ECONOMIC BURDEN OF TRAUMATIC SPINAL CORD INJURY AMONG THE SPINAL CORD INJURY PATIENTS AND THEIR FAMILIES IN ODISHA – AN EXPLORATORY STUDY

K. Shruti Lekha

**Dissertation submitted in partial fulfillment of
the requirement of the degree of
Master of Public Health**

Achutha Menon Centre for Health Science Studies

Sree Chitra Tirunal Institute for Medical Sciences & Technology

Thiruvananthapuram, Kerala

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Dedicated to my dear parents, aunt and the almighty

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CERTIFICATE

Certified that the dissertation entitled "**Economic burden of traumatic spinal cord injury among the spinal cord injury patients and their families in Odisha – an exploratory study**" is a record of original research work undertaken by K.Shruti lekha , in partial fulfillment of the requirements for the award of the degree of "Masters of Public Health", under my guidance and supervision.

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June, 2020

DECLARATION

I hereby declare that this dissertation titled "**Economic burden of traumatic spinal cord injury among the spinal cord injury patients and their families in Odisha – an exploratory study**" is the bonafide record of my original field research. It has not been submitted to any other university or institution for the award of any degree or diploma. Information derived from the published or unpublished work of others has been duly acknowledged in the text.

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GLOSSARY OF ABBREVIATIONS

1. WHO- World health organization
2. SCI- spinal cord injury
3. TSCI- Traumatic spinal cord injury
4. NSS- national sample survey
5. SIDPA- Scheme for implementation of rights of persons with disabilities
6. CNS-Central nervous system
7. QOL- quality of life
8. SPSS- Statistical package for social science
9. RTA-road traffic accident
10. PT- Physiotherapy
11. OT- Occupational therapy
12. NGO – Non government organization
13. BPL- below poverty line
14. RSBY- Rastriya Swasthya Bima Yojna
15. BKKY- Biju Krushi Kalyan Yojna
16. MGNREGA- Mahatma Gandhi national rural employment guarantee act
17. DHH- district headquarter hospital
18. BSKY- Biju Swasthya Kalian Yojna
19. PWD- Persons with disabilities
20. DRM- Disability rights movement
21. ADIP- Assistance to disabled persons for purchase / fitting of aids and appliances
22. CRC- Composite regional centers
23. DRC- District rehabilitation centers

24. RRTC- Regional rehabilitation training center

25. NICDR- National Information Center on Disability & Rehabilitation

26. DDRS- Deendayal Disabled Rehabilitation Scheme

27. OPD- out patient department

28. AYUSH- Ayurveda, yoga, unani, sidha, homeopathy

29. SES- Socio economic status

30. WTP- Willingness to pay

ABSTRACT

Background: Traumatic spinal cord injury (TSCI) is sudden in onset and makes a person disabled for a lifetime. The economic burden of spinal cord injury is enormous and it has an impact not only on the person with injury but also on their families. People sustaining SCI are between ages 20 to 39 years. Approximately 20,000 people sustain SCI every year in India and 90 percent of them are due to traumatic causes. We aim to find the economic burden of TSCI.

Methodology: An institution-based study was conducted and the expenditure related to Direct, Indirect and Intangible costswere recorded.This included the loss of income of the person due to injury as well as the loss of time due to care-giving. I also explored the ways they coped with the economic burden. WHO QOL- BREF was used to estimate the quality of life.

Results: The mean and median of the total direct cost of TSCI is Rs.817672.33 and Rs. 552156 respectively. The mean and median of the total indirect cost of TSCI is Rs.225624.30 and Rs.120000 respectively. Mean quality of life for persons with TSCI in the physical, psychological, social, and environmental domain is 10.32+/-3.9, 10.56+/-3.98, 11.97+/-3, and 11.05 +/- 3 respectively. In the group I studied 54.9 percent of people use their savings, 28.6 percent sell their assets or take loans and only 16.5 percent get help from an insurance, programs and other benefits to cope with the economic burden of injury.

Conclusion: The economic burden of TSCI is huge and it being a sudden occurrence people are never prepared adequately to face it. The need of the hour is increasing the umbrella of benefits and creating awareness among people with TSCI.

CHAPTER - 1
BACKGROUND

Injury to the spinal cord is one of the major reasons of disability around the world. It is estimated that the annual incidence of SCI around the world is between 250000 to 500000people (Furlan et al., 2013). In India, the estimated incidence is 20 per million per year (Singh et al., 2012).

Spinal cord injury (SCI) can occur because of traumatic and non-traumatic reasons. The traumatic spinal cord injury (TSCI) is most commonly abrupt in onset and most of the time results in a lifetime loss of body functions (McDonald and Sadowsky, 2002). Loss of functions of the lower half of the body is termed as paraplegia which occurs due to injury at the thoracic and lumbar level. Loss of function in upper limbs, trunk, and lower limb is called quadriplegia, it occurs due to the injury at the cervical level. If the injury is in the upper cervical region there may be additional respiratory system-related complications (Sekhon and Fehlings, 2001)

The people having spinal cord injury are mainly in the age range of 20–39 (Agarwal et al., 2007). SCI poses a great social and economic burden on society. Often the spinal injured subject is in the prime of life and the sole breadwinner (Goel et al., 2016). It has a significant lifetime impact on the persons as well as their caregivers who are mostly their families.

In the early 20th century SCI was considered untreatable. In 1934, the mortality rate was over 80% in the first two years of injury. This was mostly due to urinary tract infections and pressure sores (Chacko et al., 1986). Development in imaging, surgery, medical care, and rehabilitation medicine in 20th century contributed to an improvement in SCI care. Subsequently, improved

care has been accompanied by the increased life expectancy of people with SCI (McDonald and Sadowsky, 2002).

Neglected TSCIs are injuries in which comprehensive management is not initiated in a timely fashion. Lack of or inadequate awareness was a common cause for a high number of neglected TSCIs. Neglected TSCIs add to the complexity of vertebral lesion management, physical and psychosocial rehabilitation. The neglected TSCI has a much higher incidence of complications, which are more severe and difficult to manage (Chhabra and Arora, 2013). Due to the lack of awareness about rehabilitation in our country as well as the lack of adequate public sector facilities for treatment and rehabilitation, the family is called upon to bear the expenses of hospitalization and ongoing care. In the case of neglected TSCIs too. The lack of knowledge about the treatment, rehabilitation, and self-care is shown to lead to various complications (Gupta and Raja, 2017).

The usual course of treatment and rehabilitation of SCI is long, expensive, and exhausting (Nas et al., 2015) The cost of spinal cord injury includes medical expenses, expenses for travel, lost wages, and earning potential and long term expenses (Villines, 2016). Hidden costs include food related costs during travel for treatment, travel expenses, and other similar expenses. Only 11.7% of people with a spinal cord injury are employed after one year of injury (Villines, 2016)Long term expenses include long term health issues, mental health issues, home modifications, and additional equipment (Kawu et al., 2011).

A person with spinal cord injury has to cope with economical (both self as well as family), psychological, and social burden. Insurance plays an important role in coping with financial burden during the acute phase where a large part of the expenditure may be borne by the

insurance companies. But in the absence of significant insurance coverage in general (only 14 percent rural and 19 percent urban population by health NSS 75th round July 2017- June 2018), and in the face of severe shortage in government rehabilitation facilities across the country, the families of the spinal cord injury individuals tend to cope with the cost of the injury in many ways such as personal saving, family saving, a loan from other sources, selling of personal assets as well as family assets, curtailing some basic habits and provisions made by the government for disabled persons. There are high opportunity cost and low availability of resources (Sauerborn et al., 1996).

The government has taken measures to help the people in offsetting some costs. There are a number of government schemes available. These include i) the scheme for setting up of state spinal injury center in all state capitals and union territories with a minimum of 12 beds. It aims in providing rehabilitation services to the economically poor people. ii) Scheme for Implementation of rights of Persons with Disabilities Act, 2016 (SIPDA) for providing financial assistance for undertaking various activates outlined in the Persons with disability Act. iii) Assistance to disabled persons for purchase/fitting of aids and appliances aims to provide assistive devices to people with disabilities at the district level.

There are Indian Spinal Injuries Centers, recognized by the government as a tertiary level center other than that few regional centers have come up and more are planned by the government. Most aspects of management are being looked into and there is a growing government – non-government organization cooperation in this regard (Chhabra, 2019).However, my experience as physiotherapist showed that very few patients whom I treated for SCI actually knew about and got benefits from these schemes.

Owing to the severity of problem of TSCI and huge economic burden this study aims to calculate the cost of TSCI, document quality of life of people with TSCI, know about the pattern of coping, and to see the how the benefits of government helps to offsetting the economic burden.

CHAPTER-2

LITERATURE REVIEW

The literature review will focus on spinal cord, spinal cord injury, stages of its management, cost of illness study methods, types of cost, various cost studies conducted on SCI, quality of life, and various coping strategies followed. Search engines like Google scholar, PubMed, Science direct, and Springerlink has been used for the published literature. Other sites for health and economics were also searched like WHO, World Bank and other government websites as well as other unpublished research works including working papers and MPH thesis of SCTIMST and TISS.

2.1 SPINAL CORD AND ITS INJURY

Spinal cord

The spinal cord is an extension of the brain and is a part of the central nervous system (CNS), which extends caudally and is protected by the bony structures of the vertebral column. The spinal cord is divided into cervical, thoracic, lumbar, and sacral segments. It gives off 21 pairs of spinal nerves, 8 pairs from the cervical segment, 12 pairs from thoracic, 5 from lumbar, 5 from sacral, and 1 from the coccygeal segment (Nógrádi and Vrbová, 2013).

The spinal cord provides the motor, sensory, and autonomic supply to the upper and lower limbs, chest, and abdomen (Vaskovic, 2020). It also helps in coordinating many reflexes and reflex arcs that control reflexes independently. It controls voluntary movements like moving hands or legs and involuntary movements like breathing (Rabischong, 2004; Reeve Foundation, 2019.)The spinal cord has two prominent enlargements one at cervical (C7) level which provides nervous supply to upper limbs and another at lumbar level (L1) supplies the lower limb (spinal cord injury.pdf, rehabilitation council of India 2014.)

The spinal column or vertebral column is the bony support that extends from the head to the pelvis. It is made up of 33 bony rings (vertebrae). The main function of the spinal column is to provide us with stability to bear the body weight, flexibility to carry out movements like bending, standing, and twisting, etc (Nógrádi and Vrbová, 2013)

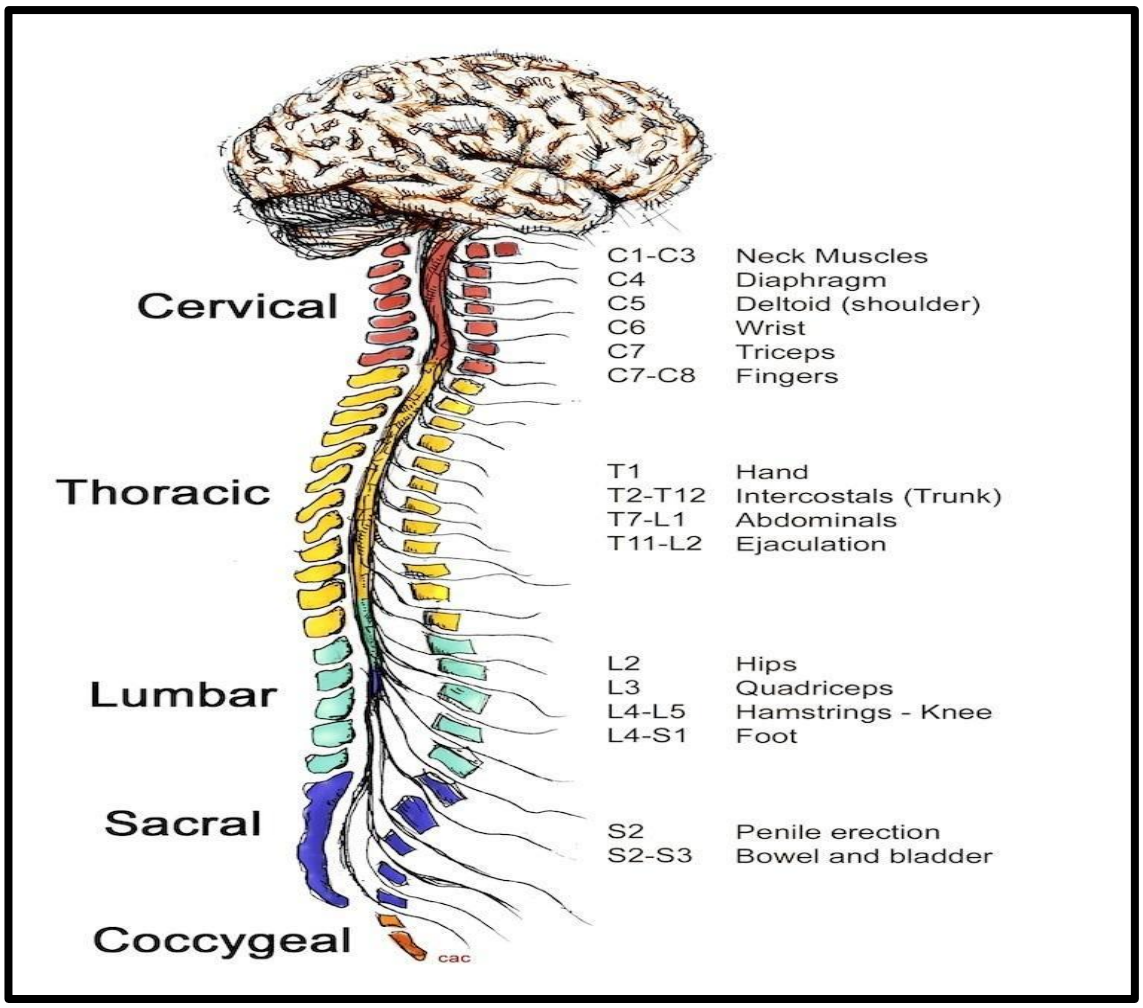


Figure-2.1Anatomy and physiology of Spinal cord(Reeve Foundation, 2019)

Spinal cord injury

'Spinal cord injury' refers to "damage to the spinal cord resulting from trauma (e.g. a car crash) or from disease and degeneration (e.g. cancer)". Traumatic spinal cord injury occurs due to falls,

road traffic accidents, violence, recreational activities. Causes for non-traumatic spinal cord injury are congenital and developmental degenerative disorders, infections like transverse myelitis, inflammatory ischemia, tumors, stenosis, or syringomyelia, etc (DeVivo, 1997; McDonald and Sadowsky, 2002).

The spinal cord could sustain an injury at any level. More than 50 percent of the injuries affect the cervical spine where as other 50 percent occur in thoracic spine, in the border between the thoracic and lumbar spine, and in lumbar spine alone (García-Altés et al., 2012).

The severity of SCI depends on the level of injury. If the injury is at the neck level then there is paralysis of all four limbs, trunk, and chest region called quadriplegia whereas injury below neck causes paralysis of only lower limbs and decrease in movements of trunk called paraplegia. If the injury is in the upper cervical (C1-C4) region there may be additional respiratory system-related complications (Collie et al., 2010; Nas et al., 2015). The consequences of SCI have a significant impact not only on the independence and physical function of an individual but may also have other complications like neurogenic bladder, pressure ulcer, spasticity, etc (McDonald and Sadowsky, 2002).

TABLE 2-2: DEFINITIONS FOR CLASSIFYING SCI SEVERITY

Last spinal cord segment injured	SCI classification	Associated morbidity
Cervical (spinal cord segments C1 to T1)	Quadriplegia[6]	Reduction or loss of motor and/or sensory function in the arms as well as in the trunk, legs, and pelvic organs.
Thoracic, lumbar or sacral (below the T1 cord segment)	Paraplegia	Reduction or loss of motor and/or sensory function in the trunk, legs, and pelvic organs.

Source: QSCIS (2001), AIHW (2008).

Figure 2.2: Level of injury and the severity

2.2 EPIDEMIOLOGY OF SPINAL CORD INJURY

International scenario

The incidence as well as the prevalence of spinal injuries, has been on the rise. The incidence rate is estimated to be 40 to 80 cases per million populations (WHO fact sheet, 2013) which has increased from 15 to 40 cases per million in 2004 worldwide (Jackson et al., 2004).Ninety percent of total cases are traumatic SCI. There is a rise in the non-traumatic SCI in recent years (WHO fact sheet, 2013).The incidence of SCI in developing countries was 25.5/million/ year. Males are more likely to sustain SCI than females. The mean age of SCI occurrence was 32.4 years (James et al., 2019; Rahman et al., 2018)

Indian scenario

In India, approximately 1.5 million people live with SCI and the estimated incidence is 20 per million per year (Singh et al., 2003) and 60-70% of these individuals are from a poor socio-economic background with poor educational achievement. The majority of them are males in the age group of 16-40 years and most common being 20- 39 years, signifying higher incidence in the young, active, and productive population of the society (Rahimi-Movaghar et al., 2013)

Road traffic accidents are most common cause of injury followed by falls and injuries at work places (Rastogi et al., 2014). TSCI is more common among rural people than in people from urban areas (Singh et al., 2003).

2.3 THE MANAGEMENT OF SPINAL CORD INJURY-

The management of TSCI is a long process and has many phases. First is the acute and sub-acute phase, usually between six to eight weeks post-injury. It usually includes a period of hospitalization and spine stabilization with or without surgery followed by bed rest. In this phase, the main areas of expenditure are on medicines, hospitalization, investigations, and surgery (Sekhon and Fehlings, 2001).

After the sub-acute phase during post-discharge phase, the main issue that the patient faces is the need for modification of his / her home in order to adapt to the disability caused by the SCI. This may lead to expenditure on environmental modifications, like ramps and railings, and assistive devices like wheelchairs. In this stage, the main areas of expenditure are on medicines and rehabilitation along with expenditure on the modification and assistive devices.

Chronic rehabilitation is the third phase and it aims at achieving the maximum ability post-trauma which includes hospitalization or multiple sessions in a rehabilitation center, which leads to change in the level of quality of life, depression, stress, and anxiety. The expenditure in this phase is mainly on medicines, rehabilitation sessions, and treating secondary complications (Barbeau et al., 1999; Lalwani et al., 2014; Mukherjee A K, 1999; Silver, 2005).

Post rehabilitation phase or in the late rehabilitation phase, there is an overall decrease in the quality of life, loss of income and an increase in depression, stress, anxiety along with expenditure on medicines, treating of secondary complications (Mukherjee A K, 1999; Silver JR, 2005).

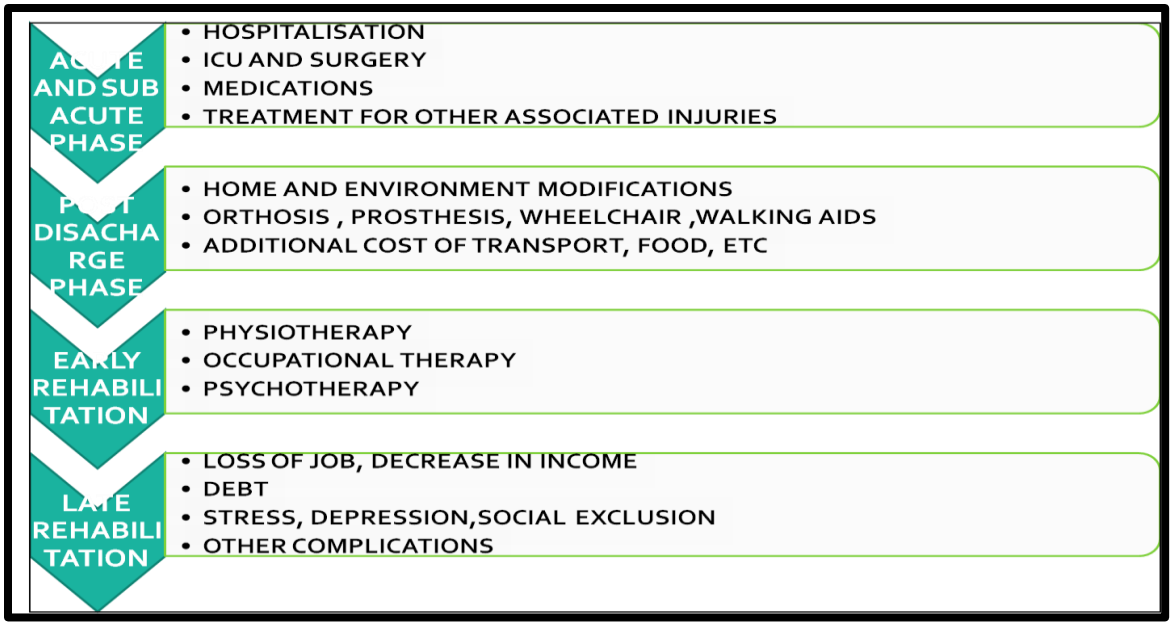


Figure-2.3 stages of spinal cord injury, its management, and complications(spinal cord injury.pdf by rehabilitation council of India, .)

2.4 ECONOMIC STUDIES

There are mainly four types of economic studies. They are cost-benefit analysis, cost-effectiveness analysis, cost-minimization analysis, and cost of illness. The cost of illness study is one of the commonly used economic evaluation methods.

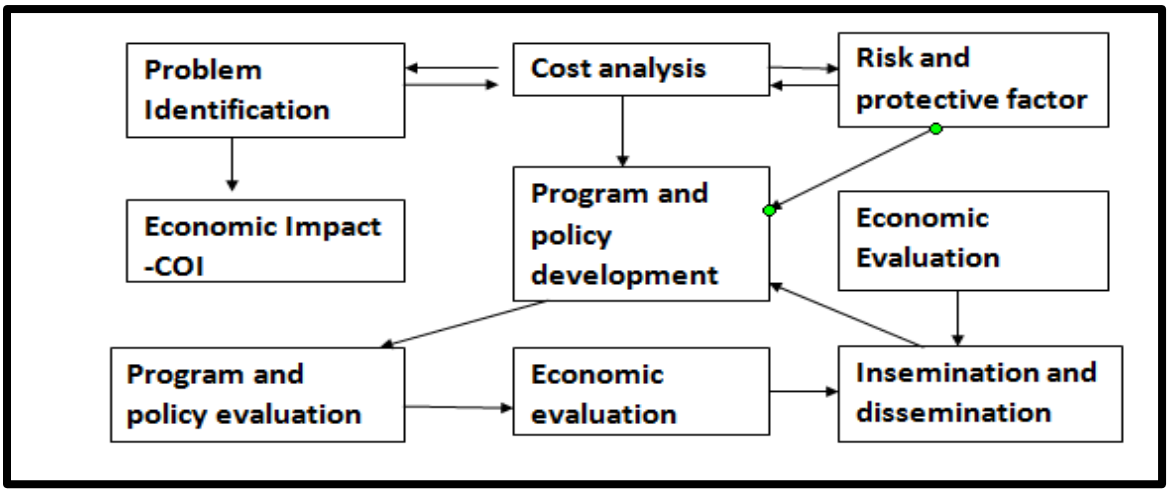


Figure 2.4: economic impact analysis (Lane and Soyemi,)

Economic impact analysis is also called as the cost of illness estimates. The primary outcome of this study is an estimate of the cost of illness. Strengths of the cost of illness study are that it is a preferred economic evaluation to government decision-makers and it is easily understood by non-academicians (Goel et al., 2016), however the limitations of this study design are that it does not incorporate clinical outcomes or patient preferences. The costs are often calculated as gross costs and not condition-specific costs (Chan et al., 2013).

There are two methods of cost of illness study—the prevalence and incidence method. The prevalence method is the commonest and estimates the total cost of a disease incurred in a given year. The impact and the direct, indirect, and intangible cost was calculated for a year (Karande et al.2019). The incidence method involves calculating the lifetime costs of cases first diagnosed in a particular year, providing a baseline against which new interventions can be evaluated (Byford et al., 2000).

There are two approaches of collecting data for this research design. They are referred as top-down approach and a bottom-up approach. It measures the proportion of a disease that is caused due to exposure to a disease or a risk factor. The bottom-up approach estimates cost by calculating the average cost of treatment of the illness and multiplying it by the prevalence of the illness (Segel, 2006).

