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RESEARCH PROJECT

TITLE

A STUDY TO DETERMINE CAREGIVER EXPERIENCES AND EXPECTATIONS IN CARING FOR PATIENTS WITH TRAUMATIC SPINAL CORD INJURIES AT UNIVERSITY TEACHING HOSPITAL.

BY

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
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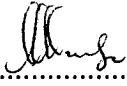
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DECLARATION

I hereby declare that the work presented in the study in partial fulfilment for attainment of the Bachelor of Science Degree in Physiotherapy is purely as a result of my individual effort and hard work and that it has not been presented anywhere else for any other degree.

Signed.....

Student

Signed.....

Supervisor

APPROVAL

This dissertation is presented to the University of Zambia, School of Medicine in partial fulfilment of the requirement of the BSc Degree in Physiotherapy.

Rex Ngoma

BSc Physiotherapy Student

Computer number (26118068)

Examiners

Signature..... Date.....

Signature..... Date.....

APPROVAL

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Rex Ngoma

BSc Physiotherapy Student

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Examiners

Signature..... Date.....

Signature..... Date.....

DEDICATIONS

I dedicate this research to my family, especially my mother, and all my close friends. They have all played a significant role in my education and well being. Special mention goes out to my elder brother Eric, who has been with me through thick and thin. I thank him whole heartedly for believing in me when no one else did and for sponsoring me throughout my education. I also thank Chalwa Syasyiipa for all the support and comfort through this difficult and challenging journey. But most of all I thank God for the strength and courage he has given me to overcome the challenges I faced and for simply giving me this opportunity.

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ABSTRACT

BACKGROUND AND PURPOSE

Spinal cord injuries are a serious problem and a major case of disability in Africa. A lot of individual have accidents that cause these injuries each year and many of these patients are cared for in the home setting, by family caregivers. The care giving experience is often stressful and can result in negative physical, social, emotional and mental health outcomes for the family caregiver.

The purpose of this study was to determine caregiver's experiences and their expectations in caring for these patients with spinal cord injuries at the University Teaching Hospital, Lusaka.

METHODOLOGY

The study was qualitative and used a semi-structured questionnaire as a data collection tool. The data was collected by doing face to face interviews of the respondents using the aid of the semi-structured questionnaire. The study sample was informal caregivers of patients with traumatic spinal cord injuries who have been caring for their patient for not less than 2 weeks. The study site was the University Teaching Hospital.

RESULTS

The results showed that the caregivers have several needs which include tackling the occurrence of pressure sores, patient's infections means to provide comfort to the patient, comfort of the patient and other issues like privacy in the hospital. The caregivers also showed lack of information and know-how on how to tackle these problems. The study also revealed that the caregivers of SCI patients are experiencing social, emotional, psychological, physical and economical hardships without any attention being given to them. All these hardships also being exaggerated by the disappointment they face after initially having unrealistic expectations in the recovery the SCI they are caring for.

CONCLUSION

The study therefore revealed the complexity of the care giving role and its challenges. It also highlighted the importance of a care giver in not only the management spinal cord injuries but also other chronic conditions of this nature.

LIST OF ABBREVIATIONS

ADLs	Activities of Daily Living
CHAZ	Churches Health Association of Zambia
CSO	Central Statistical Office
LDHMB	Lusaka District Health Management Board
MoH	Ministry of Health
SCI	Spinal Cord Injury
UTH	University Teaching Hospital
WHO	World Health Organisation

LIST OF KEY WORDS

Caregivers

Experiences

Expectations

Patients

Spinal cord injuries

Traumatic

DEFINITIONS OF KEY TERMS

Caregivers: refer to unpaid relatives or friends of a disabled individual who help that individual with his or her activities of daily living.

Experiences: is the knowledge of or skill in or observation of something or some event gained through involvement in or exposure to that thing or event.

Expectations: these are strong beliefs that something will happen or will be the case.

Patients: these are people receiving or registered to receive medical attention, care, or treatment.

Spinal cord injury: refers to any injury to the spinal cord that is caused by trauma instead of a disease.

Traumatic: relating to or denoting physical injury.

CHAPTER ONE

1.1 BACKGROUND/INTRODUCTION

Officially the Republic of Zambia is a landlocked country in Southern Africa. The neighbouring countries are the Democratic Republic of the Congo to the north, Tanzania to the north-east, Malawi to the east, Mozambique, Zimbabwe, Botswana and Namibia to the south, and Angola to the west. The capital city is Lusaka, located in the south-central part of the country. The population is concentrated mainly around the capital Lusaka in the south and the Copperbelt to the northwest. With a tropical climate this country consists mostly of high plateau, with some hills and mountains, dissected by river valleys. At 752,614 km² (290,586 sq. mi) it is the 39th-largest country in the world (C.S.O, 2000).

Zambia is one of the most highly urbanized countries in sub-Saharan Africa with 44% of the population concentrated in a few urban areas along the major transport corridors, while rural areas are sparsely populated. Unemployment and underemployment in urban areas are serious problems, while most rural Zambians are subsistence farmers. The population comprises approximately 72 ethnic groups, most of which are Bantu-speaking. In the year 2000 the population of Zambia stood at 10,285,631 of 5,070,891 were males and 5,219,740 were females (C.S.O, 2000)

The Ministry of Health (MoH) of the Republic of Zambia is the major health provider of the nation running several clinics and hospitals nationwide. However, only 3 major referral hospitals are in the whole country. These hospital's in question being, Ndola Central Hospital, Kitwe Central Hospital and the University Teaching Hospital (www.ZambianDoctors.com).

The University Teaching Hospital is a hospital in Lusaka, Zambia. It is the largest hospital in Zambia, with 1655 beds. It is a teaching hospital and, as such, is used to train local medical students and nurses. UTH offers both inpatient and outpatient care and is a centre for specialist referrals from across the country (www.ZambiaDoctors.com).

1.2 STATEMENT OF THE PROBLEM

Patients with Spinal Cord Injuries (SCI) involuntarily place a heavy burden on the health care system. Therefore all research to further improve their management is always welcome. The burden is not only in the phase of acute care, but also in the first years following injury. It is inevitable to have secondary complications which will need further hospitalization (e.g. urinary tract infection and pressure sores). There is also need for home care services and for extra physician contacts. And other health care problems that are more common in people with SCI are psychological disorders (Evans et al, 2007).

Zambia being a low income country, acquiring specialized care for patients with SCI is financially straining. The average Zambian family cannot afford these services. Therefore the major role in the management of these patients will be played by the Caregivers. Caregivers refer to unpaid relatives or friends of a disabled individual who help that individual with his or her activities of daily living (Levine, 2004). Patients with SCI are very dependent on these caregivers. As a medical practitioner, recognition of the role of the caregiver and inclusion of the caregiver in the rehabilitation will be beneficial to the SCI patient (Atchison et al, 2007). Atchison and the other author's further state that knowing the caregivers experiences and expectations will provide a better understanding of their role and it will prove easier to work with them. Experiences are the knowledge of or skill in or observation of something or some event gained through involvement in or exposure to that thing or event (Coanes and Stevenson, 2003). By virtue of being a caregiver, these people have first-hand knowledge and skill of handling the patients with SCI, which can be incorporated in the management. Having knowledge of their expectations is very vital in the patient-caregiver relationship over the long run of the rehabilitation of these patients. An expectation is a strong belief that something will happen or be the case (Coanes and Stevenson, 2003). We need to find out what is motivating the caregiver to continue providing the care, what their hopes are and if these hopes are realistic. This knowledge is important because caregiving is stressful and can result in negative physical, social, psychological, spiritual and mental health outcomes for the family. There is clear evidence from earlier research that caregivers experience a lot of demands that can cause

insufficient rest, interrupted sleep, chronic fatigue, economic hardships and depression, all which place caregivers at risk of emotional and physical problems (George and Gwyther, 1996).

The University Teaching Hospital being the country's largest referral hospital is an ideal location for being in contact with patients with spinal cord injuries. In recent years there has been a significant rise in spinal cord injuries from the increased number of road traffic accidents due to the increased number of vehicles on the Zambian roads. Other reasons for this significant rise are due to the poor safety standards in most work environments leading to several accidents including spinal cord injuries.

The researchers' motivation originated from experience of handling SCI patients at the University Teaching Hospital. Most of these patients are unable to afford to manage the spinal cord injuries surgically as the medical fees are too expensive and therefore the management is done conservatively where a caregiver plays a major role. These caregivers range from spouses, brothers, sisters, nephews, nieces, children and other family members.

1.3 SIGNIFICANCE OF THE STUDY

An effective patient management program should be tailored to a patient's individual and specific needs. To determine these individual and specific needs a full assessment of the patient should be done. The caregiver, being in contact almost all the time can be a very important source of this information (experiences). The caregiver can also give back feedback on how the treatment modalities being used are affecting the patient. It is also important to note the effect the condition of the patient has on the caregiver. A common outcome is Caregiver stress or exhaustion. Caregiver stress is a mixture of physical, emotional, and mental exhaustion which leads to fatigue, anxiety attacks, and even depression (Epstein-Lubow et al, 2010). If this happens it has detrimental effects on the management of the patient. In other cases it is also important to notice if the patient is pessimistic or too optimistic. Either of them has a negative effect.

While much has been researched regarding the need for the benefits of health promotion, caregivers have not been the major focus of research in health promotion. Among many key factors affecting the caregivers health promotion practices are caregiving self-efficacy and social support reactions to caregiving. Burton et al (1997) found that caregivers with low level of caregiving self-efficacy had negative health behaviours compared with caregivers with high level of self-efficacy.

Therefore this study will provide information on how best to deal with the above issues. The significance of this study is that the information got from the research will help in the education of caregivers on the condition of Spinal cord injuries and what to expect. The findings will provide information which could be used by rehabilitation professional's especially physiotherapists to understand the complex role of the carers and advise them on the strategies they can use to assist managing this role. It can also bring light on other issues like the effect of patient-caregiver relationship on the prognosis of spinal cord injuries.

1.4 RESEARCH TOPIC

Caregiver experiences and expectations in caring for patients with traumatic spinal cord injuries at University Teaching Hospital

1.5 MAIN OBJECTIVE

To identify the experiences caregivers face and their expectation's in caring for patients with spinal cord injuries.

1.6 SPECIFIC OBJECTIVES

- To determine the needs of caregivers caring for spinal cord injury patients,
- To determine problems faced by caregivers in caring for spinal cord injury patients,
- To determine how caregiver expectations affect their role in the rehabilitation of patients with spinal cord injuries,
- To identify the type of caregivers caring for spinal cord injury patients.

1.7 RESEARCH QUESTION

What are the experiences and expectations of caregivers when providing care to patients with spinal cord injuries?

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 INTRODUCTION

A spinal cord injury (SCI) refers to any injury to the spinal cord that is caused by trauma instead of a disease (Taber et al, 2009). Depending on where the spinal cord and nerve roots are damaged, the symptoms can vary widely, from pain to paralysis to incontinence (Lin et al, 2002). The authors further state that spinal cord injuries are described at various levels of "incomplete", which can vary from having no effect on the patient to a "complete" injury which means a total loss of function.

Treatment of spinal cord injuries starts with restraining the spine and controlling inflammation to prevent further damage. The actual treatment can vary widely depending on the location and extent of the injury. In many cases, spinal cord injuries require substantial physical therapy and rehabilitation, especially if the patient's injury interferes with activities of daily life (Kirshblum et al 2001).

2.2 SPINAL CORD ANATOMY

The spinal cord has a core of tissue containing nerve cells, surrounded by long tracts of nerve fibers consisting of axons. The tracts extend up and down the spinal cord, carrying signals to and from the brain. The average size of the spinal cord varies in circumference along its length from the width of a thumb to the width of one of the smaller fingers. The spinal cord extends down through the upper two thirds of the vertebral canal, from the base of the brain to the lower back, and is generally 15 to 17 inches long depending on an individual's height (Kirshblum et al, 2001).

The interior of the spinal cord is made up of neurons, their support cells called glia, and blood vessels. The neurons and their dendrites (branching projections that help neurons communicate with each other) reside in an H-shaped region called "grey matter." The H-shaped

grey matter of the spinal cord contains motor neurons that control movement, smaller interneurons that handle communication within and between the segments of the spinal cord, and cells that receive sensory signals and then send information up to centers in the brain (Taber, et al, 2009).

Surrounding the grey matter of neurons is white matter. Most axons are covered with an insulating substance called myelin, which allows electrical signals to flow freely and quickly. Myelin has a whitish appearance, which is why this outer section of the spinal cord is called "white matter" (Kirshblum et al, 2001)

Axons carry signals downward from the brain (along descending pathways) and upward toward the brain (along ascending pathways) within specific tracts. Axons branch at their ends and can make connections with many other nerve cells simultaneously. Some axons extend along the entire length of the spinal cord.

The descending motor tracts control the smooth muscles of internal organs and the striated (capable of voluntary contractions) muscles of the arms and legs. They also help adjust the autonomic nervous system's regulation of blood pressure, body temperature, and the response to stress. These pathways begin with neurons in the brain that send electrical signals downward to specific levels of the spinal cord. Neurons in these segments then send the impulses out to the rest of the body or coordinate neural activity within the cord itself.

The ascending sensory tracts transmit sensory signals from the skin, extremities, and internal organs that enter at specific segments of the spinal cord. Most of these signals are then relayed to the brain. The spinal cord also contains neuronal circuits that control reflexes and repetitive movements, such as walking, which can be activated by incoming sensory signals without input from the brain.

The circumference of the spinal cord varies depending on its location. It is larger in the cervical and lumbar areas because these areas supply the nerves to the arms and upper body and the legs and lower body, which require the most intense muscular control and receive the most

sensory signals. The ratio of white matter to grey matter also varies at each level of the spinal cord. In the cervical segment, which is located in the neck, there is a large amount of white matter because at this level there are many axons going to and from the brain and the rest of the spinal cord below. In lower segments, such as the sacral, there is less white matter because most ascending axons have not yet entered the cord, and most descending axons have contacted their targets along the way.

To pass between the vertebrae, the axons that link the spinal cord to the muscles and the rest of the body are bundled into 31 pairs of spinal nerves, each pair with a sensory root and a motor root that make connections within the grey matter. Two pairs of nerves - a sensory and motor pair on either side of the cord - emerge from each segment of the spinal cord.

The functions of these nerves are determined by their location in the spinal cord. They control everything from body functions such as breathing, sweating, digestion, and elimination, to gross and fine motor skills, as well as sensations in the arms and legs.

Together, the spinal cord and the brain make up the central nervous system (CNS). The CNS controls most functions of the body, but it is not the only nervous system in the body. The peripheral nervous system (PNS) includes the nerves that project to the limbs, heart, skin, and other organs outside the brain. The PNS controls the somatic nervous system, which regulates muscle movements and the response to sensations of touch and pain, and the autonomic nervous system, which provides nerve input to the internal organs and generates automatic reflex responses. The autonomic nervous system is divided into the sympathetic nervous system, which mobilizes organs and their functions during times of stress and arousal, and the parasympathetic nervous system, which conserves energy and resources during times of rest and relaxation.

