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Lived Experience of Care Givers to Patients With Spinal Cord Injury at Muhimbili Orthopedic Institute

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Abstract

Spinal Cord Injury (SCI) is a devastating, life altering injury and a challenge to treat as well as in long term health caring. A spinal cord injury (SCI) damages the communication pathway between the brain and certain parts of the body. Depending on the extent of the damage and its location in the cord, serious and permanent physical consequences will result in varying degrees of severity. Limbs or organs will not function as they did before. Injury to the spinal cord, also known as a spinal lesion, can affect certain physiological functions. The ability to move muscles, as well as touch sensation may be affected. Spinal cord injury is associated with the requirement of long term support.

Introduction

Every year, around the world, between 250 000 and 500 000 people suffer from spinal cord injury (WHO, 2013). The majority of spinal cord injuries are due to preventable causes such as road traffic crashes, falls or violence. Spinal cord injury may render a person dependent on caregivers. An estimated 20-30% of people with spinal cord injury show clinically significant signs of depression, which in turn has a negative impact on improvements in functioning and overall health (WHO, 2013).

Spinal Cord Injury can result in paralysis or paresis of the affected areas of the body and the extent of this injury determined by how high or low on the spine the damage occurs, leading finally to tertaplegia or paraplegia (Thuret et al., 2006). However, there are many secondary complications that the individuals with SCI must face such as urinary infection, pulmonary complications and complications related to the skin (Montgomerie, 1997). Extensive study has been done on pattern of SCI over the years ago. Many investigations were limited to descriptive epidemiology, race and ethnicity, aetiology and mortality (Dollfus, 1990). Due to differences in social structure, therapeutic procedures and data gathering system it becomes challenging to match epidemiological data from one country to another or continent with another (Eng et al., 2006). The studies conducted in other countries cannot be applied in Tanzania.

Despite the known impact of disease and its effect to the families' children, siblings, parents, and other relatives, little is known of its care among family members in the country as well as regarding family members lived experience on how to take care of their patients.

Key words *care givers, patients, spinal cord injury*

Materials and Methods

Study adopted a descriptive, exploratory qualitative study design and convenience sampling techniques was used to collect data from 15 family caregivers. Data used in this study was collected through in-depth interview and observation. Cognitive behavioural therapy theory was used since engage patient and caregiver in managing challenges and enhance coping towards the situation.

Study Area

The study was conducted at Muhimbili Orthopaedic Institute at Dar es Salaam region. Dar es Salaam is the largest city which harbours different types of people with different values, beliefs, and cultural background.

Study Design

The study employs a descriptive, exploratory qualitative research design which helps to explore the lively experience of caregivers for the patient with SCI patients. According to Given (2008) exploratory research design is appropriate under two main conditions; when the area of the study has received little attention or not studied, and it has been largely examined using control rather than flexibility and open mindless. Krugler and Newman (2006) “exploratory research design frequently used qualitative data which help to familiarized with the basic facts, settings and concerns. It also creates general mental picture of conditions and formulate precise questions for future researchers to answer.

Population

The study involve all caregivers of SCI patients admitted in MOI wards for treatment as well as SCI patients who are attending physiotherapy department and outpatient follow up SCI clinics during the study. There is a total population of 45 SCI patients on a monthly basis (MOI, Admission Registration Book, and August – September 2014).

Study Sample and Sampling Procedures

A sample is a subset of population. In order to do a research there should be a sample to represent majority. According to Huskey (1997), a good sample is one which presents be for the sample and can be taken as true for the whole population; therefore random sampling technique was used to select the sample.

The minimum sample size for this study was 15 caregivers of SCI patients out of 45 SCI patients received at the institution on monthly basis. The sample size was drawn from Nassiuma’s formula which states that;

- If a population is <1000 use 1/3 of the population

  If population is >1000 use the following formula

$$n = \frac{NC^2}{C^2 + (N-1)(e^2)}$$

Where:

n- Is the sample size to be determined

N- Is the total number of the targeted population within a population in the study area

C- The coefficient of variation ≤30% usually acceptable

e- is the relative standard error, 5% is acceptable (Nassiuma, 2000).