There are two perspectives from which costs are considered. First is the employer or system's point of view. This includes analysis of the impact of the injury on the basis of productive loss, labor loss, increased expenditure on health care, etc. This can be done by calculating operational cost per person (Shepard et al., 2014) or calculation of cost from the national data base (Dzajkovska et al., 2007). The second one is from the perspective of individual, household,

firms, or government. This includes the loss of income, increase in consumption, increase in expenditure of the household, depletion of savings, and time loss(Verma and Srivastava, 1990)

Type of costs calculated in a cost of illness study

Direct costs

Direct costs refer to 'costs associated with the consumption of goods and services of a certain value during medical treatment' (Anders et al., 2013). Direct medical costs include expenditure on hospitalization, doctor consultation, nursing home care, hospice care, rehabilitation care, diagnostic tests, prescription drugs, and medical supplies (Segel, 2006; Thomas et al., 2001). Direct non-medical costs include transportation costs to health care providers, and costs of making changes to one's diet, house, car, or related items (Dryden et al., 2005; Sharma et al., 2016).

Indirect costs

Indirect costs refer to 'the value of potential output that is lost as a result of any reduction or elimination of work or other activity due to SCI. These costs are measured as the losses that occur due to the reduction in productivity that results from morbidity or mortality attributable to SCI' (Krueger et al., 2013), loss of jobs or studies because of illness (Krishnan et al., 2004) , absence from work or low productivity (Sharma et al., 2016) or on income foregone and days of inactivity due to illness (Patankar and Trivedi, 2011).

Intangible cost

Intangible cost refers to " an unquantifiable cost emerging from the spinal cord injury which usually negatively impacts the overall wellbeing of the person(Hayes, 2020.). It includes pain, suffering, and long-term effect of the disease like psychological. It is usually in the form of

quality of life measures (Segel, 2006; Villines, 2016) or by decreased social interaction (de Putter et al., 2014). It can also be collected by documenting the willingness-to-pay (WTP) (Karande et al., 2019).

Summary of literature on the costs of spinal cord injury

SCI is a very expensive condition. Its effect being life long, the cost is also very high. SCI with admissions were more costly in Australia. The mean cost of SCI with complications is $A43, 410, and SCI without complication is $A10, 102 (New and Jackson, 2010).

In Belgium, the mean cost for inpatient and outpatient rehabilitation is approximately $33,000 and $5,700 for paraplegia and approximately $51,000 and $7,700 for tetraplegia, respectively (Kiekens et al., 2011).

In Canada, the cost is very high in the 1st year of injury compared to subsequent years. $121,600 per person is the attributable cost for person with complete SCI and $42,100 per person in an incomplete SCI during 1st year post injury. After five years the cost came down to $5400 and $2800 for complete and incomplete SCI (Dryden et al., 2005). The cost of SCI with an associated head injury is more than only spinal cord injury (Bradbury et al., 2008). The net lifetime cost of SCI was $336000 per person. The lifetime cost for concurrent pressure ulcer was $479,600Costs were higher for cervical and thoracic spinal cord injury or those needing inpatient rehabilitation (Chan et al., 2019).

In Nigeria, the mean cost for six weeks is $1598.29. More than 50 percent of patients' annual income was less than $1per day. Mean cost of hospitalization was 14.9 percent of the total cost of TSCI (Kawu et al., 2011).

In U.S the cost of injury varied with cause of injury. The cost of SCI was $233,947 for vehicle crashes, $217,868 for violence, $295,643 for sports, $185,019 for falls and $208,762 for other causes. Recurring annual charges in US for each cause averaged to $33,439, $17,275, $27,488, $26,238 and $23,510 (DeVivo, 1997). The cost of injury increased in presence of complications as there is an increase in unplanned hospitalizations. Urinary tract infection is the most common complication (DeVivo and Farris, 2011).

The general picture of the cost of SCI is (WHO fact sheet, 2013)

- The cost of SCI is higher in higher level injuries (e.g. tetraplegia vs. paraplegia) (Kiekens et al., 2011)
- Direct costs are highest in the first year post SCI and then decrease significantly over time (Dryden et al., 2005)
- Indirect costs, in particular, lost earnings, often exceed direct costs (Spinal Cord Injuries by the Numbers, 2002.).
- People with SCI bear most of the cost (LaphamRandlov, 1994)

In India cost of illness studies are mainly on Autism, Diabetes and its complications, attention deficit disorder, burns, and T.B (Deshpande, 2012; Mohan et al., 2004; Rajeswari et al., 1999). There are no studies on the cost of illness of spinal cord injury. Some economic evaluation studies are in progress but none published as of now.

*1$A= 0.68$, 1$A= 48.36 Rupees, 1$=71.25Rupees

2.5QUALITY OF LIFE

Quality of life (QOL) is a multidimensional concept that primarily tells about the effect of disease or the burden of disease on the social, psychological, physical, and environmental well-being of the person (Satheesh et al., 2017.). Quality of life is a measure to assess the unquantifiable effect of spinal cord injury on a person. QOL in SCI is defined as living independently and without any suffering (Khupantavee et al., 2008). QOL is an important factor to access in the case of people with TSCI as it helps to assess the improved treatment outcome and post-injury lifestyle (Hill et al., 2010). WHO-QOL-BREF is a unidirectional scale that is widely accepted to assess the quality of life of a person with TSCI. The mean scores of the physical, psychological, social and environmental domains of QOL was 49.76 ± 18.74, 48.57 ± 17.04, 57.88 ± 17.04 and 49.85 ± 17.77, respectively in a study done among the thoracic and lumbar level injury patients in Odisha in 2010 (Ganesh and Mishra, 2016)

2.6 COPING STRATEGIES

Coping strategies are defined as ‘a set of measures that aims to take care of the costs of an event (shock) or process that threatens the welfare of some or all of the household members. Ultimately coping strategies are seeking to sustain the economic viability and sustainability of the household’ (Sauerborn et al., 1996).Coping strategies could be further divided into strategies to cope with direct costs and strategies to cope with indirect costs.

Major coping strategies for major health events in countries like India are borrowing, debt, selling of properties and other valuable assets, and occasionally, help from government interventions and income from vocational activities (Palmer et al., 2011; Sauerborn et al., 1996).

Distress financing is a term that includes risky financial activities such as borrowing loans and selling assets (Huffman et al., 2011; Murphy et al., 2013).

The government's approach to the support of people with disabilities and especially spinal cord injury is laid out in the 'Government policy for people with disability2016', which aims in providing a barrier-free environment for people with disabilities.

Strategies to cope with costs are further divided into:

Strategies to cope with the direct costs of illness: 'are current income and savings; selling of assets, borrowing from social networks or landlords (in case of rural areas) both with or without interest; selling food stores; reducing consumption of food and other essential items; diversifying income sources; reducing investments (e.g. withdrawing a child from school); selling productive assets such as livestock, land or machinery' (Mclntyre et al., 2015; Russell, 2004).

Strategies to cope with the indirect costs of illness include all the above mention strategies, but a specific strategy for coping with the loss of a worker is intra-household labor substitution (Sauerborn et al., 1996)

CHAPTER - 3

POLICIES AND BENEFITS FOR PEOPLE WITH TSCI

The government of India as well as state has rolled out schemes to provide free treatment and reimburse the treatment cost of people below the poverty line to ensure equal opportunity and utilization of health care by all. Similarly, some benefits are policies are exclusively designed and implemented for people with disabilities (PWD). This section gives an insight to some of these policies and benefits.

3.1 HEALTH INSURANCE SCHEMES BY THE GOVERNMENT

There are many health care financing schemes in India. Rashtriya swasthya bima yojana is one such initiative by the government of India in 2008. RSBY provides insurance coverage on in-patient care up to Rs.30000 per family per year. It includes people below the poverty line, people enrolled under Mahatma Gandhi national rural employment guarantee act, and people of other backward castes.

The Government of Odisha had introduced Biju Krushi Kalian Yojna(BKKY), a health coverage scheme for farmers of Odisha. A new scheme Biju Swasthya Kalian Yojna(BSKY) was introduced recently based on the concept of 'Universal health coverage' which provides free treatment for all up to DHH level and annual insurance coverage up to Rs.5lakhs per family to 70 lakh families belonging to lower socioeconomic status in government and some private hospitals. This is for the people who were enrolled under RSBY(BPL, MGNREGA, and B&OCW), farmer families (BKKY-I), and farmer families under RSBY (BKKY-II).

The cash and cashless benefits are helpful for people having at least one of these cards during the treatment and surgery immediately posts injury. This also helps during the treatment of co-morbidities and complications post spinal cord injury of those with disabilities even to those who do not have a disability certificate.

3.2 POLICIES AND BENEFITS FOR A PERSON WITH DISABILITIES

A "Person with Disability"(PWD) means "a person suffering from not less than 40 percent of any disability as certified by a medical authority" (PWD ACT.pdf, 1995.). They are a vulnerable section of the society who are denied equal rights and social protection.

Many NGOs started operating within the disability sector between 1970-1990 and this subsequently provided further momentum to the disability rights movement (DRM). After a series of petitions and protests, the govt. passed the Persons with Disabilities Act, 1995 (or PWD Act), equal opportunities, protection of rights, and full participation for PWDs(Jha, 2016).

So the year 1995 became a benchmark year for the DRM, which stands for the start of a new era altogether, during which people affected by disability found entry in educational institutions and government services. In due course, the PWD has become the main focus group in the framework of government policy(Jha, 2016).

PWD act 1995 included people with Blindness, leprosy-cured, hearing impairment, locomotor disabilities, cerebral palsy mental retardation, and mental illness. Subsequently, the number of disabilities covered was increased to 21 in the revised PWD act, 2016. The following are the disabilities covered under the revised PWD act 2016 loss of vision, low vision, leprosy cured, hearing impairment, locomotor disabilities, dwarfism, intellectual disability, cerebral palsy,

muscular dystrophy, chronic neurological conditions, specific learning disabilities, multiple sclerosis, speech and language disability, thalassemia, hemophilia, sickle cell disease, multiple disabilities, parkinsonism and acid attack survivors (WeCapable, 2018).

Spinal cord injury results in quadriplegia and paraplegia which come under the locomotor disabilities and accounts for up to 90% and up to 75% of disability respectively. Thus, the people with spinal cord injury are entitled to get all the benefits provided by the government for people with locomotor disabilities.

The various benefits provided to people with disabilities possessing a disability certificate are as follows:

1. **Assistance to disabled persons for purchase/fitting of aids and appliances (ADIP) Scheme (1981) (**Puri**,** 2005**)**

ADIP scheme is one of the main initiatives of the Ministry of Social Justice & Empowerment, Govt. of India. This scheme is implemented to help a person with disabilities in procuring durable, modern, ergonomically designed and standard aids and appliances to improve the physical, social, psychological wellbeing of persons with disabilities by reducing the consequences of disabilities and proving help to manage the burden due to the expenditure on assistive devices. Assistive devices are given to PWDs who have a family income of less than Rs. 20000 per month with an aim to enhance their independent functioning, tolimit the extent of disability or development of secondary disability, and to reduce the burden of expenditure. The assistive devices are given only to people with a disability certificate with 40 percent or more

disability got during the rehabilitation phase("The Scheme of Assistance to Differently Abled Persons for Purchase/Fitting of Aids/Appliances (ADIP), 2013).

Amount of assistance based on the monthly income of the family

(i) Up to Rs. 15,000/- per month: Full cost of aid/appliance

(ii) Rs.15, 001/- to Rs. 20,000/- per month: 50% of the cost of aid/appliance

2. **Rehabilitation services for people with disabilities** (Kumar et al., 2012)

The main aim at the various rehabilitation schemes designed and implemented by the government is to provide free or low-cost rehabilitation services to people with disabilities in the district level. The following are the schemes-

- Composite Regional Centers for Persons with Disabilities (CRCs): they aim is to provide services like health education, vocational training and employment, research and manpower development, and rehabilitation for persons with disabilities.

- District Rehabilitation Center (DRC) Project- launched in 1985 to set up district level centers that can provide rehabilitation services to disabled people from rural parts in India. This also includes the following activities like surveys for people with disabilities, prevention, early detection and treatment, orthotics, assistive devices, therapeutic services, and opportunities for education and employment.

- Regional Rehabilitation Training Center (RRTC)- four regional rehabilitation centers have been functional since 1985 in Cuttack, Mumbai, Chennai, and Lucknow. They are

responsible for the training of village-level functionaries, developing materials and manuals which would help in creating community-level awareness.

- National Information Center on Disability & Rehabilitation (NICDR)- A national-level information center was set up under CACU in 1987 to provide a database that would provide information on all facilities and welfare schemes and services for people with disabilities.

3. DDRS(Deendayal Disabled Rehabilitation Scheme,2009) (Abhiyan, 2019)

The approach of this Scheme is to supply financial assistance to voluntary organizations to form available the entire range of services necessary for the rehabilitation of persons with disabilities including early intervention, development of daily living skills, education, skill-development oriented towards employability, training and awareness generation. The main intension of trust is the inclusion of persons with disabilities within the mainstream of society and actualizing their potential by education and training programs. In order to realize the objectives of the scheme the key strategies (Abhiyan, 2019; InsightsIAS, 2019) are-

For rehabilitation:

- Implementation of outreach and comprehensive Community Based Rehabilitation programs in urban and rural environments.
- To set up well-equipped resource centers at different levels. To promote and support the event of self-help groups, parent organizations, and independent living.
- To determine and support facilities for sport, recreation, leisure-time activities, excursions, creative and humanistic discipline, cultural and socially inclusive activities.

For education, training and employment opportunities

- To enhance educational opportunities at all levels and in all forms and enlarge the scope of vocational and professional opportunities, income generation, and gainful occupations.
- To support all such measures as may be necessary for promoting formal as well as informal employment and placement opportunities.
- To support activities to develop manpower to train required personnel at different levels for all programs/ projects/activities for persons with disabilities.
- To support the development, publication, and dissemination of information, documentation, and training materials.
- To encourage coordination, cooperation, networking, and multi-sectoral linkages.
- To support people with disabilities in projects those are environment friendly.
- To support construction and maintenance of buildings, provision of furniture and fixtures, and installation and maintenance of machinery and equipment.
- To support and facilitate the availability of appropriate housing, homes, and hostel facilities.

Protection of people with disabled

- To support the effort to ensure the protection of human, civil, and consumer rights of persons with disabilities.
- To support legal literacy, including legal counseling, legal aid and analysis and evaluation of existing laws.
- To support such other measures, which may meet the needs of the persons with disabilities and fulfill the obligations as mentioned in the People with Disabilities (Equal Opportunities and Protection of Rights) Act of 1995.

Research for further development

- To support the conduct of surveys and other forms of epidemiological studies.
- To promote research in various developmental areas, innovative strategies, assistive devices, and enabling technologies and support production of such devices ensuring quality control.

4. The National Handicapped Finance and Development Corporation

The government of India set up a corporation for the welfare of people with disabilities with a capital of Rs. 400 crores. The aim of this corporation was to make people with disabilities self-dependent, economically productive, and mainstreaming them. Some of the facilities of NHFDC are providing loans for setting up of small-scale businesses, higher studies or professional training, and production of devices and services for people with disabilities and self-employment.

5. Divyangjan Swavalamban Yojna scheme for persons with disabilities (2017)

This scheme aims at providing loans with low-interest rates for PWDs for the starting of any income-generating activity, higher studies, training in professional and vocational skills, and for purchasing assistive devices.

6. Indira Awaas Yojana (1996-97)

It is a national level program to provide houses to people below the poverty line. 3% of total funds are allocated for people with physically and mentally challenged persons below the poverty line at a unit cost of Rs. 20,000 in plains and Rs. 22,000 in hilly areas.

7. Swavlamban insurance scheme

This is a health insurance scheme for people with disabilities by the government of India. This scheme is not publicized much. It is the insurance of sum of Rs 2 lakh for a period of 12 months with a premium of Rs 356. People with disabilities with a family income of less than Rs 3 lakh of annual income can be a part of this scheme.

The services covered are OPD, inpatient treatment, pre- or post-hospitalization under modern medicine, and AYUSH(James et al., 2019).

8. **SIPDA scheme (Scheme for Implementation of rights of Persons with Disabilities Act, 2016)**

The SIPDA scheme has been implemented from 28.1.2016. Provision of following activities has been provided under the SIPDA Scheme:

For treatment and rehabilitation

- To support Composite Rehabilitation Centers (CRCs)/ Regional Centers/Outreach Centers and District Disability Rehabilitation Centers (DDRCs) and also to set up new CRCs and DDRCs as and when required.
- To assist the State Government to organize camps of issuance of disability certificates.
- To set up/support resource centers facilitating the dissemination of information on disability issues, counseling and providing support services

For improving the living conditions

- To provide barrier-free environment for persons with disabilities which include access to the built environment in schools, colleges, academic and training institutions, offices and public

buildings, recreational areas, and health centers/hospitals. This would include provision for ramps, rails, lifts, modification of toilets for wheelchair users, brail signage's and auditory signals, tactile flooring, causing curb cuts and slopes to be made in the pavement for the easy access of wheelchair users, engraving on the surface of zebra crossing for the blind or for persons with low vision, engraving on the edges of railway platforms for the blind or for low vision and devising appropriate symbols of disability, etc.

- To make Government websites at the Centre/State and district levels accessible to PWDs as per guidelines for Indian Government website issued by NIC and Department of Administrative Reforms and Public Grievances (D/o AR&PG), Government of India, which are available on their website "http://darpg.nic.in"
- Skill Development Program for PWDs.
- To enhance the accessibility of the built environment, transport system, and information and communication eco-system. The department has conceptualized the "Accessible India Campaign (Sugamya Bharat Abhiyan)" as a nation-wide flagship campaign for achieving universal accessibility that will enable PWDs with equal opportunity to live independently and take part fully in all aspects of life. The campaign will include the conduct of accessibility audits and making the public places/infrastructure fully accessible in built-up environment, transportation, and eco-system
- To create awareness campaigns and sensitization programs for various stakeholders and other Information Education Communication.
- To promote accessibility of libraries, both physical and digital, and other knowledge centers.
- Grant to the State Governments/UTs for the Offices of State Commissioner for PWDs for infrastructure facilities.

- Support for sporting events at the National/State level.
- To promote research and development activities in the field of disability rehabilitation.

9.<u>Special benefits for people with disabilities</u> (Concessions given by the central and state governments for the disabled, 2000; Special Benefits for Persons with Disabilities, 2012.).

There are some other benefits provided by the government to people with locomotor disabilities. They need to possess a disability certificate to avail of the following benefits.

- Concession on railways- A concession of 75% for a person with disabilities and persons accompanying them in first- and second-class tickets.
- Air travel concessions- A 50% concession for people with 80% or more.
- Conveyance allowance- All central government employees get a conveyance fee of Rs100 per day or 5% of basic pay who are blind or orthopedically challenged.
- Award of the dealership by oil companies – The ministry of petroleum and natural gas has reserved 7.5% of all types of dealership agencies of public sector companies for people with disabilities.
- Posting of PWDs is done on a regional basis and appointments are close to native places.
- Economic assistance by public sector banks- PWDs are given loans and advances at low-interest rates and a subsidy of 50% up to a maximum of Rs.5000/-.
- Integrated education facilities for people with disabilities.
- Income tax concessions- 20% concession of income tax for people with disabilities.
- Reservation of jobs and other facilities for disabled persons- three percent of jobs are reserved for group ‘C’ and ‘D’ jobs for people with disabilities.

- Marriage incentive scheme for disabled- A cash mount of Rs.50,000/- was awarded if either of the spouses is with disability. They should be of legal age and must possess a disability certificate.
- Benefits during exams and entrance tests- A disabled student is entitled to get extra time, writer facility, and low cut off marks in case of entrance tests and writer facility and extra time in case of school or college exams.
- Allowances are provided by the state governments for modification of houses and making it wheelchair accessible.

These are the various policies and schemes by government from which a person with TSCI could benefit.

CHAPTER – 4

METHODOLOGY

Rationale of the study

Spinal cord injury (SCI) is a catastrophic event that leads to an expensive life-altering state requiring specialized intensive rehabilitation resulting in high direct medical, direct non-medical, indirect, and intangible costs. The high costs have an impact on the quality of life.

There are studies that suggest that there are a high number of neglected spinal cord injury cases mainly due to lack of awareness and lack of recourses (Chhabra and Arora, 2013). The studies from other countries are showing the variation in costs but there are no studies done in India studying the cost of illness of spinal cord injury. Thus, the proposed study would be an exploratory study to see the direct and indirect cost of spinal cord injury and its effect on the quality of life.

Major objectives:

1. To estimate the Direct and Indirect health care costs to households having a member affected by the traumatic spinal cord injury.
2. To document the intangible costs of spinal cord injury by estimating the quality of life.
3. To document the coping mechanisms by patients and members of their households to meet the direct and indirect costs.

Minor objective:

To explore the extent the present government policies, help in offsetting some of these costs.

METHODOLOGY

Study type/Design:

This study is a cost of illness study with a bottom-up approach with a focus on for spinal cord injury. This study includes the calculation of various costs incurred from an individual with spinal cord injury and their family's perspective. I have used the prevalence-based method which also means I have calculated the cost over a period of one year, however I have in addition also include onetime costs that occurred over the duration of the injury as mentioned below.

Study setting:

The focus of the research is patients whose rehabilitation is going on as well as those who have completed the rehabilitation. In order to reach out to the specified target group, Swami Vivekanand National Institute of Rehabilitation Training and Research (SVNIRTAR) and Santa Memorial rehabilitation center located in Odisha state have been selected. The state spinal association was contacted to obtain the contacts of persons with spinal cord injury who underwent rehabilitation in these centers in the past.

Sample size and sample selection procedure

Inclusion criteria- People with traumatic spinal cord injury of are more than 18 years of age, undergoing rehabilitation in government or private rehabilitation centers or those who have already undergone rehabilitation.

Exclusion criteria- Traumatic spinal cord injury patients with associated head injury or multiple compound fractures.

As this is an exploratory study all people with spinal cord injury who came to the rehabilitation center during the period of my study i.e. December 2019 and Feb 2020 and who fulfilled the inclusion criteria were invited to be part of this study. The individuals with spinal cord injury who have completed the rehabilitation were contacted with the help of a voluntary group of spinal cord injury patients in Odisha.

Development of data collection tools

An interview schedule is developed with a section of questions related to demographic details, socioeconomic details, injury status, expenditures on various aspects, coping strategies and open-ended questions to see the helpfulness of the policies and benefits of the government and to assess the coping mechanisms used by the family to cope with the increased burden of spinal cord injury on both the patient and the family as a whole.

The interview schedule has two standardized scales that were used to assess the functional status of the patient and their quality of life. The interview schedule has been translated and back-translated into the local language (Odia) to make the fieldwork easier and smoother.

