Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal

by

Srijana Gautam

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

Department of Medicine

University of Alberta

Abstract

Spinal Cord Injury (SCI) results in physical impairments, psychosocial issues, increased mortality and morbidity that challenge individuals and demand lifelong support, which starts from acute care. Understanding the experience after SCI in acute care is essential as it may impact the Person(s) with Spinal Cord Injury (PWSCI's) subsequent journey to the rehabilitation centre and community. While similar studies were conducted in Western countries, this experience has yet to be studied in low-resource countries like Nepal, where there are distinct socioeconomic and cultural differences.

This thesis focused on how PWSCI (1) perceive overall positive and negative experiences regarding their care, (2) are involved in decision-making for their care, and (3) are educated about secondary complications during their acute care hospital stay in Nepal.

We interviewed participants (n=24) admitted at the Spinal Injury Rehabilitation Centre who were treated for their acute SCI in nine different acute hospitals in Nepal. We used a semi-structured interview guide co-developed with SCI experts and PWSCI of Nepal. We identified five main themes: (1) Limited communication; (2) Limited education and knowledge; (3) Limited participation in decision-making for care; (4) Limited access to resources; (5) The importance of providers' demeanour and conveyance of hope. These themes were mapped under the World Health Organization (WHO) 's three core domains of quality of care: patient-centredness, effectiveness, and safety. We observed positive experiences among PWSCI in some aspects, while ample room for improvement remains in others. These include delayed surgery in government hospitals, insufficient involvement of PWSCI in effective communication and decision-making processes before surgery, and transitioning to rehabilitation hospitals. Additionally, inadequate education sessions for preventing secondary complications were identified as areas for improvement. Despite limitations in communication, education, participation, and resource access, the words of kindness from the care team significantly impacted patients.

Opportunities exist to improve the acute care experience for PWSCI in Nepal, especially within government hospitals. PWSCI desired to be well-informed about their condition and prognosis and to be actively engaged in decision-making processes. They expect positive behaviour, a compassionate demeanour, and respectful treatment from the care team.

Keywords: Acute care, Nepal, spinal cord injury

Preface

This thesis is an original work by Srijana Gautam. The research project of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "EXPERIENCE OF PATIENTS WITH SPINAL CORD INJURY REGARDING THE QUALITY OF CARE DURING AN ACUTE HOSPITAL STAY IN NEPAL," No. Pro00120912, July 4, 2022.

This study was conceived by Srijana Gautam, with some modifications and ideas by Dr. Chester Ho. Dr. Kiran Pohar Manhas, Dr. Raju Dhakal, Dr. Christine Groves, and Dr. Vivian K. Mushahwar assisted in formulating and editing the interview guide. Srijana Gautam finalized the study design and conducted the data collection. Srijana Gautam, Prabita Shrestha, and Mandira Baniya analyzed the data.

Srijana Gautam wrote the literature review in Chapter 1. Chapters 2 and 3 were written by Srijana Gautam, with supervisors Dr. Ho and Dr. Mushahwar providing feedback. This research's abstract with preliminary findings was published in the National Spinal Cord Injury Conference, held on November 21 to 23, 2023, in Toronto, Canada, organized by the Canadian Spinal Cord Injury Rehabilitation Association.

Dedications

To my patients, who shared their experiences, stories, and journeys with me and became the motivation to do this research.

My former workplace, Spinal Injury Rehabilitation Centre, where I gained valuable experience, opened my pathways to research and met my life partner.

My enthusiastic participants, without whom this research would have never been possible.

Acknowledgements

I am thankful to each one listed below:

My supervisors, Dr. Chester Ho and Dr. Vivian Mushahwar thank you for your continuous effort, teaching, motivation, and support throughout my journey.

My mentor, Dr. Hope Jervis-Rademeyer, with whom I learned so much and could ask for any help.

Dr Kiran Pohar Manhas and Prof. Dr. Lorrain Venturato, thank you for helping me understand qualitative studies better.

Thank you to my committee members, Dr. Christine C Groves and Dr. Raju Dhakal, for all the feedback and support.

Ms. Prabita Shrestha, Ms. Mandira Baniya, Dr. Jacqueline Krysa, Mr. Rishi Dhakal, Ms. Kalpana Bista, Mr. Michel Gauthier, Mrs. Manon Fraser and SIRC for all their support.