In this study one third of the population was used; therefore;

1/3 x 45 = 15

The sampling was done conveniently depending of the availability of the SCI caregivers during study time. Involved caregivers were those having SCI patient with long stay in the hospital from the period of one month and above, also the caregivers with SCI patient with early discharge but being taken care at home was also be recruited. Selection of respondents was based on their accessibility at the institution; this was managed through visiting them in the wards, Outpatients department (OPD) as well as Physiotherapy department. This study covered only SCI patients attended at MOI.

Data Collection Methods

To answer the research questions, this study employed a qualitative data collection method. The use of qualitative research helps in understanding the given research problem or topic from perspective of the sample population. Guest et al., (2005), noted that, qualitative research lies primarily from its inductive approach, its focus on specific situations or people and its ability to generate culture to specific and contextually rich data. Generally qualitative research was employed so as to explore and understand the burden family members of the victim are facing while caring for the spinal cord injury patients.

In depth interview method was used to collect data from the participants. The interview guide questions were consisting of two sections; Section "A" comprise of socio-demographic characteristics, while Section B comprise of specific information consistence to lively experience of caregivers to patient with SCI.

Data Analysis

Qualitative data were thematically analysed. In the first stage the transcripts were read several times and compared to recorded data to ensure accuracy of the transcription. The data were coded to ensure into text so as to bring meaning during analysis stage. The analysis was done on the defined themes.

Results and discussion

The finding of this study reveals that family caregivers' encounters several challenges while caring for their patients. The identified common challenges include; lack of knowledge about caring spinal cord injury patients as well as lack of proper information from health care giver. Furthermore, the study findings indicates that family caregivers are overwhelmed by their routine daily work; caring for the spinal cord patient is an additional task which accelerate emotional suffering. Additionally, the findings show that most of caregivers experience isolation; as cannot participate in social activities which leads to social economical dissemination.

Findings in Table 4.1 show that, out of 15 interviewed respondents, 8 (53.3%) were male and 7 (46.7%) females. Consideration was also given into age groups of study. Findings also show that 5 (33.3%) of the respondents here aged between 21 – 30 years of total respondents, this age group was ranked higher compared to other age groups. The followed age group is the one ranging from 31 – 40 years this was represented with 26.6% of the study respondents.

In this study male respondents outnumber female counterparts this implies that majority of SCI patients were males. The findings are is support with the study done by Fazlul-Hoque, Grangeon & Reed, 1999 who reported that predominance may be determined or influenced by the social structure, economic and cultural differences by the fact that women stay at home as house wives, while men performed high risk activities at work environment in developing countries.

Apart from age, respondents' occupations were assessed. A summary of responses from respondents is provided in Table 4.2

Findings indicate that 3 (20.0%) of respondents were employed, 7 (46.7%) are unemployed and 5 (33.3%) respondents were retired but all taking care of SCI patients. From these findings imply that caring of SCI patients requires time and devotion since from those employed they have divided their time so as to take care for their sick one.

Respondents were asked if they leave their jobs leave their job for the sake of caring their patients; the finding show that, 60% left their jobs and 40% divide their time and perform other activities for their wellbeing. This is in line with the study done by Faro (2001) and Blanes (2006) which indicate that the caregivers of individuals with SCI have to divide time between care provided and other activities, leaving little or no time for leisure activities and rest.

The relationship between respondents and SCI patient was assessed and findings are presented in the Table 4.3;

Majority of caregivers were males. These data were conveniently taken from caregivers depending on their availability during study time. Involved caregivers were those having SCI patient with long stay in the hospital from the period of one month and above, and those with early discharge from hospital but come for the clinic. Since majority of the SCI patients were males, they are admitted in male wards of which male relatives are responsible to take care of the sick male patients unless deemed impossible.