The spinal cord acts as the primary information pathway between the brain and all the other nervous systems of the body. It receives sensory information from the skin, joints, and muscles of the trunk, arms, and legs, which it then relays upward to the brain. It carries messages downward from the brain to the PNS, and contains motor neurons, which direct voluntary

movements and adjust reflex movements. Because of the central role it plays in coordinating muscle movements and interpreting sensory input, any kind of injury to the spinal cord can cause significant problems throughout the body.

2.3 AETIOLOGY

Spinal cord injuries are most often traumatic, caused by lateral bending, dislocation, rotation, axial loading, and hyper flexion or hyperextension of the cord or Cauda equine (Bogdanov et al 2009). SCIs can also be of a non-traumatic origin, as in the case of cancer, infection, intervertebral disc disease, vertebral injury and spinal cord vascular disease (Berg et al 2010). The main causes and their respective percentages of incidence according to the Quadriplegic Association of South Africa (2010) are as follows:

- Motor Vehicle, Motorbike and Pedestrian accidents - 51.1%
- Falls - 19.8%
- Water Sport - 13.0%
- Crush Injury - 5.3%
- Violence - 3.1%
- Sport - 3.7%
- Horse Riding - 0.6%
- Other Trauma 3.4%

2.4 PATHOPHYSIOLOGY

A spinal cord injury usually begins with a sudden, traumatic blow to the spine that fractures or dislocates vertebrae. The damage begins at the moment of injury when displaced bone fragments, disc material, or ligaments bruise or tear into spinal cord tissue. Axons are cut off or damaged beyond repair, and neural cell membranes are broken. Blood vessels may rupture and cause heavy bleeding in the central grey matter, which can spread to other areas of the spinal cord over the next few hours.

Within minutes, the spinal cord swells to fill the entire cavity of the spinal canal at the injury level. This swelling cuts off blood flow, which also cuts off oxygen to spinal cord tissue. Blood pressure drops, sometimes dramatically, as the body loses its ability to self-regulate. As blood pressure lowers even further, it interferes with the electrical activity of neurons and axons. All these changes can cause a condition known as spinal shock that can last from several hours to several days.

Although there is some controversy among neurologists about the extent and impact of spinal shock, and even its definition in terms of physiological characteristics, it appears to occur in approximately half the cases of spinal cord injury, and it is usually directly related to the size and severity of the injury. During spinal shock, even undamaged portions of the spinal cord become temporarily disabled and can't communicate normally with the brain. Complete paralysis may develop, with loss of reflexes and sensation in the limbs.

The crushing and tearing of axons is just the beginning of the devastation that occurs in the injured spinal cord and continues for days. The initial physical trauma sets off a cascade of biochemical and cellular events that kill neurons, strips axons of their myelin insulation, and trigger an inflammatory immune system response. Days or sometimes even weeks later, after the second wave of damage has passed, the area of destruction may increase, and sometimes to several segments above and below the original injury and so has the extent of disability.

The following may happen and the following are the consequences:

1. Changes in blood flow in and around the spinal cord begin at the injured area, spread out to adjacent, uninjured areas, and then set off problems throughout the body. Immediately after the injury, there is a major reduction in blood flow to the site, which can last for as long as 24 hours and becomes progressively worse if untreated. Because of differences in tissue composition, the impact is greater on the interior grey matter of the spinal cord than on the outlying white matter. Blood vessels in the grey matter also begin to leak, sometimes as early as 5 minutes after injury. The combination of leaking, swelling, and sluggish blood

flow prevents the normal delivery of oxygen and nutrients to neurons, causing many of them to die.

2. After the injury, an excessive release of neurotransmitters (chemicals that allow neurons to signal each other) can cause additional damage by overexciting nerve cells.

Glutamate is an excitatory neurotransmitter, commonly used by nerve cells in the spinal cord to stimulate activity in neurons. But when spinal cells are injured, neurons flood the area with glutamate for reasons that are not yet well understood. Excessive glutamate triggers a destructive process called excitotoxicity, which disrupts normal processes and kills neurons and other cells called oligodendrocytes that surround and protect axons.

3. Under normal conditions, the blood-brain barrier (which tightly controls the passage of cells and large molecules between the circulatory and central nervous systems) keeps immune system cells from entering the brain or spinal cord. But when the blood-brain barrier is broken by blood vessels bursting and leaking into spinal cord tissue, immune system cells that normally circulate in the blood (primarily white blood cells) can invade the surrounding tissue and trigger an inflammatory response. This inflammation is characterized by fluid accumulation and the influx of immune cells which include neutrophils, T-cells, macrophages, and monocytes.

Neutrophils are the first to enter, within about 12 hours of injury, and they remain for about a day. Three days after the injury, T-cells arrive. Their function in the injured spinal cord is not clearly understood, but in the healthy spinal cord they kill infected cells and regulate the immune response. Macrophages and monocytes enter after the T-cells and scavenge cellular debris.

The up side of this immune system response is that it helps fight infection and cleans up debris. But the down side is that it sets off the release of cytokines - a group of immune system messenger molecules that exert a malign influence on the activities of nerve cells.

4. Another consequence of the immune system's entry into the CNS is that inflammation accelerates the production of highly reactive forms of oxygen molecules called free radicals.

Free radicals are produced as a by-product of normal cell metabolism. In the healthy spinal cord their numbers are small enough that they cause no harm. But injury to the spinal cord, and the subsequent wave of inflammation that sweeps through spinal cord tissue, signals particular cells to overproduce free radicals.

5. Cells in the injured spinal cord also die from a kind of programmed cell death called apoptosis, often described as cellular suicide, which happens days or weeks after the injury. Apoptosis is a normal cellular event that occurs in a variety of tissues and cellular systems. It helps the body get rid of old and unhealthy cells by causing them to shrink and implode. Nearby scavenger cells then gobble up the debris. Apoptosis seems to be regulated by specific molecules that have the ability to either start or stop the process.
6. Mechanisms of secondary damage, restricted blood flow, excitotoxicity, inflammation, free radical release, and apoptosis all increase the area of damage in the injured spinal cord. Damaged axons become dysfunctional, either because they are stripped of their myelin or because they are disconnected from the brain. Glial cells cluster to form a scar, which creates a barrier to any axons that could potentially regenerate and reconnect. A few whole axons may remain, but not enough to convey any meaningful information to the brain.

2.5 SIGNS AND SYMPTOMS

Signs and symptoms will vary depending on where the spine is injured and the extent of the injury. These are all determined by the area of the body that the injured area of the spine innervates. A section of skin innervated through a specific part of the spine is called a dermatome, and spinal injury can cause pain, numbness, or a loss of sensation in the relevant areas. A group of muscles innervated through a specific part of the spine is called a myotome, and injury to the spine can cause problems with voluntary motor control. The muscles may contract uncontrollably, become weak, or be completely unresponsive. The loss of muscle

function can have additional effects if the muscle is not used, including atrophy of the muscle and bone degeneration.

A severe injury may also cause problems in parts of the spine below the injured area. In a "complete" spinal injury, all functions below the injured area are lost. In an "incomplete" injury, some or all of the functions below the injured area may be unaffected. If the patient has the ability to contract the anal sphincter voluntarily or to feel a pinprick or touch around the anus, the injury is considered to be incomplete. The nerves in this area are connected to the very lowest region of the spine, the sacral region, and retaining sensation and function in these parts of the body indicates that the spinal cord is only partially damaged.

A complete injury frequently means that the patient has little hope of functional recovery. The relative incidence of incomplete injuries compared to complete spinal cord injury has improved over the past half century, due mainly to the emphasis on better initial care and stabilization of spinal cord injury patients (Sekhon and Fehlings, 2001). Most patients with incomplete injuries recover at least some function. In addition to sensation and muscle control, the loss of connection between the brain and the rest of the body can have specific effects depending on the location of the injury.

Determining the exact "level" of injury is critical in making accurate predictions about the specific parts of the body that may be affected by paralysis and loss of function. The level is assigned according to the location of the injury by the vertebra of the spinal column. While the prognosis of complete injuries is generally predictable since recovery is rare, the symptoms of incomplete injuries can vary and it is difficult to make an accurate prediction of the outcome. The following are the clinical presentations of SCI's depending on the location of the injury:

2.5.1 CERVICAL SPINE

Cervical spine (neck) injuries usually result in full or partial tetraplegia (Quadriplegia). However, depending on the specific location and severity of trauma, limited function may be retained.

- Injuries at the C-1/C-2 levels will often result in loss of breathing, necessitating mechanical ventilators or phrenic nerve pacing.
- C3 vertebrae and above: Typically results in loss of diaphragm function, necessitating the use of a ventilator for breathing.
- C4: Results in significant loss of function at the biceps and shoulders.
- C5: Results in potential loss of function at the shoulders and biceps, and complete loss of function at the wrists and hands.
- C6: Results in limited wrist control, and complete loss of hand function.
- C7 and T1: Results in lack of dexterity in the hands and fingers, but allows for limited use of arms.

Patients with complete injuries above C7 typically cannot handle activities of daily living and cannot function independently.

Additional signs and symptoms of cervical spine injuries include are inability or reduced ability to regulate heart rate, blood pressure, sweating and hence body temperature. Others include autonomic dysreflexia or abnormal increases in blood pressure, sweating, and other autonomic responses to pain or sensory disturbances.

2.5.2 THORACIC SPINE

Complete injuries at or below the thoracic spinal levels result in paraplegia. Functions of the hands, arms, neck, and breathing are usually not affected.

- T1 to T8: Results in the inability to control the abdominal muscles. Accordingly, trunk stability is affected. The lower the level of injury, the less severe the effects.
- T9 to T12: Results in partial loss of trunk and abdominal muscle control.

2.5.3 LUMBOSACRAL SPINE

The effects of injuries to the lumbar or sacral regions of the spinal cord are decreased control of the legs and hips, urinary system, and anus.

- Bowel and bladder function is regulated by the sacral region of the spine. In that regard, it is very common to experience dysfunction of the bowel and bladder, including infections of the bladder and anal incontinence, after traumatic injury.
- Sexual function is also associated with the sacral spinal segments, and is often affected after injury. During a psychogenic sexual experience, signals from the brain are sent to spinal levels T10-L2 and in case of men, are then relayed to the penis where they trigger an erection. A reflex erection, on the other hand, occurs as a result of direct physical contact to the penis or other erotic areas such as the ears, nipples or neck. A reflex erection is involuntary and can occur without sexually stimulating thoughts. The nerves that control a man's ability to have a reflex erection are located in the sacral nerves (S2-S4) of the spinal cord and could be affected after a spinal cord injury.

2.5.4 OTHERS

- Spinal shock is a state of transient physiologic (rather than anatomic) reflex depression of cord function below the level of injury, with associated loss of all sensorimotor functions. An initial increase in blood pressure due to the release of catecholamines, followed by hypotension, is noted. Flaccid paralysis, including of the bowel and bladder, is observed, and sometimes sustained priapism develops. These symptoms tend to last several hours to days until the reflex arcs below the level of the injury begin to function again (e.g. .bulbocavernosus reflex, muscle stretch reflex [MSR]).
- Neurogenic shock is manifested by the triad of hypotension, bradycardia, and hypothermia. Shock tends to occur more commonly in injuries above T6, secondary to the disruption of the sympathetic outflow from T1-L2 and to unopposed vagal tone, leading to a decrease in vascular resistance, with associated vascular dilatation. Neurogenic shock needs to be

differentiated from spinal and hypovolemic shock. Hypovolemic shock tends to be associated with tachycardia.

2.6 CLASSIFICATION

Due to the complexity of the pathology of spinal cord injuries there is more than one way of classification. One of the most common means of classification is the one formulated by the American Spinal Injury Association (ASIA) classification which was first published in 1982, called the International Standards for Neurological and Functional Classification of Spinal Cord Injury. Now in its sixth edition, the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) is still widely used to document sensory and motor impairments following SCI. It is based on neurological responses, touch and pinprick sensations tested in each dermatome, and strength of ten key muscles on each side of the body, including hip flexion (L2), shoulder shrug (C4), elbow flexion (C5), wrist extension (C6), and elbow extension (C7). Traumatic spinal cord injury is classified into five categories on the ASIA Impairment Scale:

- A - Indicates a "complete" spinal cord injury where no motor or sensory function is preserved in the sacral segments S4-S5.
- B - Indicates an "incomplete" spinal cord injury where sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5. This is typically a transient phase and if the person recovers any motor function below the neurological level, that person essentially becomes a motor incomplete, i.e. ASIA C or D.
- C - Indicates an "incomplete" spinal cord injury where motor function is preserved below the neurological level and more than half of key muscles below the neurological level have a muscle grade of less than 3, which indicates active movement with full range of motion against gravity.
- D - Indicates an "incomplete" spinal cord injury where motor function is preserved below the neurological level and at least half of the key muscles below the neurological level have a muscle grade of 3 or more.

- E - Indicates "normal" where motor and sensory scores are normal. Note that it is possible to have spinal cord injury and neurological deficits with completely normal motor and sensory scores.

Other classifications of SCI include the following:

- Central cord syndrome often is associated with a cervical region injury and leads to greater weakness in the upper limbs than in the lower limbs, with sacral sensory sparing.
- Brown-Séquard syndrome, which often is associated with a hemi-section lesion of the cord, causes a relatively greater ipsilateral proprioceptive and motor loss, with contralateral loss of sensitivity to pain and temperature.
- Anterior cord syndrome often is associated with a lesion causing variable loss of motor function and sensitivity to pain and temperature; proprioception is preserved.
- Conus medullaris syndrome is associated with injury to the sacral cord and lumbar nerve roots leading to areflexic bladder, bowel, and lower limbs, while the sacral segments occasionally may show preserved reflexes (e.g. bulbocavernosus and micturition reflexes).
- Cauda equina syndrome is due to injury to the lumbosacral nerve roots in the spinal canal, leading to areflexic bladder, bowel, and lower limbs.

7 EVALUATION AND DIAGNOSIS

General clinical neurological signs

In individuals with spinal-cord injury, the entire nervous system should be carefully examined because traumatic brain injury, especially mild forms, accompanies nearly half of all traumatic injuries to the spinal cord, and multilevel cord injury is also possible. Assessment should include mental status, cranial nerves, motor, sensory, and autonomic systems, coordination, and gait (it also ascertains systemic injury). Severity of injury is accurately conveyed by the simple five-level A—E American Spinal Injury Association (ASIA). International standards for neurological and functional classifications of spinal-cord injury¹⁸ assess motor function in ten muscle groups

(arms, C5—T1; legs, L2—S1) and sensation (light touch and pinprick) in 28 dermatomes (C2—S4/5) on both sides of the body.