University of Alberta Spinal Cord Injury Endowed Research Chair funds for funding.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

NTSCI: Non-Traumatic Spinal Cord Injury

PWSCI: Person(s) with Spinal Cord Injury

RTI: Road Traffic Incident

SCI: Spinal Cord Injury

SIRC: Spinal Injury Rehabilitation Centre

TSCI: Traumatic Spinal Cord Injury

WHO: World Health Organization

Chapter 1: Introduction

1. Background

1.1. A brief history of Spinal Cord Injury

Spinal Cord Injury (SCI) has been considered a life-threatening condition since ancient times. Around 2500 BC, an unidentified Egyptian physician identified the clinical features of SCI and labelled it as a condition with a poor prognosis that cannot be treated. (Swain & Grundy, 2002). Later in World War I, approximately 90 % of the patients with traumatic SCI died within a year of injury, whereas only 1% survived beyond two decades (Swain & Grundy, 2002). Those who survived had low-impact or minor injuries (Swain & Grundy, 2002). However, in the latter half of the twentieth century, huge improvements were seen due to scientific advancement, surgery, and rehabilitation (Lin & Cardenas, 2003; Swain & Grundy, 2002). The contribution of various personnel, such as Dr. Donald Munro, a neurosurgeon from the United States (US) and Sir Ludwig Guttmann from England, to modern SCI care, has been highly appreciated throughout history (Ropper & Brown, 2005; Swain & Grundy, 2002).

However, in Nepal, there is a lack of knowledge in the healthcare system about SCI and the evolution of its treatment. Colonel David Hamilton shared the extracts of an essay by Tikaram Rai in a 1978 paper, which includes the struggle and positive outcomes of some patients with paraplegia in Nepal (Hamilton & Rai, 1978). The author mentioned how patients with paraplegia were brought into the hospital after 10-12 days of being carried under the armpits and the patients holding their paraplegic limbs. Similarly, some people died in the hospital while waiting for their turn to be examined, and some of them had severe pressure injuries (Hamilton

& Rai, 1978). Spinal tuberculosis was the most common cause of SCI (Hamilton & Rai, 1978). The use of wheelchairs was uncommon due to accessibility issues (Hamilton & Rai, 1978).

1.2. Definition, Incidence, Etiology and Management of Spinal Cord Injury

Spinal cord injury is a condition that occurs when external impacts such as falls and accidents or other non-traumatic conditions like infections, tumours and other diseases damage the spinal cord (Ahuja et al., 2017). Spinal cord injury can be divided into two broad categories: traumatic spinal cord injury (TSCI) and non-traumatic spinal cord injury (NTSCI) (O'Sullivan & Schmitz, 2006). The worldwide incidence of TSCI is estimated to be around 5.1 to 150.48 cases per million (Jazayeri et al., 2023). In developed countries, the incident rate is higher in North America (39 cases per million individuals) than in Western Europe (15 cases per million individuals) (Ahuja et al., 2017). In the case of developing countries, data from 2009 to 2020 show an incidence of 22.55/million/per year for TSCI, with males constituting 80.09% of those injured and the major affected age group being under 30 (Golestani et al., 2022). The most common causes of TSCI were road traffic incidents and falls, and cervical injuries were more prevalent than injuries at other levels (Golestani et al., 2022). The incidence rate for NTSCI varies from 6 to 68 per million population per year in developed countries (Western Europe: 6 per million population per year & Canada: 68 per million population per year) (New et al., 2014). The common NTSCI in developed countries is degenerative and vascular conditions and tumours, while tuberculosis and tumours are more prominent in developing countries (New et al., 2014).

When there is a traumatic incident, the spinal cord undergoes contusion, concussion, shearing, or squeezing forces, and there is damage to the grey and white matter, which may result in bleeding and necrosis at the level of injury or 1 or 2 segments above and below it (Ropper & Brown, 2005). Spinal cord injuries can be divided into three phases based on the biological response to the SCI: acute, secondary and chronic (Liverman & Institute of Medicine (U.S.), 2005). The acute phase starts within seconds of the injury and lasts up to minutes. During this phase, changes occur inside the body, such as hemorrhage, decreased oxygen supply, and cell death at the site of injury due to direct insult (Liverman & Institute of Medicine (U.S.), 2005). The body also goes into a spinal shock where the spinal reflexes are absent below the level of injury with or without hypotension and may last from hours to months (Ziu & Mesfin, 2024). Consequently, impaired sensation, limb weakness, and other dysfunctions are seen in the acute phase, depending on the extent and area of the injury (Ropper & Brown, 2005). The secondary phase lasts from minutes to weeks Free-radical production and releasing neutrophils and cytokines lead to neuron injury or death. In the chronic phase that lasts months to years, programmed cell death continues, and spinal cord scarring occurs by glial cells. Demyelination followed by regeneration, sprouting or spontaneous recovery may occur (Liverman & Institute of Medicine (U.S.), 2005).

