMEFRAME

Activities	October to february 2023	March to May 2023	Jun-23	Jun-23	Jun-23
Proposal writing and presentation	🟨				
Ethical approval		🟩			
Data collection			⬛		
Data analysis				🟥	
Results and thesis submission					🟦

STUDY BUDGET

Category	Total (Kenyan shillings)
Proposal development	10,000
Ethical clearance	2,000
Data collection	8,000
Data Analysis(statistician)	15,000

Thesis printing-drafts Copies	5,000 15,000
Contingency fund	5,000
Total	**60,000**

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APPENDICES

Zarit Burden Interview

Circle the response that best describes how you feel.

	Never	*Rarely*	*Sometimes*	*Quite frequently*	*Nearly always*
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Scoring instructions: Add the scores for the 22 questions. The total score ranges from 0 to 88. A high score correlates with higher level of burden.

(American Academy of family physician, 2020)

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

The objective of the study is to
determine the level burden of care among the caregivers of individuals with spinal cord injury at National Spinal Injury Referral Hospital.

1. Age

____

2. Sex

Mark only one oval.

○ Male
○ Female
○ Other: _______________________________

3. Residence

____

4. Reigion

Mark only one oval.

○ Catholic
○ Muslim
○ Protestant
○ Hindu
○ Other: _______________________________

5. Highest form of education

Mark only one oval.

○ Informal
○ Primary
○ Secondary
○ Tertiary(College or University)

6. Marital status

Mark only one oval.

○ Single
○ Married
○ Divorced
○ Widow/ed

7. Occupation

Mark only one oval.

○ Employed
○ Unemployed

8. Income

Mark only one oval.

○ Option 1

9. Kinship between the caregiver and the recipient

Mark only one oval.

○ Spouse
○ Parent
○ Child
○ Sibling
○ Other: ____________________

10. Level of injury

Mark only one oval.

○ Cervical
○ Thoracic
○ Lumbar

11. Duration of injury

____

Socio-demographic characteristics of the patient questionnaireAge

in years…………

Sex: female ………….

Male…………….

Causes of injury: Road Traffic Accidents…………

Infections (Specify)…………….

Gunshot injury…………….

Stab wound…………………

Fall from height…………….

Occupational (lifting of heavy objects………….

Kiswahili translation of the socio-demographic characteristics

(Mgonjwa)

1. Umri katika miaka………………..

2. Jinsia:kiume …………………..

Kike………………………….

3. sababu ya kuumia: Ajali ya Barabarani………..

Kuugua ugonjwa wa maambukizi(kifua kikuu)……………….

Kuanguka kutoka urefu……………………

Jeraha la risasi……………………………..

Jeraha la kisu.. Kiswahili translation for socio-demographic characteristics

1.Umri: katika miaka….. ……………………………..

2. Jinsia:

kiume………

kike……………

3. Hali ya ndoa :

Moja …………

Kuolewa………..

Kinachotengwa………….

Talaka…………..

Mjane………….

4. Kiwango cha juu cha elimu: Shule ya msingi………….

Shule ya secondary………

Chuo kikuu

Kutoenda /kumaliza elimu………

5. Kazi: Ajira………..

Asiyekuwa na ajira……….

6. Makazi…………..

7. Dini:wakatoliki……

Wakristo wasioshiriki kanisa la katoliki………….

Waislamu………..

Dr.Catherine Wanjiku Waweru who is currently a medical resident at the Department of Psychiatry, University of Nairobi, is running a research project on the burden of care among caregivers of individuals with spinal cord injuries at the National Spinal Injury Referral Hospital and would like to request for your participation.

Study purpose

The goal of this research project is to determine the level of burden of care among the caregivers of individuals with spinal cord injuries at the National Spinal Injury Referral Hospital.

Study procedure

You have a full choice whether or not to join this study, and if you do, you can withdraw at any moment without facing any repercussions at the hospital. There will be no compensation provided to you for taking part in the research.

Should you decide to engage in the research, you'll have to respond to some questions regarding the study title, the questions will be in 2 categories

Part 1 will include questions about socio –Demographic factors

Part 2 will comprise questions pertaining burden of caregiving among caregivers

Potential Benefits

The findings of this study will be useful to the administration and the social department in terms of increasing their awareness of the challenges faced by those who provide care for family members who have spinal cord injuries. The findings and recommendations of the study will be communicated by the primary investigator to the medical superintendent, hospital Administrator, and the social department of NSIRH. These individuals may use the information to develop initiatives that will assist in easing the strain of caregiving borne by caregivers.

Risks and Discomfort

A potential risk of the study may include concerns about personal privacy as a result of the research, you can rest assured that every piece of information you provide will be treated as strictly secret.

Regarding the confidentiality of the information provided by respondents, no names or other personal identifiers will be used in any publications that result from the research. The primary investigator and the statistician are the only ones who will have access to the data that was collected. The questionnaire as well as the reports from the zarit burden interviews will be kept in a lockable container, and the primary investigator will be the only person who has access to the key.