Cerebrospinal fluid examination

Cerebrospinal fluid (CSF) analysis is not part of routine assessment of traumatic spinal-cord injury. By contrast, analysis is essential for differentiation of medical causes.

Imaging

Antero-posterior, lateral, and special-view radiographs (odontoid, neural foramina views) can define integrity and alignment of bony structures. If a cervical fracture is suspected, a radiograph is essential to visualise T1 to ensure that low cervical fracture or subluxation is not overlooked. However, radiographs can miss fractures, especially facet fractures. So if a fracture is noted, additional ones should be looked for at other levels. Absence of fracture on radiographs does not ensure spinal-column stability. Dynamic views e.g. in flexion-extension movement of the spine can provide additional information, but these views are contraindicated when neurological dysfunction is acute. For these cases, computed tomography or magnetic resonance imaging (MRI) is necessary.

Computed tomography (CT scan) better defines bony structures than radiography, and can be used when radiographs suggest injury or include poorly visualised areas. Computed tomography can also detect soft-tissue changes. Cord oedema, infarction, demyelination, cysts, or abscesses reduce signal density, whereas haemorrhages and calcifications increase density. Combination of computed tomography and myelography better defines abnormalities in the spinal canal than computed tomography alone. The combination is especially useful when spinal hardware makes MRI difficult. Canal compromise and extradural lesions (tumour, arteriovenous malformations) are especially well defined in computed tomography myelograms.

MRI is the best method to use for definition of neural tissue and help to establish prognosis. Methods for diffusion-weighted MRI of the spinal cord are expected to radically transform early

imaging of spinal-cord injury, since these methods have revolutionised imaging of early brain injury. So far, we can only see blood products, oedema-related swelling of neural elements, or misalignment of spinal elements. New techniques that use paramagnetic tracers and molecular diffusion can track migration of transplanted cells, cell birth, and long-tract integrity.

2.8 MANAGEMENT

2.8.1 MEDICAL

Modern trauma care includes a step called clearing the cervical spine, where a patient with a suspected injury is treated as if they have a spinal injury until that injury is ruled out. The objective is to prevent any further spinal cord damage. Patients are immobilized at the scene of the injury until it is clear that there is no damage to the highest portions of the spine. This is traditionally done using a device called a long spine board. SCI patients often require extended treatment in an intensive care unit. Inflammation can cause further damage to the spinal cord, and patients are sometimes treated with a corticosteroid drug such as methylprednisolone to reduce swelling. The drug is used within 8 hours of the injury. This practice is based on the National Acute Spinal Cord Injury Studies (NASCIS) I and II, though other studies have shown little benefit and concerns about side effects from the drug have changed this practice. A food dye, brilliant blue G, has also been shown to have some effect at reducing inflammation after spinal injury.

One experimental treatment, therapeutic hypothermia, is used but there is no evidence that that it improve outcomes. Maintaining mean arterial blood pressures of at least 85 to 90 mmHg using intravenous fluids, transfusion, and vasopressors to ensure adequate blood supply to nerves and prevent damage is another treatment with little evidence of effectiveness.

2.8.2SURGICAL

Surgery may also be necessary to remove any bone fragments from the spinal canal and to stabilize the spine. Inflammation can cause further damage to the spinal cord, and patients are sometimes treated with a corticosteroid drug such as methylprednisolone to reduce swelling.

2.8.3 PHYSIOTHERAPY

Physical therapy includes exercise programs geared toward muscle strengthening. Occupational therapy helps redevelop fine motor skills. Bladder and bowel management programs teach basic toileting routines, and patients also learn techniques for self-grooming. People acquire coping strategies for recurring episodes of spasticity, autonomic dysreflexia, and neurogenic pain.

2.8.4 REHABILITATION

No two people will experience the same emotions after surviving a spinal cord injury, but almost everyone will feel frightened, anxious, or confused about what has happened. It's common for people to have very mixed feelings: relief that they are still alive, but disbelief at the nature of their disabilities.

Rehabilitation programs combine physical therapies with skill-building activities and counselling to provide social and emotional support. The education and active involvement of the newly injured person and his or her family and friends is crucial.

A rehabilitation team is usually led by a doctor specializing in physical medicine and rehabilitation (called a physiatrist), and often includes social workers, physical and occupational therapists, recreational therapists, rehabilitation nurses, rehabilitation psychologists, vocational counsellors, nutritionists, and other specialists. A case-worker or program manager coordinates care.

In the initial phase of rehabilitation, therapists emphasize regaining leg and arm strength since mobility and communication are the two most important areas of function. For some, mobility will only be possible with the assistance of devices such as a walker, leg braces, or a wheelchair. Communication skills, such as writing, typing, and using the telephone, may also require adaptive devices.

Vocational rehabilitation begins with an assessment of basic work skills, current dexterity, and physical and cognitive capabilities to determine the likelihood for employment. A vocational rehabilitation specialist then identifies potential work places, determines the type of assistive equipment that will be needed, and helps arrange for a user-friendly workplace. For those whose disabilities prevent them from returning to the workplace, therapists focus on encouraging productivity through participation in activities that provide a sense of satisfaction and self-esteem. This could include educational classes, hobbies, memberships in special interest groups, and participation in family and community events.

Recreation therapy encourages patients to build on their abilities so that they can participate in recreational or athletic activities at their level of mobility. Engaging in recreational outlets and athletics helps those with spinal cord injuries achieve a more balanced and normal lifestyle and also provides opportunities for socialization and self-expression.

2.9 EPIDEMIOLOGY

A report from the National Spinal Cord Injury Statistical Centre (NSCISC) in the year 2005 estimated the annual incidence of SCI, not including those who die at the scene of the accident, to be approximately 40 cases per million population or approximately 11 000 new cases each year.

There are an estimated 10,000 to 12,000 spinal cord injuries every year in the United States. A quarter of a million Americans are currently living with spinal cord injuries. The cost of managing the care of spinal cord injury patients approaches \$4 billion each year (National Spinal Cord Injury Statistical Centre, U.S.A 2010)

In the UK 2-3 people every day become paralysed as a result of spinal cord injury. That is 700+ each year adding to the 40,000 living here that are already paralysed. The figures for incomplete injuries may indeed be much higher because they don't take account of those people who have been treated by general hospitals instead of a specialist spinal injuries unit (Spinal Injury Network, 2004).

The average age at the time of injury has slowly increased from a reported 29 years of age in the mid-1970s to a current average of around 40 in the U.S. A, though worldwide the average ages range from 15-35 years of age (National Spinal Cord Injury Statistical Centre U.S.A 2010). The statistical centre further states that over 80% of the spinal injuries reported to major national databases occurred in males.

2.10 COMPLICATIONS

Individuals who survive a spinal cord injury will most likely have medical complications such as chronic pain and bladder and bowel dysfunction, along with an increased susceptibility to respiratory and heart problems.

Successful recovery depends upon how well these chronic conditions are handled day to day.

The complications are discussed further below:

1. Breathing

Any injury to the spinal cord at or above the C3, C4, and C5 segments, which supply the phrenic nerves leading to the diaphragm, can stop breathing. People with these injuries need immediate ventilatory support. When injuries are at the C5 level and below, diaphragm function is preserved, but breathing tends to be rapid and shallow and people have trouble coughing and clearing secretions from their lungs because of weak thoracic muscles. Once pulmonary function improves, a large percentage of those with C4 injuries can be weaned from mechanical ventilation in the weeks following the injury.

2. Pneumonia

Respiratory complications, primarily as a result of pneumonia, are a leading cause of death in people with spinal cord injury. In fact, intubation increases the risk of developing ventilator-associated pneumonia (VAP) by 1 to 3 per cent per day of intubation. More than a quarter of the deaths caused by spinal cord injury are the result of VAP. Spinal cord injury

patients who are intubated have to be carefully monitored for VAP and treated with antibiotics if symptoms appear.

3. Irregular heart beat and low blood pressure

Spinal cord injuries in the cervical region are often accompanied by blood pressure instability and heart arrhythmias. Because of interruptions to the cardiac accelerator nerves, the heart can beat at a dangerously slow pace, or it can pound rapidly and irregularly. Arrhythmias usually appear in the first 2 weeks after injury and are more common and severe in the most serious injuries.

Low blood pressure also often occurs due to loss of tone in blood vessels, which widen and cause blood to pool in the small arteries far away from the heart. This is usually treated with an intravenous infusion to build up blood volume.

4. Blood clots

People with spinal cord injuries are at triple the usual risk for blood clots. The risk for clots is low in the first 72 hours, but afterwards anticoagulation drug therapy can be used as a preventive measure.

5. Spasm

Many of our reflex movements are controlled by the spinal cord but regulated by the brain. When the spinal cord is damaged, information from the brain can no longer regulate reflex activity. Reflexes may become exaggerated over time, causing spasticity. If spasms become severe enough, they may require medical treatment. For some, spasms can be as much of a help as they are a hindrance, since spasms can tone muscles that would otherwise waste away. Some people can even learn to use the increased tone in their legs to help them turn over in bed, propel them into and out of a wheelchair, or stand.

6. Autonomic dysreflexia

Autonomic dysreflexia is a life-threatening reflex action that primarily affects those with injuries to the neck or upper back. It happens when there is an irritation, pain, or stimulus to the nervous system below the level of injury. The irritated area tries to send a signal to the brain, but since the signal isn't able to get through, a reflex action occurs without the brain's regulation. Unlike spasms that affect muscles, autonomic dysreflexia affects vascular and organ systems controlled by the sympathetic nervous system.

Anything that causes pain or irritation can set off autonomic dysreflexia: the urge to urinate or defecate, pressure sores, cuts, burns, bruises, sunburn, pressure of any kind on the body, ingrown toenails, or tight clothing. For example, the impulse to urinate can set off high blood pressure or rapid heartbeat that, if uncontrolled, can cause stroke, seizures, or death. Symptoms such as flushing or sweating, a pounding headache, anxiety, sudden high blood pressure, vision changes, or goose bumps on the arms and legs can signal the onset of autonomic dysreflexia. Treatment should be swift. Changing position, emptying the bladder or bowels, and removing or loosening tight clothing are just a few of the possibilities that should be tried to relieve whatever is causing the irritation.

7. Pressure sores (or pressure ulcers)

Pressure sores are areas of skin tissue that have broken down because of continuous pressure on the skin. People with paraplegia and quadriplegia are susceptible to pressure sores because they can't move easily on their own.

Places that support weight when someone is seated or recumbent are vulnerable areas. When these areas press against a surface for a long period of time, the skin compresses and reduces the flow of blood to the area. When the blood supply is blocked for too long, the skin will begin to break down.

Since spinal cord injury reduces or eliminates sensation below the level of injury, people may not be aware of the normal signals to change position, and must be shifted periodically

by a caregiver. Good nutrition and hygiene can also help prevent pressure sores by encouraging healthy skin.

8. Pain

People who are paralyzed often have what is called neurogenic pain resulting from damage to nerves in the spinal cord. For some survivors of spinal cord injury, pain or an intense burning or stinging sensation is unremitting due to hypersensitivity in some parts of the body. Others are prone to normal musculoskeletal pain as well, such as shoulder pain due to overuse of the shoulder joint from pushing a wheelchair and using the arms for transfers. Treatments for chronic pain include medications, acupuncture, spinal or brain electrical stimulation, and surgery.

9. Bladder and bowel problems

Most spinal cord injuries affect bladder and bowel functions because the nerves that control the involved organs originate in the segments near the lower termination of the spinal cord and are cut off from brain input. Without coordination from the brain, the muscles of the bladder and urethra can't work together effectively, and urination becomes abnormal. The bladder can empty suddenly without warning, or become over-full without releasing. In some cases the bladder releases, but urine backs up into the kidneys because it isn't able to get past the urethral sphincter. Most people with spinal cord injuries use either intermittent catheterization or an indwelling catheter to empty their bladders.

Bowel function is similarly affected. The anal sphincter muscle can remain tight, so that bowel movements happen on a reflex basis whenever the bowel is full. Or the muscle can be permanently relaxed, which is called a "flaccid bowel," and result in an inability to have a bowel movement. This requires more frequent attempts to empty the bowel and manual removal of stool to prevent faecal impaction. People with spinal cord injuries are usually put on a regularly scheduled bowel program to prevent accidents.

10. Reproductive and sexual function

Spinal cord injury has a greater impact on sexual and reproductive function in men than it does in women. Most spinal cord injured women remain fertile and can conceive and bear children. Even those with severe injury may well retain orgasmic function, although many lose some if not all of their ability to reach satisfaction.

Depending on the level of injury, men may have problems with erections and ejaculation, and most will have compromised fertility due to decreased motility of their sperm. Treatments for men include vibratory or electrical stimulation and drugs such as sildenafil (Viagra). Many couples may also need assisted fertility treatments to allow a spinal cord injured man to father children.

Once someone has survived the injury and begun to psychologically and emotionally cope with the nature of his or her situation, the next concern will be how to live with disabilities. Doctors are now able to predict with reasonable accuracy the likely long-term outcome of spinal cord injuries. This helps patients set achievable goals for themselves, and gives families and loved ones a realistic set of expectations for the future (Lynsemeyer, 2000)

2.11 CAREGIVERS

Carer or caregiver are words normally used to refer to unpaid relatives or friends of a disabled individual who help that individual with his or her activities of daily living(Levine, 2004). The words may be prefixed with "family" "spousal", "child" to distinguish between different care situations, and also to distinguish them definitively from the paid version of a caregiver, a Personal Care Assistant or Personal Care Attendant (PCA). A general definition of a carer/caregiver is someone who is responsible for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age (Levine, 2004).

According to the National Alliance for Caregiving and the United Hospital Fund (2005), an individual can be said to be a caregiver if:

- They care of someone who has a chronic illness or disease.
- They manage medications or talk to doctors and nurses on someone’s behalf.
- They help bathe or dress someone who is frail or disabled.
- They take care of household chores, meals, or bills for someone who cannot do these things alone.

With an increasingly aging population and increase of chronic illnesses in all developed societies, the role of carer has been increasingly recognized as an important one, both functionally and economically. Many organizations which provide support for persons with disabilities have developed various forms of support for carers as well.

2.11.1 CAREGIVER STRESS

Caregiver Stress is a syndrome that can lead to exhaustion and has some traits in common with exhaustion. The stress caregivers experience is a mixture of physical, emotional, and mental exhaustion. This is often called "burnout". Caregivers may experience burnout when they don't get adequate help or when they overextend themselves physically, mentally, or financially. Fatigue, anxiety attacks, and even depression may come from this caregiver burnout. One of the problems with them getting help, however, is that they often feel a strong sense of guilt if they take more personal time or give themselves the attention they need. They are driven to help others and can become obsessed with the idea that apart from only the most basic necessities they shouldn't take any time for, or expend any effort on, themselves. The symptoms of Caregiver Stress include:

- Increased and constant irritability.
- Self-seclusion; separating yourself from family, friends, even spouse or lover.
- Feeling physically fatigued or emotionally spent on a constant basis.
- Irrationally feeling a desire to cause pain to the people you care for or harm yourself.