In addition, causes of injury were also examined. Findings are presented in Table 4.4;

As illustrated; motor vehicle accident accounted to 53.3% of SCI, followed by Motorcycles accidents, fall and violence.

The findings concur with those of Burt (2004) that found that the main causes of traumatic SCI globally are motor vehicle accidents and falls. Divanoglou and Levi (2009) also found that motor vehicle accidents are the leading causes of death in the developed countries followed by falls.

However, the findings are different/vary from those reported by Hart and Williams (1994) that suggested violence (56%) was the most common cause of traumatic SCI in South Africa. Thus causes of SCI vary from country to country, depending on social and economic factors.

Moreover, types of injury were also analysed, the findings are presented in Table 4.5;

Findings indicated that; 80.0% of SCI cases are paraplegic while 20.0% of SCI cases are quadriplegic. Paraplegic is the paralysis of lower half of the body including both legs due to damaged spinal cord. On the other hand Quadriplegic is when the paralysis is in both four limbs, it is an indicative of spinal cord injury in the upper cervical area. Spinal cord injury represents a serious medical problem for society on all continents.

Problems that face family caregivers of patients with SCI

As the study attempted to find out problems that caregivers of patients with SCI face. This was done by asking caregivers to state the problems they are face, and that hinder service delivery to their patients and what is the support required by SCI patients. The findings are presented into themes as well as subthemes;

Lack of knowledge about caring spinal cord injury patients

This also goes in hand with lack of information from health care givers, it was observed that family caregivers lack basic knowledge about the spinal cord injury as well as information of proper handling of these patients. Participants reported,

> *"Although I take care of him for nine months now, I did not know how to lift him .... I have been using pampers but i don't know for how long am I supposed to change my patient, sometimes I don't know where to find them for a cheaper price when they are finished" (Caregiver 5).*

Two participants reported;

> *"I take care of him with my own experiences .... sometimes I don't know if what I am doing is right for him or not ...... for example when I want to shower him, I take a towel with a basin of water and force him to seat while I am doing the bath (Caregiver 3 and 8)"*

These findings indicated that caregivers of individuals with SCI are facing a number of problems. Findings correspond with those of Venturini (2007) who contended that individuals with spinal cord injury and their families are facing several difficulties. He identified the difficulties as; inadequate structure of health services, difficulties to deficiencies in physical infrastructure, lack of ramps, waiting lines and shortages of care by specialized professionals.

Inadequate knowledge of caregivers of individuals with SCI patients was also observed in this study. Bucher (2001) and Schumacher, (2000) found that family caregivers often feel unprepared to provide care and have inadequate knowledge to deliver proper care, and receive little guidance from the formal healthcare providers

Although most of the caregivers wanted to know the clarity of the service which they are suppose to be given, some of the needs is not met. In this study it was found that majority of the services provided to them in the hospital are not clear to them, one participant said;

> *"Since we are hospitalized, it is two months now but nobody bothers giving me straight answer of what is going on about my patient, I don't even know the doctor of my patient, he is being seen by many practitioners, hence made it difficult ..... Nurses are always*

> *available but if you asked sometimes you receive a positive response but... they say just wait for his doctor to come and explain.... (Caregiver 6)"*

Another participant reported that;

> *"No one bothers, information is problem, and there are a lot of problems sometimes I don't know what is going on!!! Though there is a time I think patients are too congested in the ward and they are also become overwhelmed hence they do not have enough time to give us information.... and there was not specific place to give information (Caregiver 8).*

Most of the family caregivers are not aware of any policy in regarding to treatment; for example exemptions; during interview all participants reported;

> *"We do not know any policy that constituted by any rule to guide spinal cord injured patient*" *(All caregivers, n = 15)*

Based on the above findings caregivers need certain knowledge and skills both to provide the best possible care and to protect their own well-being. There is no educative system for caregivers to receive guidance to delivery of safety care to their patients. Some of the findings are similar from previous studies for example Levine (1998) reported that caregivers get very little help from healthcare professionals in managing their task and the emotional demands of care giving. The findings are also in line with the reported from Naylor's (2003) that there is a breakdown in care during the transition from hospital to home results in negative outcomes.