Data collection techniques-

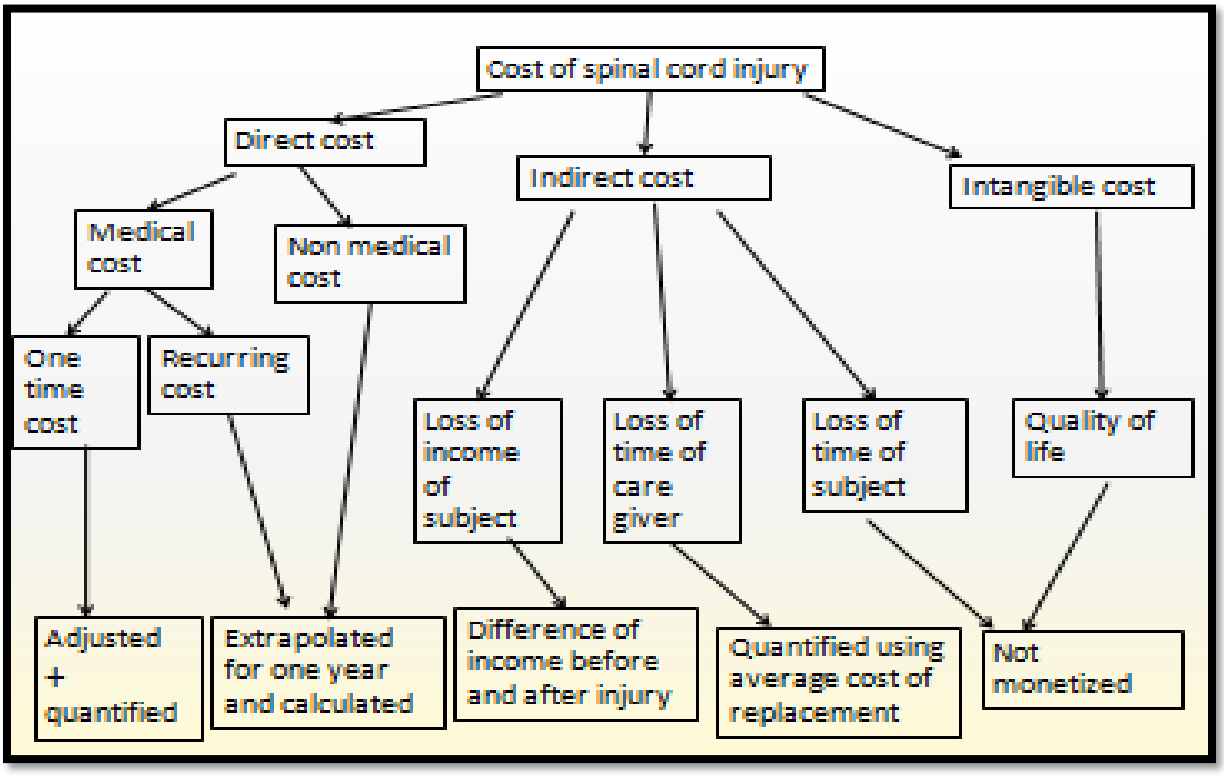
The collection of data was done in a systematic manner. All the persons coming to rehabilitation institutes with TSCI and the people who had come to these rehabilitation centers in the last few years and lived in a radius of 30 kilometers around the rehab center were contacted and were requested to take part in the study. All the persons with TSCIs who agreed to take part in the study were recruited. Prior to the collection of data the consent was taken. The principal investigator used the interview schedule to collect information with regards to direct medical,

direct non-medical, indirect costs including the hospitalization costs in the last one year and hospitalization and rehabilitation cost over the period of injury. All recurring monthly costs were recorded as per the information given by the patient. All details regarding the severity of injuries, functional status, previous procedures, etc., were extracted from the case sheet of individual patients and incase of discharge summaries and medical records for those in the community. In the case of hospitalization, we requested the participant to show the bills / final bill for verification.

Intangible costs are estimated by assessing the quality of life of the person with TSCI. This was obtained using the Odia translated and validated version of the WHO QOL BREF. All the permissions for the use of the same have been obtained before the start of data collection.

Statistical analysis:

Figure 4.1- flowchart on the analysis of cost of TSCI



The costs of spinal cord injury were divided into 3 sections which are direct cost, indirect costs, and intangible cost. The direct cost includes onetime medical costs, recurring medical costs, and non-medical costs. The onetime medical costs were adjusted for time parity for the base year of 2019-2020 and then calculated. The recurrent medical costs were extrapolated for one year and then calculated. The non-medical costs were also extrapolated for a year and then included in the total costs.

The indirect costs were calculated on the basis of loss of income of a person post-injury, time loss by the person with injury for medical consultations and rehabilitations, and time loss by the caregiver. Income loss was calculated by the years of income lost because of injury by considering that a person can earn till the age of 60. Similarly, Time loss by the person with injury and caregiver were quantified using the average cost of replacement method. An amount of Rs 29.46 per hour was obtained as the care giving cost averaging the amounts mentioned by those reporting the hiring of a caregiver (n=6). Thus the time loss in care giving was quantified using the obtained per hour care giving expenditure. This cost of time loss of care giving was extrapolated for one year.

The costs obtained were compared with respect to the level of injury, duration of injury, income status occupation of the person with spinal cord injury, and if the person underwent surgery immediately within 48 hours of injury or not.

The intangible cost was obtained using the WHO-QOL BREF questionnaire under physical, psychological, social, and environmental domains. They were compared with respect to the level of injury, duration of injury, income status, and involvement in sports.

The coping mechanism was derived from the ways and the sources from which the person with injury and his/her family arranged the funds during various phases of injury and its management.

The awareness and benefits obtained from policies are obtained using open-ended questions and further analyzed to see the number of people getting benefits and types of benefits.

SPSS 25 version software is used to do cross-tabulations and find the trend of change in the occupation; change is the use of addictive substances, change in marital status, and change in the occupation of family members.

Direct costs, indirect costs, and quality of life was explored with respect to variables like age at which injury occurred, gender, occupation, socio-economic status, social support, duration of injury, time of surgery and level of injury, etc.

Case studies

In order to enliven the data collected, I have noted the life stories of a few individuals I met in the form of case studies. These case studies highlight some of the key aspects of the findings of my study. These case studies collected together in Appendix-I and are referred in both the results and discussion section to highlight a few of the point I am making.

Ethicalconsideration

The study was conducted after receiving clearance from Institutional ethics committee of SCTIMST, Trivandrum. An informed consent was taken from every participant before data collection.

WORKING DEFINITIONS:

1. **Social support**- Social support was classified under groups like formal support from employers, insurance agencies and support from public sector. Informal support constitutes of support from friends, relatives and well-wishers. No support comprises of people with TSCI who did not have any kind of support or help.
2. **Direct cost** – Direct cost include medical and non-medical expenditures. Medical costs like expenditure on investigation, consultation, medicines, hospitalization and rehabilitation.
3. **Annual expenditure**- Total expenditure on medicines for injury, medicines for co-morbidities, consultation with doctor, rehabilitation, assistive devices, addictive substances, extra expenditure due to change in diet and expenditure on measures to control urine incontinence was collected for one month and then extrapolated for one year. Assistive devices cost was taken annually because most of them changed their wheelchairs in one or two years because of wear and tear where as some had rented their assistive devices. The expenditure in the last one year if any was noted and added directly to the direct cost of TSCI.
4. **One-time expenditure** – This could include expenses like acute hospitalization expenditure; expenditure on home modification and expenditure on other treatments like local methods, massage, Ayurveda, acupuncture religious activities and homeopathy are one-time huge expenditures. These have been included in calculation of direct costs as these big expenditures couldn't be left out. They constituted a major part of the burden of TSCI. The expenditure on acute hospitalization has been adjusted for time parity using inflation index and then added to the total cost (see point 6 below). Expenditure on other treatment methods

and home modifications couldn't be adjusted to the time parity as most couldn't specify the year of the expenditure on home modification and expenditure on other traditional treatment methods was over a period of time and not time specific. Moreover, these costs were limited to some people and most of them were recent injuries.

5. **Adjustment of cost** – Acute hospitalization of people with TSCI and income of persons with TSCI with injury more than 12 years was adjusted to time parity. The adjustment was done using inflation index. This calculation was done using formula

   FV = PV (1 + i)*n, where:

   FV: Future Value

   PV: Present Value

   i: Interest rate (inflation)

   n: Number of times the interest is compounded

   This calculation was done using online tool 'https://www.inflationtool.com/Indian-rupee' for base year of 2020.

6. **Estimation of direct cost**- This is the sum total of all annual expenditures, expenditure on home modification, expenditure on traditional treatment, and adjusted expenditure on acute treatment.

7. **Indirect cost**- This is the total time loss of person with TSCI, loss of wages/income of person with SCI and loss of time/productivity by the caregiver.

8. **Estimation of indirect cost**-

- Time loss by the person with TSCI on consultation, Rehabilitation are calculated and extrapolated for a year. They are presented in terms of hours of time lost.

- Wages or income loss of person with TSCI is taken as a difference between the monthly income before injury and monthly income post injury. People with injury of more than 12years which is before the 6^{th} pay commission came into effect was adjusted for time parity as 6^{th} pay commission in 2008 changed the income pattern people from all fields of life.
- Time loss by care giver was quantified. The expenditure on informal caretaker by few TSCIs was considered. The mean monthly expenditure was Rs.8248.8 and per hour cost wasRs.29.46. The time lost by care giver per day was asked, hours lost in a day were calculated and this was converted to monetary using the replacement method. The per day cost was then extrapolated for one year and loss of time by a care giver in one year was quantified.

9. **Intangible cost**- WHO QOL-BREF was used to document the quality of life of people under four domains like physical, psychological, social and environmental. This was compared with the total direct and total indirect cost.
10. **Coping mechanism**- these are the ways in which a person tries to manage his/ her additional expenses and also the ways to cope with burden of injury.
11. **Reimbursement**- the refund or benefits provided by governments, employers, and insurances where the treatment cost is borne by them in turn relieving the person from TSCI from the economic burden.
12. **Distress financing**- these are the methods adopted by people in dire situations like selling of assets like land and jewelry or taking loans and borrowing of money.

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METHODOLOGICAL LIMITATION OF THE STUDY:

The subjects were only taken from those who came to the selected rehabilitation centers for rehabilitation or had been to these rehabilitation centers earlier for their treatment.

The people who never came to these rehabilitation centers or never underwent rehabilitation were tried to be contacted with the help of state spinal association, physiotherapists working at the community level, social worker of both government and private rehabilitation centers but establishing contact and rapport for the study was not possible in the limited time of the hence I could not include individuals from this group in the study. These groups of people may have discontinued their treatment or never underwent rehabilitation because of a lack of finances, awareness, or other reasons. They may also be completely unaware of any government facilities and benefits and may be deprived of that.

The subjects taken from the rehabilitation center may not be a representative sample of all the people with TSCI. They may be taking up the rehabilitation post-injury either because they can afford it or manage to arrange the funds for the same. However, the burden of injury is high even among those who are able to access the rehabilitation services. More than 50 percent of the people included in the study are unaware of the government benefits and are not being able to benefit from them. So, the burden of injury is going to be huge for people who belong to lower-income groups and who do not undergo rehabilitation. However, given the time available for the research, it was decided to proceed with the institution-based sample and identify a few of those who have been admitted in the institution and who had completed rehabilitation for my sample.

CHAPTER 5

RESULTS AND FINDINGS

The findings of this study are presented in this section. All the results is for 79 individuals.

- Contacted participants total= 84
- Incomplete interviews= 3
- Complete interviews=79
- Denied participation= 2

A. Demographic andinjury detail

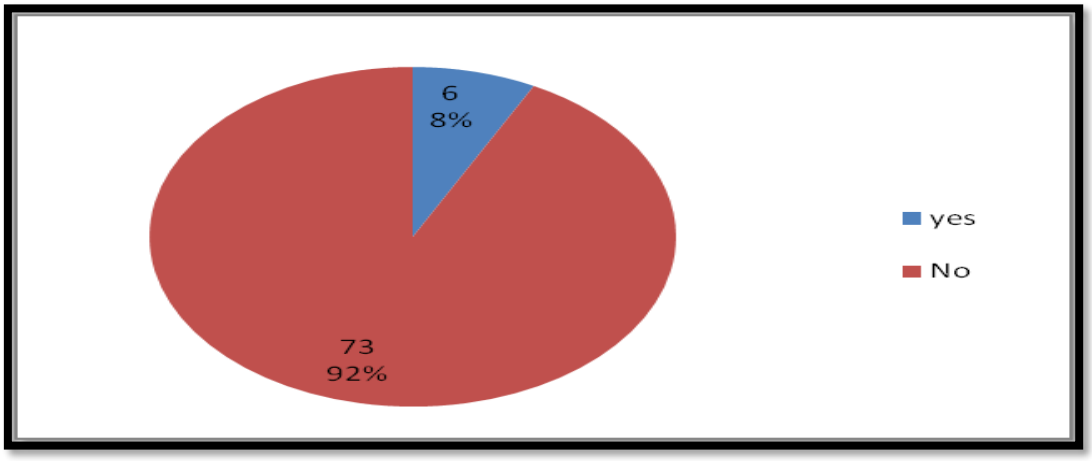
Table 5.1 Demographic and injury details			
Variable name	**Category**	**Frequency**	**Percent**
Place of interview			
	Government rehab center	45	57
	Private rehab center	2	2.5
	Completed rehab	32	40.5
Gender			
	Male	69	87.3
	Female	10	12.7
State of residence			
	Assam	1	1.3
	Bihar	1	1.3
	Chhattisgarh	2	2.5
	Himachal Pradesh	1	1.3
	Jharkhand	3	3.8
	Odisha	70	88.6
	West Bengal	1	1.3
SES Group (B.G.Prasad Scale)			
	I – High(more than Rs7,487)	62	78.5
	II - Upper middle(3743-7486)	6	7.6
	III – Middle(2246-3742)	1	1.3
	IV- Lower middle(1123-2245)	1	1.3
	V- Lower(less thanRs.1123)	9	11.4
Marital status			
	Unmarried	37	46.8
	Married	39	49.4
	Widow/widower	3	3.8

Variable name	Category	Frequency	Percent
Area of residence			
	Urban	29	36.7
	Rural	50	63.3
Cause of injury			
	RTA	39	49.4
	Fell from height	23	29.1
	Fell from tree	6	7.6
	Others	11	13.9
Level of injury			
	Cervical(C1_C7)	24	30.4
	Thoracic(T1-T11)	38	48.1
	Lumbar(L1-L5)	17	21.5
Duration of injury			
	<=to 2 years	34	43
	3to 6 years	26	32.9
	>=7 years	19	24.1
Phase of injury			
	Acute phase	0	0
	Rehabilitation phase	35	44.3
	Post rehabilitation phase	44	55.7
Age at which injury occurred			
	Less than 18 years	9	11.4
	18-40 years	52	65.8
	More than 40 years	18	22.8
Functional ability			
	Totally dependent	19	24.1
	Very dependent	5	6.3
	Partially dependent	21	26.6
	Minimally dependent	32	40.5
	Independent	2	2.5

Out of the 79 individuals, males constitute 87.3 percent and females constitute only 12.7 percent. More than 88.6 percent of the studied individuals are from Odisha and 11.4 percent are from other states. The individuals from other stated have come to undergo physiotherapy and

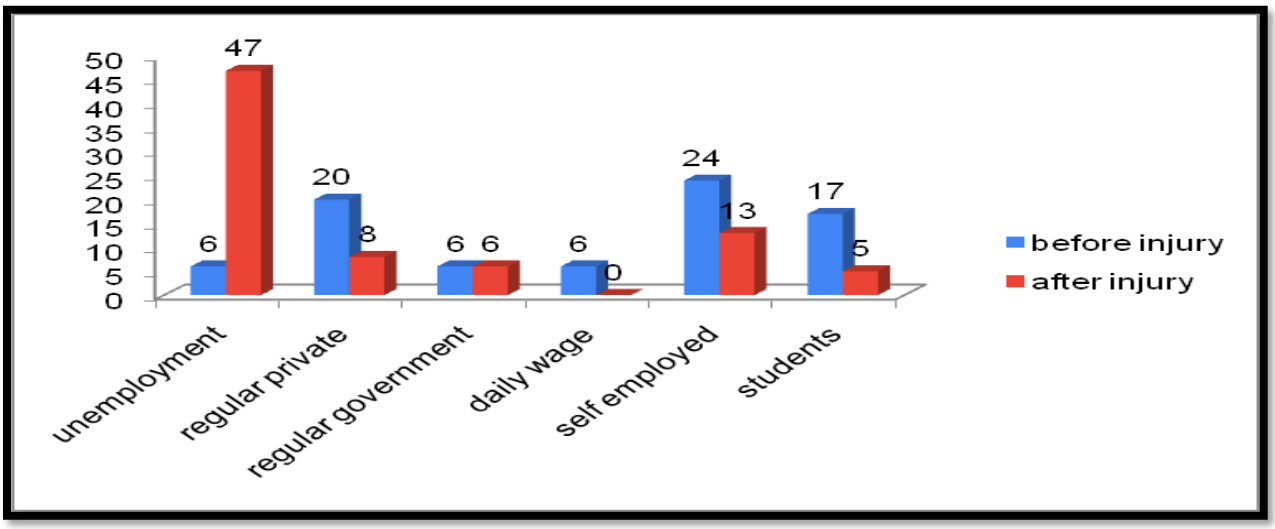
occupational therapy at the government rehabilitation center in Odisha. 78.5 percent of the total 79 individuals are in high, 7.6 percent in upper middle and 11.4 percent in low socio-economic group according to the B.G Prasad scale. Out of the 79 TSCI individuals 63.3 percent belong to rural area s and 36.7 belong to urban areas. RTA is the most common cause of injury as 49.4 percent individuals had injury because of RTA, followed by fall from heights and other causes like fall from stairs, slipping in bathroom or injury during farming. Out of the total population 34 had injury in the last two years, 26 had injury in last three to six years and 19 had injury seven or more years back. 44.3 percent of the studied individuals are undergoing rehabilitation where as 55.7 percent have completed their rehabilitation. 65.8 percent of the total 79 people were in age between 18 years to 40 years when they sustained injury. Functional ability was assessed using Barthel's index (Appendix-2). It was found that 40.5 percent are minimally dependent, 26.6 percent are partially dependent, 24.1 percent are totally dependent, 6.3 percent are very dependent and 2.5 percent are independent.

Figure5.1- Change in marital status post injury



There has been a change in the marital status of six people out of the total 79 people post injury. Four of them (all males) have got married post injury where as two of them have lost their partners after sustaining spinal cord injury. One of them lost his/her partner to natural illness where as other lost his/her partner in the same accident which caused the spinal trauma to the subject. Young women who sustain SCI are very worried of rejection of marriage proposals as mentioned in the case number 10 where she is working too hard at rehab centers to improve her quality of life.

Figure 5.2 Occupation before and after injury



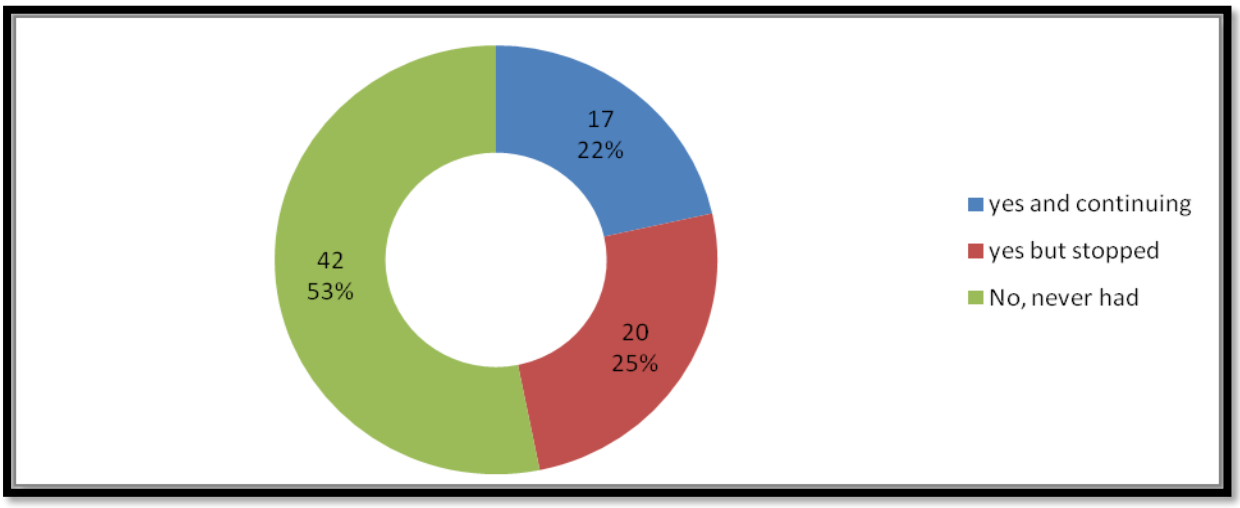
Out of the total of 79only six were unemployed before injury, 20 were working in private sector, six were working in government sector, six were daily wage workers, 24 were self-employed and 17 were students.

After injuries 48 out of 79 were unemployed, eight were working in private sector, six continued to be employed in government sector, 13 were self-employed and five students.

There were none working in daily wages all the six who were working on daily wages are unemployed post injury. Out of the eight working in the private sector post injury two started their job post injury whereas only six continued to have their job post injury with or without salary.

Out of 12 who are self-employed, five became self-employed after injury and eight continued to be self-employed. Out of these who continued to be self-employed three had to change their businesses to suit their physical constrictions post injury. 12 who were self-employed but become unemployed post injury were mainly farmers, drivers or those involved in physical work like electricians and plumbers. Out of 17 students before injury five continued their studies post injury whereas one finished study post injury but rest 11 dropped out of their studies.

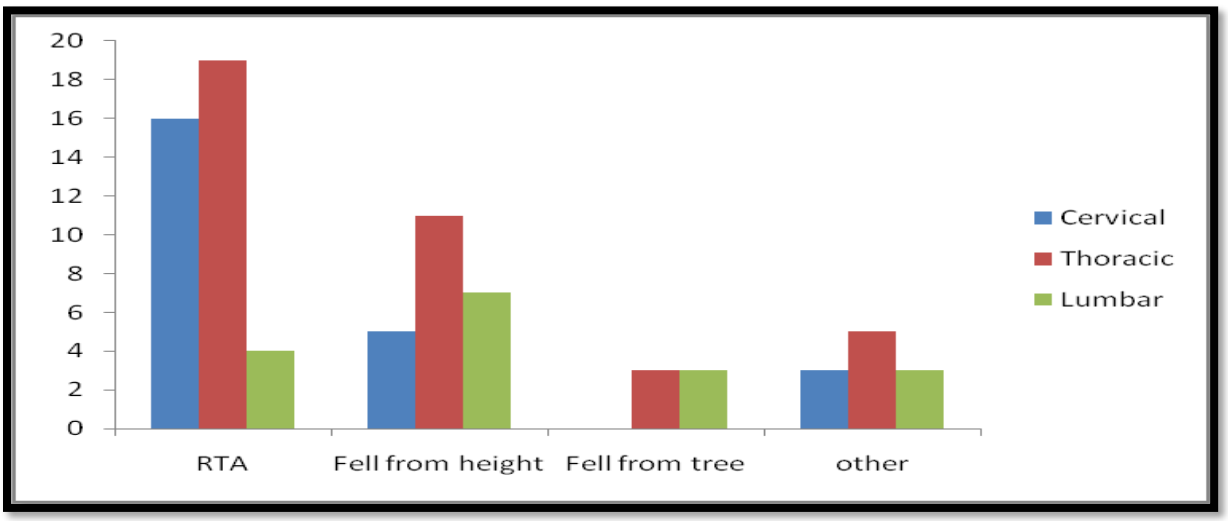
Figure 5.3 Use of addictive substances and change in habit of consuming addictive substances



17 out of 79 presently consume any kind of addictive substances like alcohol tobacco or pan. Out of the 62 who are not consuming any substance presently, 20 have stopped taking addictive substances after injury because of losing of interest in consuming the addictive substance, not

having any convenience of getting them or no one to buy them, stopped taking these substances on the advice of doctor, or to manage the extra expenditure due to injury.

Figure 5.4 Cause of injury and level of injury



Road traffic accidents (RTA) are the most common cause for spinal cord injury among the 79 people. Out of 39 who had RTA, 16 had cervical injury, 19 had thoracic level injury and four had lumbar level injury.17 people belonging to urban areas where as 22 belong to rural areas sustained injury due to RTA.

Second most common cause of injury among the 79 is fall from heights that is falling from pole or building. Out of 23 who injured themselves by falling from height, five had cervical injury, 11 had thoracic level and seven had lumbar level injury. Among these nine are from urban areas and 14 from rural areas. Four out of these 23 had endured injury because of electric shock when they had climbed an electric pole.

Falling from trees is mainly a cause of injury among rural people. All the six people belong to rural region.Out of 79 people, 11 sustained injuries because of other cause. Other causes include

injury during farming activities, slipping in bathroom and slipping on stairs. Three of them have cervical, five have thoracic and three have lumbar level injuries.