- Low or zero interest in things you always take joy or pleasure in.
- Getting the blues all the time with hardly any let-up.
- Having strong feelings of despair or helplessness.
- Becoming more susceptible to illness.
- Becoming more heavily affected by allergies.
- Losing sleep or having marked changes in your sleeping patterns.
- Significant loss or gain in appetite, weight, or both together.

Caregiver Stress can be prevented or "cured" by following certain methods:

- Receiving counselling from a professional or simply talking to someone trusted about how an individual feels.
- Being realistic in setting personal care giving goals.
- Stepping back and being rational about the patient an individual is caring for.
- Attending to one's personal needs as much as you are attending other people's needs do.

CHAPTER THREE

3.0 METHODOLOGY

3.1 INTRODUCTION

This chapter describes the methodology used in the study. It explains the rationale for the study design and describes the research setting. The population, the sampling method, data collection and analysis are described. In conclusion the ethical considerations regarding the study are explained.

3.2 RESEARCH DESIGN

The research design is a set guidelines and instructions to be followed in conducting a research (Sim and Wright, 2000). To address the research problem a qualitative research method was chosen. In qualitative method, qualitative theory gathered provide rich descriptions that enable the researchers to understand, emphasize and make sense of clinical reality (Morse and Field, 1998). One of the major distinguishing characteristics of qualitative research method is that the researcher attempts to understand people in terms of their own definition of their world that cannot be obtained in a quantitative research method. Sim and Wright (2000) further state that the design offers the researcher the opportunity to focus on finding answers to the questions cantered on the experiences of caregivers of patients with spinal cord injuries.

3.3 RESEARCH SETTING

The study was carried out at the University Teaching Hospital. This is the biggest government hospital catering for both adults and children. It is a teaching hospital attached to the University of Zambia. The latter offers undergraduate and postgraduate degrees in medicine and nursing and the undergraduate degrees in Physiotherapy, Pharmacy and Biomedical Science. The University Teaching Hospital is also a referral hospital and receives patients from all over the country for both medical care and rehabilitation.

3.4 RESEARCH SUBJECTS AND SAMPLING

The population under study were informal caregivers of patients with spinal cord injuries at the University Teaching Hospital who were accessing both in-patient and out-patient services. The wards in which the research was carried out were the Trauma (G-Block), Orthopaedic (C-Block) and the Physiotherapy out-patient department. The study used a qualitative research method and the sample consisted of 14 willing participants.

3.5 INCLUSION CRITERIA

The study included caregivers who had been caring for spinal cord injury patients for not less than 2 weeks.

3.6 EXCLUSION CRITERIA

The following were excluded from the study:

- Caregiver's who had been caring for spinal cord injury patients for less than a 2 weeks,
- Professional caregiver's e.g. Medical staff.

3.7 PILOT STUDY

A pilot study was conducted prior to the actual data collection with 2 caregivers who were not part of the study. This was undertaken as a trail run to determine whether the questions in the questionnaire were clear and appropriate to the study.

3.8 DATA COLLECTION

Data was collected at the University Teaching Hospital (UTH) in the following wards and department:

- Trauma (G-Block),
- Orthopaedic (C-Block),
- Physiotherapy out-patient department.

3.9 INSTRUMENT

A semi-structured interview guide with open-ended question informed by the existing literature on the subject was used. The instrument consisted of Section A, where demographic data of the patient such as age, gender, address and employment status was obtained. Section B was used to collect demographic data of the caregiver and Section C had the interview guide. The interviews were conducted in the language the person being interviewed was comfortable with and one that could be understood clearly. In situations where there was a language barrier, an appropriate translator was identified to help with the translation.

3.10 DATA ANALYSIS

Robson (1999) defines data analysis as a three linked sub-process: data reduction, data display and conclusion drawing verification. Sim and Wright (2000) describe it as the procedure categorizing, structuring and putting meaning to mass of collected data. The data was identified and interpreted for common, recurrent and emergent themes. These themes were then coded and tabulated to reach conclusions.

3.11 ETHICAL CONSIDERATION

Research ethics were observed in all aspects of the research. The Research Ethics Committee of the University of Zambia was sought out for approval of the methodology of the research. Permission was also sought out from the University Teaching Hospital. And informed consent was obtained before carrying out the study. The aim of the study was explained to the participants, prior to the interview and participation was voluntary and participants had the right to withdraw from the study at any time. A signed consent was obtained from each participant before commencement of interviews. Participants were assured confidentiality of the information given and in order to maintain anonymity, their names were not used in the study.

CHAPTER FOUR

4.0 DATA ANALYSIS AND PRESENTATION OF RESULTS

4.1 INTRODUCTION

This chapter describes the demographic data of patient, caregiver and the results obtained on the experiences of caregivers of Spinal Cord Injuries. The aim of this study was to determine caregiver’s experiences and expectations in caring for Spinal Cord Injury patients at the University Teaching Hospital. This chapter endeavours to give meaning to the data by presenting it clearly using a qualitative method. The analysis and interpretation of the qualitative responses obtained through face-to-face interviews are described under themes and categories. The interviews were conducted within a period of January to March, 2012. A semi-structured interview guide was used to collect data. This is based on the informants, personal experiences in caring for their spinal cord injury patients.

.2 DEMOGRAPHIC DATA OF THE PARTICIPANTS

The informants consisted of 14 participants from the University Teaching Hospital Orthopaedic (C-Block) and Trauma (G-Block) wards. Construction of charts and frequency tables, and analysis was aided by the use of the Statistical Package for Social Sciences (SPSS). The following charts and frequency tables are a summary of the findings in the study.

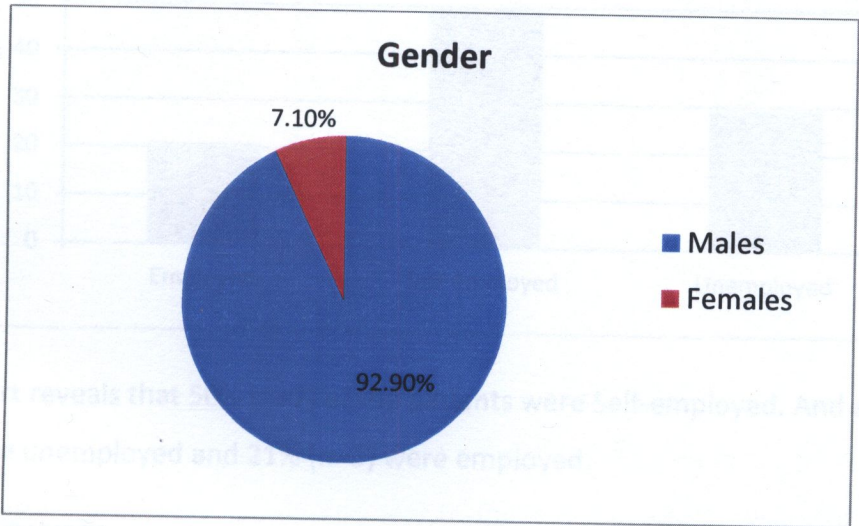
.3 DEMOGRAPHIC DATA OF THE PATIENT

AGE

Age range (years)	Frequency	Per cent	Cumulative Per cent
15-30	4	28.6	28.6
31-45	6	42.9	71.5
46-60	3	21.4	92.9
61 and above	1	7.1	100
Total	14	100	

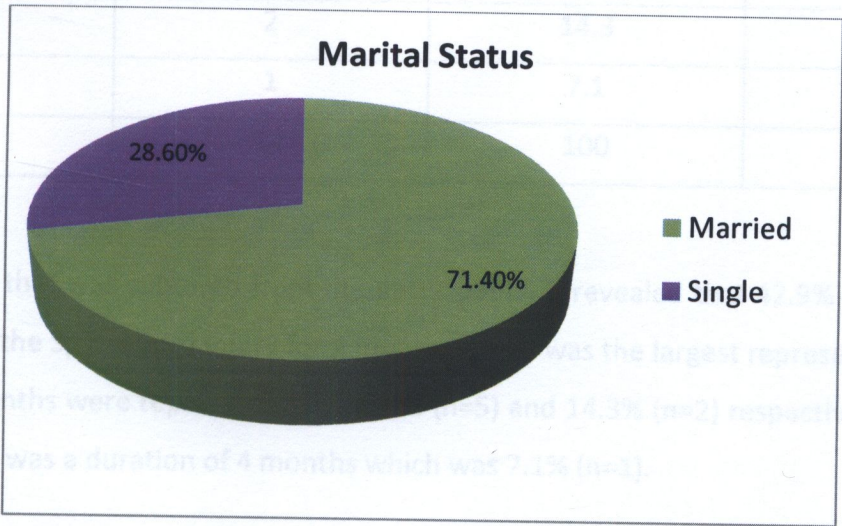
The table shows the ages of patients from which data was collected from. This table was able to reveal the age distribution of the patients with Spinal Cord Injuries. The age range of 31-45 years is the most affected with 42.9% and the least affected is individuals who were 60 years and above with 7.1%. The other age ranges which were 15-30 years and 46-60 years were represented by 28.6% and 21.4% respectively.

GENDER



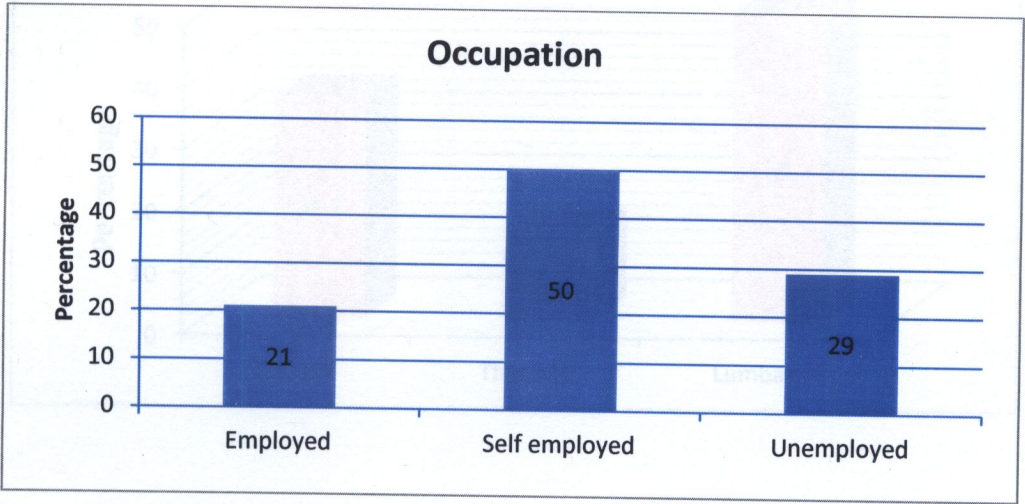
The above chart shows that more males were affected by Spinal Cord Injuries and were represented by 92.9% (n=13) as compared to women who were represented by 7.1% (n=1).

MARITAL STATUS



The chart shows that most of the patients that participated in the study were married represented by 71.4% (n=10) and that the rest were single represented by 28.6% (n=4).

OCCUPATION



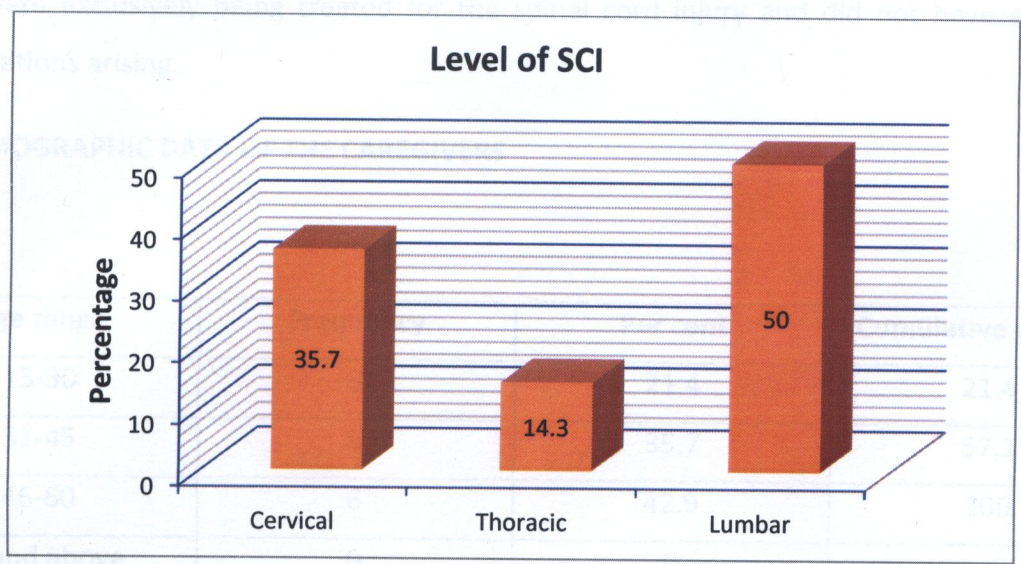
The above chart reveals that 50% (n=7) of the patients were Self-employed. And as for the rest 29% (n=4) were unemployed and 21% (n=3) were employed.

DURATION OF ILLNESS

Months	Frequency	Per cent	Cumulative Per cent
1	5	35.7	35.7
2	6	42.9	78.6
3	2	14.3	92.9
4	1	7.1	100
Total	14	100	

From the data that was captured from the participants, it revealed that 42.9% (n=6) had been suffering from the Spinal Cord Injury for 2 months which was the largest representation. And as for 1 and 3 months were represented by 35.7% (n=5) and 14.3% (n=2) respectively. The lowest representation was a duration of 4 months which was 7.1% (n=1).

LEVEL OF SPINAL CORD INJURY



The chart above reveals that the most common site of spinal cord injuries among the patients was the Lumbar region which was represented by 50% (n=7). The other sites of spinal cord injuries were also the Cervical region and the Thoracic region represented by 35% (n=5) and 14.3% (n=2) respectively.

COMPLICATIONS

Complication	Frequency	Per cent	Cumulative per cent
Pressure sores	9	64.3	64.3
Respiratory	2	14.3	78.6
Urinary tract infection	1	7.1	85.7
No complication	2	14.3	100
Total	14	100	

From this table we can show that most the patients have complications which have arisen from the spinal cord injury. The most prevalent complication was the occurrence of pressure sores which was represented by 64.3% (n=9). The other complications were respiratory complications

represented by 14.3% (n=2) and urinary tract infections represented by 7.1% (n=1). Only 14.3% (n=2) were exclusively being treated for the spinal cord injury and did not have any other complications arising.