Physical Tiredness.

Family caregivers are overwhelmed by work since they are working full time and have multiple roles, in this regard some of the caregivers dropped their jobs to care for their loved ones as a mother for his/her children and as a wife.

Caregivers are overwhelmed where they spent a lot of time in providing care

Participant said;

> *" I was a medical attendant working in one of the private hospital, ever since my husband got an accident and paralysed, I left the job and take a full time job caring for my husband and my children" (Caregiver7).*

Another Participant reported;

> *Previously I used to do washing for my kids and my husband used to do his, he was very generous helping me to do some home activities, but now he is full depending on me ….. my kids are also missing some of the things which we used to do together, …. It hurts me, my kids are asking me tough questions as to when their dad will be able to walk and work again as he used to…..? (Caregiver 5).*

Additionally, family caregivers spent a lot of time in providing care in a wide range of activities such as; bathing them, feeding them; take them to the hospital for physiotherapy and other regular check-up. Experience they gained in doing this work on a daily basis causing inner conflicts within them. One participant reported;

> *"This kind of a disease is a problem, it is a penal to me ……… Shifting my patient from one position to another is a chaotic job… I have never experienced … I have to do this kind of job on a daily basis, day and night, I am now having a back pain……"(Caregiver, 6)*

In this study most of caregiver suffers emotional stress. Previous study had also clarified that emotional stress is greatly affecting family caregivers as well as SCI patients (Chan, 2000). Furthermore, physical stress, emotional stress, burnout, fatigue, anger and resentment were also reported by Weitzenkamp, et al. (1997).

Emotional exhaustion

It was elaborated that care givers of the patients with spinal cord injury passed through some of experienced challenges.

Experiences which family caregiver's faces fear, social isolation and lack of hope.

Most caregivers suffer internally after knowing their beloved ones will never walk again and the task of care giving is there for their remaining life. One participant clarified,

> *"I feel very bad, when looking at my patient, since we are hospitalized, some of the patients are admitted and discharged living us in the ward ….. it even more painful since he was the bread winner ……. (Caregiver, 14)"*

Another participant explained;

> *"I feel shy even to look at the people …. It is so sad she is my sister …. I can't do anything ... though it pains me a lot" (Caregiver 2).*

Another participant said;

> *"I don't feel anything ….. it happened and I won't change anything, He is my son .. I wish if I will have a source of money so that I can continue taking care of my son" (Caregiver, 13).*

Another participant ;

> *"My friends are no more coming …. this makes me sad; my neighbours as well are not even asking how I am getting along with my patient ….. I am embarrassed with this situation …. ah! (Caregiver, 9)"*

Most of the family caregivers are losing hope and have fear; others are not getting sleep at night. Previous studies also have similar results. For example Chan (2000) and Weitzenkamp et al. (1997) said that care giving has been associated with constrain in the social, vocational, recreation and isolation.

Lack of social support

Most of caregivers experience isolation and mostly are upset/discouraged due to lack of support included are financial support as well as moral support. Caregivers also lack support from member of their families hence make the situation become worse.

Lack of financial and family support

Financial constrain is reported by most family caregivers. Even though other patient has health insurance still family caregivers incur costs to buy medication and other hospital requirements. Several studies reveal that the caregivers who had low incomes and inadequate social support might experience more distress and burden. Consequently, in order for them to reduce stress formal support and other resources should be provided (Dekargy, et al., 1998; Eliot & Shwechuk, 1998; Schulz, 1999; Viitanen, 2007).