B. Direct cost

Table 5.2 median, mean of one-time expenditure (in INR)

Cause expenditure	**Median expenditure**	**Range**	**Mean**	**Standard deviation**
Acute hospitalization	300000	0-4000000	476645.57	571340.485
Acute hospitalization adjusted to time parity	377824.51	0-4475836.46	627592.51	710600.10
Structural modifications at home(n=23)	20000	500-400000	88586.96	124424.4
Other traditional treatment methods(n=55)	55000	500-1360000	119612.7	233325.5

Note: Onetime costs are adjusted for time parity an calculated (details page 47)

Acute hospitalization cost, structural modifications and expenditure on traditional treatments post injury are a onetime expenditure for a person with spinal cord injury. The mean and median expenditure for hospitalization in the acute phase and sub-acute phase is Rs.476645.57 and Rs.300000 respectively and after adjusting to time parity the mean and median expenditure on hospitalization in acute phase is Rs.627592.51 and 377824.51. The median expenditure for home modification of the 23 people who have done is 20000 and of the traditional treatment is Rs.55000

Table 5.3 Annual median expenditure for additional cause (in INR)

Cause of expenditure	Frequency of individuals reporting	Median	Range	Mean	Standard deviation
Medicine	36	18000	3600-84000	24181	19914.64
Consultation with doctor	17	4800	40-140000	22431.11	42803.64
Assistive devices	78	5000	0-200000	4904.54	6559.65
PT/OT	46	19200	4800-192000	41008.26	48131.12
Change in diet	18	17460	4800-72000	20980	18017.93
Medication and treatment of co morbidities	25	8400	0-300000	27350.4	59963.85
Urine incontinence	66	6000	0-24000	6196.36	4985.358
Addictive substances	17	2400	120-360000	24977.65	86464.13
Hospitalization	39	20000	2000-400000	82000	124161.2
Care taker	6	99000	60000-228000	117000	61861.13

Note: These are the costs reported by individuals under these cost heads(details page 46)

Median annual expenditure on medicines by the 36 people who are under medications is Rs. 18000. Out of 79 people, 17 people go for consultation with a neurologist or orthopedician at least once in 3 months and their median annual expenditure is Rs.4800. Median expenditure on assistive devices of the 78 people who use assistive devices is Rs. 5000 per year. 46 people out of the total 79 are undergoing physiotherapy or occupational therapy to manage their physical condition. The median expenditure for PT/OT is Rs19200 per year. There has been a change in the diet post injury for 18 people and the median of additional expenditure due to change in the diet is Rs 17460 for one year. 25 people are under medications and treatment for co-morbidities like diabetes and urinary tract infection. The median expenditure for medication of co-

morbidities is Rs. 8400 for one year. Sixty-six people have urine incontinence and they tend to spend on catheters, uro-bags and diapers. The median expenditure for managing urine incontinence is Rs.6000 for one year. The median annual expenditure on addictive substances is Rs. 2400. There are 39 people who were hospitalized in the last one year and their median expenditure is Rs. 20000. The six people who have a care taker have a median expenditure of Rs. 99000 on caretaker in one year.

Total direct cost is compared with respect to level of injury, duration of injury and age at which injury occurred

Table 5.4 - Total direct cost (including adjusted cost of acute hospitalization) with respect to level of injury, duration of injury and age at which injury occurred (in INR)

	Median cost	**Range**	**Mean**	**Standard deviation**	**F value**	**Significance**
Level of injury						
Cervical	701888.42	30840.00-2790000	980141.03	926167.49	0.717	0.492
Thoracic	506330.78	113920-5360000	768268.12	875410.29		
Lumbar	594249.92	243257.57-1850000	698737.69	446297.76		
Duration of injury						
<=2years	442156.00	113920-2710000	577193.40	468225.92	3.215	0.04(<0.05)
3 to 6 years	546608.57	30840-5360000	898787.98	1068445.12		
>=7years	953684.94	142460.7-2790000	1137002.69	829608.56		
Age at the time of injury						
<18 years	419424.41	142464-1850000	849862.25	683597.72	0.237	0.789
18-40 years	553078.00	155200-5360000	725884.67	900069.67		
>40 years	552040.54	30840-2710000	625259.96	635154.04		

Note: Annual costs of each individual is calculated, adjusted one-time expenditure if had were added and total cost for each person was calculated and then compared as mentioned in point 3-7 in working definitions. (Details page 47)

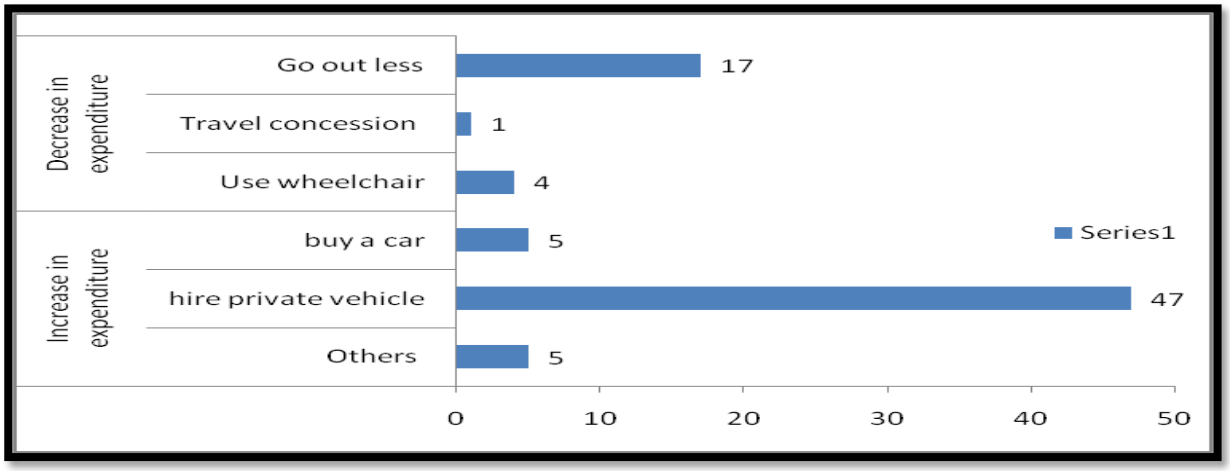
The mean of total expenditure on medical and non-medical factors is highest when people suffer from injury at an age less than 18 years of age and it decreases with the increase in age at which injury occurred. Total direct cost after adjusting for time parity is between Rs.308400 to

Rs.5364036.46. Mean and median of total direct cost being Rs.817672.33 and Rs.552156 respectively.

Change in transportation expenditure

All the 79 people have said to have a change in their transport cost. Earlier they could walk, ride a 2-wheeler or use public transportation as a means of transportation but post injury it was not possible to commute through public transport like share autos or buses. None could specify the exact cost but could tell the overall cost and how they cope with it.

Figure 5.5 Change in expenditure on transport



Out of 79, there has been an increase in the cost incurred due to transport in 57 where as 22 have said to have a decrease in the transport expenditure post-injury. From the 57 whose expenditure on transport had increased, 47 had an increase in cost as they have to hire a private vehicle, five bought a car for their easy transport and five are taking other methods which have increased their travel cost post injury.

From the 22 whose travel cost is said to have decreased post injury 17 said they don't go out unless unavoidable, four of them use their wheelchairs efficiently and commute so there has been

a decrease in their expenditure, for one person the travel concessions with disability certificate has helped in decreasing the travel expenses.

C. Indirect cost

Indirect cost is mainly the loss of productivity, and income by the person with spinal cord injury as well as the caregiver.

1. Time loss of person with TSCI in hours

Mean time loss of the person with spinal cord injury for rehabilitation and consultation with doctor for one year is 289.51 +/-291.31 hours. Median time loss for the person with injury is 240 hours in one year.

Table 5.5 Time loss (in hours) for the person with spinal cord injury for one year with respect to level of injury and age at which injury occurred

	Range	**Mean time loss**	**Median time loss**
Level of injury			
Cervical	0-972	360+/-300.4	468
Thoracic	0-1020	239.36+/-258.1	240
Lumbar	0-1104	302+/-340.45	324
Age at which injury occurred			
<18 years	0-972	290+/-337.5	240
18-40 years	0-1104	249.92+/-295.31	54
>40 years	0-840	403+/-235.80	480

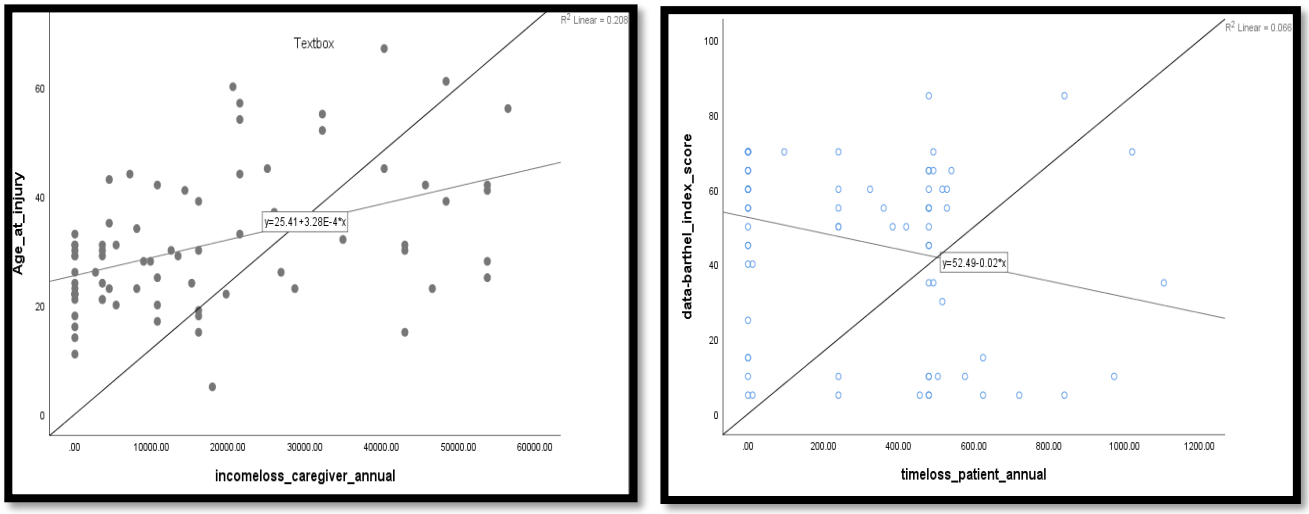
Note: the time loss per day is taken and then extrapolated for one year as in point 9 of running definition (details page 47)

A person with spinal cord injury requires time for doctor consultation, physiotherapy and occupational therapy sessions. This time required by the person with SCI is more in case of cervical level injury who are quadriplegics compared to thoracic and lumbar level injury who are paraplegics. Similarly, time required by a person with SCI is highest in case of person who had sustained injury at more than 40 years of age followed by less than 18 years of age compared to people who sustained injury between ages of 19-39 years.

Table 5.6Pearson's Correlation between time loss and age of injury and functional ability (Barthel's index score)

	Age of injury	**Functional ability**
Pearson's correlation coeff.	0.230	-0.257
Sig. (2 tailed)	0.042	0.022

Figure 5.6 Scatter plots of loss of time of person with injury with age at which injury occurred and functional ability score (Barthel's index)



The correlation between time loss for person with spinal cord injury is significant with the age at which injury occurred and functional ability. Time loss is positively correlated with age of injury whereas negatively correlated with functional ability among the studies subjects.

2. Loss of wages for person with TSCI

Loss of wages occurs due to either loss of job or change in occupation post injury mainly because of the decrease in physical ability because of the level of injury.

Table 5.7 Loss of wages (for one year) before and after injury for person with spinal cord injury with respect to level of injury and age at which injury occurred (in INR)

	Range	**Mean wage loss**	**Median wage loss**	**Standard deviation**	**F value**	**Sig(2-tailed)**
Level of injury						
Cervical	0-600000	190277.77	120000	203260	3.249	0.82
Thoracic	0-240000	163508.77	120000	511771.4		
Lumbar	0-480000	87058.85	36000	148013		

Age at which injury occurred						
<18 years	0-4800000	32592	0	160000	4.861	.000
18-40 years	0-2160000	153974.35	108000	330486.8		
>40 years	0-2400000	217037.03	162000	547126.3		

Note: the difference in monthly salary before and after injury were taken as mentioned in point no 9 in running definitions (details page 47-48)

The one-year loss of wages because of injury is highest when the person sustaining injury has a cervical level injury or is more than 40 years of age. The association between loss of wages for person with spinal cord injury is significant with duration of injury but insignificant with level of injury

Life time loss of wages of person with SCI

Lifetime loss of wages for person with spinal cord injury is calculated assuming that a person works and earn till an age of 60 and finding the difference between the monthly income before and after injury. The income has been adjusted for time parity. Mean and median lifetime loss of wages is Rs5566177.2 and Rs. 2160000 respectively. The mean and median lifetime loss of wages is highest among people with thoracic level injury, and least among people with lumbar level of injury.

3. Loss of productivity of care giver

Loss of productivity of caregiver includes the time lost by the caregiver for care giving activities. The time is monetized using replacement method

Table 5.8 Productivity loss (in INR) per year by caregiver of person with SCI with respect to level of injury and age at which injury occurred

	Range	**Median**	**Mean**	**Standard deviation**	**F value**	**Sig(2-tailed)**
Level of injury						
Cervical	0-56452.73	411667.48	36573.13	16108.72	42.03	0.000
Thoracic	0-40323.38	4928.41	8284.76	10135.11		
Lumbar	0-25986.18	4480	7282.80	8952		

Age at which injury occurred						
<18 years	0-43011.6	10752	10443.14	14171.33	8.654	0.000
18-40 years	0-53764.5	6720.56	13234.33	15719.65		
>40 years	4480.38-56452.73	28674.4	30566.11	16712.92		

Note: Loss of time of care taker taken and it is quantified by using average hourly expenditure of a care taker as mentioned in point no 9 in running definitions. (Details page 47-48)

Loss of productivity for caregiver is highest among the caregivers of people with cervical level of injury compared to thoracic or lumbar level injury. Similarly, loss of productivity in hours and loss of productivity in rupees is highest for people who sustained injury at more than 40 years of age. There is a significant association between annual time and income loss of care giver and level of injury and age at which injury occurred.

Table 5.9 Total indirect cost is calculated by taking one-year income loss of the person with TSCI and productivity loss of caregiver.

	Range	**Median**	**Mean**	**Standard deviation**
Total indirect cost with level of injury				
Cervical	16129.35-610752.90	165699.82	236055.66	199884.15
Thoracic	0-2410000	127616.63	173224.11	510572.85
Lumbar	0-505986.18	51584.3	94341.62	14989.68
Total indirect cost with age at which injury occurred				
<18 years	0-480000	16129.35	45425.27	156252.67
18-40 years	0-2160000	120000	211811.26	329287.22
>40 years	21505.8-2389247.10	196946.92	345899.44	542426.66

Note: total indirect cost was calculated by adding income loss of the person with TSCI and productivity loss of care giver as mentioned by point no 11 in running definitions (details page 47-48)

Total indirect cost is highest in case of people with cervical injury and who had injury at an age above 40 years of age.

Total indirect cost after adjusting for time parity is between Rs. 0to Rs.2410752.90. Mean and median of total indirect cost being Rs.225624.30 and Rs.120000 respectively.

D. Intangible costs of spinal cord injury by accessing quality of life.

TheWHO-QOL-BREF is a tool used to measure the quality of life. It is a measure to see the physical, psychological, social and environmental wellbeing of a person. This gives a measure of intangible cost of TSCI. All the scores have been transformed to the values between 0-20.

Table 5.10 Mean quality of life

Domain	**Mean+/-SD**	**Median**
Physical	10.32+/-3.9	10
Psychological	10.56+/-3.98	11
Social	11.97+/-3	12
environmental	11.05+/-3	10

Table 5.11 Quality of life with respect to involvement in various activities

categories / Domain			
Sports/co-curricular activities	**Play sports**		**Do not play sports**
Physical	11.00+/-3.64		10.13+/-3.98
Psychological	10.89+/-4.01		10.43+/-3.98
Social	11.83+/-3.65		12.02+/-3.471
environmental	11.22+/-2.48		11.00+/-3.15
Surgery	**Immediately within 48 hours**		**Not immediately**
Physical	10.56+/-3.645		10.14+/-4.16
Psychological	10.89+/-3.52		10.23+/-4.32
Social	11.86+/-3.65		12.07+/-3.38
environmental	11.19+/-3.20		10.93+/-2.87
Benefits from government	**Received benefits**		**Not received benefits**
Physical	10.72+/-3.89		10.00+/-3.94
Psychological	10.86+/-3.67		10.26+/-4.02
Social	11.67+/-3.54		12.23+/-3.463
environmental	11.53+/-2.83		10.65+/-3.08
Age of injury	**Less than 18**	**18-40 years**	**More than 40**
Physical	11.89+/-5.06	10.37+/-3.66	9.44+/-3.98
Psychological	12.22+/-3.99	10.33+/-3.85	10.28+/-4.30
Social	13.56+/-3.16	11.54+/-3.39	12.44+/-3.80
environmental	12.89+/-2.66	11.00+/-2.82	10.28+/-3.42

People with SCI who are involved in sports or other kind of extracurricular activities like wheelchair marathon, wheelchair basketball, wheelchair fencing, and etc have a high quality of life in physical, psychological and environmental domain.

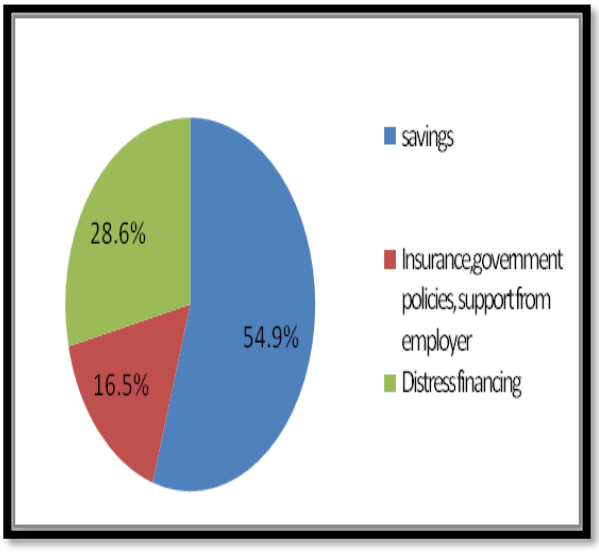
Quality of life of people who had a surgery immediately that is within 48 hours of injury has is high in physical, psychological and environmental domain. The people who received benefits that are any kind of support post injury have a high quality of life

Quality of life of all domains is highest among people who sustained injury below the age of 18. This seems less the indirect cost more is quality of life. The people who have injury after the age of 40 have low quality of life in physical, psychological and environmental domain but high QOL in social domain compared to people who had injury at the age between 19-40 years.

COPING OF EXPENDITURE

Table 5.12 and figure 5.7 to know about the coping mechanisms followed by the affected family

Financial Coping strategies	percentage	No of responses
Family savings	32.4	75
Self-Savings	22.5	52
Loans with interest	20.8	46
Insurance	2.2	5
Sale of assets	7.8	20
Help from others	9.5	22
Help from government	4.8	11



Financial coping of the overall expenditure includes 54.9 percent through personal and family saving, 28.6 percentthrough distress financing like sale of assets and loans, and 16.5percent by help from government, help from employers, friends and insurance.

Table 5.13 and figure 5.8Coping during acute treatment (Surgery, hospitalization within 6 weeks of injury)

Financial coping strategies	Percentage	No of responses
Saving	39.3	57
Loan	28.3	41
Insurance	3.4	5
Sale of assets	10.3	15
Government help	6.9	10
others	11.7	17

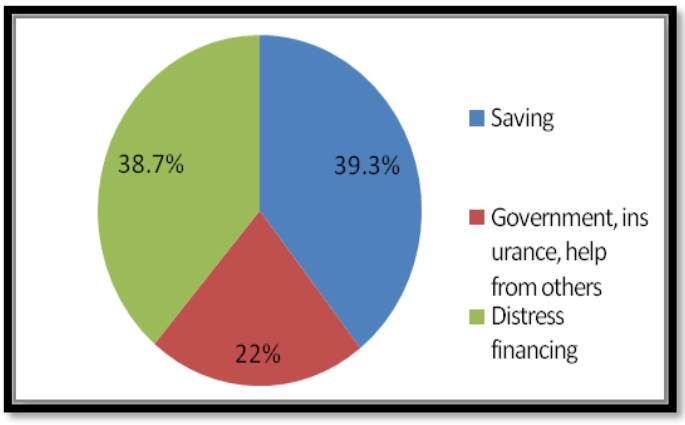
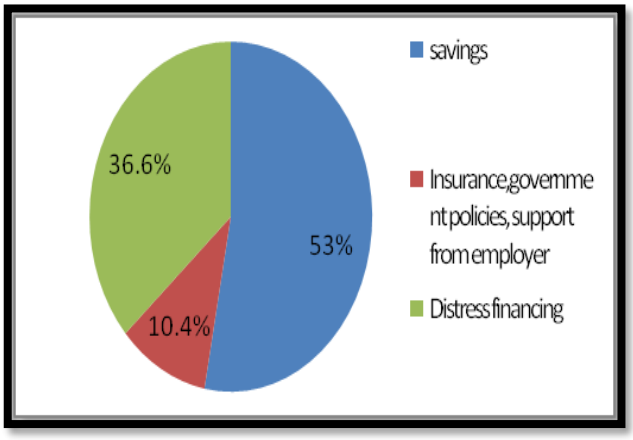


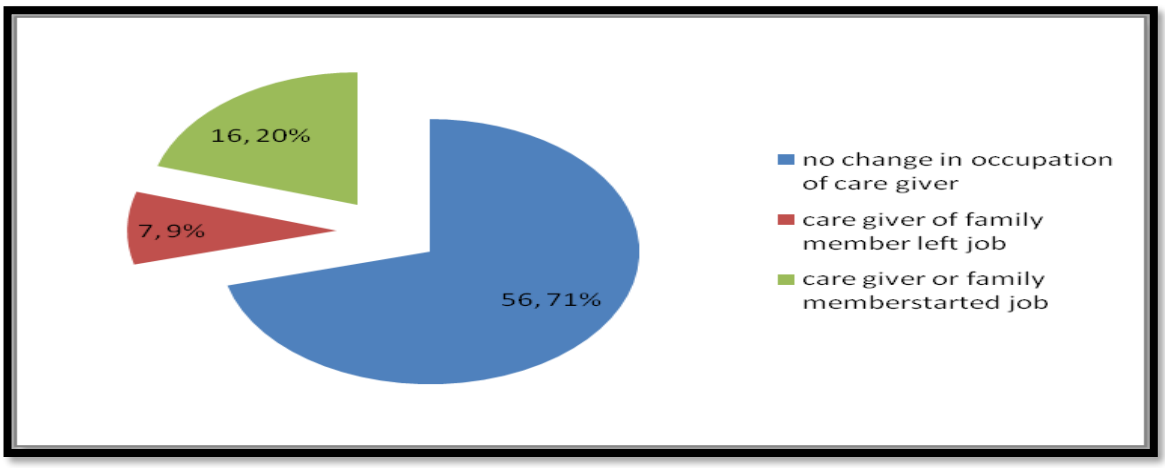
Table 5.14and figure 5.9 Coping during rehabilitation phase (post acute and sub acute phase)

Financial coping strategies	Percentage	No of responses
Saving	53	61
Loan	26.2	30
Insurance	0	0
Sale of assets	10.4	12
Government help	2.6	3
others	7.8	9



From table 5.13 and 5.14, 38.3 percent used their personal and family savings during acute phase where as 53 percent used their savings during rehabilitation phase. 6.9 percent got help from government only during acute phase and 3.4 percent could claim their insurance for acute treatment which was absent during rehabilitation. Distress financing accounted to 38.7 percent during acute phase and 36.6 percent during rehabilitation phase.

Figure 5.10 change in occupation of care giver

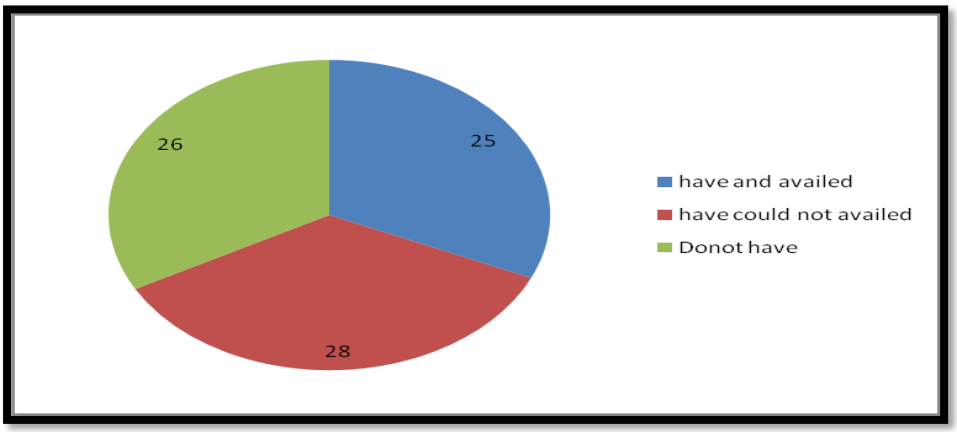


Family members of 16 people with spinal cord injury started working to compensate the loss of income due to injury whereas family members of nine percent left jobs to take care of the person with TSCI.