4.4 DEMOGRAPHIC DATA OF THE CAREGIVERS

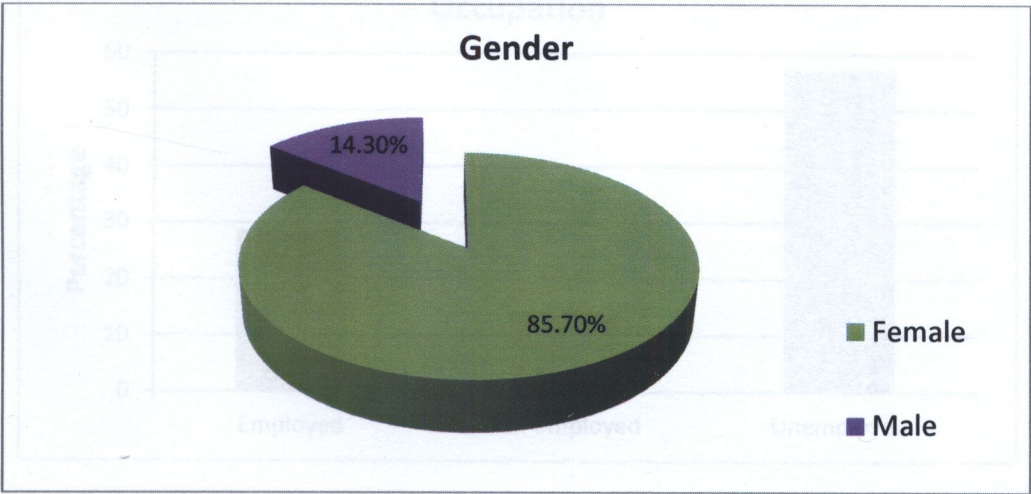
AGE

Age range	Frequency	Per cent	Cumulative per cent
15-30	3	21.4	21.4
31-45	5	35.7	57.1
46-60	6	42.9	100
60 and above	0	0	
Total	14	100	

The table above shows the ages of caregivers of spinal cord injury patients from which data was collected from. This table was able to reveal the age distribution of these caregivers. The age range of 46-60 years had the most caregivers with a representation 42.9% (n=6). The other age ranges were 31-45 years and 15-30 years which were represented by 35.7% (n=5) and 21% (n=3) respectively.

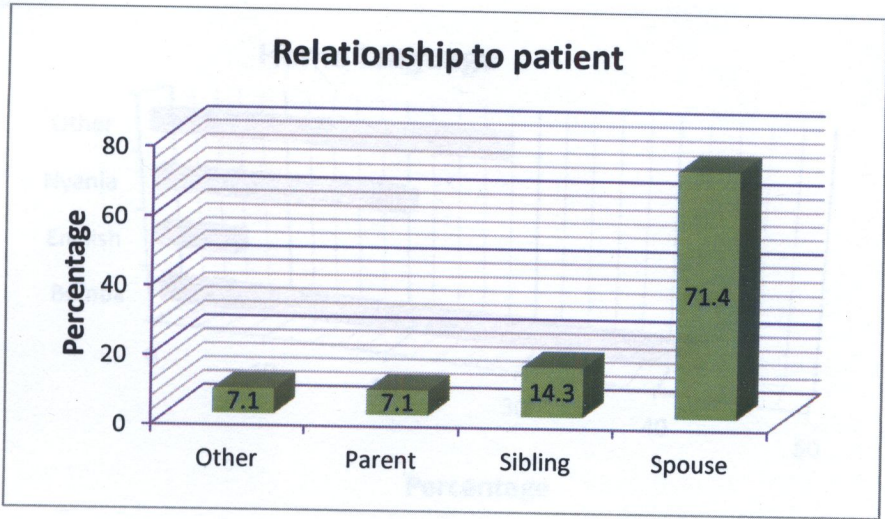
OCCUPATION

GENDER



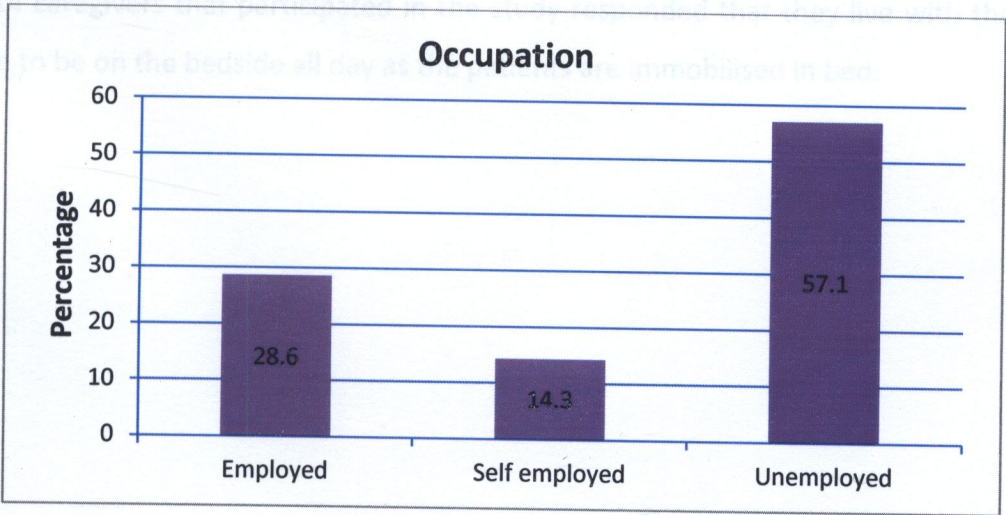
The chart shows that more females were taking up the role of being the caregiver of the spinal cord injury and were represented by 85.7% (n=12) as compared to men who were represented by 14.3% (n=2).

RELATIONSHIP TO THE PATIENT



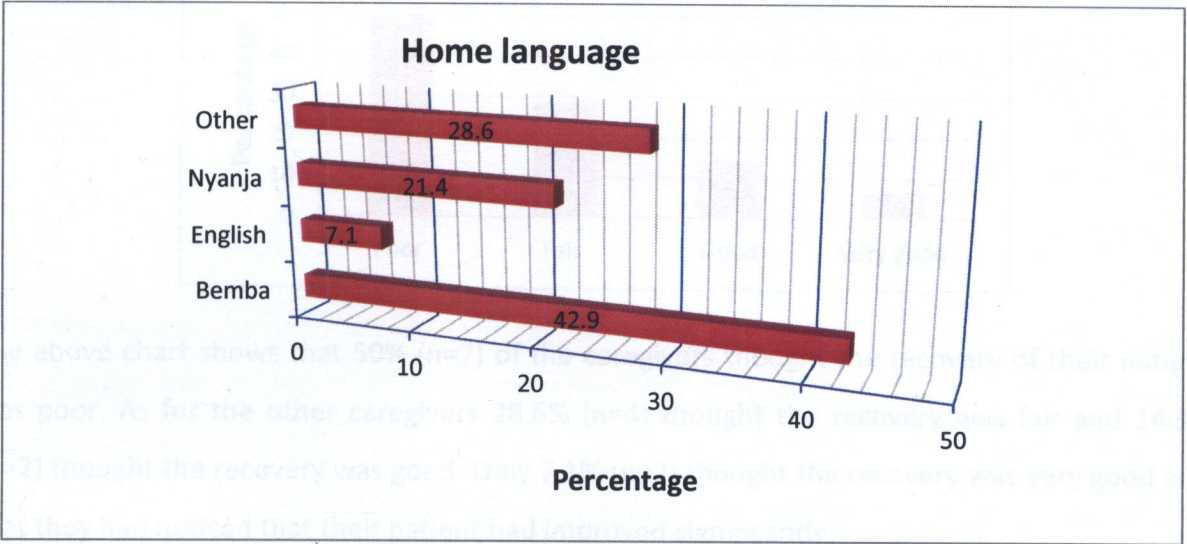
The above chart reveals that majority of the caregivers were spouses to the spinal cord injury patients and were represented by 71.4% (n=10). Other caregivers included siblings represented by 14.3% (n=2), parents represented by 7.1% (n=1) and other relatives represented by 7.1% (n=1).

OCCUPATION



The chart reveals that 57.1% (n=8) of the caregivers of spinal cord injury patients were unemployed. And as for the rest 28.6% (n=4) were self-employed and 14.3% (n=2) were employed.

HOME LANGUAGE



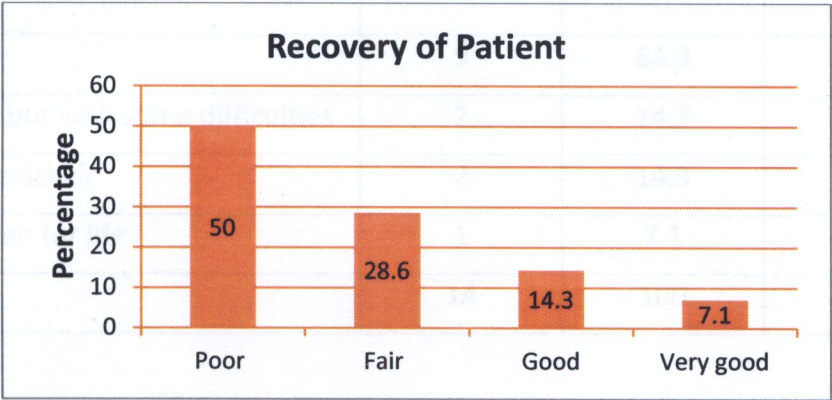
The chart most used home language was Bemba represented by 42.9% (n=6) and the least used home language was English represented by 7.1% (n=1). Nyanja was represented by 21.4% (n=3) and the other languages were grouped and represented 28.6% (n=4).

CAREGIVER LIVING WITH THE PATIENT

All the 14 caregivers that participated in the study responded that they live with the patients and have to be on the bedside all day as the patients are immobilised in bed.

.4 EXPERIENCES AND EXPECTATIONS IN CARING FOR SPINAL CORD INJURY PATIENTS

RECOVERY OF THE PATIENT



The above chart shows that 50% (n=7) of the caregivers thought the recovery of their patient was poor. As for the other caregivers 28.6% (n=4) thought the recovery was fair and 14.3% (n=2) thought the recovery was good. Only 7.1% (n=2) thought the recovery was very good and that they had noticed that their patient had improved significantly.

EXPERIENCE ON A TYPICAL DAY OF CARING FOR THE PATIENT

Response	Frequency	Per cent	Cumulative per cent
Don't get a chance to rest	4	28.6	28.6
It is very tiring	8	57.1	71.4
It is manageable	2	14.3	100
Total	14	100	

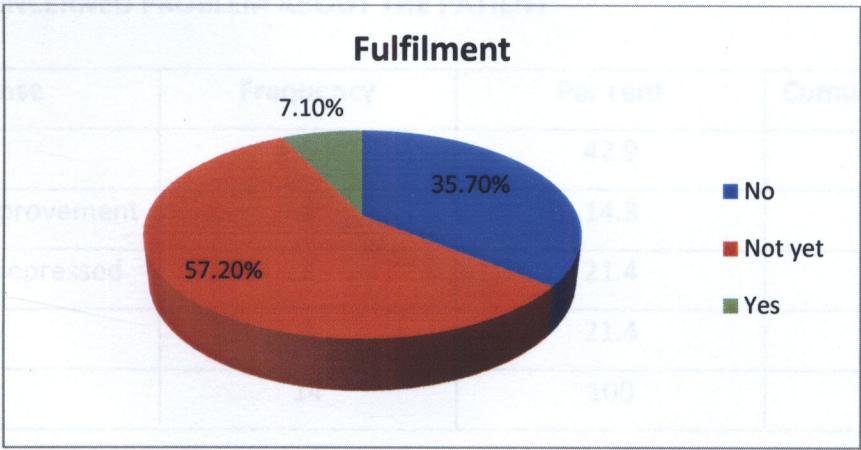
The table shows that 57.1% (n=8) their experience of a typical day was very tiring as they had to feed, bath, wash after and carry out other tasks for their patient. Some complained that they just did not have time for themselves and did not get a chance to rest and were represented by 28.6% (n=4). Only 14.3% (n=2) found atypical day manageable.

THE INITIAL EXPECTATIONS IN THE RECOVERY OF THE PATIENT

Recovery	Frequency	Per cent	Cumulative per cent
Full recovery	9	64.3	64.3
Patient walking but with some difficulties	2	14.3	78.6
Patient in a wheelchair	2	14.3	92.9
Patient bedridden for life	1	7.1	100
Total	14	100	

The table above reveals that most of the caregivers were quite optimistic in their initial expectations with 64.3% (n=9) of them expecting full recovery after the patient receives medical attention. Another group expected that the patient would eventually walk but with some difficulties which was represented by 14.3% (n=2) and another 14.3% (n=2) expected that the patient would be wheelchair bound after treatment. Only 7.1% (n=1) thought that their patient would be bedridden for life and were not optimistic.

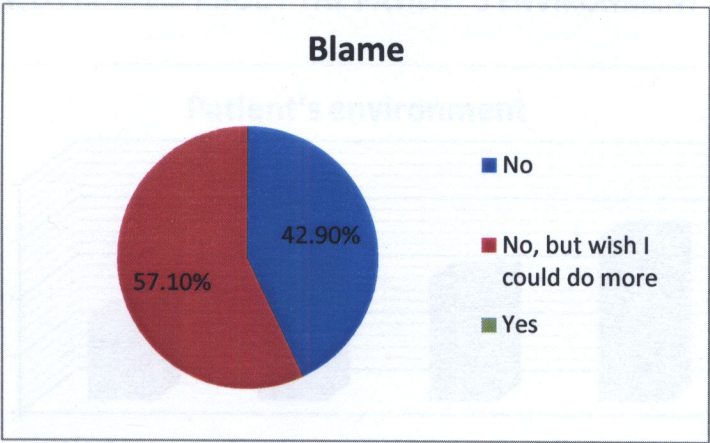
HAVE ANY OF THE INITIAL EXPECTATIONS BEEN FULFILLED?



The above chart shows that 57.2% (n=8) believe that even though their initial expectations in the recovery of their patient had not happened at the time of the interview, it would eventually happen. Another 35.7% (n=5) admitted that their initial expectations were too optimistic and

that they had not been fulfilled and did not look likely to happen. Only 7.1% (n=1) revealed that their initial expectations had been fulfilled.

DO YOU BLAME YOURSELF FOR SOME OR ALL OF THE EXPECTATIONS NOT BEING FULFILLED?



The chart above reveals that 57.1% (n=8) of the participants did not blame themselves for the expectations not being fulfilled, but wished they could do more to help the patient with the spinal cord injury. On the other hand 42.9% (n=6) revealed that they did not blame themselves too but further stated that they had done the possible best to help their patients. None of the participants blamed themselves.