One participant reported;

> *"Soon after hospitalization many relatives used to visit us and bring some of the things to help .... but as days pass the number of relatives reduced ... and sometime if you call no one is picking ..."(Caregiver, 9)"*

Another participant reported;

> *Although we are discharged and we are at home ...... I did my effort and borrow some money to buy him a wheelchair which at least helps in taking him out and when going to the hospital ... but when I ask help from other relatives they refuse to help .... (Caregiver11)."*

Another participant reported;

> "*My sister has the health insurance card, but not all medication or equipments are covered by health insurance, as a family we had to contribute and buy the missing item, additionally health insurance has unnecessary protocol which are tiresome and take longer time to get medicine"(Caregiver,10)"*

Additionally, another participant reported;

> *"Medication is expensive; a little amount we are getting is all spent to the hospital and medication. Due to cost sharing of health treatment families should pay patients costs" it is hard time now for the government to exempt patients who are not categorized".*

Assessment of coping and adjustment mechanisms of caregivers

In an attempt to find out how caregivers cope and adjust to the stress of long term care, participants were asked to say if they ever received counselling service from nurses, doctors or social workers/counsellor. Participants reported;

> *"I received counselling from social workers who at least gave me the condition of my patient... it feel very good talking to them since I thought the whole world was on my shoulder"*

Other participants reported that;

> *"I did not receive any psychotherapy rather I am told the condition of my patient"*

Another participant explained;

> *"I did not receive any counselling .... with this task you are doing ... you will help me know the whereabouts of my patient"*

It is well known that counselling is an effective way of helping caregivers to cope with the situation. The finding of this study are differing with cognitive behavioural therapy of which coping is related to thought and actions that are applied in certain situation in decreasing emotional distress (Ruth, 2005). In its reality, in coping process there is a focus on what a person actually does in specific situation rather than how the person usually reacts to a stressor. Caregivers deserve to be recognized and supported for the vital part they play in the lives of people with SCI.

Suggested ways of properly handling the problem Table 7;

93.3% reported that special rehabilitation centres for SCI patients in the country are required; routine education to relatives on how to take care of SCI patients, this should go abreast with advertisement on the media (Television, newspapers and radio), having enough number of qualified doctors and nurses who have this speciality and greater time (ample) for Physiotherapy and enough physiotherapists was also reported (73.3%, 66.7% and 60.0% respectively). Government support to SCI patients as well as having required equipments and other gadgets in the hospitals was also reported.

In this report a number of challenges which caregivers do face in taking care of SCI patients are escalating. Paula (2013) in her study found that caregivers complained about the difficulty in acquiring necessary resources for assistance in the home, as well as the lack of guidance and referrals to specialized rehabilitation services let alone having them in place. The very same are reported in this study too; government support for SCI patients is indicated by 53.3% of the study respondents. In line with that is affordability of caregivers to pay for the Computerized Tomography (CT) and Magnetic Resonance Imaging (MRI) to see the extent of damage to the vertebral column, spinal cord and spinal stability (Winter and Pattern, 2008) is also a challenge hence government support.

In taking care of SCI patients also they had complains of having special rehabilitation centre , forming enthusiastic facilities can evidently make change. These findings are in compliance with the study done in Zimbabwe by Levis et al., (1998) who found that 90% individual with Tetraplegic or paraplegic died within 1 year of discharge, half of individuals survived 1 year following establishment of Rehabilitation Centres and involvement of family members and the training family members received about caring their injured relatives.

Three participants reported,

> *“Transportation to the hospital and way back home is a problem, since I have to incur a taxi when visiting the hospital”*

Other participants reported that;

> *“Inadequate knowledge of handling SCI patients is also a problem since we have a very few hours to stay with them in the hospital of which after being discharged from hospital, I was supposed to take a full charge of caring”*

Other participants reported that;

> *“Hospital environment is also not conducive, first the patients are mixed, no separation of SCI patients and other Traumatic patients, the toilets as well are not friendly, this is very upsetting”*

Conclusion

Spinal cord injury is an ongoing challenge around the globe and improving long term health of the spinal cord injured patients requires participation of families and community at large. Lively experience of caregivers of SCI patients in developed world may be more documented than developed world. The findings of this study contribute to the scanty information available in Africa and Tanzania. It is apparent that lively experience of caregivers of individuals with SCI patients differs from that reported in other research undertaken in developed nations. Therefore further research into this area is recommended.