Table 5.15 Possession of government cards and concession in treatment expenditure

Possession	Frequency	Percent
Yes	53	67.1
No	26	32.9
Total	79	100.0

Figure 5.11 Availing insurance schemes



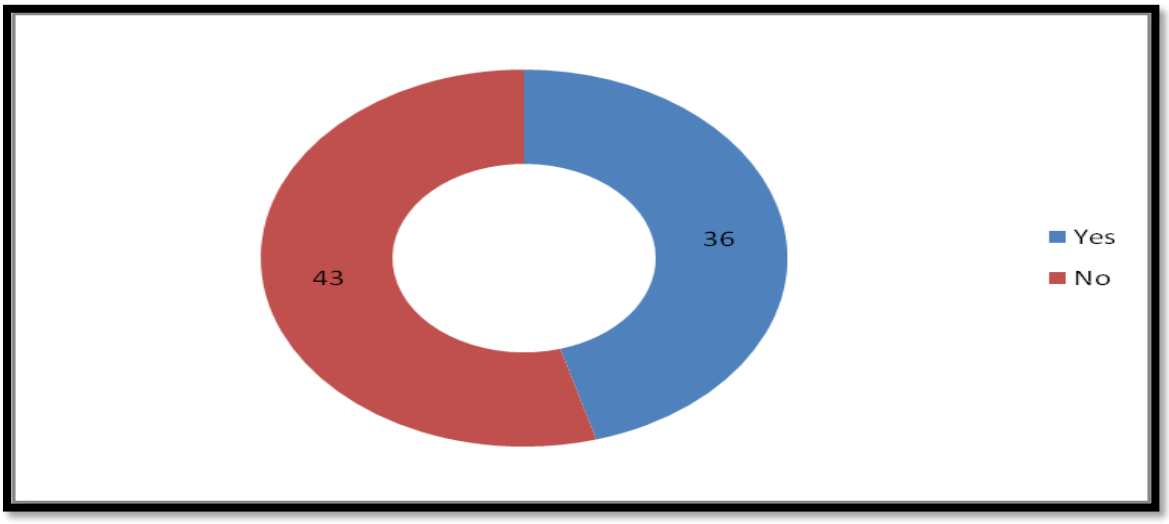
Government card like BPL card, krushak health card, RSBY and other similar cards are helpful in decreasing the expenditure of treatment in a government hospital. Out of the total 79 people 53 people possess one or more of the above mentioned cards. Only 25 of these 53 people availed the benefits during the course of management of the SCI.

Table 5.16 Awareness and availing about benefits from government programs and policies

Awareness	**Frequency**	**Percent**
Yes	36	45.6
No	43	54.4
Total	79	100.0

Out of the total 79 people only 36 are aware about the government policies and benefits present for people with SCI. They also know about the procedure of applying for the benefits.

Figure 5.12 availing the benefits**.**



36 out of the 79 have applied for a disability certificate, posses it and are availing the benefits they get.

Table 5.17 Ways of availing government benefits

		Responses		Percent of Cases
		N	Percent	
Benefits availed with the help of disability certificate	ration card	5	11.1	15.2
	pension	24	53.3	72.7
	train concession	7	15.6	21.2
	marriage allowance	2	4.4	6.1
	scholarship	1	2.2	3.0
	house construction allowance	1	2.2	3.0
	income tax	1	2.2	3.0
	exam facilities	1	2.2	3.0
	loan with less interest	1	2.2	3.0
	free treatment	2	4.4	6.1
Total		45	100.0	136.4

Benefits people with SCI get due to possessing a disability certificate. 11.1 percent have got a ration card on their name which helps them to get rice and pulses at subsidized prices. 53.3 percent are getting a pension of Rs 700, 15.6 percent have availed concession on train fare, 4.4 percent each have got marriage allowance of 1.5 lakh rupees, and free treatment, 2.2 percent each have got benefits like scholarship, house construction allowance, income tax relaxation, writer facility during exam , extra time during exams, and loan with less interest.

CHAPTER-5

DISCUSSION

In this study I have explored the various economic impacts of spinal cord injuries among patients who were undergoing or had completed rehabilitation. I have collected information with regards to direct, indirect and intangible costs. While I have attempted to monetize most of these,but I have left some of the costs un-monetized.

In this discussion I will highlight some of the significant findings on the impact of spinal injury on patients, the costs as well as some insights with reference to the coping mechanisms / strategies adopted.

Characteristics of persons with TSCI

Male to female ratio from the interviewed 79 people is high. The males comprise 87.3 percent whereas females are only 12.7 percent. This is similar to the results Rahimi-Movaghar et .al found in the Epidemiology of traumatic spinal cord injuries in developing countries where males constituted 82.8 percent and females constituted 17.2 percent of the study population. Similarly a study from North-East showed similar 85.3 percent males to 14.7 percent females. (Rahimi-Movaghar et al., 2013; Rastogi et al., 2014).

In my study I found more people from rural areas had sustained spinal cord injuries than urban areas. Out of the 79 people, 63.3 percent are from rural areas and 36.7 percent are from urban areas respectively.

There were some interesting trends with reference to change in the occupation post-injury. I found that a large number of people became un-employed after injury. The only group that has

no break in employment status was those in the regular government sector. All the six such individuals had their employment unchanged in this sector. But, some had a loss of pay because of the long absence from work. The government is paying for the treatment of three people whereas among the other three people working in government sector two people are getting a full salary and are able to manage their treatment-related expenses like in case number 8 where the government provided support to its TSCI employee.

There were 17 students who were studying at the time of injury but nine of them had dropped out of their studies post injury. The main reasons stated by them are lack time to manage their studies along with treatment. This is especially so in the initial days of injury, after this however this gaps in the studies makes it difficult for them to get back to their studies. Inaccessibility and the feeling of inferiority because of their disability were some other reasons that were mentioned for discontinuing their studies.

All people involved in work with daily wages had to stop working post-injury because of the physical demands of the type of their job. Similarly, many people who were self-employed in activities like farming and businesses and people working in private sector jobs that require a lot of physical activity had to quit their jobs post-injury.

However, some of these people can start earning and make a livelihood by taking the help of the government facilities like low-interest loans for setting up of business like in case number 7who could change his business.

Contrary to the belief that people tend to get addicted due to the stress post-injury 20 out of the 37 people who used to consume addictive substances like alcohol or tobacco stopped taking them

post-injury mainly because of lack of accessibility to shops selling them, following doctor's advice or to compensate the extra expenses on treatment.

Road traffic accident and fall is the leading causes of injury. RTA is a cause in 49.4 percent of cases and fall from height causing injury in 36.7 percent of cases. This is similar to the findings in the epidemiology of traumatic spinal cord injury in developing countries. According to the paper, RTA with 41.4 percent and falls with 34.9 percent are the leading causes of spinal cord injury (Rahimi-Movaghar et al., 2013). Whereas Rastogi et .al found falls causing TSCI in 51 percent of people as the leading cause of injury in her study followed by RTA causing TSCI in 37.23 percent of people(Rastogi et al., 2014).

RTA, Falling from height by slipping is a cause of injury in both males and females but causes like fall in the bathroom seems to be common in females whereas fall from trees, fall from height due to electric shock, injury during farming activities or injury due to fall of a heavyweight on them in workplaces like in case number 12 seem to be causes for injury among the male population.

The direct and indirect cost of SCI

The total direct cost includes medical and non-medical costs. The mean and median cost of hospitalization in the acute stage is Rs. 476645.57 and Rs. 300000 respectively without any adjustment. The cost of acute treatment of TSCI is higher than surgical innervations like a cesarean section, hysterectomy, open cholecystectomy, external fixation, coronary artery bypass grafting, and craniotomy in India (Chatterjee and Laxminarayan, 2013).

The expenditure on assistive devices and urine incontinence has to be borne by a person with TSCI and his family for the whole life. Similarly, increased cost on transportation, loss of income of the person with TSCI due to injury, and loss of productivity of the caregiver are the factors that contribute to the economic burden of injury for the whole life. The high direct and indirect cost of TSCI with respect to the level of injury is similar to the high direct and indirect costs of TSCI in studies done in countries where the cost of the cervical level was higher than thoracic or lumbar level (Kiekens et al., 2011). The cost of injury increased with duration may be because of the increase in co morbidities and expenditure on its treatment with time; this is different from the findings in Canada where cost came down after five years of injury (Chan et al., 2013).

Time loss by the person with the spinal cord for the activities of daily living, rehabilitation, and consultation is negatively correlated to functional ability. Loss of wage of the person with TSCI post-injury as significantly associated with the duration of injury and age at which injury occurred. This may be due to higher functional ability means less loss of functions so, it requires less time in doing activities.

Time loss of caregiver is also significantly associated with age at which injury occurred. This may be because of the higher ability among young people to adapt and learn modified means of self-care. The significant association of loss of productivity of caregiver with the level of injury is maybe because of the association between functional ability and level of injury.

Quality of life of TSCI

Quality of life is measured to know the overall wellbeing of a person with spinal cord injury. The quality of life in all domains is very low compared to international standards. Similar to the other studies QOL in the case of people with injury at a lumbar and thoracic level is higher than people with injuries at the cervical level. Quality of life is better in the case of people who underwent surgery within 48 hours of injury; this is similar to findings of the study on prognosis of spinal trauma. (Fehlings et al., 2019.). The quality of life is higher in the case of people who are involved in games or in other activities. This can be further highlighted by the case number 6 who is a national level player and incase of case number 4 where the person has a very high Barthel index and is involved in sports activities.

The government benefits like loans with low-interest rate, travel concessions, etc act as support to the person with disabilities. These benefits help a person to live a better life thus improving the quality of life. The quality of life in the physical, psychological, and environmental domains is higher in the case of those who are availing of the government benefits. Travel concession has helped in decreasing the travel expenses for the person with injury like is case number 4 and in case of case number 7 where he is able to start his business and become financially independent. This financial independence also played an important role in him getting married post-injury and has a high quality of life.

The quality of life is related to the age at which injury occurs. The higher the age at which injury occurred the lower is the quality of life. As seen in the indirect cost calculations the time of care needed increases with the age at which injury occurred which implies that dependency increases thus, quality of life decreases with an increase in the age of the injury.

The mean score for all domains of quality of life with the level of injury, functional ability and age of the person at the time of injury is similar with the findings of the study of QOL on SCI done in Odisha in 2010 (Ganesh and Mishra, 2016).

Coping of families of a person with SCI

The coping strategies adopted by the families with a person of spinal cord injury are saving, help from the government and other formal sources, insurance, selling of assets, or by borrowing.

Out of the total expenditure, it is found that 28.6 percent was through distress financing which is borrowing and selling of assets. This is similar to 32.2 percent of distress financing in the study on the economic burden of hospitalization due to injuries in north India (Prinja et al., 2016).

There is a change in the ways of coping during the acute injury phase and during the rehabilitation phase of injury. The insurance coverage and help from the government as in case number 2 where the government compensated for acute treatment or as in case number 8 where the government reimbursed the cost of treatment for its employee is only during the acute phase. Insurance does not cover rehabilitation whereas only very few could avail the provisions of government for free rehabilitation as in case number 13 who got rehabilitation services free of cost as he was working in the NGO.

There are a few organizations, employers who support the person with spinal cord injury throughout the course of treatment as in case number 12 and sometimes government pays for the treatment as a compensation as in case number 2 for the bus accident.

Thus distress financing like selling off assets, borrowing is means adopted by few to undergo rehabilitation like case number 10. The study by Chabbra et .al suggests that the number of

neglected SCI is high in rural parts of the country where the people have fewer means to cope with the burden of injury (Chhabra and Arora, 2013).

Thus, the most common way to cope with the economic burden is by using self, family savings. This accounts for 39.3 percent during the acute phase and 53 percent during the rehabilitation phase.

Out of the total expenditure, only 2.2 percent is by insurance and it is only during acute treatment as there is not much insurance that covers the prolonged rehabilitation cost. Many of the insurances do not provide the umbrella for the people with disabilities and the one insurance provided by the government is not much publicized and also it does not cover the rehabilitation expenditure.

The families tend to compensate for the loss of income of the person with injury by family members starting jobs or in case of people like case number 3 family pension helps them. Out of the total 79, family members of 16 people started jobs to compensate for the loss of income like case number 1. In some exceptional cases like the case number 11 family members with less job security quit a job so that the financial security of the family is intact as well as the person with an injury is well-taken care off.

Benefits of government policies

Odisha government issues BPL cards, RSBY(Rashtriya swasthya bima yojana) cards for people below the poverty line krishak swasthya cards for farmers. These cards help people to get concessions on treatments in government hospitals. Out of the 79 people included in my study, 53 people possessed one of the above-said cards but only 25 of them availed the concessions

during their course of treatment. The reasons stated were mainly because they either underwent treatment in the private hospital or because of not having cards with them when visiting hospitals for treatment.

A spinal cord injury causes locomotor disability. Quadriplegia, paralysis of all the four limbs, in case of injury in the cervical level or paraplegia, paralysis of lower limbs, accounts for 90 percent and 75 percent of motor disability respectively. They are entitled for disability certificates and can avail of the associated benefits. Out of the total 79 only 36 have disability certificates and availing some of the benefits like disability pension, train concessions, and income tax concession like case numbers 4, 7, 14 and 15.

Out of the 43 who do not possess a disability certificate is either because they are unaware or because of the lack of availability of necessary documents. Under the rights of persons with disability bill, 2004 the spinal cord injuries do not come under the neurological disabilities and there is no mention of terms like paraplegia or quadriplegia. The people with spinal cord injury can apply for disability certificate on the basis of motor disability (Math et al., 2016) which also acts as a barrier for easy access to government benefits.

Thus, families of individuals with TSCI cope in different ways depending on the problems they face. Individuals who have complications because of treatment like case number 5 tend to stop their treatment or in families similar to that of families of individual as in case number 9 become afraid of repetition of the incident and this affects career choices of other members of family.

On the contrary people like case numbers 4, 6,7,12 and 13 who are getting some kind of support from government policies and benefits are living a partially independent or independent life with

a very high quality of life. The benefits got are helping them to be financially independent and also get recognition which in turn is influencing them to life a happy life.

CHAPTER – 7

CONCLUSION AND RECOMMENDATIONS

CONCLUSION

Traumatic spinal cord injury is abrupt in onset and the leading causes being road traffic accidents and fall from heights. The median total direct cost is Rs.552156. Total indirect cost includes the loss of income of a person with SCI and loss of productivity of the caregiver. The median indirect cost is Rs.120000. There is a change in transportation related costs among everyone post-injury. Quality of life is a measure used to calculate the intangible cost. The mean quality of life in the social domain is highest and lowest in the physical domain. The total cost of injury is high in a higher level of injury. Quality of life tends to be higher among people with TSCI who are actively involved in sports or other extra-curricular activities. The economic burden of the TSCI is huge and the people with TSCI and their families tend to cope with the economic burden by using the saving, help from well-wishers, distress financing and, very limited help from the benefits of government and other agencies. In some cases, the family members change their occupation to manage the burden of injury. Only 45.6percent of the 79 people are aware of benefits by government. The people who are getting some kind of help from government benefits have a better quality of life compared to those who do not get any kind of support. Thus the need of the hour is to decrease the burden of injury on the person with TSCI by increasing the umbrella of benefits for them.

POLICY RECOMMENDATIONS:

1. Extending the UHC for all disabled and not limiting it to the people with disabilities who are below the poverty line.

The direct medical, direct non-medical, as well as an indirect cost, is high in case of spinal cord injury and they have a lot of difficulty in managing the expenses. Thus, providing health insurance would help them to undergo treatment post spinal cord injury.

2.Increasing the inclusion criteria for the swaviman insurance scheme.

Swaviman scheme is limited to people with income less than 3lakhs per year. Given the calculation of direct and indirect cost it is clear that this band needs to be increased and this will help the people to not neglect and treat themselves for complications post the spinal trauma.

3.Provision of good quality rehabilitation services at a low price or free of cost for people with spinal cord injury and resulting in locomotors disabilities.

The spinal injury centers that are set up regionally need to be strengthened and more such centers need to be set up across India to improve the rehabilitation services to the spinal cord injured persons.

4. Provision of Income security

Increasing job opportunities for people with SCI who lose their jobs because of physical impairment post an injury to the spinal cord, improving job security for people who sustain injuries causing lifetime disability.

5. Strengthening of the health system

48 – 72 hours post spinal cord injury tends to be very crucial and this decides the prognosis of the person. So, an effective referral system needs to be in place to ensure that proper treatment is provided immediately post-injury.

6. Encouraging co-curricular activities at the local level.

Co-curricular activities like sports make a person's quality of life better. This also improves the physical health of the person as well as the functional ability. Thus, a sports scholarship, provision of training, and facilities will help young people with spinal cord injury to lead a life of respect. As these wheelchair sports like wheelchair basketball and wheelchair fencing gave an identity to case numbers 4, 6, and 13 similarly it could show a way of life to many others.

7.Facilities of vocational training at the district level- A district-level training may be set up to train people SCI and other disabilities to learn vocational skills which to generate income facilities according to the needs and facilities available in that district.

8. Awareness of benefits for the disabled by the government

The persons having a spinal cord injury need to make them aware at the PHC and Anganwadi level about the various schemes and benefits provided by the government. This would help them to decrease the burden of injury at least in a small amount like in case numbers 7 and 12.

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ANNEXURE I – CASE STUDIES

1. Occupational Impact of self and other family members

27 years ago, a 57-year-old man sustained spinal cord injury by slipping from a height of 10 feet resulting injury at L1 level. He didn't undergo operation immediately rather he had undergone treatment with other stabilization methods available at that time. He spent around Rs50000/- for his treatment in the acute stage. He was working in the construction sector before injury but during post injury period he joined in an NGO which is working for people with spinal cord injury. Being an employee, he underwent his **rehabilitation free of cost** in the associated NGO. **His wife started to work** as a teacher to meet the financial crises raised during post injury period. He has been driving a modified two-wheeler for last 20 years and a self-driving car with modified steering wheel for last four years. He had a cardiac surgery two years back for which he spent two lakh and 50 thousand. He was admitted to hospital in last two months for urinary infection

2. SCI due to Bus Accident

In the year 2018 a 23-year-old lady sustained spinal cord injury due to a bus accident while going for her interview and she had T12-L1 injury. But due to unavailability of ICU she had to wait for a period of 8 days for operation. **Government paid four lakh rupees required for the treatment in the acute condition** as a part of rehabilitating the victims of bus accident. She has applied for disability certificate but yet to get it.

3. Family pension as a means of coping

Three years back a 42-year-old lady along with her husband was met with road accident in which the husband lost his life and she got spinal cord injury. She underwent a surgery after 18 days of

injury as there was delay in taking decision by her family members regarding her course of treatment. As her husband was a government servant, she is in a bit comfortable position to manage **her treatment expenditure as well as education of her children with the pension of her deceased husband**.

4. Travel concession

In the year 2016, a 27-year-old female sustained an injury by falling from a height resulting L1 level injury. She is a basketball player and has a Barthel's index of 75 out of total score of 100. She said that 'there has been a decrease in the expenditure related to travel during post-injury period as she got the facility to avail travel concession meant for disable person while traveling by train or bus'.

5. Side effects of electrotherapy.

A 47-year-old person met with an accident in 2006 and sustained a c4-c5 level injury. Prior to the injury he was working in a private sector. But soon after the injury he had to leave the job and subsequently started doing freelancing work. Simultaneously his wife also started working to compensate for the economic loss raised due to injury. He was undergoing physiotherapy till 2019 but stopped after **he had a burn injury by the muscle stimulator used for muscle stimulation during therapeutic treatment** for which he had to spend two lakhs. In spite of having a disability certificate he is not in favor of taking a pension. He is of opinion that there are no of people who are poor and in need of money to survive whereas he has his own livelihood to survive.

6. Disability can never be a barrier to get recognition

In the year 2014, a 28-year-old male person who was a cable operator in profession fell down while playing volleyball and sustained an injury in the T6 level. After injury, he could not

manage with his profession and forced to stop working as a cable operator. He underwent rehabilitation in the government rehabilitation center at Olatpur, Odisha. During his stay at the center, he was motivated by the staff of the institute as a result of which he made his mind to **involve himself in sports like wheelchair fencing, wheelchair marathon and wheelchair basketball. His active involvement and strong determination could not keep him away from winning a prize of Rs one lakh in 2019 sports.** Subsequently he has become a brand ambassador of the company manufacturing wheelchairs and got a wheelchair as a gift on behalf of the said company. During his stay in the rehabilitation institute, h**e voluntarily motivates the patients with spinal cord injury to enhance their self -confidence.** Presently he has become a good trainer for the wheelchair marathon players of Odisha. He works closely with the spinal cord injury association of India for the welfare of people with spinal cord injury. **He says, "This spinal cord injury has done good to me, now people recognize me and it has given me an identity".**

7. Proper awareness of government policies can change the life of an individual

In 2015, a 27-year-old male fell from a tree and injured his spinal cord at the T4-T5 level. Prior to the injury he was working as a vegetable vendor but after the injury he could not manage with the said work and shifted his occupation to a minor repairing work. Subsequently, he got married and become eligible to apply for getting Rs. **1.5 lakh as incentive provisioned by the government for the marriage of disabled**. As he is well aware of the provisions for a disabled person under different government programs, **he got a loan and started a photocopying shop** in his own village. Further, **he got Rs 1, 60,000 from District collector's fund under 'Biju Upakar Yojana' to renovate his house.**

8. Support of government to its SCI employee

In 2017 a 42-year-old male met with an accident and had an injury at the C4-C5 level. He is a government employee of Jharkhand state. Though he belongs to Jharkhand he traveled to Delhi for his treatment as he did not get proper treatment there. Being a government servant most of his expenditure towards treatment was reimbursed except the cost of air ambulance as the person is not entitled to get the cost of it**.** He has the support of his parents to look after his children. Presently he is under leave without pay.

9. The mental state of parents with a son who sustained spinal cord injury

In the year 2009, a 29-year-old person met with a road accident and sustained a T6 level of injury. Subsequently, he stopped his studies. His mother was his primary caregiver. His parents were so scared that **they were reluctant to allow their other son to drive a car or to take up driving as a profession**.

10**. Additional** s**tress because of social norms and beliefs**

In the year 2018 a 20-year-old girl fell from a height and injured at L1 level. She stopped her studies after her injury. Her treatment expenses are met by using family savings, loans from other sources as well as selling household assets. She has a Barthel's index of 80 which means she can lead an independent life. But she is still undergoing rigorous physiotherapy and occupational therapy with an aim to improve her functional ability. **She is very much worried that her existing functional inability would be major reason for rejection of marriage proposals from groom's side**.

11. **Proper planning to meet the financial crises**

A 29-year-old B. tech graduate fell from the terrace of his house in 2019 and sustained an injury at the C4-C5 level. His surgery was delayed by 10 days as the treatment facilities were not

available because of the FANI cyclone which hit Odisha coast in April 2019. He also underwent hospitalization for pressure sore during last one year. As both, the parents are permanent government servants and their income is very much essential in the present situation his brother left his job to take care of him. His treatment expenditure is being met with the family income, saving and loan from other sources.

12**. Employer‘s support after the accident of an employee**

in the year 2019 a 23 year old male while working in a private company sustained injury at L3 level when about 200 bundles of material fell on him during unloading. As the incident occurred while he was on duty **the company has taken the responsibility of bearing the expenditure towards treatment as well as living expenses**. Further the company sanctioned leave without pay. He has a Barthel’s index of 80 and he is expecting to go back to work soon. He is very thankful to his employer for extending his support during treatment.

13. **Government provision (ARMY) for unmarried children of people from armed forces.**

In the year 2012, a 22-year-old man fell from a height and sustained an injury at the T10 level. His father is army personnel and as per the army norms (Govt will take care of the unmarried child below the age of 24) **the expenditure towards the treatment was reimbursed by the government**. Being a sportsman, he is associated with sports companies for which he is getting a sponsorship. **He got wheelchair at free of cost from the government and spinal foundation of India.**

14. **Support of the family and acquaintances**

A 27-year-old male fell from electric pole after sustaining an electric shock in 2019 and had a T12 level injury. He is an employee in the private sector and he is currently under a paid leave. His sister, a nurse by profession, left her job to take care of his brother. Besides his sister, his

friends, colleagues and doctor friends of his father are extending their support for facilitating his treatment.