Additional Information

If you have any question or concerns about participating in this research that has not been answered above, you can reach the following people:

Principal investigator:

Dr. Catherine. W. Waweru

Tel:0728640748

Email: kwanjiku693@gmail.com

CONSENT FORM (Statement of consent)

Participants statement

I have read this content form or had the information read to me. I have had a chance to discuss this research with the researcher. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw anytime.

I agree to participate in this research study: Yes No

Participants signature or Thumb stamp………………...Date……….

Researchers statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and willingly and freely given his /her consent.

Dr. Catherine Wanjiku

Signature…………………Date………

VIAMBATANISHO VIAMBATANISHO A: FOMU YA RUHUSA YAMWANAFUNZI

Utangulizi

Daktari Catherine Wanjiku Waweru ambaye kwa sasa ni mkazi wa tiba katika Idara ya Saikolojia, Chuo Kikuu cha Nairobi, anafanya mradi wa utafiti kuhusu mzigo wa uangalizi kwa walezi wa watu wenye majeraha ya uti wa mgongo katika Hospitali ya Rufaa ya Majeraha ya Utio wa Mgongo ya Kitaifa na anapenda kuomba ushiriki wako.

Lengo la utafiti

Lengo la mradi huu wa utafiti ni kubainisha kiwango cha mzigo wa uangalizi kwa walezi wa watu wenye majeraha ya uti wa mgongo katika Hospitali ya Rufaa ya Majeraha ya Utio wa Mgongo ya Kitaifa.

Mchakato wa utafiti

Una uhuru kamili wa kuamua ikiwa utajiunga na utafiti huu au la, na ikiwa utaamua kujiunga, unaweza kujiondoa wakati wowote bila kukabiliwa na madhara yoyote katika hospitali. Hakutakuwa na fidia inayotolewa kwako kwa kushiriki katika utafiti.

Ikiwa utaamua kushiriki katika utafiti, utalazimika kujibu maswali kuhusu kichwa cha utafiti. Maswali hayo yatakuwa katika makundi 2:

Sehemu ya 1 itajumuisha maswali kuhusu sababu za kijamii na kiuchumi

Sehemu ya 2 itajumuisha maswali kuhusu mzigo wa uangalizi kwa walezi

Manufaa Yanayowezekana

Hitimisho la utafiti litakuwa na manufaa kwa utawala na idara ya kijamii katika kuongeza uelewa wao wa mzigo wa uangalizi kwa walezi wa wanafamilia wenye majeraha ya uti wa mgongo. Mtafiti mkuu atashiriki matokeo ya utafiti na mapendekezo na msimamizi wa matibabu, msimamizi wa hospitali, na idara ya kijamii katika NSIRH ambao wanaweza kuitumia kuja na mikakati ya kupunguza mzigo wa uangalizi kwa walezi.

Hatari na Usumbufu

Hatari inayowezekana ya utafiti inaweza kujumuisha wasiwasi kuhusu faragha ambapo unaweza kuwa na uhakika kuwa kila taarifa utakayoshiriki itakuwa ni siri.

Usiri: Hakutakuwa na jina au kitambulisho chochote cha kibinafsi kitakachotumika katika machapisho ya washiriki yanayotokana na utafiti huu. Data iliyokusanywa itakuwa inapatikana tu kwa mtafiti mkuu na mchambuzi takwimu. Swali la utafiti na ripoti ya mahojiano ya mzigo wa Zarit zitahifadhiwa katika kabati lililofungika na ufunguo utashughulikiwa tu na mtafiti mkuu.

Maelezo Zaidi

Ikiwa una swali au wasiwasi wowote kuhusu kushiriki katika utafiti huu ambao haujajibiwa hapo juu, unaweza kuwasiliana na watu wafuatao:

Mtafiti mkuu:

Dkt. Catherine. W. Waweru

Simu: 0728640748

Barua pepe: kwanjiku693@gmail.com

FOMU YA RUHUSA (Kauli ya ruhusa)

Kauli ya mshiriki

Nimesoma fomu hii ya ruhusa au habari imesomwa kwangu. Nimepata fursa ya kujadili utafiti huu na mtafiti. Nimepata majibu ya maswali yangu kwa lugha ninayoelewa. Hatari na manufaa yameelezewa kwangu. Ninaelewa kwamba ushiriki wangu katika utafiti huu ni wa hiari na naweza kuchagua kujiondoa wakati wowote.

Nakubali kushiriki katika utafiti huu: Ndiyo Hapana

Sahihi ya mshiriki au Muhuri wa kidole………………...Tarehe……….

Kauli ya mtafiti

Mimi, ambaye nimesaini hapa chini, nimeelezea kikamilifu maelezo muhimu ya utafiti huu kwa mshiriki aliyeitwa hapo juu na ninaamini kuwa mshiriki ameelewa na ametoa ridhaa yakekwa hiari na kwa uhuru.

Dkt. Catherine Wanjiku Sahihi…………………Tarehe………