SCI is a devastating, life altering injury and a challenge to treat as well as care for. In this study it was confirmed that caregivers are burdened, stressed but there is no other options than to take care of their relatives. The findings also confirmed that there is a need for rehabilitation centers were SCI patients and their families can obtain services. It was also noted that caregivers of the individuals with SCI are financially deprived since affordability of certain examinations was reported as problem.

From the aforementioned, more attention health should be paid to family caregivers to acquire more care related knowledge and support. Government as well as policy makers should work hand to hand in order to help family caregivers. International organizations (NGO) and community support is highly needed and linking them to formal social service.

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Conflict of interest

There are no conflicts of interest

Respondents Profile

Table 4.1: Frequency distribution table showing Respondents Profile n = 15

Variable	**Category**	**Number (%)**
Gender	Male	8 (53.3%)
	Female	7 (46.7%)
Age	≤ 20years	1 (6.7%)
	21 - 30	5 (33.3%)
	31 – 40	4 (26.6%)
	41 – 50	1 (6.7%)
	51 – 60	3 (20.0%)
	61years and above	1 (6.7%)
Marital Status	Married	14 (93.3%)
	Single	1 (6.7%)
Academic Qualification	Primary	11 (73.3%)
	Secondary	3 (20.0%)
	High School	1 (6.7%)

Table 4.2: Respondents Occupation

Category	**Number (%)**
Employed	3 (20.0%)
Unemployed	7 (46.7%)
Retired	5 (33.3%)
Total	**15 (100.0%)**

Table 4.3: Respondents relationship with SCI patient

Category	**Number (%)**
Spouse (wives)	3 (20.0%)
Mother	2 (13.3%)
Father	5 (33.3%)
Sister	1 (6.7%)
Brother	2 (13.3%)
Others (1 social welfare and charity officer)	2 (13.3%)
Total	**15 (100.0%)**

Table 4.4 Causes of Injury of SCI

Category	**Number (%)**
Motor vehicle accidents	8 (53.3%)
Fall	1 (6.7%)
Violence	1 (6.7%)
Motorcycle accidents	3 (20.0%)
Others	2 (13.3%)
Total	**15 (100.0%)**

Table 4.5 Types of Injury

Category	**Number (%)**
Paraplegic	12 (80.0%)
Quadriplegic	3 (20.0%)
Total	**15 (100.0%)**

Table 4.6 Lively experience of caregiver to SCI patients

Theme	**Subtheme**
1. Lack of care related knowledge	Lack knowledge about caring spinal cord injury patients, lack of information, clarity of the services they required to know
2. Physical Tiredness	Overwhelmed of work by caregiver working full time, multiple roles,
3. Emotional exhaustion	Fear, social isolation, lack of hope
4. Lack of Support	Lack of familial support, lack of financial support

Table 7: **Ways/Strategies that could be used to reduce problems**

Strategy	**Frequency (%)**
- Establish special rehabilitation centre for SCI patients in	14 (93.3%)

the country	
- The Government should invest more in healthcare and support to SCI patients	8 (53.3%)
- There should be enough number of qualified doctors and nurses who can provide support to people with SCI	10 (66.7%)
- Greater time (ample) for Physiotherapy and enough physiotherapists	9 (60.0%)
- Routine education to relatives on how to take care of SCI patients, this should go abreast with advertisement on the media (Television, newspapers and radio)	11 (73.3%)
- All the required equipment for SCI patients should be available at all hospitals	8 (53.3%)

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