15. **Disability cannot be a barrier to achieve one's goal**

A 57-year-old person met with an accident in 1986 and sustained a T7-T8 level injury. He left his then private job and did master's in finance and Ph.D. in management. He is currently working is a faculty position in a reputed college. **He fractured both his legs last year during shifting from the wheelchair in an aircraft while traveling to New Delhi.** He had to undergo surgery and currently is under the rehabilitation of his legs. He is well aware of government policies and is availing tax relaxation benefits.

ANNEXURE II - BARTHEL INDEX

Introduction

Barthel index is a 10-item scale developed by Mahoney and Barthel in 1965. It was modified by Collin, Wade, Davies, and Horne in 1988. This index was developed to assess the functional ability in rehabilitation patients with stroke, spinal cord injury or other neuromuscular and musculoskeletal disorders. It is an internationally standardized ordinal scale used to measure performance in activities of daily living (ADL).

It has 10 variables like grooming, bathing, etc describing the activities of daily living and mobility. The higher score is associated with greater degree of independence to do the activities of daily living. The scoring should exclude the adaptations made to the physical environment.

Validity and sensitivity

The Barthel's index has fair to moderate reliability. The alpha internal consistency is 0.87 to 0.92.(Shah et al., 1989). Validity was found to be between 0.73 and 0.77 when compared with an index of motor ability for 976 stroke patients. (Wade and Hewer, 1987). Roy et al. found an inter-rater correlation of 0.99 and with patient self-report, 0.88 in stroke patients.

In Spinal cord injury patients internal consistency is 0.88 which is good(A. Küçükdev, 2000). The kappa level is more than 0.5 thus having a moderate level of inter rater agreement.

Inter class correlation was 0.77 for spinal cord injury.

Administration and Scoring

The MBI is 10-item ordinal scale (range: 0 to 100) with ratings for feeding, moving from wheelchair to bed and return, grooming, transferring to and from a toilet, bathing, walking on a

level surface(propelling a wheelchair if unable to walk), going up and down stairs, dressing, and continence of the bowels and bladder (Granger et al., 1979).

The scale is ordinal with each item scored in terms of the ability to perform a task i.e. 0= unable, 1=needs help, 2=independent.

The responses of each categories are defined and rated in scales (0,5), (0,5,10), (0,5,10,15) depending on the item. An overall scoring is done by adding the scores of each rating. Scores range from 0-100. The scores of 0-20 indicate "total" dependency, 21-60 indicate "severe" dependency, 61-90 indicate "moderate" dependency, and 91-99 indicates "slight" dependency(Shah et al., 1989).

Bowels 0 = Incontinent or needs enemas 1 = Occasional accident (1x/wk) 2 = Continent	**Transfer (bed to chair and back)** 0 = Unable, no sitting balance 1 = Major help (1 or 2 people), can sit 2 = Minor help (verbal or physical) 3 = Independent
Bladder 0 = Incontinent or needs enemas 1 = Occasional accident (1x/wk) 2 = Continent	**Mobility** 0 = Immobile 1 = Wheelchair independent (including corners) 2 = Walks with the help of 1 person (physical or verbal help) 3 = Independent (may use aid)
Grooming 0 = Needs help with personal care 1 = Independent (including face, hair, teeth, shaving	**Dressing** 0 = Dependent 1 = Needs help – can do ~ ½ unaided 2 = Independent (including buttons, zips, laces, etc.)
Toilet Use 0 = Dependent 1 = Needs some help 2 = Independent	**Stairs** 0 = Unable 1 = Needs help (verbal or physical) 2 = Independent
Feeding 0 = Unable 1 = Needs help, e.g. cutting 2 = Independent	**Bathing** 0 = Dependent 1 = Independent (bath or shower)

ANNEXURE III - WHO QOL BREF

Introduction

WHOQOL-BREF is a standardized scale developed by world health organization (WHO) to measure the quality of life of a person. It is a shorter version of the WHOQOL-10HOQOL-BREF version is convenient to use in clinical trials or research studies(Kumar and Gupta, 2016) or in studies where a brief assessment of quality of life is required. This tool can also be used for assessment and evaluation of a treatment method.

WHO-QOL BREF is most commonly and acceptable tool to measure quality of life after SCI(Hill et al., 2010). It consists of 26 questions based on a 5 point likart scale(Kumar and Gupta, 2016). One question is on over all perception of QOL of the person with SCI, second question is on perception of the person with SCI on their own health, and other 24 question are grouped under physical, psychological, social and environmental domain. There are seven questions under physical health domain, six questions under the psychological domain, three questions under social domain and eight questions under environmental domain.

Validity

WHOQOL-BREF is a sound and valid tool to assess quality of life under four domains(Skevington et al., 2004). The Cronbach's alpha range 0.74-0.78 and all the domains have good internal consistency.(Jang et al., 2004). The instrument has shown good differentiation, content validity and test-retest reliability(The Whoqol Group, 1998). The discriminant validity of the WHOQOL- BREF assessment in people with SCI was satisfactory. (Jang et al., 2004).

Administration and scoring

The four domains score is the individual's perception on QOL in that domain. Physical domains include questions on dependence on treatment, mobility, sleep, pain, ability to work and discomfort. Psychological domain has questions to assess self esteem, negative feelings, positive feelings, personal beliefs and memory. Social domain includes questions on personal relationships and social support. Environmental domain includes questions on financial condition, environment, surroundings and transport. The raw scores obtained are transformed to a range of 4-20 and 0-100. This scale is in positive direction and high score denotes high quality of life of that person.

ANNEXURE IV - INTERVIEW SCHEDULE

- Serial Number-
- Place of Recruitment- Government rehab center/ Private rehab center/Non institution
- Date of Interview-

SOCIO-DEMOGRAPHIC		
SL.NO	**QUESTION**	**RESPONSE**
1.	Date of birth of the participant	
2.	Gender of the participant	1. Male 2. Female 3. Others 4. Don't want to reveal
3.	What is the state of residence-(*name of the state the person resides)*	
4.	What is the place of residence(*place where patient usually resides)*	1. Urban 2. Rural
5.	What is your present marital status?	1. Never married 2. Married 3. Divorced/separated 4. Widow/widower
6.	Has your marital status changed in the past?	1. Yes 2. No
7.	What is it earlier?	1. Never married 2. Married 3. Divorced/separated 4. Widow/widower
8.	When did it change?	

SOCIO-ECONOMIC

9.	What is your highest attained (completed) educational status?	1. No formal education 2. Primary(1-5 class)pass/fail 3. Secondary (6-10 class) pass/fail 4. Higher secondary(11-12 class) pass/fail 5. Graduate- pass/ fail 6. Post graduate- pass/ fail

10. Please give me the details regarding your occupation-

BEFORE INJURY	code	AFTER INJURY	code
Unemployed	1	Unemployed	1
Regular employee private	2	Regular employee private	2
Regular employee government	3	Regular employee government	3
Contract employee	4	Contract employee	4
Daily wage earner	5	Daily wage earner	5
Self employed	6	Self employed	6
Student	7	Student	7

11. Family income-(*need to ask from patient, including self)*

I.	How many members are there in your family	
II.	How many earning members are there in your family?	

III. What is the occupation of your family members?(*codes as ques no-10)*

Sl.no	Relationship with patient	Occupation	
		Before injury	After injury

IV.	What is the total monthly income of your family members?	
V.	What is your family's monthly income from other sources- 1) Rent- 2) Agricultural land- 3) Shares- 4) From relatives-	
VI.	Total monthly income of the family-(*need to match IV+V)*	

12.	What is the type of your house you usually live-	1. Kaccha 2. Semi Kaccha 3. Pacca
13.	Who is the owner of the house in which you stay-	1. Self 2. Other family members 3. Others
14.	Do you or any of your family member have any government beneficiary cards on your name?(*from patient or care giver)*	1. Yes 2. No
15.	If Yes, which of these?	1. Ration card 2. BPL card 3. RSBY card(Rashtriya Swasthya Bima Yojna) 4. Anantyodaya card 5. Any other

16. Do you have a habit of consuming any of these?

INJURY STATUS

Sl.no	substance	Yes(1) No(2)	Since how long	Expenditure per day	Expenditure per month	Expenditure for 3 months
1	Alcohol					
2	Bidi/ Cigarettes					
3	Drugs/Khaini/bhang					
4	Any other					

17.	Date of injury	
18.	Cause of Injury	
19.	What is the type or severity of injury? (ASIA SCALE*)	1. A-Complete 2. B- Incomplete sensory 3. C-Incomplete motor 4. D-Incomplete motor 5. E- Normal

**A = Complete. No sensory or motor function is preserved in the sacral segments S4-5.*

B = Sensory Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5

C = Motor Incomplete. Motor function is preserved at the most caudal sacral segments for voluntary anal contraction, less than half of key muscle functions below the single NLI have a muscle grade ≥ 3.

D = Motor Incomplete. Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3.

E = Normal.

2	Level of injury*(will be taken from the case sheet or will be calculated by the interviewer who is a trained physiotherapist)*	

21. Functional ability-(*from patient or case sheet*)
(Dependent-1/Requires assistance-2/Independent-3)*(If '1' and '2'then fill collumn 'b' and 'c')*

	**Barthal index*	A	**B**	**C**
Sl.no	Function	Ability	Who helps	Time spent
1	Feeding			
2	Grooming			
3	Dressing upper body			
4	Dressing lower body			
5	Transfer			
6	Wheelchair propulsion			
7	Bowel and bladder			

22.	Did you need to undergo surgery immediately after the injury	1. Yes 2. No
23.	If yes, Did you undergo the surgery immediately?	1. Yes 2. No
24.	If No, why?	1. Waiting for stabilization 2. Opted for other methods 3. Financial reasons 4. Health facilities inaccessible 5. others Waiting for stabilization
25.	Was there any hospitalization (for any reason) in last 1 year?	1. Yes 2. No
26.	If yes causes-	
27.	Was there any hospitalization (for any reason) in the last 3 months?	1. Yes 2. No
28.	If yes, causes	

29. Who stayed with you and for how many days?

Sl no	Who stayed	No of days

EXPENDITURE

30.		Expenditure for hospitalization or hospitalizations in the last 3 months –	
31.		Total number of days of hospital stay in last 3 months	

32. What was your expenditure in last 1 month (*1 month for all, 3 month only if there was no expenditure for a particular thing in the last 1 month*)

I. Medicine-

Sl no	Medicines	Tablets per day	Tablets per week	Cost per 10 tabs	Tablets per month	Expenditure for 1 month	Expenditure for 3 months
1							
2							
3							
	Do you have a companion during your visit to the doctor?					1. Yes 2. No	

III. Consultation with Doctors-

Sl.no	Doctor	Fee per visit	Fee for investigation/ Procedures during visit	Duration per visit	No of visits in a month	No. of visits in 3 months	cost for 3 months
1	Neurologist						
2	Orthopedic						
3	Urologist						
4	Others						

IV. What is your expenditure on Rehabilitation

slno	Therapy name	fee per session	Other expenditure per session	Time needed per session	Cost for one session	No of sessions per week	Cost for 3 months
1	Physiotherapy						
2	Occupational therapy						

3	Psychotherapy						
4	Others						

V.	Do you have a companion during your rehabilitation sessions?	1. Yes- throughout the session 2. Yes- but only some part of the session 3. No
33.	Do you have urine incontinence?	1. Yes 2. No

34. If yes, how do you deal with it?

Sl no		Cost per one unit	No of units required per day	Expenditure per month	Expenditure in 3 months
1	Diaper				
2	Catheter				
3	Container				
4	Others				

35.	Do you use any assisted devises	1. Yes 2. No

Sl no	Where did you get it from?	How much did it cost or under what scheme?
1	Bought from shop	
2	Rented it	

3	Got it from rehab center or government	
4	Got it from a acquaintance	

If yes, then what-

36.	Did you make any changes in your diet post injury?	1. Yes 2. No

37. If yes, what are the changes?

changes	Expenditure per day	Expenditure per month	Expenditure for 3 months

38. Transport- How do you travel to following places

Place	Usual mode of transport	Did it change or get restricted post injury? Yes(1), No(2)	why did it change?	How do you travel now	Cost per travel	No of times you go in a month	Cost of travel in 3 months
To hospital							
To rehab center							
To work place							
Shopping							
Leisure(sports,movies, others)							
Others							

39.	Expenditure for a care taker (if any) per month-	

40.CO-MORBIDITIES

What are the other conditions apart from spinal cord injury for which you are undergoing treatment?

sl.no	Conditions	Yes (1) No(2)	Duration (in months)	Fee Per consultation in one month	Cost Investigation in one month	Medicines cost in one month	Total Cost for one month	Cost for last 3months
1	Diabetes							
2	Hypertension							
3	Urinary infection							
4	Respiratory infection							
5	Pressure ulcer							
6	Pain(Nocciceptive/ Neuropathic)							
7	Deep vein thrombosis							
8	Contractures							
9	Heterotrophic ossification							
10	Osteoporosis							
11	Autonomic Dysreflexia							
12	Spastic							

	Hypertonia							
13	Skeletal fracture							
14	Bladder and bowel dysfunction							

41	Did you make any modifications to your house post injury?	1. Yes 2. No
42.	If yes? What all modifications	1. Entrance 2. Steps 3. Toilets 4. Kitchen 5. Any other
43.	How much did the modification cost?	

44.<u>COPING STRATEGY</u>

Sl.no	Phase of injury	Total Expenditure	Source of funds	Proportion of total expenditure covered by these funds
1	Acute phase- Hospitalization, surgery , etc.		Self-savings	
			Family pool(no interest)	
			Loan(with interest)	
			Insurance	
			Sale of assets	
			Government program or assistance	
2	Rehabilitation phase		Self-savings	

			Family pool(no interest)	
			Loan(with interest)	
			Insurance	
			Sale of assets	
			Government program or assistance	
3	Maintenance – day to day expenses		Self – savings.	
			Family pool (no interest)	
			Loan (with interest)	
			Sale of assets	
			Insurance	
			Government program/ assistance	

45.	Are you aware of government schemes, facilities or policies for people with spinal cord injury?	1. Yes 2. No
46.	If yes, how did you come to know about it?	1. Health worker / professional told 2. Newspaper / Radio 3. Friends / neighbor. 4. NGO 5. Others
47.	What are the available government policies or facilities?	
48.	Did you avail any government facilities or programs?	1. Yes 2. No
49.	In what ways that policy or facility was/is helpful or beneficial to you?	

50.	Did you face any difficulties in availing them?	1. Did not have necessary documents. 2. Too long waiting time 3. Not available locally 4. Corruption 5. Others
51.	If No, Why didn't you avail?	
52.	What other things do you think the government could do to help you?	
53.	How did you try to manage your finances or compensate for the extra expenditure apart from the answers given above?	

54. From the date of injury till date what are the treatment procedures did you undergo?

Sl. no	Treatment procedures	Cause for undergoing treatment	Duration of treatment

WHO QOL BREF QUESTIONNAIRE

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What isyour**gender**? Male Female

What is you **dateofbirth**? _____ /_____/_____

Day /Month /Year

What is the highest **education**you received? None atall

Primary school Secondary school Tertiary

What is your**maritalstatus**? Single Separated

Married Divorced

Livingasmarried Widowed

Are youcurrently**ill**? Yes No

Ifsomethingiswrongwithyourhealthwhatdoyouthinkitis?

_____illnes

s/problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Pleasekeepinmindyourstandards,hopes,pleasuresandconcerns.Weaskthatyouthinkaboutyourlife**inthela st two weeks.** For example, thinking about the last two weeks, a question mightask:

	Do you get the kind of support from others that you need?	Not at all 1	Not much 2	Moderate ly 3	A great deal 4	Complet ely 5

Youshouldcirclethenumberthatbestfitshowmuchsupportyougotfromothersoverthelasttwoweeks.Soyou would circle the number 4 if you got a great deal of support from others asfollows.

	Do you get the kind of support from others that you need?	Not at all 1	Not much 2	Moderate ly 3	A great deal 4	Complet ely 5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks

Please read each question, assess your feelings, and circle the number on the scale for each question

that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5

13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	poor nor good	Good	Very good
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

PARTICIPANT INFORMATION SHEET

My name is Dr. K. Shruti Lekha(BPT) and I am a student of Masters of Public Health (MPH) at AMCHSS, SCTIMST, Trivandrum, and Kerala. I am proposing to do my MPH dissertation on "The economic burden of spinal cord injury and the coping strategies among the spinal cord injury patients and their families – an exploratory study". This study aims to find out what the Economic burden of spinal cord injury is and how the patients and families deal with it. By costs I mean the costs related to your treatment, the transport and food-related costs during treatment, the loss of wages during the treatment and subsequent to the injury and any change in the quality of your life after injury.

If you agree to participate in the study, I would ask questions related to the spinal cord injury and regarding income, medical and non-medical expenditure, quality of life and coping strategies. The questions would be asked to you in private. Answering these questions will take about 45 minutes of your time.

Your participation in this survey is voluntary. No compensation will be paid to you for participating in this study. You can also opt not to take part. You can choose not to answer a particular question at any time without giving any reason. Your rights to health care in the government hospitals or any other rights will not be affected by it. During the study, I will be assessing your awareness and utilization of various government schemes. If it is revealed that you are not aware of or able to access any of these schemes, I will refer you to the institutional social work department that will help you with the same. Apart from this participating in this survey may not have special benefit for you but it may benefit the community as a whole, as it may help us to understand the problem and its potential solutions. After analyzing the results, it will be shared with the participants, rehabilitation centers and the health officials, so that the right measures can be taken to decrease the economic burden among spinal cord injury patients.

The collected information will be between you, me and my guide Dr. Rakhal Gaitonde, Professor, Achuta Menon Center for Health Science Studies. Your name won't be written in this form. A code will be used instead. Only I will know the key to this code and keep it confidentially. The codes will be destroyed as the dissertation is over.

If you have any doubts regarding the research, you can contact me at my number 9439487691 and E.mail i.d-kslekha@sctimst.ac.in Or Dr. Mala Ramanathan, IEC Member-Secretary, at the number - 0471-2524234 And E.mail i.d- iec.mem.sec@sctimst.ac.in .

If you are agreeing to participate, we will proceed now.

Signature /Thumb impression of the participant

Date:

Name of the interviewer

Dr. K. Shruti Lekha(BPT)

Ph.No- 9439487691
Email-
lekha.shruti@gmail.com

CERTIFICATE OF CONSENT

I have read all the provided information, or it has been read to me and I understand the content of the information sheet. I have had the opportunity to clear my doubts about it and I have been answered the questions to my satisfaction. I voluntarily give my consent to participate in the study "The Economic burden of spinal cord injury and the coping strategies among the spinal cord injury patients and their families – an exploratory study" and I understand that I have the right to withdraw from the study at any time without affecting my further medical care in any way.

I give my consent to share the contents of the interview with the guide

Name of the interviewer
Dr. K.Shruti Lekha(BPT)

Name of the study participant

Signature of the interviewer

Signature/thumb impression of the study participant

ANNEXURE V - _INTERVIEW SCHEDULE

- Serial Number-
- Place of recruitment- Government rehab center/ Private rehab center/Non-institutional
- Date of Interview-

କ୍ରଃ ନ	ପ୍ରଶ୍ନ	ଉତ୍ତର
1.	ଅଂଶଗ୍ରହଣକାରୀଙ୍କଜନ୍ମତାରିଖ	
2.	ଅଂଶଗ୍ରହଣକାରୀଙ୍କଲିଙ୍ଗ	5. ପୁରୁଷ 6. ସ୍ତ୍ରୀ 7. ଅନ୍ୟାନ୍ୟ 8. .ପ୍ରକାଶକରିବାକୁରାଜିନୁହନ୍ତି
3.	ଆପଣବସବାସକରୁଥିବାରାଜ୍ୟକଣ?	
4.	ଆପଣବସବାସକରୁଥିବାଅଞ୍ଚଳକଣ?	3. ସହରାଞ୍ଚଳ 4. ଗ୍ରାମାଞ୍ଚଳ
5.	ଆପଣଙ୍କବବୈାହିକସ୍ଥିତିକଣ?	5. ଅବିବାହିତ 6. ବିବାହିତ 7. ଅଲଗାହବୋ/ଛାଡପତ୍ରହେ·ାଇଥିବା 8. ବିଧବା /ବିପତ୍ନୀକ
6.	ଆପଣଙ୍କବବୈାହିକସ୍ଥିତିରବୈଗତଦିନରକୈଛିପରିବର୍ତ୍ତନହେ·ାଇଥିଲାକି?	3. ହଁ 4. ନା
7.	ଅତୀତରବେବୈାହିକସ୍ତିତିକଣଥିଲା?	5. ଅବିବାହିତ 6. ବିବାହିତ 7. ଅଲଗାହବୋ/ଛାଡପତ୍ରଦବୋ 8. ବିଧବା /ବିପତ୍ନୀକ
8.	ଏହିପରିବର୍ତ୍ତନକବେହେଲେ।	

ସାମାଜିକ-ଆର୍ଥିକସ୍ଥିତି

9.	ଆପଣଙ୍କରସର୍ବୋଚ୍ଚଶିକ୍ଷାଗତଯୋଗ୍ୟତାକଣ?	1. କୌଣସିଅନୁଷ୍ଠାନିକଶିକ୍ଷାନାହିଁ 2. ପ୍ରାଥମିକ (୧ରୁ୫) 3. ମାଧ୍ୟମିକ(୬ରୁ୧୦) 4. ଉଚ୍ଚମାଧ୍ୟମିକ (୧୧ରୁ୧୨) 5. ସ୍ନାତକ 6. ସ୍ନାତୋକତ୍ତର

10. ଆପଣଙ୍କରବୃତ୍ତିଗତବିଷୟରମେତସୂଚନାଦବେକି?

ଘଟଣାପୂର୍ବରୁ	Code	ଘଟଣାପରେ	code
ବରେୋଜଗାର	1	ବରେୋଜଗାର	1
ନିୟମିତଘରୋଇକର୍ମଚାରୀ	2	ନିୟମିତଘରୋଇକର୍ମଚାରୀ	2
ନିୟମିତସରକାରୀକର୍ମଚାରୀ	3	ନିୟମିତସରକାରୀକର୍ମଚାରୀ	3
ଠିକାକର୍ମଚାରୀ	4	ଠିକାକର୍ମଚାରୀ	4
ଦିନମଜୁରିଆ	5	ଦିନମଜୁରିଆ	5
ସ୍ୱରୋଜଗାର	6	ସ୍ୱରୋଜଗାର	6
ବିଦ୍ୟାର୍ଥୀ	7	ବିଦ୍ୟାର୍ଥୀ	7

11. <u>ପରିବାରଆୟ (ଚିକିତ୍ସାଧୀନବ୍ୟକ୍ତିଓଅନ୍ୟପରିବାରରସଦସ୍ୟମାନଙ୍କର)</u>

VII.	ପରିବାରରକେତେଜେଣସଦସ୍ୟରହନ୍ତି	
VIII.	ଆପଣଙ୍କପରିବାରରକେତେଜେଣରୋଜଗାରକ୍ଷମସଦସ୍ୟଅଛନ୍ତି?	

IX. ପାରିବାରସଦସ୍ୟମାନଙ୍କରବୃତ୍ତିକଣ?*codes as ques no-10)*

କ୍ରଂନ	ରୋଗୀସହିତସମ୍ପର୍କ	ବୃତ୍ତି	
		ଆଘାତପୂର୍ବରୁ	ଆଘାତପରେ

X.	ଆପଣଙ୍କପରିବାରସଦସ୍ୟମନକରମୋଟାମୋଟିମାସିକରୋଜଗାରକତେ?	

XI.	ଆପଣଙ୍କପରିବାରରମାସିକରେ·ାଜଗାରରଅନ୍ୟପନ୍ଥାକଣ 5) ଘରଭଡା 6) ଚାଷଜମି 7) ଅଂଶିଦାରରୁ 8) ପରିବାରବର୍ଗଙ୍କଠୁ	
XII.	ପରିବାରରସର୍ବମରେ·ାଟମାସିକରେ·ାଜଗାର	

12.	ଆପଣରହୁଥିବାଘରକଉଁପ୍ରକାରରଅଟେ	1. କଚ୍ଚାଘର 2. ଆଂଶିକକଚ୍ଚାଘର 3. ପକ୍କାଘର
13.	ଆପଣରହୁଥିବାଘରରମାଲିକକିଏ?	1. ନିଜେ 2. ଅନ୍ୟପରିବାରସଦସ୍ୟ 3. ଅନ୍ୟସ୍ଥଲରେ·ାକ
14.	ଆପଣକିମ୍ବାଆପଣଙ୍କପରିବାରରକେୌଣସିବ୍ୟକ୍ତିଙ୍କନାମରସେରକାରଙ୍କ ରହିତାଧିକାରୀକାର୍ଡଅଛିକି ?	1. ହଁ 2. ନା
15.	ଯଦିହଁକଉଁଟିଅଛି?	1. ରସେନକାର୍ଡ 2. ବିପିଏଲକାର୍ଡ 3. ଆରଏସବିୱାଇକାର୍ଡ 4. ଅନ୍ତରେ·ାଦ୍ଧବ୍ୟକାର୍ଡ 5. ଅନ୍ୟାନ୍ୟ

16. ଆପଣନିମ୍ନରଥିବାନିଶାଦ୍ରବ୍ୟସବେନକରିବାରଅେଭ୍ୟସ୍ତକି?