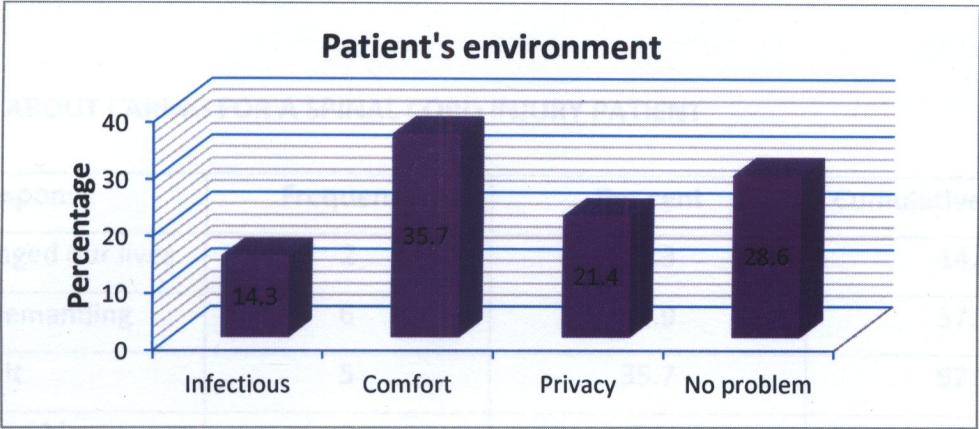
THE MOST CONCERNED PROBLEM ABOUT THE PATIENT

Response	Frequency	Per cent	Cumulative per cent
Immobility	6	42.9	42.9
No signs of improvement	2	14.3	57.2
Patient looks depressed	3	21.4	78.6
Pressure sores	3	21.4	100
Total	14	100	

From the table above the data revealed that 42.9% (n=6) of the caregivers were more concerned about their patient’s immobility than any other problem the patient had. The lack of improvement in the patient’s condition was the most concerned problem for 14.3% (n=2) of the

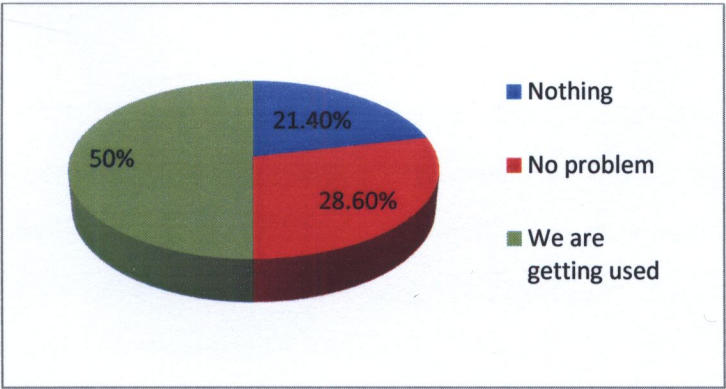
caregivers. Another set of caregivers were more concerned about the way their patient presented in a depressed manner and represented 21.4% (n=3). Pressure sore were the most concerned problem for 21.4% (n=3).

THE MOST CONCERNED PROBLEM ABOUT THE PATIENT'S ENVIRONMENT



From the chart above we can notice that 35.7% (n=5) of the caregivers were immensely concerned about the comfort of the patient they were caring for. They were concerned that the patient was not comfortable with the long stay in the hospital. Another set of caregivers were most concerned about the privacy in the ward, as everything had to be done for the patient had to be done on the bed. Fourteen point three per cent (14.3, n=2) were concerned about the high infection rate in the hospital and the difficulty to tackle the infections. Although 28.6% (n=4) revealed that there was no problem they were concerned with apart from performing their caregiver role.

WHAT HAS HELPED WITH DEALING WITH THE PROBLEM?



The chart reveals that 50% (n=7) of the caregivers that they have adjusted and gotten used to the situation as a solution to their most concerned problem. Another set of caregivers revealed that they have tried several attempts to find a solution but nothing had worked and were represented by 21.4% (n=3). The rest of the caregivers who were represented by 28.6(n=4) still that there was no problem and that their main concern was performing their role as a caregiver.

FEELINGS ABOUT CARING FOR A SPINAL CORD INJURY PATIENT

Response	Frequency	Per cent	Cumulative per cent
It has changed our lives	2	14.3	14.3
It is very demanding	6	42.9	57.2
It is difficult	5	35.7	92.9
It is manageable	1	7.1	100
Total	14	100	

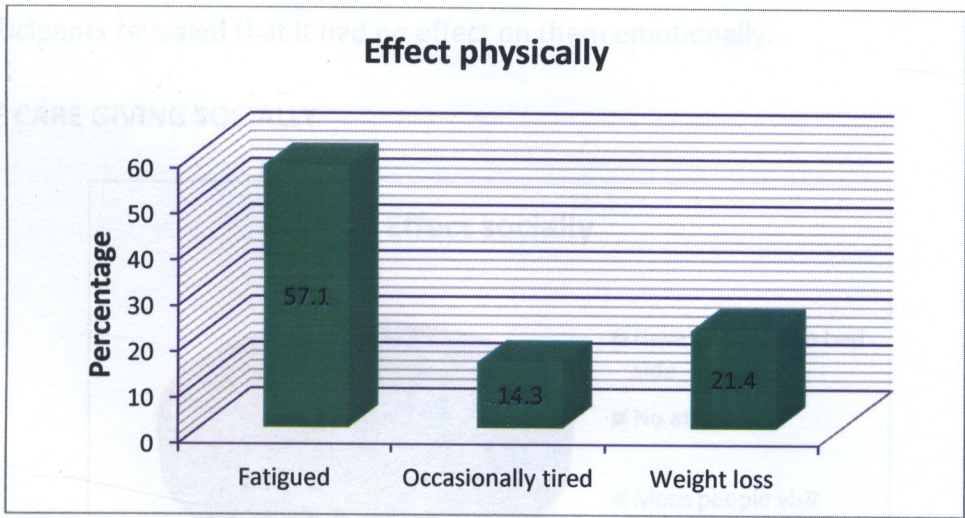
When interviewed about how they feel about caring for spinal cord injury patients 42.9% (n=6) of the participants revealed that it was very demanding and the role does not allow other personal activities. The other participants in the study revealed that it was difficult as some tasks were new to them and very hard to complete, these were represented by 35.7% (n=5). The others admitted that caring for a spinal cord injury patient had changed their lives and all aspects of their lives were not the same, these were represented by 14.3 (n=2). Only 7.1% (n=1) responded by saying it was manageable and that they were coping well.

EFFECT OF CARE GIVING ON RELIGIOUS PRACTICES

Response	Frequency	Per cent	Cumulative per cent
More religious	12	85.7	85.7
No change	2	14.3	100
Less religious	0	0	100
Total	14	100	

As to regards of the role of being a caregiver having any effect on their religious practices, 85.7% (n=12) of the participants revealed that they were more religious and prayed more. Though 14.3% (n=2) of the caregivers revealed that they were still as religious as they were prior to occurrence of the spinal cord injury of their patient. None of the participants revealed that they were less religious.

EFFECT OF CARE GIVING PHYSICALLY



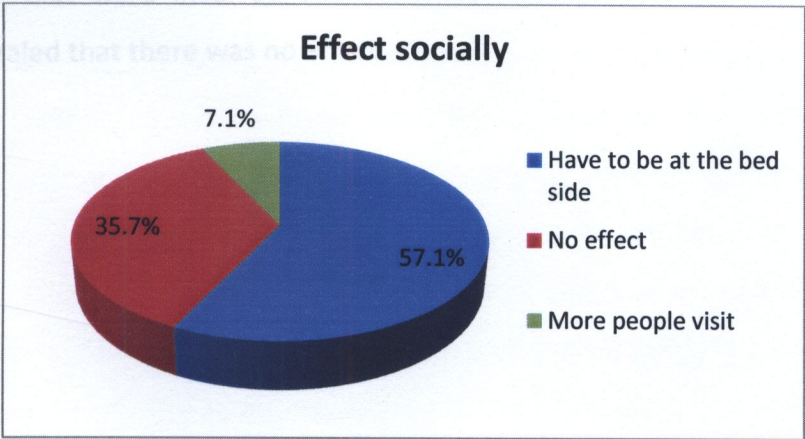
As to regards to the effect of care giving on the physical aspect, 57.1% (n=8) of the participants revealed that they were constantly tired and felt fatigued. For another set of caregivers they revealed that they had noticed some weight loss and were represented by 21.4% (n=3). Although some of the caregivers revealed that only occasionally did they feel tired and usually they were fine, these were represented 14.3% (n=2).

EFFECT OF CARE GIVING EMOTIONALLY

Response	Frequency	Per cent	Cumulative per cent
It is depressing	4	28.6	28.6
I feel sorry/bad	8	57.1	85.7
I have become emotional	2	14.3	100
No effect	0	0	
Total	14	100	

As regards to the effect of care giving emotionally 57.1% (n=8) of the participants revealed that they felt sorry and bad for the patient. For 28.6% (n=4) of the participants revealed that taking up the role of the caregiver and seeing their patient in the state they were in was quite depressing and that they were usually in a low mood. Another set of participants revealed that during the period in which they took up the role of being a caregiver for a patient with a spinal cord injury, they had become very emotional and every set back would see them in tears. None of the participants revealed that it had no effect on them emotionally.

EFFECT OF CARE GIVING SOCIALLY



As to regards the effect of care giving socially, 57.1% (n=8) of the participants revealed that their social life had been disrupted as they had to be on the bed side to tend to their patient. Only 7.1% (n=1) revealed that they were able to socialise more as there were a lot of visitors

who were trooping in to see the patient. As for 35.7% (n=5) of the participants, they revealed that their social life was more or less the same and that there was no effect.

EFFECT OF CARE GIVING ECONOMICALLY

Response	Frequency	Per cent	Cumulative per cent
Cannot go for work	4	28.6	28.6
More bills	3	21.4	50
Patient was the breadwinner	7	50	100
No effect	0	0	
Total	14	100	

As regards to the effect of care giving economically, 50% (n=7) revealed that they had been severely affected as the patient with the spinal cord injury was the breadwinner and as long as they were hospitalised there was no other source of income. As for 28.6% (n=4) of the participants they revealed that as far as they were performing the role of caregiver then they could not work as the role was very demanding. Another set of participants revealed that there were more bills that were incurred and were represented by 21.4% (n=3). None of the participants revealed that there was no effect.

CHAPTER FIVE

5.0 DISCUSSION

5.1 INTRODUCTION

In this chapter, the results are discussed with reference to the objectives of the study, as well as the available literature which are relevant to the study. The study sought to determine caregiver experiences and expectations in caring for spinal cord injury patients at the University Teaching Hospital. The sample size consisted of 13 participants that were available and fitted the criteria of the study.

5.2 DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

After analysing the data collected and analysed the type of individuals that were usually affected by spinal cord injuries was identified. It is important to note that in Zambia as is the rest of the developing world there are no established national trauma or SCI registries. Similarly there is no population based data on SCI available from majority of the developing world countries. This is complicated by the fact that medical record keeping is poorly managed in most of the hospitals (Thanni and Kehinde 2006). Though the general demographics of SCI in the developing world share some similarities with the epidemiological pattern reported from the developed countries. For example SCI is primarily a disease of the young males. But there are many important differences as well that need to be considered. Motor vehicle accidents are the leading causes of death in the developed countries followed by falls (Divanoglou and Levi 2009). The reverse is true for most of the developing countries (Chacko et al. 1986, Maharaj 1996, Singh et al. 2003, Rathore et al. 2008). Diving and sports injuries are another important cause of traumatic SCI in the Western world (Boden and Jarvis 2009) but this has rarely been reported from the developing countries. Among the non traumatic SCI, spinal tuberculosis is still an important cause in the underdeveloped countries of the world (Turgut 2001), while it is rarely seen in the developed countries nowadays.

AGE

The study was able to reveal the age distribution of the patients with Spinal Cord Injuries. The age range of 31-45 years is the most affected with 42.9% and the least affected is individuals who were 60 years and above with 7.1%. The other age ranges which were 15-30 years and 46-60 years were represented by 28.6% and 21.4% respectively.

From this we can conclude that spinal cord injuries were more prevalent in the ages 15-45 years and were represented by 71.5% (n=10). This information further backs how devastating spinal cord injuries are to the individuals who suffer them and to the society as a whole, as the prevalence is high the most productive age range. The International Campaign for Cures of spinal injury Paralysis (ICCP) released a general information which revealed that the average age of injury was 33.4 years and most injuries occurred at the age of 19 worldwide.

GENDER AND MARITAL STATUS

In terms of gender it was clear that more males were affected by Spinal Cord Injuries and were represented by 92.9% (n=13) as compared to women who were represented by 7.1% (n=1). And of these participants 71.4% (n=10) were married and that the rest were single represented by 28.6% (n=4).

From this information it can explain how difficult it is for the males who are at a productive age to adjust to relinquish their role as breadwinner in the marriage as most of the individuals with the SCI were males (92.9%) and married (71.4%). Spinal cord injury significantly affects marriages. In general, people with spinal cord injury are less likely to be married and more likely to be divorced (DeVivo and Fine, 1985). Given the disruptive effects of spinal cord injury on the family, the burden of care giving being carried by the spouse, and impairment of sexual function, most people assume that spinal cord injury causes divorces and strongly discourage post-injury marriages. However, the effects of spinal cord injury on marital rates and marital relationships are less deleterious than commonly assumed. While divorces are more common after spinal cord injury, divorce rates are highly variable. Finally, sexual function and children are not only possible but common after spinal cord injury.

OCCUPATION

Occupation is another important factor that should be discussed as regards to SCI patients. From the data collected and analysed it revealed that 50% (n=7) of the patients were Self-employed. And as for the rest 29% (n=4) were unemployed and 21% (n=3) were employed. Depending on the severity of the SCI, a patient may lose all their independence. Adjustments have to be made as they will not be able to provide for themselves any more.

The independence of individuals with spinal cord injury may affect family relationships. Spinal-injured individuals who are more independent tend to perceive their family environment as more responsive and more open (McGowan & Roth, 1987). Even when corrected for injury severity and disability, the productivity of an individual after spinal cord injury is most influenced by the following variables in order: education, ability to drive a car, other transportation indices, and age (Noreau, et al., 1999). Boekamp, et al. (1996) reviewed the literature for potential causes of depression after spinal cord injury and found that social support and recent stressful events can be used to identify patients at a high risk of depression but that they are less likely to become depressed if they are independent. Adjustment to spinal cord injury and quality of life can be adversely affected by inadequate home facilities that make a person more dependent (Seki, et al., 2002). Expectations of independence decline steadily with increasing age (McColl, et al. 1999).

LEVEL OF SPINAL CORD INJURY AND COMPLICATIONS

The most common site of spinal cord injuries among the patients was the Lumbar region which was represented by 50% (n=7). The other sites of spinal cord injuries were also the Cervical region and the Thoracic region represented by 35% (n=5) and 14.3% (n=2) respectively. The level of injury will also determine the severity of the disease and quality of life the SCI patient will have. The outcome and severity of the SCI as regards to the level of injury was well outlined in the literature review (Chapter 2).

As for complications as a result of SCI, most the patients had complications and were represented by 87.5% (n=12). The most prevalent complication was the occurrence of pressure

sores which was represented by 64.3% (n=9). The other complications were respiratory complications represented by 14.3% (n=2) and urinary tract infections represented by 7.1% (n=1). Only 14.3% (n=2) were exclusively being treated for the spinal cord injury and did not have any other complications arising.