କ୍ର: ନ	ପଦାର୍ଥ	ହଁ(1), ନା(2)	କତେଦିନରୁ	ଦନୈିକ ଖର୍ଚ	ମାସିକଖର୍ଚ	ତିନିମାସିରଖର୍ଚ
1	ମଦ					
2	ବିଡି/ସିଗାରଟେ					
3	ଗୁଟୁକା/ଖଇନି/ ଭାଙ୍ଗ					

4	ଅନ୍ୟାନ୍ୟ					

17.	ଆଘାତପାଇଥିବାତାରିଖ	
18.	ଆଘାତପାଇବାର କାରଣ	
19.	ଆଘାତର ତୀବ୍ରତା କିପରକାରର ଅଟେ? (ASIA SCALE*)	6. A-Complete 7. B- Incomplete sensory 8. C-Incomplete motor 9. D-Incomplete motor 10. E- Normal

ଆଘାତ ସ୍ଥିତି

**A = Complete. No sensory or motor function is preserved in the sacral segments S4-5.*
B = Sensory Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5
C = Motor Incomplete. Motor function is preserved at the most caudal sacral segments for voluntary anal contraction, less than half of key muscle functions below the single NLI have a muscle grade ≥ 3.
D = Motor Incomplete. Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3.
E = Normal.

20.	ଆଘାତରସ୍ତରକଣ?	

21. କାର୍ଯ୍ୟକ୍ଷମରସାମର୍ଥ୍ୟ(ଚିକିତ୍ସାଧୀନବ୍ୟକ୍ତିକିମ୍ବାଚିକିତ୍ସାନଥିପତ୍ରରୁ)
ନିର୍ଭରଶୀଳ -୧/ ସହାୟକଆବଶ୍ୟକ -୨/ ସ୍ୱାଧୀନ-୩(୧ଓ୨କ୍ଷତ୍ରେରବୈଓସିପୂରଣକରିବେ)।

	**Barthal index*	A	b	C
Sl.no	କାର୍ଯ୍ୟକ୍ଷମ	ସାମର୍ଥ୍ୟ	କିଏସାହାର୍ଯ୍ୟକରନ୍ତି	କତେସେମୟକରନ୍ତି
1	ଖାଇବା			
2	ନିତ୍ୟକର୍ମ			
3	ଶରୀରରଉପରଭାଗପରିଷ୍କାରକରିବା			
4	ଶରୀରରତଳଭାଗପରିଷ୍କାରକରିବା			
5	ସ୍ଥାନାନ୍ତର			
6	ହୁଇଲଚୟୋରରବ୍ୟବହାର			
7	ଅନ୍ତନାଳୀଓମୂତ୍ରାଶୟ			

22.	ଆଘାତପାଇବାସଙ୍ଗସେଙ୍ଗଅେସ୍ତ୍ରେ·ାପଚାରଆବଶ୍ୟକତାହେ·ାଇଥିଲାକି?	3. ହଁ 4. ନା
23.	ଯଦି ହଁ, ଆପଣସଙ୍ଗସେଙ୍ଗଅେସ୍ତ୍ରେ·ାପଚାରକରାଇଥିଲେକି?	3. ହଁ 4. ନା
24.	ଅସ୍ତ୍ରେ·ାପଚାରସଙ୍ଗସେଙ୍ଗନେକରାଇବାରକାରଣକଣ?	1. ଅନ୍ୟପଦ୍ଧତିପାଇଁଅପକ୍ଷା 2. ଅନ୍ୟକୌଣଶିଉପଚାର 3. ଆର୍ଥିକକାରଣ 4. ଚିକିତ୍ସାଳୟଅନୁପଲବ୍ଧି 5. ଅନ୍ୟାନ୍ୟ
25.	ଗଲାଏକବର୍ଷଭିତରଚେିକିତ୍ସାଳୟରଚେିକିତ୍ସାଧୀନଥିଲେକି?	1. ହଁ 2. ନା
26.	ଯଦିହଁ,କାରଣକଣ?	
27.	ଗଲାତିନିମାସଭିତରେ(ଯକେୌଣସିକାରଣରୁ) ଚିକିତ୍ସାଳୟରଚେିକିତ୍ସାଧୀନଥିଲେକି?	1. ହଁ 2. ନା
28.	ଯଦିହଁ,କାରଣକଣ'?	

29. ଅପଣଙ୍କସହକିଏଥିଲାଓକତେଦେିନ?

କିଏ ରହିଥିଲେ	କତେଦେିନ

30.	ଗଲାତିନିମାସଭିତରଚେିକିତ୍ସାବାବଦରହେ·ାଇଥିବାଖର୍ଚ୍ଚ	
31.	ଗଲାତିନିମାସଭିତରକେତେଦେିନଚିକିତ୍ସାଳୟରରେହିଥିଲେ	

32. ଗଲାମାସରକେତେଖେର୍ଚହେ·ାଇଥିଲା?(ଯଦିଗଲାମାସରକେୈଣସିବାବଦରକେିଛିଖର୍ଚହେ·ାଇନାହିଁତାହଲେଗେତତିନି ମାସରଖର୍ଚନିଆହବେ।

I. ଔଷଧ

Sl No	ଔଷଧ	ଦନୈିକବଟିକା	1ଟ6/10ଟା ବଟିକା ର ଖର୍ଚ	ସାପ୍ତାହିକବଟିକା	ମାସିକବଟିକା	ମାସିକଖର୍ଚ	ତିନିମାସରଖର୍ଚ
1							
2							
3							

II	ଡାକ୍ତରଙ୍କସହିତପରାମର୍ଶକୁଗଲାବଳେଆେପଣଙ୍କସହିତକିଏଯାନ୍ତିକି?	1. ହଁ 2. ନା

III. ଡାକ୍ତରଙ୍କସହିତପରାମର୍ଶ

Sl.no	ଡାକ୍ତର	ଗ6·ାଟିଏ ସାକ୍ଷାତ୍କାରପାଇଁ ଖର୍ଚ	ସାକ୍ଷାତ୍କାରସମ୍ଭରହେଉଥିବା ପରୀକ୍ଷାରଖର୍ଚ	ପ୍ରତ୍ଯକେସା କ୍ଷାତ୍କାରପାଇଁଆବଶ୍ଯକସମଯ୍ଭ	ମାସକୁକେତ6·ାଟିସାକ୍ଷାତ୍କାର	ତିନିମାସର6 କତେ6·ାଟିସାକ୍ଷାତ୍କାର	ତିନିମାସରଖର୍ଚ
1	ସ୍ନାଯୁବିଶଷେଜ୍ଞ						
2	ଅସ୍ଥିବିଶଷେଜ୍ଞ						
3	ଯୁରେ·ାଲେ·ାଜିଷ୍ଟ						
4	ଅନ୍ଯାନ୍ଯ						

IV. ଥଇଥାନବାବଦରଆେପଣଙ୍କରକକତେଖେର୍ଚହେ·ାଇଛି?

slno	ଚିକିତ୍ସାପଦ୍ଧତିରନାମ	ପ୍ରତ୍ଯକେଅଧିବଗେନରମୂଲ୍ଯ	ପ୍ରତ୍ଯକେଅଧିବଗେନରଅନ୍ଯାନ୍ଯଖର୍ଚ	ପ୍ରତ୍ଯକେଅଧିବଗେନପାଇଁଆବଶ୍ଯକସମଯ୍ଭ	ଗ6·ାଟିଏଅଧିବଗେନପାଇଁଖର୍ଚ	ସପ୍ତାହରେ6 କତେ6·ାଟିଅଧିବଗେନ	ତିନିମାସରଖର୍ଚ
1	ବ୍ଯାଯମପଦ୍ଧତି (physiotherapy)						
2	ଅକୁପସେ·ାନାଲଥରୋପି						
3	ମନସ୍ତାତ୍ତ୍ବିକପଦ୍						

	ଧତି						
4	ଅନ୍ୟାନ୍ୟ						
V.	ଥଇଥାନସମସ୍ତରଥୋପଣଙ୍କସହିତକିଏରହନ୍ତିକି?				1. ହଁପୁରାଅଧିବଗେନ 2. ହଁକିନ୍ତୁଅଧିବଗେନରକିଛିସମସ୍ୟ 3. ନା		
33.	ଆପଣଙ୍କରପରିସ୍ରାରତେ।କିନପରିବାରଦୁର୍ବଳତାଅଛିକି?				1. ହଁ 2. ନା		

34. ଯଦିହଁତାହଲେକେପରିସମାଧାନକରନ୍ତି

Sl no	ଜିନିଷ	ଗତେ।ଟିଏ ଦିନର ଖର୍ଚ	ଗତେ।ଟିଏମାସରଖର୍ଚ	ତିନିମାସରଖର୍ଚ
1	ଡାଇଫର			
2	କଥୈଟେର			
3	ବତେ।ତଲ			
4	ଅନ୍ୟାନ୍ୟ			

35.	ଆପଣକିଛିସହକାରୀଜନ୍ତ୍ରବ୍ୟବହାରକରିଛନ୍ତିକି?	1. ହଁ 2. ନା

ଯଦିହଁ,ତାହଲେକେଣ?

	ସହକାରୀଜନ୍ତ୍ରକଉଁଠୁପାଇଲ।	ଏହାରଦାମକତେଓକଉଁଯତେ।ଜନାରୁପାଇଲତେ
1	ଦତେ।କାନରୁକିଣିଲି	
2	ଭଡାରଥୋଣିଲି	
3	ଥଇଥାନକନ୍ଦ୍ରରୁ / ସରକାରଙ୍କଠୁ	
4	ଚିହ୍ନଲତେ।କଙ୍କଠୁ	

36.	ଆଘାତପରତେ ଆପଣଆପଣଙ୍କଖାଦ୍ୟରକୌଣ୍ଚିପରିବର୍ତନହତେ।ଇଛିକି	ହଁ ନା

37. ଯଦିହଁକିପ୍ରକାରପରିବର୍ତ୍ତନ

ପରିବର୍ତ୍ତନ	ଦନୈିକଖର୍ଚ	ମାସିକଖର୍ଚ	ତିନିମାସକୁଖର୍ଚ

38. ଯାତାୟାତ: ନିମ୍ନରଦେିଆଯାଇଥିବାଜାଗାକୁଆପଣକିପରିଯାଉଥିଲେ

ସ୍ଥାନ	ସମାନ୍ୟ ଯାତାୟାତ କଣ?	ଆଘାତପରକୈଛିପରିବର୍ତ୍ତନହେ·ାଇଛିନାକ ମିଛି ହଁ (1)ନା(2)	ବଦଳିବାର କରଣ କଣ?	ଏବେ ଆପଣ କିପରି ଯାତାୟାତକରୁଛନ୍ତି?	ଥରକର ଖର୍ଚ	ମାସରେ କେତେଥରଯାନ୍ତି	ତିନିମାସରଯାତାୟାତଖର୍ଚ କେତେ
ଚିକିତ୍ସାଳୟକୁ							
ଥଇଥାନକନେ୍ଦ୍ରକୁ							
କାମକରୁଥିବାଜାଗାକୁ							
ବଜାରଗଲାବେଳେ							
ଅବସରସମୟରେ(ସିନେମା,ଖେଳେଇତ୍ୟାଦି)							
ଅନ୍ୟାନ୍ୟ							

39.	ସହାୟକବ୍ୟକ୍ତିବାବଦରହେ·ାଇଥିବାମାସିକଖର୍ଚ କେତେ?	

40. <u>ଅନ୍ୟାନ୍ୟଅସୁସ୍ଥତା</u>

ଏସସିଆଇଛଡାଅନ୍ୟକେଉଁଅସୁସ୍ଥତାପାଇଁଆପଣଚିକିତ୍ସାଧୀନଅଛନ୍ତି।

sl.no	ଅସୁସ୍ଥତା	ହଁ (1)(2) ନା	ସମୟଅବଧି	ଗେ·ାଟିଏ ମାସରପେରାମର୍ଶଖର୍ଚ	ମାସକୁପରୀକ୍ଷାଖର୍ଚ	ମାସକୁଔଷଧଖର୍ଚ	ମାସକୁମେ·ାଟଖର୍ଚ	ତିନିମାସକୁମେ·ାଟଖର୍ଚ
1	ମଧୁମେହ							
2	ଉଚ୍ଚରକ୍ତଚାପ							
3	ମୂତ୍ରମାର୍ଗସଂକ୍ରମିତ							
4	ଶ୍ୱାସନଳୀସଂକ୍ରମିତ							
5	ଚାପଜନିତଘା							
6	ସ୍ନାୟୁଜନିତଯନ୍ତ୍ରଣା							

7	ଧମନୀରରକ୍ତଜମାଟ ବନ୍ଧିବା							
8	କଣ୍ଟ୍ରାକଚର							
9	ହଟ୍ରେ।ଟ୍ରେ।ଫି କଓଗିଫିକସେ।ନ							
10	ହାଡଦୁର୍ବଳ							
11	ଅଟେ।ମଟିକଡାଇସ ରଫ୍ଲକେସିଆ							
12	ସ୍ପାଷ୍ଟିକହାଇପର ଟେ।ନିଆ							
13	ହାଡଭଙ୍ଗା							
14	ମୂତ୍ରାଶୟଜନିତଅସୁସ୍ଥତା							

41.	ଆଘାତପରଘେରକେଛିପରିବର୍ତ୍ତନକରାଯାଇଛିକି	1. ହଁ 2. ନା
42.	ଯଦିହଁ,କିପ୍ରକାରରପରିବର୍ତ୍ତନ?	1. ପ୍ରବେଶଦ୍ୱାର 2. ପାହାଚ 3. ଶୌଚଳସ୍ଥ 4. ରେ।ଷଇେଘର 5. ଅନ୍ୟାନ୍ୟ
43.	ପରିବର୍ତ୍ତନପାଇଁକେତେଖର୍ଚହେ।ଇଥିଲା?	

44. ମୁକାବିଲାକରିବାରକୌଶଳ

କ୍ର: ନ	ଆଘାତରପ୍ରଥମସେ।ପାନ	ମେ।ଟଖର୍ଚ	ଅନୁଦାନରଉତ୍ସ	ଆସିଥିବାଅନୁଦାନ ମେ।ଟଖର୍ଚର କେତେଅନୁପାତଥିଲା
1	ଗୁରୁତରପର୍ଯ୍ୟାୟ(ଚିକିତ୍ସାଳସ୍ଥରଭେର୍ତ୍ତିହବେ।,ଅସ୍ତ୍ରେ।ପଚାର)		ସ୍ୱବସଞ୍ଚଯ	
			ପରିବାରରସଞ୍ଚସ୍ଥ	
			ସୁଧରଧୋରଆଣି	
			ବୀମା	
			ସମ୍ପତ୍ତିବିକ୍ରି	

			ସରକାରୀସହାୟତା	
2	ଥଇଥାନପର୍ଯ୍ୟାୟ		ନିଜସଞ୍ଚୟରୁ	
			ପରିବାରରସଞ୍ଚୟରୁ	
			ସୁଧରଧୋରଆଣି	
			ବୀମା	
			ସମ୍ପତ୍ତିବିକ୍ରି	
			ସରକାରୀସହାୟତା	
3	ଦନୈନ୍ଦିନଭରଣପୋଷଣରଖର୍ଚ		ସ୍ୱସଞ୍ଚୟ	
			ପରିବାରସଞ୍ଚୟରୁ	
			ସୁଧରଧୋରଆଣି	
			ସମ୍ପତ୍ତିବିକ୍ରି	
			ବୀମା	
			ସରକାରୀସହାୟତା	

45.	ଏସସିଆଇରପୌଡିତମାନଙ୍କପାଇଁସରକାରଙ୍କତରଫରୁଦିଅଯାଉଥିବସୁବିଧାସୁଯୋଗ ଓଅନ୍ୟାନ୍ୟକାର୍ଯ୍ୟକ୍ରମବିଷୟରଜୋଣିଛନ୍ତିକି?	1. ହଁ 2. ନା
46.	ଯଦିହଁ,ଆପଣକେମିତିଜାଣିଲେ?	1. ସ୍ୱାସ୍ଥ୍ୟକର୍ମୀ/ ସହେିବୃତ୍ତିରବ୍ୟକ୍ତି 2. ଖବରକାଗଜ/ରେଡିଓ 3. ସାଙ୍ଗ/ ସାଇପଡିଶା 4. ବସେରକାରୀସଂସ୍ଥା 5. ଅନ୍ୟାନ୍ୟ

47.	ସରକାରଙ୍କତରଫରୁଏସସିଆଇରପୌଡିତମାନଙ୍କପାଇଁକରାଯାଇଥିବାଯେ।ଜନାଓସୁବିଧାଗୁଡିକକଣ?	
48.	ଆପଣସରକାରଙ୍କଦ୍ୱାରାଦିଆଯାଉଥିବାସୁବିଧାଗୁଡିକରସାହାର୍ଯ୍ୟନଇେଛନ୍ତିକି?	1. ହଁ 2. ନା
49.	ସରକାରଙ୍କରପ୍ରଚଳିତଯେ।ଜନାଓସୁବିଧାଗୁଡିକଦ୍ୱାରାଆପଣକିପରିଉପକୃତହେ।ଇଛନ୍ତି?	
50.	ସହେିସୁବିଧାପାଇବାରକେେୈଣସିଅସୁବିଧାରସମ୍ମୁଖିନ୍ନହେ।ଇଛନ୍ତି ?	1. ଆବଶ୍ୟକୀୟକାଗଜପତ୍ରନାଥିବାରୁ। 2. ବହୁତସମୟଅପକ୍ଷୋକରିବାକୁପଡେ। 3. ଆଞ୍ଚଳିକସ୍ତରରେପଲବ୍ଧନୁହଁେ 4. ଦୁର୍ନିତି 5. ଅନ୍ୟାନ୍ୟ
51.	ଯଦିନା,ସସେବୁରସୁଯେ।ଗକାହିଁକିନଲେନୋହିଁ?	
52.	ସରକାରଙ୍କଠୁଆଉକିପ୍ରକାରରସାହାର୍ଯ୍ୟଆପଣମାନଙ୍କୁମିଳିପାରିବବେ।ଲିଭାବୁଛନ୍ତି?	
53.	ଉପରଦେିଆଯାଇଥିବାତଥ୍ୟଛଡାଅନ୍ୟକେଉଁକେଉଁଉପାୟରଆେପଣଆପଣଙ୍କରଅତିରିକ୍ତଖର୍ଚବହନକରିବାରସେମର୍ଥ ହେ।ଇଥିଲେ।	

54. ଘଟଣାଦିନରୁଆଜିପର୍ଯ୍ୟନ୍ତକେଉଁକେଉଁଚିକିତ୍ସାପଦ୍ଧତିରଚେିକିତ୍ସତହେ।ଇଛନ୍ତି?

କ୍ର: ନ	ଚିକିତ୍ସାପଦ୍ଧତି	ଚିକିତ୍ସାହବୋରକାରଣ	ଚିକିତ୍ସାଅବଧି

ବିଶ୍ୱ ସ୍ୱାସ୍ଥ୍ୟ ସଂଗଠନ

ହୁକ୍ୱାଲ-ବ୍ରିଫ / WHOQOL-BREF

ଜୀବନ ଗୁଣମାନ ଅନୁସନ୍ଧାନ ଓ ଉନ୍ନୟନ ପ୍ରତିଷ୍ଠାନ, ଭୁବନେଶ୍ୱର, ୭୫୧୦୧୮

ନିମ୍ନଲିଖିତ ପ୍ରଶ୍ନସବୁ ଆପଣଙ୍କ ଜୀବନର ଗୁଣମାନ (କ୍ୱାଲିଟି), ସ୍ୱାସ୍ଥ୍ୟ ଏବଂ ଜୀବନର ଅନ୍ୟାନ୍ୟ କ୍ଷେତ୍ରରେ ଆପଣ କିପରି ଅନୁଭବ କରୁଛନ୍ତି ସେସବୁ ବିଷୟରେ । ମୁଁ ଆପଣଙ୍କୁ ପ୍ରତ୍ୟେକ ପ୍ରଶ୍ନ ସହିତ ଏହାର ମନୋନୀତ ଉ୍ତରଗୁଡିକ ମଧ୍ୟ ପଢ଼ି ଶୁଣେଇବି । ଦୟାକରି, ଯେଉଁ ଉ୍ତର ଆପଣଙ୍କ ପାଇଁ ସବୁଠାରୁ ଉପଯୁକ୍ତ ମନେ ହେଉଥିବ ତାକୁ ବାଛନ୍ତୁ । କୌଣସି ପ୍ରଶ୍ନର ଉ୍ତର ସମ୍ପର୍କରେ ଆପଣ ଅନିଶ୍ଚିତ ହେଲେ, ପ୍ରଥମେ ଚିନ୍ତା କରିଥିବା ଉ୍ତର, ଅଧିକାଂଶ ସମୟରେ ସବୁଠାରୁ ଉ୍ତମ ବିବେଚିତ ହୋଇଥାଏ ।

ଦୟାକରି ଆପଣଙ୍କର ଷ୍ଟାଣ୍ଡାର୍ଡ (ଜୀବନର ସ୍ତର), ଆଶା, ଆନନ୍ଦ ଓ ଚିନ୍ତା ସବୁକୁ ବିଚାର କରନ୍ତୁ । ଆପଣ ଆପଣଙ୍କ ଜୀବନର ଗଲା ଚାରି ସପ୍ତାହ ଉପରେ ଆଧାର କରି ଏ ପ୍ରଶ୍ନସବୁର ଉ୍ତର ଦିଅନ୍ତୁ ।

		ବହୁତ ଖରାପ	ଖରାପ	ଖରାପ ନୁହେଁ କି ଭଲ ନୁହେଁ	ଭଲ	ବହୁତ ଭଲ
୧	ଆପଣଙ୍କ ଜୀବନର ଗୁଣମାନ (କ୍ୱାଲିଟି) କେତେ ବୋଲି ଭାବୁଛନ୍ତି ?	୧	୨	୩	୪	୫

		ବହୁତ ଅସନ୍ତୁଷ୍ଟ	ଅସନ୍ତୁଷ୍ଟ	ଅସନ୍ତୁଷ୍ଟ ନୁହେଁ କି ସନ୍ତୁଷ୍ଟ ନୁହେ	ସନ୍ତୁଷ୍ଟ	ବହୁତ ସନ୍ତୁଷ୍ଟ
୨	ନିଜର ସ୍ୱାସ୍ଥ୍ୟକୁ ନେଇ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫

ନିମ୍ନଲିଖିତ ପ୍ରଶ୍ନସବୁ, କିଛି ବିଷୟ ଗଲା ଚାରି ସପ୍ତାହ ଭିତରେ ଆପଣ କେତେ ଅନୁଭବ କରିଛନ୍ତି ତାହା ସମ୍ପର୍କରେ ।

		ଆଦୌ ନୁହେଁ	ଅଳ୍ପ	ମଧ୍ୟମ ପରିମାଣରେ	ଅଧିକ	ବହୁତ ଅଧିକ ପରିମାଣରେ
୩	ଆପଣଙ୍କର ଯେଉଁ କାମ କରିବା ଦରକାର ସେଥିରେ ଶାରୀରିକ ଯନ୍ତ୍ରଣା କେତେ ବାଧା ସୃଷ୍ଟି କରୁଛି ବୋଲି ଆପଣ ଭାବୁଛନ୍ତି ?	୫	୪	୩	୨	୧
୪	ଜୀବନର ନିତିଦିନିଆ କାମ କରିବା ପାଇଁ ଆପଣ କେତେ ପରିମାଣରେ କୌଣସି ଡାକ୍ତରୀ ଚିକିତ୍ସା ଆବଶ୍ୟକ କରନ୍ତି ?	୫	୪	୩	୨	୧
୫	ଆପଣ ଜୀବନକୁ କେତେ ଉପଭୋଗ କରୁଛନ୍ତି ?	୧	୨	୩	୪	୫
୬	ନିଜ ଜୀବନକୁ ଆପଣ କେତେ ସାର୍ଥକ ବୋଲି ଅନୁଭବ କରୁଛନ୍ତି ?	୧	୨	୩	୪	୫

		ଆଦୌ ନୁହେଁ	ଅଳ୍ପ	ମଧ୍ୟମ ଭାବରେ	ଅଧିକ	ବହୁତ ଅଧିକ
୭	ମନ ସ୍ଥିର (ଏକାଗ୍ରତା) ରଖିବାରେ ଆପଣ କେତେ ସକ୍ଷମ ?	୧	୨	୩	୪	୫
୮	ନିତିଦିନିଆ ଜୀବନରେ ଆପଣ ନିଜକୁ କେତେ ସୁରକ୍ଷିତ ଭାବୁଛନ୍ତି ?	୧	୨	୩	୪	୫
୯	ଆପଣଙ୍କ ପରିବେଶ କେତେ ସ୍ୱାସ୍ଥ୍ୟକର ?	୧	୨	୩	୪	୫

ନିମ୍ନଲିଖିତ ପ୍ରଶ୍ନସବୁ, କିଛି ବିଷୟ, ଗଲା ଚାରି ସପ୍ତାହ ଭିତରେ ଆପଣ କେତେ ଅନୁଭବ କରିଛନ୍ତି, ବା କିଛି କରିପାରିଛନ୍ତି, ତାହା ସମ୍ପର୍କରେ ।

		ଆଦୌ ନାହିଁ	ସାମାନ୍ୟ ଭାବରେ	ମଧ୍ୟମ ଭାବରେ	ଅଧିକାଂଶ ଭାବରେ	ସମ୍ପୂର୍ଣ୍ଣ ଭାବରେ
୧୦	ନିତିଦିନିଆ ଜୀବନ ପାଇଁ ଆପଣଙ୍କର ଯଥେଷ୍ଟ ଶକ୍ତି ଅଛି କି ?	୧	୨	୩	୪	୫
୧୧	ଆପଣଙ୍କ ଚେହେରାରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୧୨	ନିଜର ଆବଶ୍ୟକତା ପୂରଣ ପାଇଁ ଆପଣଙ୍କର ଯଥେଷ୍ଟ ପଇସାପତ୍ର ଅଛି କି ?	୧	୨	୩	୪	୫
୧୩	ଆପଣଙ୍କ ନିତିଦିନିଆ ଜୀବନରେ ଆବଶ୍ୟକ ଜାଣିବା କଥାସବୁ ଆପଣଙ୍କୁ କେତେ ମିଳିପାରୁଛି ?	୧	୨	୩	୪	୫
୧୪	ଖୁସିବାସି ପାଇଁ ଆପଣଙ୍କର କେତେ ସୁବିଧା ସୁଯୋଗ ରହିଛି ?	୧	୨	୩	୪	୫

		ବହୁତ ଖରାପ	ଖରାପ	ଖରାପ ନୁହେଁ କି ଭଲ ନୁହେଁ	ଭଲ	ବହୁତ ଭଲ
୧୫	କେତେ ଭଲରେ ଆପଣ ଯିବାଆସିବା, ଚଲାବୁଲା କରିପାରୁଛନ୍ତି ?	୧	୨	୩	୪	୫

		ବହୁତ ଅସନ୍ତୁଷ୍ଟ	ଅସନ୍ତୁଷ୍ଟ	ଅସନ୍ତୁଷ୍ଟ ନୁହେଁ କି ସନ୍ତୁଷ୍ଟ ନୁହେଁ	ସନ୍ତୁଷ୍ଟ	ବହୁତ ସନ୍ତୁଷ୍ଟ
୧୬	ଆପଣଙ୍କ ନିଦରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୧୭	ନିତିଦିନିଆ ଜୀବନର କାମସବୁ କରିପାରିବାରେ ନିଜ ସାମର୍ଥ୍ୟରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୧୮	କାମ କରିବାର ନିଜ ସାମର୍ଥ୍ୟରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୧୯	ଆପଣ ନିଜ ଉପରେ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୨୦	ନିଜ ବ୍ୟକ୍ତିଗତ ସମ୍ପର୍କଗୁଡିକରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୨୧	ନିଜ ଯୌନ ସମ୍ପର୍କ ନେଇ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୨୨	ବନ୍ଧୁମାନଙ୍କ ଠାରୁ ପାଉଥିବା ସାହାଯ୍ୟ ସହଯୋଗରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୨୩	ନିଜ ଘରଦ୍ୱାରର ଅବସ୍ଥାରେ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫
୨୪	ସ୍ୱାସ୍ଥ୍ୟସେବା ପାଇବା ପାଇଁ ଆପଣଙ୍କ ସୁବିଧା ସୁଯୋଗ ନେଇ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୪
୨୫	ନିଜ ଯିବା ଆସିବାପାଇଁ ଯାନବାହନର ସୁବିଧା ନେଇ ଆପଣ କେତେ ସନ୍ତୁଷ୍ଟ ?	୧	୨	୩	୪	୫

ନିମ୍ନଲିଖିତ ପ୍ରଶ୍ନ, କିଛି ବିଷୟ ଗଲା ଚାରି ସପ୍ତାହ ଭିତରେ ଆପଣ କେତେଥର ଅନୁଭବ କରିଛନ୍ତି, ସେ ସମ୍ପର୍କରେ ।

		କେବେ ନୁହେଁ	କ୍ୱଚିତ୍	ବେଳେ ବେଳେ	ଅଧିକାଂଶ ସମୟରେ	ସବୁବେଳେ
୨୬	କେତେଥର ଆପଣଙ୍କର ମନ ଖରାପ (ନକାରାତ୍ମକ ଅନୁଭବ) ଯଥା ମନଦୁଃଖ, ହତାଶା, ଚିନ୍ତା, ଛାନିଆ ଲାଗିବା, ମାନସିକ ବିଷାଦ ଆଦି ହୋଇଛି ?	୫	୪	୩	୨	୧

ଏହି ପ୍ରଶ୍ନସବୁ ବିଷୟରେ ଆପଣଙ୍କର କିଛି ମତ ବା ମନ୍ତବ୍ୟ ଅଛି କି ?

ଆପଣଙ୍କ ସହଯୋଗ ପାଇଁ ଅଶେଷ ଧନ୍ୟବାଦ ।

ଏହି ଲିଖିତ ପ୍ରଶ୍ନାବଳୀର ବିତରଣ ସାଧାରଣ ଜନତାଙ୍କ ପାଇଁ ନୁହଁ, ଏବଂ ଏହାର ପୂର୍ଣ୍ଣ ଅଧିକାର ବିଶ୍ୱ ସ୍ୱାସ୍ଥ୍ୟ ସଂଗଠନ ଦ୍ୱାରା ଆରକ୍ଷିତ । ଏହି ଲିଖିତ ପ୍ରଶ୍ନାବଳୀର ପୁନଃ-ନାରିକ୍ଷଣ, ଫଟୋପଜରଣ, ଅବତରଣ, ପୁନଃ-ଉତ୍ପାଦନ ବା ଅନୁବାଦ, ଆଂଶିକ ବା ପୂର୍ଣ୍ଣ ଭାବରେ, ବିଶ୍ୱସ୍ୱାସ୍ଥ୍ୟ ସଂଗଠନର ପୂର୍ବଲିଖିତ ଅନୁମତି ବିନା ହେବା ଅନୁଚିତ । ଏହି ଲିଖିତ ପ୍ରଶ୍ନାବଳୀର କୌଣସି ଅଂଶ ବିଶ୍ୱସ୍ୱାସ୍ଥ୍ୟ ସଂଗଠନର ପୂର୍ବଲିଖିତ ଅନୁମତି ବିନା, ପୁନଃ-ପ୍ରାପନୀୟ ଅବସ୍ଥାରେ ରଖିବା, ବା ଅନ୍ୟ କିଛି ମାଧ୍ୟମ ବା ସାଧନରେ - ଇଲେକ୍‌ଟ୍ରୋନିକ୍, ଯାନ୍ତ୍ରିକ ବା ଅନ୍ୟ – ସଂଚାରଣ କରିବା ଅନୁଚିତ ।

ଅଂଶଗ୍ରହଣକାରୀଙ୍କପାଇଁ ପାଇଁ ତଥ୍ୟ ଫର୍ଦ

ସ୍ନହେର ଅଂଶଗ୍ରହଣକାରୀ,

ମୁଁ ଡଂକ ଂଶୁତିଲଖୋ (ବିପିଟି), ଶ୍ରୀଚିତ୍ରା ତିରୁମାଲା ଇନ୍ସଟିଟିଉଟ ଓଫ ମେଡିକାଲ ସାଇନ୍ସ, ତ୍ରିଭାଡ୍ରମ, କେରଳର ଏମପିଏଚ ଛାତ୍ରୀ । ମୁଁ ଏମପିଏଚରେ , "The economic burden of spinal cord injury and the coping strategies among the spinal cord injury patients and their families"ଉପରେ ଗବଷେଣାତ୍ମକ ଅଧ୍ୟୟନ କରିବାପାଇଁ ପ୍ରସ୍ତାବ ଦେଇଛି । ଏହି ଗବଷେଣାର ମୁଖ୍ୟ ଉଦ୍ଦଶ୍ୟ ହେଉଛି spinal cord injuryରେ ହେଉଥିବା ପ୍ରକୃତ ବ୍ୟୟ ଓ ସହେି ଖର୍ଚ ଭାରକୁ ରୋଗୀ ତଥା ତାର ପରିବାର ବର୍ଗ କିପରି ବହନ କରୁଛନ୍ତି । ଚିକିତ୍ସା ଓ ଅଣ ଚିକିତ୍ସା ବାବଦରେ ହେଉଥିବା ଖର୍ଚ, ଜୀବନ ଶଳୈୀର ପରିବର୍ତ୍ତନ ଇତ୍ୟାଦି ପ୍ରକୃତ ବ୍ୟୟରେ ଅନ୍ତରଭୁକ୍ତ ।

ଆପଣ ଯଦି ଏହି ଗବଷେଣା କାର୍ଯ୍ୟକ୍ରମରେ ଭାଗ ନବୋକୁ ଚାହାନ୍ତି ତା ହଲେେ ମୁ ଆପଣଙ୍କୁ ଆପଣଙ୍କର ଆସ୍ଥବ୍ୟସ୍ଥ,ଆପଣଙ୍କ ଯତ୍ନ ନଉଥିବା ବ୍ୟକ୍ତିର ଆସ୍ଥ ଏବଂ ସହେି ପରିସ୍ଥିତିକୁ ମୁକାବିଲା କରିବାପାଇଁ ବ୍ୟବହୃତ ହାଇଥିବା କୌଶଳ ବିଷୟରେ ଜାଣିବା ପାଇଁ କତେଗୁଡିଏ ପ୍ରଶ୍ନ ପଚରାଯାଇପାରେ । ଏହି ପ୍ରଶ୍ନ ପଚାରିବାବଳେେ ଗୋପନୀୟତା ରକ୍ଷା କରିବାପାଇଁ ସ୍ବତନ୍ତ୍ର ଦୃଷ୍ଟି ଦିଆଯିବ ଓ ଅତିକମରେ 45 ମିନିଟ ସମୟ ଲାଗିବ ।
ଏହି ସର୍ବକ୍ଷେଣ କାର୍ଯ୍ୟକ୍ରମରେ ଭାଗ ନବୋରେ କୌଣସି ବାଧ୍ୟ ବାଧକତା ନାହିଁ । ଆପଣ ସ୍ବେଚ୍ଛାକୃତ ଭାବରେ ଅଂଶଗ୍ରହଣ କରିପାରିବେ । ଏଥିପାଇଁ କୌଣସି ପାରିଶ୍ରମିକର ବ୍ୟବସ୍ଥା ନାହିଁ । ପ୍ରସ୍ତୁତ କରାଯାଇଥିବା ପ୍ରଶ୍ନ ଗୁଡିକର ଉତ୍ତର ଦବୋପାଇଁ ଆପଣଙ୍କୁ ସ୍ବାଧୀନତା ଦିଆଯାଇଛି । କୌଣସି ପ୍ରଶ୍ନ ଭଲ ନା ଲାଗିଲେ ତାର ଉତ୍ତର ନ ଦବୋ ପାଇଁ କୌଣସି କାରଣ ଦର୍ଶାଇବା ଦରକାର ନାହିଁ । ଏହା ଦ୍ବାରା ଆପଣଙ୍କର କୌଣସି ସ୍ୱାସ୍ଥ୍ୟ ଜନିତ ଅଧିକାର କ୍ଷୁର୍ଣ୍ଣ ହବେନାହିଁ । ଏହି ସର୍ବକ୍ଷେଣ କାର୍ଯ୍ୟକ୍ରମରେ ଭାଗନଲେେ ଆପଣଙ୍କର କୌଣସି ଲାଭ ହବେନାହିଁ । କିନ୍ତୁ ଆମକୁ ଏହି ସମସ୍ୟାକୁ ବୁଝି ତାର ସମ୍ଭାବ୍ୟ ସମାଧାନ ବାହାର କରିବାରେ ସହାୟକ ହବେ ଯାହାକି ଭବିଷ୍ୟତରେ ସମଗ୍ର ମାନବ ସମାଜ ପାଇଁ ଲାଭବାନ ହବେ । ସଂଗ୍ରହ ହୋଇଥିବା ତଥ୍ୟକୁ ବିଶ୍ଳଷେଣ କରିବା ପରେ ଏହାର ଫଳାଫଳକୁ ସମସ୍ତ ଅଂଶଗ୍ରହଣକାରୀ ଓ ସ୍ୱାସ୍ଥ୍ୟ ଅଧିକାରୀମାନଙ୍କ ସହିତ ଆଲୋଚନା କରାଯାଇ spinal cord injuryରେ ଚିକିତ୍ସାହେଉଥିବା ରୋଗୀ ମାନଙ୍କର ଆର୍ଥିକ ଭାରକୁ କମାଇବାପାଇଁ ପଦକ୍ଷପେ ନିଆଯାଇପାରିବ ।

. ସଂଗ୍ରହ କରାଯାଇଥିବା ତଥ୍ୟ ଆପଣ, ମୋ ଓ ମୋର ଗବଷେଣା ପ୍ରଦର୍ଶକ ଡଂରାଖାଲ ଗଇତୋଣ୍ଡେ, ପ୍ରୋଫସେର, ଅଚ୍ୟୁତ ମନେନ ସେଣ୍ଟର ଫର ହଲେଥ ସିଷ୍ଟମ ସ୍ଟଡିସଙ୍କ ଭିତରହେଁି ରହିବ । ଆପଣଙ୍କ ନାମ କେଉଁଠି ବି ଲଖୋ ହବେ ନାହିଁ । ଆପଣଙ୍କ ନାମ ବଦଳରେ ଗୋଟିଏ ସାଙ୍କତେିକ ଚିହ୍ନ ଦିଆହବେ ଏବଂ ମୋ ଛଡା ଆଉ କହେି ସେ ଚିହ୍ନ ଜାଣିବେ ନାହିଁ । ଏହି ଚିହ୍ନକୁ ଗୋପନ ରଖା ହବେ । ଗବଷେଣାର ଲଖୋ ସାରିଲାପରେ ସହେି ଚିହ୍ନକୁ ଲିଭାଇ ଦିଆଯିବ ।

ଏହି ସର୍ବକ୍ଷେଣ ବିଷୟରେ ଯଦି କିଛି ସନ୍ଦହେ ଥାଏ ତା ହଲେେ ଆପଣ ସିଧା ସଳଖ 9439487691 କିମ୍ବା ଇ-ମଲେ kslekha@sctimst.ac.inଅଥବାଡା. ମାଲା ରାମନାଥନଆଇଂଇଂସିଂମମ୍ବେର ସକ୍ରେଟୋରିଙ୍କ ନମ୍ବର0471-2524234ଏବଂ ଇ- ମଲେ iec.mem.sec@sctimst.ac.inମାଧ୍ୟମରେ ପଚାରି ବୁଝି ପାରିବେ ।ଆପଣ ଯଦି ରାଜି ଆମେ ଆରମ୍ଭ କରିବା ।

Date:

Name of the interviewer
Dr. K. ShrutiLekha(BPT)
Ph.No- 9439487691

Email- kslekha@sctimst.ac.in

Signature /Thumb impression of the participant

ସ୍ୱୀକୃତି ପତ୍ର

ମୁ ଦିଆଯାଇଥିବା ତଥ୍ୟ ଫର୍ଦ୍ଦ ପଢିଲି ଓ ସଥେିରେ ଲଖୋଯାଇଥିବା ବିଷୟ ବସ୍ତୁ ବୁଝିଲି । ଏଥିରେ ମେ।ର ସନ୍ଦହେ ଦୂର କରିବା ପାଇଁ ସୁଯେ।ଗ ରହିଛି ତଥା ଦିଆଯାଇଥିବା ପ୍ରଶ୍ନର ଉତ୍ତର ମେ। ହିସାବରେ ଦବୋର ସ୍ୱାଧୀନତା ମଧ୍ୟ ରହିଛି। ମୁ ସ୍ୱେଚ୍ଛା କୃତଭାବେ ଏହି ଗବଷେଣା "*The Economic burden of spinal cord injury and the coping strategies among the spinal cord injury patients and their families – an exploratory study*" କାର୍ଯ୍ୟସ୍ଥରେ ଭାଗ ନବୋପାଇଁ ମେ।ର ସନ୍ନତି ପ୍ରଦାନ କରୁଛି । କିନ୍ତୁ ମୁଁ ଚାହିଁଲେ ଯେ କୌଣସି ସମୟରେ ଗବଷେଣା କାର୍ଯ୍ୟସ୍ଥରୁ ଓହରିଯାଇପାରିବି ଯାହାକି ମେ।ରଚିକିତ୍ସା କ୍ଷତ୍ରେରେ କୌଣସି ପ୍ରତିବନ୍ଧକ ସୃଷ୍ଟି କରିବ ନହିଁ । ସଂଗ୍ରହ କରାଯାଇଥିବା ତଥ୍ୟ ଗୁଡିକ ଗବଷେଣା ପ୍ରଦର୍ଶକଙ୍କ ସହିତ ଆଲେ।ଚନା କରିବା ପାଇଁ ମେ।ର ପୂର୍ଣ୍ଣ ସହମତି ଅଛି ।

Name of the interviewer
Dr. K.ShrutiLekha(BPT)

ଅଂଶଗ୍ରହଣକାରୀଙ୍କ ନାମ

ଦସ୍ତଖତ/ଟିପ ଚିହ୍ନ

श्री चित्रा तिरुनाल आयुर्विज्ञान और प्रौद्योगिकी संस्थान, त्रिवेन्द्रम
तिरुवनन्तपुरम - ६९५०११, केरल, इंडिया
SREE CHITRA TIRUNAL INSTITUTE FOR MEDICAL SCIENCES AND TECHNOLOGY, TRIVANDRUM
Thiruvananthapuram - 695 011, Kerala, India
(An Institute of National Importance under Govt. of India)
Grams : Chitramet, Phone : +91-471-2443152, Fax : +91-471-2550728 / 2446433, E-mail : sct@sctimst.ac.in, Website : www.sctimst.ac.in

Institutional Ethics Committee

(IEC Regn No. ECR/189/Inst/KL/2013/RR-16)

SCT/IEC/1461/NOVEMBER-2019 14.11.2019

Dr. K. Shruti Lekha
MPH Student, AMCHSS
SCTIMST, Thiruvananthapuram

Dear Dr. Shruti Lekha,

The Institutional Ethics Committee reviewed and discussed your application to conduct the study entitled "ECONOMIC BURDEN OF TRAUMATIC SPINAL CORD INJURY AMONG THE SPINAL CORD INJURY PATIENTS AND THEIR FAMILIES IN ODISHA – AN EXPLORATORY STUDY" (IEC/1461) on 5th November, 2019.

The following documents were reviewed:

Original submission

1. *Covering letter addressed to the Chairperson, IEC, SCTIMST with checklist*
2. *Forwarding Letter from Guide/HOD*
3. *Research protocol*
4. *IEC application form*
5. *Interview schedule in English and Odia*
6. *TAC Approval letter*
7. *Patient information sheet and Consent Form in English and Odia*
8. *WHO –QOL BREF questionnaire*
9. *CV of Principal Investigator*
10. *Permission letters from SVNIRTAR and SMRC*

Revised submission

1. *Covering letter addressed to the Chairperson, IEC, SCTIMST with checklist*
2. *Forwarding Letter from Guide/HOD*
3. *Research protocol*
4. *IEC application form*
5. *Interview schedule in English and Odia*
6. *TAC Approval letter*
7. *Patient information sheet and Consent Form in English and Odia*
8. *WHO –QOL BREF questionnaire*
9. *CV of Principal Investigator*
10. *Permission letters from SVNIRTAR and SMRC*
11. *Copy of IEC Recommendation Letter dated 7.11.2019*

The following members of the Ethics Committee were present at the meeting held on 5th November, 2019 at G. Parthasarathi Board Room, AMCHSS, SCTIMST

SL. No.	Member Name	Highest Degree	Gender	Scientific /Non Scientific	Affiliation with Institution(s)
1.	Dr. R V G Menon	M Tech, PhD	Male	Lay Person (Chairman)	No
2.	Dr. Kala Kesavan. P	MBBS, MD	Female	Basic Medical Scientist	No
3.	Dr. K R S Krishnan	M.E., Ph.D.	Male	Medical Technology	Yes
4.	Dr. Harikrishna Varma PR	Ph.D(Materials Science)	Male	Medical Technology	Yes
5.	Dr. S S Giri Sankar	LL.M. Ph.D.	Male	Legal Expert	No
6.	Dr. V. Raman Kutty	M D, M Phil, M P H	Male	Health Sciences Expert/Clinician	Yes
7.	Dr. Aneesh V Pillai	BA. LLB (Hons.), LLM, Ph. D, SET (Law)	Male	Legal Expert	No
8.	Smt. Sathi Nair	MA (English Literature)	Female	Lay Person	No
9.	Dr. P. Manickam	BSMS, MSc (Epid).,PhD	Male	Health Science Expert/ Social Scientist	No
10.	Dr. Harikrishnan S	MD, DM (Cardiology) DNB (Cardiology)	Male	Clinician	Yes
11.	Mr. Satheesh Chandran	MSW, PGDPM	Male	Lay person/ NGO/ Social Scientist	No
12.	Dr. Christina George	MD Psychiatry	Female	Clinician	No
13.	Dr. Mala Ramanathan	PhD	Female	Social Scientist (Member Secretary)	Yes

IEC Decision

The IEC approved the conduct of the study in the present form.

Remarks:

The Institutional Ethics Committee expects to be informed about the progress of the study, any SAE occurring in the course of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

There was no member of the study team / Guide who participated in voting / decision making process. The ethics committee is organized and operated according to the requirements of Good Clinical Practice and the requirements of the Indian Council of Medical Research (ICMR).

Sincerely,

Mala Ramanathan
Member Secretary, IEC

URKUND

Document Information

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Submitter email	rakhal.gaitonde@sctimst.ac.in
Similarity	3%
Analysis address	gaitonde.rakhal.sctims@analysis.urkund.com

Sources included in the report

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W	URL: https://www.genetherapy.me/category/spinal-cord-injury Fetched: 12/5/2019 4:07:21 PM	1
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W	URL: https://apps.who.int/iris/bitstream/10665/94190/1/9789241564663_eng.pdf Fetched: 10/20/2019 12:33:54 PM	1
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SA	URL: Jose Antony - PhD - Burden and Coping Strategies of Family Caregivers of Persons w ... Fetched: 4/5/2019 10:51:00 AM	5
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