SCI results in complications affecting nearly all systems of the body, leading to an increased morbidity and mortality in this group of patients. The complications profile reported from the developing countries are similar to that of the developed world with notably increased incidence (Chacko et al. 1986). The high frequency of preventable complications indicates a general lack of awareness in the health care professionals as well as inability of the patients to adhere to a lifelong prevention regime. In developing countries the problem of pressure sores is more critical because of lack of access to specialized technologies and adequate medical and pressure sore risk assessment. In some cases these pressure sores even prove fatal for the patient (Rathore et al. 2008, Gosselin and Coppotelli 2005). Urinary tract infections also occur with a very high frequency with possible etiological factors as indicated by Rathore and colleagues (2007). Another important factor may be inability to use disposable catheters for clean intermittent catheterization due to the expenses involved. The reported incidence of thrombo-embolic disorders like pulmonary embolism and deep vein thrombosis in the SCI population in West is high (Weingarden 1992, Green 2003) despite adequate use of thromboprophylaxis. A vast majority of SCI patients in the developing world are not given standard thromboprophylaxis. Still the frequency of PE and DVT in these patients, especially from Asian region is low in many studies (Toe 1978, Lee et al. 2000, Rathore et al. 2008). The reason for this disparity is not clear although many mechanisms have been proposed. These include genetic factors, low prevalence of obesity and heart failure in the developing world, and possibly early mobilization and massage of lower limbs and role of dietary factors (Aito et al. 2007).

5.3 IDENTIFYING THE TYPES OF CAREGIVERS

Life after a SCI often means a loss of independence for the injured person, and to function in everyday life, patients often need caregivers. Caregivers assist with daily activities such as bathing, dressing, bladder management, and transportation. Family members or friends who take on the role of caregiver after a loved one is injured often find themselves serving in many different roles.

Demographic data was collected to identify the types of caregivers that are providing care for spinal cord injury patients at the University Teaching Hospital.

AGE AND GENDER

From the caregivers that were interviewed it revealed that the age range of 46-60 years had the most caregivers with a representation 42.9% (n=6). The other age ranges were 31-45 years and 15-30 years which were represented by 35.7% (n=5) and 21% (n=3) respectively. It further went to reveal that there were more females taking up the role of being the caregiver of the spinal cord injury and were represented by 85.7% (n=12) as compared to men who were represented by 14.3% (n=2).

Many studies have looked at the role of women and family care giving. Although not all have addressed gender issues and care giving specifically, the results are still generalised to women because they are the majority of informal care providers. Estimate's of the percentage of family or informal caregivers who are women range from 59% to 75%. The average caregiver is age 46 and although men also provide assistance, female caregivers may spend as much as 50% more time providing care than male caregivers (Family Caregiver Alliance fact sheet, 2001).

RELATIONSHIP TO THE PATIENT

It is also important to discuss the relationship of the caregiver to the SCI patient as it affects the quality of care that will be rendered. The study revealed that the majority of the caregivers were spouses to the spinal cord injury patients and were represented by 71.4% (n=10). Other

caregivers included siblings represented by 14.3% (n=2), parents represented by 7.1% (n=1) and other relatives represented by 7.1% (n=1).

The burden of care giving most frequently falls on the spouse. Care giving spouses are often severely stressed, particularly due to health issues that arise after spinal cord injury. Chan (2000) studied this phenomenon in Hong Kong, finding that spouses of persons with spinal cord injury suffer emotional stress that is comparable to or greater than those of the injured partner. Spouses who are caregivers for people with spinal cord injury may be more depressed than their partners with disabilities. Caregivers have a higher incidence of physical stress, emotional stress, burnout, fatigue, anger, and resentment (Weitzenkamp, et al. 1997) than their partners or spouses who are not the caregivers. Chan, et al. (2000) report that the impact of spinal cord injury is more severe on marriages that began before than after the injury. An early study suggested that disabled people in pre-injury marriages receive more daily personal care assistance from their spouses than those in post-injury marriages (Crewe, et al, 1979).

Little is known about the effects of spinal cord injury on siblings, except for a few anecdotal stories (Shaddinger, 1995). The effects of injury of course depend on the age and closeness of the siblings. Very little has been published on the potential disruptive effects of spinal cord injury on the life, education, attitudes, and adjustment of siblings. Interestingly, there are several studies of the effect of spinal cord injury on identical twins. Tirch, et al. (1999) assessed depression in 11 monozygotic twins with one spinal-injured member and found no significant differences of depression, suggesting that depression may have a genetic basis and spinal cord injury does not inevitably lead to depression. An alternative interpretation is that depression in one member of the pair leads to depression in the other. Twin studies, however, have provided a variety of insights into spinal cord injury induced changes in body composition and metabolism (Spungen, et al., 2000; Bauman, et al. 1999). Likewise, Kahn, et al. (2001) examined platelet function in 12 pairs of monozygotic twins and showed significant differences in platelet function related to loss of high-affinity prostanoid receptors, perhaps explaining the greater incidence of coronary disease in people with spinal cord injury. Sibling studies have also been

used to assess the insulin resistance and sympathetic functions in high spinal cord injury (Karlsson, 1999).

OCCUPATION

Occupation is on aspect of the caregiver's life that will be affected after they take up this role. From the data analysis it revealed that 57.1% (n=8) of the caregivers of spinal cord injury patients were unemployed. And as for the rest 28.6% (n=4) were self-employed and 14.3% (n=2) were employed.

As the majority of the caregivers were unemployed or not in any sort of formal employment, they had to take up the role of being the provider and still play their role as caregiver.

5.4 THE EXPECTATIONS OF THE CAREGIVER

It is important to know the expectations of the caregiver as they are care for their patient. This will help the clinician who is providing care for the patient to know whether these expectations are realistic or not. From the data that was collected from the participants the following can be discussed.

THE INITIAL EXPECTATIONS IN THE RECOVERY OF THE PATIENT

The initial expectation's a caregiver has on the outcome of the patient's disease determines several issues. It will determine how the caregiver will approach their role. If they expect full recovery after treatment sessions, then this will motivate them to go on as they know that soon all will be well. But if they expect the patient not to improve due to the severity of the condition then they may be not so enthusiastic in taking up the role of being a caregiver as it will seem like a lifelong duty. In other cases their optimism can lead to great disappointments that can affect them psychologically.

From the data collected and analysed it revealed that most of the caregivers were quite optimistic in their initial expectations with 64.3% (n=9) of them expecting full recovery after the patient receives medical attention. Another group expected that the patient would eventually walk but with some difficulties which was represented by 14.3% (n=2) and another 14.3% (n=2)

expected that the patient would be wheelchair bound after treatment. Only 7.1% (n=1) thought that their patient would be bedridden for life and were not optimistic.

RECOVERY OF THE PATIENT

The rate of recovery of the patient is usually a sign to the caregiver on whether their expectations are realistic or not. It is a common tendency for caregivers to ignore these signs and be in denial as to regards to the recovery of the patient they are caring for. As for this study 50% (n=7) of the caregivers thought the recovery of their patient was poor. As for the other caregivers 28.6% (n=4) thought the recovery was fair and 14.3% (n=2) thought the recovery was good. Only 7.1% (n=2) thought the recovery was very good and that they had noticed that their patient had improved significantly.

FULFILMENT OF THE INITIAL EXPECTATIONS

As expected usually the caregivers are too optimistic in their initial expectations. This was also reflected in the participants of this study. A majority which was represented by 57.2% (n=8) believed that even though their initial expectations in the recovery of their patient had not happened at the time of the interview, it would eventually happen. Another 35.7% (n=5) admitted that their initial expectations were too optimistic and that they had not been fulfilled and did not look likely to happen. Only 7.1% (n=1) revealed that their initial expectations had been fulfilled.

TAKING THE BLAME

In some cases caregivers may begin to blame themselves for the state of the patient. They may notice that the patient is not improving as they had initially expected and may think they have played a role in this delay in improvement. This may cause severe stress for the caregiver and will eventually affect the patient's condition negatively.

In this study, 57.1% (n=8) of the participants did not blame themselves for the expectations not being fulfilled, but wished they could do more to help the patient with the spinal cord injury. On the other hand 42.9% (n=6) revealed that they did not blame themselves too but further

stated that they had done the possible best to help their patients. None of the participants blamed themselves.

5.5 CAREGIVER EXPERIENCES AND PROBLEMS FACED

FEELINGS ABOUT CARING FOR A SPINAL CORD INJURY PATIENT

The feelings of the caregiver towards the patient and the condition will determine how effective the care being offered will be. When interviewed about how they feel about caring for spinal cord injury patients 42.9% (n=6) of the participants revealed that it was very demanding and the role does not allow other personal activities. The other participants in the study revealed that it was difficult as some tasks were new to them and very hard to complete, these were represented by 35.7% (n=5). The others admitted that caring for a spinal cord injury patient had changed their lives and all aspects of their lives were not the same, these were represented by 14.3 (n=2). Only 7.1% (n=1) responded by saying it was manageable and that they were coping well.

EFFECT OF CARE GIVING ON RELIGIOUS PRACTICES

It is common that when an individual is faced with adversities they tend to turn to religion for comfort. But in the role of being a caregiver, this tendency maybe hindered because the role is very demanding. As to regards of the role of being a caregiver having any effect on their religious practices, 85.7% (n=12) of the participants revealed that they were more religious and prayed more. Though 14.3% (n=2) of the caregivers revealed that they were still as religious as they were prior to occurrence of the spinal cord injury of their patient. None of the participants revealed that they were less religious.

EFFECT OF CARE GIVING PHYSICALLY

Being a caregiver for a SCI patient may be very physically challenging. This all depends of the severity and the level of independence of the patient. As to regards to the effect of care giving on the physical aspect, 57.1% (n=8) of the participants revealed that they were constantly tired and felt fatigued. For another set of caregivers they revealed that they had noticed some

weight loss and were represented by 21.4% (n=3). Although some of the caregivers revealed that only occasionally did they feel tired and usually they were fine, these were represented 14.3% (n=2). Along with psychological repercussions of care giving, some caregivers also experience physical effects due to care giving. This is particularly true of highly burdensome care giving, as is typically the case with SCI patients that have been severely affect (Nijboer et al, 1998). Commonly, caregivers report sleep disturbances, such as fatigue or insomnia. In caregivers of severely affected patients, these disturbed sleep patterns are associated with symptoms of depression. Sometimes, caregivers may also experience a loss of appetite or may meet the criteria for an eating disorder (Petrie, Logan and DeGrasse, 2001). For caregivers experiencing burnout, there are also often physical effects. These include headaches, insomnia, backaches, lethargy, lingering colds, gastrointestinal upset and cardiovascular problems. Other reported physical repercussions of care giving include impaired immunity, high blood pressure, and arthritis. As is the case with psychological distress, research suggests that the physical repercussions that caregivers experience may be due to them neglecting their own needs and physical health in order to improve the care of the patient (Kitrungroter and Cohen, 2006).

EFFECT OF CARE GIVING EMOTIONALLY

In the case of the effect of care giving emotionally, 57.1% (n=8) of the participants revealed that they felt sorry and bad for the patient. For 28.6% (n=4) of the participants revealed that taking up the role of the caregiver and seeing their patient in the state they were in was quite depressing and that they were usually in a low mood. Another set of participants revealed that during the period in which they took up the role of being a caregiver for a patient with a spinal cord injury, they had become very emotional and every set back would see them in tears. None of the participants revealed that it had no effect on them emotionally.

Along with the psychological repercussions typical of the initial phase of treatment, many other psychological outcomes become relevant as the patient undergoes further treatment due to a number of additional stressors that the caregiver must deal with (Haley, 2003). These additional stressors may cause "intrapsychic strain, such as guilt or changes in the caregiver's self-concept". For a minority of caregivers, they may meet the criteria for a psychiatric diagnosis,

typically of depression or an anxiety disorder. But for the majority, any distress they experience does not reach clinically diagnosable levels, although they may exhibit depressive symptoms. Currently, it remains uncertain how levels of psychological distress change with time. Some studies report that psychological distress decreases over time, but others report that it increases (Haley, 2003). This increase may be a result of caregivers neglecting their own needs while caring for the patient. For some, this emotional repression may lead to feelings of resentment towards the patient. At this point of the trajectory (and ongoing), caregivers may also begin to exhibit symptoms of burnout due to the increased work-burden of caring for a SCI patient. There are many physical and emotional components to burnout. Amongst the emotional components, caregivers may experience frustration, anger, depression, resentment and insecurity.

EFFECT OF CARE GIVING SOCIALLY

As SCI may vary from mild to severe, depending on which of the two extremes the condition falls upon a caregiver's social life can be disrupted. As to regards the effect of care giving socially, 57.1% (n=8) of the participants revealed that their social life had been disrupted as they had to be on the bed side to tend to their patient. Only 7.1% (n=1) revealed that they were able to socialise more as there were a lot of visitors who were trooping in to see the patient. As for 35.7% (n=5) of the participants, they revealed that their social life was more or less the same and that there was no effect.

A number of factors regarding relationships with the patient, spouse, family or others can increase caregiver distress. One major factor is the social role changes, for example, being a caregiver and a parent. Care giving can also cause a decrease in the social activities that the caregiver usually engages in because they are required to take on extra tasks to help their loved one (Kim and Given, 2008). For some caregivers, this role strain can cause depression, resentment, or a loss of intimacy with the patient. In some families, the stress of care giving can also lead to increased family conflict (Pitceathly and Maguire, 2003). For most ill patients and their spousal caregivers, scores of marital satisfaction tend to be very similar to the normal population. But for a minority, SCI and care giving can cause relationship strain and can impact

the couple's intimacy (Pitceathly and Maguire, 2003). Depending on the level of the SCI, caregivers have also reported changes in their sexual relationships (decreases in sexual activity).

EFFECT OF CARE GIVING ECONOMICALLY

Just like any other chronic condition spinal cord injuries will be accompanied by their fair share of financial stains. As regards to the effect of care giving economically, 50% (n=7) revealed that they had been severely affected as the patient with the spinal cord injury was the breadwinner and as long as they were hospitalised there was no other source of income. As for 28.6% (n=4) of the participants they revealed that as far as they were performing the role of caregiver then they could not work as the role was very demanding. Another set of participants revealed that there were more bills that were incurred and were represented by 21.4% (n=3). None of the participants revealed that there was no effect.

5.6 THE NEEDS OF THE CAREGIVER

THE MOST CONCERNED PROBLEM ABOUT THE PATIENT

To discover the needs of the caregiver we need to first establish not only their experiences but also the problems they are concerned about. When questioned about their most concerned problem about the SCI patient it was revealed that 42.9% (n=6) of the caregivers were more concerned about their patient's immobility than any other problem the patient had. The lack of improvement in the patient's condition was represented by 14.3% (n=2) of the caregivers. Another set of caregivers were more concerned about the way their patient presented in a depressed manner and represented 21.4% (n=3). Pressure sore were the most concerned problem for 21.4% (n=3).

THE MOST CONCERNED PROBLEM ABOUT THE PATIENT'S ENVIRONMENT

The environment in which the patient is in plays a significant role in the progression of the condition and it also affects the manner in which the caregiver can operate. When questioned about what concerned the caregivers the most about the patients environment 35.7% (n=5) of the caregivers were immensely concerned about the comfort of the patient they were caring

for. They were concerned that the patient was not comfortable with the long stay in the hospital. Another set of caregivers were most concerned about the privacy in the ward, as everything had to be done for the patient had to be done on the bed. Fourteen point three per cent (14.3%, n=2) were concerned about the high infection rate in the hospital and the difficulty to tackle the infections. Although 28.6% (n=4) revealed that there was no problem they were concerned with apart from performing their caregiver role.

WHAT HAS HELPED WITH DEALING WITH THE PROBLEM?

As the caregiver spends more time with the patient than any of the medical staff, they are in a good position to help tackle some of the problems the patient may encounter. But that is not always the case and through studies like these we can find out how the caregivers are dealing with these problem and if need arises assist them. When questioned about how the caregivers were dealing with the problems they had encountered 50% (n=7) of the caregivers revealed that they had not found a solution but simply adjusted and gotten used to the situation. Another set of caregivers revealed that they have tried several attempts to find a solution but nothing had worked and were represented by 21.4% (n=3). The rest of the caregivers who were represented by 28.6(n=4) still that there was no problem and that their main concern was performing their role as a caregiver.

Therefore from this feedback it is clear that the caregivers are facing a lot of problem and that they are not well equipped in terms of finding a solution.

CHAPTER SIX

6.0 CONCLUSION, RECOMMENDATIONS AND STUDY LIMITATIONS

6.1 INTRODUCTION

This chapter allows the researcher to conclude the study and recommend some ideas and views to improve the management of patient with traumatic spinal cord injuries at the University Teaching Hospital. It also allows the researcher to reveal the study limitations.

6.2 CONCLUSION

The aim of this study was to identify the experiences caregivers face and their expectations in caring for patients with spinal cord injuries. The age range of 46-60 years has the most caregivers with a representation 42.9% (n=6). The other age ranges are 31-45 years and 15-30 years which are represented by 35.7% (n=5) and 21% (n=3) respectively. It can be concluded that there are more females taking up the role of being the caregiver of the spinal cord injury and are represented by 85.7% (n=12) as compared to men who are represented by 14.3% (n=2).

Majority of the caregivers are spouses to the spinal cord injury patients and are represented by 71.4% (n=10). Other caregivers include siblings represented by 14.3% (n=2), parents represented by 7.1% (n=1) and other relatives represented by 7.1% (n=1).

All the individuals that took part in this study were willing and consented.

The following were the objectives of the study:

- To determine the needs of caregivers caring for spinal cord injury patients,
- To determine problems faced by caregivers in caring for spinal cord injury patients,
- To determine how caregiver expectations affect their role in the rehabilitation of patients with spinal cord injuries,
- To identify the type of caregivers caring for spinal cord injury patients.

The results showed that the caregivers have several needs which include tackling the occurrence of pressure sores, patient's infections means to provide comfort to the patient,

comfort of the patient and other issues like privacy in the hospital. The caregivers also showed lack of information and know-how on how to tackle these problems. The study also revealed that the caregivers of SCI patients are experiencing social, emotional, psychological, physical and economical hardships without any attention being given to them. All these hardships also being exaggerated by the disappointment they face after initially having unrealistic expectations in the recovery the SCI they are caring for.

6.3 RECOMMENDATIONS

It is important to bear in mind that care giving is very complex and that more research has to be done. The following are the recommendations that can be suggested after completion of the study:

- As to regards of the management of SCI, a specialised team or unit has to be assembled that solely dedicated to the management of spinal cord injuries,
- Counselling should also be recommended for not only SCI patients but also the caregivers, as to effectively manage the SCI patient, the caregiver has to be in the right frame of mind,
- There should be clinics or short presentations for not only caregivers of SCI patients but also caregivers of patients of other conditions that keep patients bedridden for prolonged periods. These presentations should teach caregivers on how to take care of the patient, prevent complications (e.g. pressure sores, UTI's) and also warn the caregivers on caregiver stress.
- Encourage health professions to include the caregiver in the management of their patients.

6.4 STUDY LIMITATIONS

The following are the limitations of the study:

- The sample size was too small as these were the only available and willing participants that were able to fit the study's criteria,
- The time in the study was carried out was short as a longer duration would have allowed more participants and a variety,

- The study was restricted to only one hospital and did not explore a vast number of hospitals and the patients and caregivers they have to offer.

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www.brainandspinalcord.org

www.caregiverstress.com

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www.sasca.org.za

www.ZambiaDoctors.com

APPENDIX I

BUDGET

		QUANTITY	UNIT COST (K)	TOTAL COST (K)
	Stationery			
1	A4 Paper	3 reams	30,000	90,000
2	Pens	10	1,500	15,000
3	Pencil	5	1,000	5,000
4	Folder	1	15,000	15,000
5	Eraser	1	2,500	2,500
6	Correction fluid	1	8,500	8,500
7	Stapler	1	30,000	30,000
8	Staples	1 box	10,000	10,000
9	Folder Clips	10	1,000	10,000
	SUBTOTAL			186,000
1	Printing proposal drafts			100,000
2	Photocopying questionnaires	150	200	30,000
3	Photocopying consent forms	40	200	8,000
4	Logistics during data collection			250,000
5	Data entry			250,000
6	Data analysis			350,000
7	Binding			50,000
8	Compiling final report			200,000
	SUBTOTAL			1,238,000
	TOTAL			1,424,000
	Contingency 10%			142,400
	GRAND TOTAL			1,566,400

APPENDIX II

WORK PLAN SHEET YEAR 2011/2012

MONTH	OCT	NOV	DEC	JAN	FEB	MAR
TASK						
Project proposal writing						
Submission for approval to research ethics						
Data collection						
Data analysis						
Writing of final report						
Binding and submission of final report						

APPENDIX III

INFORMATION SHEET

Dear Participant,

I am a fifth year student at the University of Zambia, School of Medicine. As a partial fulfilment of the programme, students are required to undertake a research in any area to the provision of health care and improve knowledge. The aim of this study is to determine caregiver experiences and expectations for patients with spinal cord injuries in the University Teaching Hospital (UTH). The findings in this study will help in providing quality management to patients with spinal cord injuries and reduce caregiver stress in future.

Your taking part in this study is purely voluntary and the information that will be given shall be handled with strict confidence. Be informed that not participating in this study will not affect your receiving of treatment in this hospital.

Please note that the study is purely academic and there are no monetary benefits. I am requesting for your permission to interview you.

If you have any questions contact me or the secretary of the Research Ethics Committee.

Your support will be greatly appreciated.

Research Ethics Committee

University of Zambia

P O Box 510110

Lusaka

Rex Ngoma (5th year student)

University of Zambia

School of Medicine

Department of Physiotherapy

Ridgeway Campus

Tel: 097 7 200974 (E-mail: rexngoma88@yahoo.co.uk)

CONSENT FORM

I.....having had the aims and benefits explained to me, I am aware of my rights in not taking part in the study and that it will not affect my receiving of any services in this hospital at any given point without giving notice. I have therefore agreed/not agreed to take part in the study with my own free will.

Participant’s signature/thumb print:

Date:.....

Witness:

Date:

Researchers Signature.....

Date:.....

APPENDIX IV (LETTERS)

The University of Zambia,
School of Medicine,
Department of Physiotherapy,
P.O. Box 5110
Lusaka.

The University of Zambia,
Research and Ethics Committee,
P.O. Box 50110,
Lusaka.

The Chairman,

RE: A study to determine caregiver experiences and expectations for patients with spinal cord injuries at the University Teaching Hospital

I am a fifth year physiotherapy student at the University of Zambia pursuing Bachelor of Science in Physiotherapy.

As a partial fulfilment of the degree programme at the University of Zambia, I hereby apply to carry out a research project. In the study to determine caregiver experiences and expectations for patients with spinal cord injuries at the University Teaching Hospital, I have the following objectives:

1. To determine the needs of caregivers caring for spinal cord injury patients,
2. To determine problems faced by caregivers in caring for spinal cord injury patients,
3. To determine how caregiver expectations affect their role in the rehabilitation of patients with spinal cord injuries,
4. To identify the type of caregivers caring for spinal cord injury patients.

Yours faithfully,



Rex Ngoma

Computer number: 26118068

University of Zambia,
School of Medicine,
Department of Physiotherapy,
P.O. Box 50110,
Lusaka.

The Director (Clinical Services),
University Teaching Hospital,
P.O. Box RW IX
Lusaka.

Dear Sir

RE: permission to collect data from caregivers and patients of spinal cord injuries in the University Teaching Hospital

I am a fifth year student at the University of Zambia, School of Medicine, Department of Physiotherapy. As partial fulfilment of the programme, I am required to carry out a research study. My research topic is 'Study to determine caregiver's experiences and expectations for patients with spinal cord injuries at UTH'.

I am hereby requesting for permission to collect data for the study. Data collection will be through administering of a questionnaire to the caregivers and patients with spinal cord injuries in your institution.

Your cooperation will be highly appreciated.

Thanking you in advance.

Yours faithfully,



Rex Ngoma

Computer no: 26118068



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

4th January, 2012.

Your Ref: 004-01-12.

Mr Rex Ngoma,
School of Medicine,
Department of Physiotherapy,
Lusaka.

Dear Mr Ngoma,

RE: RE-SUBMITTED RESEARCH PROPOSAL: "A STUDY TO DETERMINE CAREGIVER EXPERIENCES AND EXPECTATIONS IN CARING FOR PATIENTS WITH TRAUMATIC SPINAL CORD INJURIES AT UNIVERSITY TEACHING HOSPITAL, LUSAKA"

The above-mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee with recommended changes. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,



Dr. J.C Manthali
CHAIRPERSON

Date of approval: 04 January, 2012

Date of expiry: 03 January, 2013

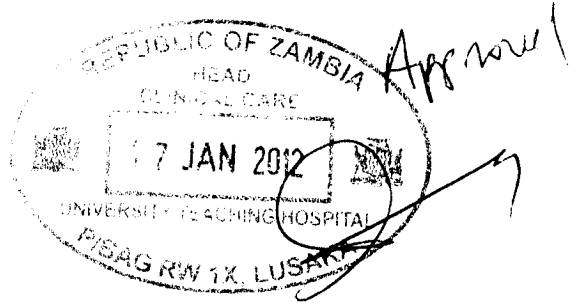


**THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE**

DEPARTMENT OF PHYSIOTHERAPY

Telephone: 257938
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-211-257938

Dean's Office
P.O. Box 50110
Lusaka, Zambia



16th January, 2012.

The Senior Medical Superintendent,
University Teaching Hospital,
P/Bag RW 1X,
Lusaka.

Handwritten notes:
1/17/12
Ryn
Vmk

Dear Sir,

**RE: REQUEST FOR PERMISSION TO ALLOW NGOMA REX
COLLECT DATA FOR HIS STUDY**

Reference is made to the subject above.

We write to introduce to you our above named 5th year student pursuing a Bachelor of Science in physiotherapy. Rex is required to carryout a Research Project in partial fulfillment of the requirements for the award of the Bachelor of Science Degree.

His proposed study is: **"To determine caregiver experiences and expectations in caring for patients with traumatic spinal cord injuries at University Teaching Hospital."**

We are therefore seeking permission from your office to enable him collect data from C21 and C22 and the G-Block. We would like to request that he be allowed to access data related to his research. The data collected will be for academic purposes only and will be treated as confidential.

Thanking you for your constant support.

Yours faithfully,

Mr. G. Moyo
Dip PT, Technical Education, BSc (Hons), MSc
ACTING HEAD – DEPARTMENT OF PHYSIOTHERAPY

APPENDIX V

QUESTIONNAIRE

SECTION A: PATIENT

Mark an X where appropriate []

1. Address.....
2. Gender
 - a. Male []
 - b. Female []
3. Age
 - a. 10-19 years []
 - b. 20-29 years []
 - c. 30-39 years []
 - d. 40-49 years []
 - e. 50-59 years []
 - f. 60 years and above []
4. Marital Status
 - a. Single []
 - b. Married []
 - c. Divorced []
 - d. Widowed []
5. Employment
 - a. Employed []
 - b. Unemployed []
6. Duration of illness.....
7. Level of spinal cord injuries
 - a. Cervical []
 - b. Thoracic []
 - c. Lumbosacral []

8. Any other complications that have arisen:

.....

SECTION B: CAREGIVER

(Mark items with an X where appropriate)

Address.....

1. Gender

a. Male []

b. Female []

2. Age

a. 10-19 years []

b. 20-29 years []

c. 30-39 years []

d. 40-49 years []

e. 50-59 years []

f. 60 years and above []

3. Home language

a. Bemba []

b. English []

c. Kaonde []

d. Lozi []

e. Lunda []

f. Luvale []

g. Nyanja []

h. Tonga []

i. Other (Specify).....

4. Marital status

- a. Single []
- b. Married []
- c. Divorced []
- d. Widowed []

5. Employment

- a. Employed []
- b. Unemployed []

6. Relationship to the patient

- a. Parent/parent in law []
- b. Spouse/partner []
- c. Sibling []
- d. Child []
- e. Friend/neighbour []
- f. Other (specify).....

7. Any other person(s) that help with caregiving? (Specify relationship to patient).....

8. Do you live with patient?

- a. Yes []
- b. No []

9. If responses to the above question is no, then how many hours on average are spent with the patient?.....

SECTION C: INTERVIEW GUIDE

INTERVIEW QUESTIONS

1. How long have you been taking care of the spinal cord injury patient?

2. How has the recovery of the spinal cord injury patient been?.....
.....
3. Tell me about your experience on a typical day of providing care for the patient with a spinal cord injury?.....
.....
4. At the time you started to care for the patient, what were your initial expectations in the recovery of the patient?.....
.....
.....
.....
5. Have any of the initial expectations been fulfilled and if so which ones?.....
.....
.....
6. Do you blame yourself for some or all of these expectations not being fulfilled and if so why?.....
.....
.....
7. What are your most concerned problems about the patient?.....
.....
8. What are your most concerned problems about the patient's environment?.....
.....
.....
9. What has helped you in dealing with the problems?.....
.....
10. Describe your feelings about caring for your patient with a spinal cord injury?.....
.....
11. How has caring for the patient affected your religious practices?.....
.....
12. How has caring for the patient affected you physically?.....
.....

13. How has caring for the patient affected you emotionally?.....
.....
14. How has caring for the patient affected you socially?.....
.....
15. How has caring for the patient affected you economically?.....
.....

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