The medical management of spinal cord injury can be different based on the various phases of injury. In the acute phase, the intervention should be focused on preventing further damage and facilitating neurorecovery (Burns et al., 2017). Early decompression spine surgery, preferably within 24 hours of the injury, is recommended after performing Magnetic resonance imaging. Rehabilitative treatments such as body weight support treadmill training, functional electrical stimulation, and gait training should be started as early as possible, depending on the patient’s exercise capacity. The other recommended medical interventions include venous thromboembolism prophylaxis treatment by administering either subcutaneous low-molecularweight heparin or fixed low-dose unfractionated heparin for preventing complications such as deep vein thrombosis (Fehlings et al., 2017). The chronic phase focuses more on the compensatory or assistive strategy (Burns et al., 2017). These various medical interventions early after SCI may influence neurorecovery, hence affecting the experience of PWSCI.

The widely accepted usual care pathway in developed countries for patients with TSCI includes pre-hospital care, acute hospital care, specialized SCI rehabilitation, and community reintegration (National Clinical Programme, 2018). Pre-hospital care involves incident scene management, extrication, stabilization, and transfer to the emergency department of an acute care hospital. In acute care, the care team carries out an assessment and provisional diagnosis, and then surgical or conservative management is done once the diagnosis is confirmed (National Clinical Programme, 2018). A multidisciplinary team's prevention of secondary complications starts when the patient is admitted to the acute hospital. After surgery, when the patient is medically stable, preliminary acute rehabilitation starts, such as early mobilization, bowel and bladder management, and optimal joint positioning. The patients are then typically referred to a specialized rehabilitation centre for multidisciplinary intervention (National Clinical Programme, 2018). The final pathway is re-integration into the community after a planned discharge from the rehabilitation centre. Implementing structured care pathways helps improve the quality of life, care experience, and long-term outcomes for PWSCI (National Clinical Programme, 2018).

This pathway mentioned above is likely appropriate for Western countries. This scenario, however, may be completely different in low-resource countries like Nepal, due to geographical barriers, inadequately trained human resources, limited medical facilities, a lack of government healthcare policies and limited public awareness regarding SCI (Shah et al., 2013).

There are, additionally, different cultural beliefs about disease causations (Subedi, 2001), which may further delay medical management if they choose to go with alternative practices first. There is, in fact, medical pluralism in Nepal (Subedi, 2001). The type of treatment a person prefers during ill health depends not only upon the culture and tradition but also on the person's economic condition (Subedi, 2001). People start treatment with cost-effective treatments like home-based self-medication, herbal medicine, and local healers, and then only shift towards expensive Western medicine (Subedi, 2001). Gaining a deeper understanding of diverse cultural contexts is crucial.

The typical clinical issues of a person experiencing an SCI include spinal shock, motor and sensory impairments, autonomic dysreflexia, postural hypotension, respiratory insufficiency, temperature dysregulation, bowel and bladder dysfunction, spasticity, and sexual dysfunction (Lin & Cardenas, 2003; O’Sullivan & Schmitz, 2006). As a result of these dysfunctions and impairments, further secondary complications may arise, such as pressure injuries, deep vein thrombosis, respiratory complications, heterotopic ossification, and contractures. (Lin & Cardenas, 2003; O’Sullivan & Schmitz, 2006). Some of these complications need lifelong support, as PWSCI might have difficulty managing them independently. This support includes long-term medical care, social care, and personal assistance from family or paid caretakers to perform activities of daily living (National Clinical Programme, 2018). The cultural and social components are vital for ongoing care in SCI. This emphasizes the importance of exploring individual cultures and their specific contexts to enhance our understanding of how to approach this care effectively. Proper education and communication among the care team and PWSCI, including their families therefore, are crucial in the early phases of injury for better patient outcomes (Khosravi et al., 2022; Krysa et al., 2022) and to significantly reduce the financial and psychosocial burden of patients and family members in the long term. The education and communication sessions between a care team, patients and families should be culturally tailored considering various backgrounds (Moore, 2007). Teaching male family members, for example, such as father-in-law or brother-in-law to change position to prevent pressure injuries of a female PWSCI who is a daughter-in-law or sister-in-law could be inappropriate in some cultures where a male family member except her husband is not allowed to touch her or see her uncovered hair or face. In such cases, the care team could explore alternative approaches, such as assisting the patient directly or involving another family member in caregiving tasks that involve touching.

1.3. Introduction to Nepal

1.3.1. History, geographical location in the world.

__Figure 1:__ Geographical location of Nepal on the world map

Reference: https://www.gettyimages.in/detail/photo/image-of-a-globe-focusing-on-southeast-asia-royalty-free-image/185105914 , Photo Credit samxmeg

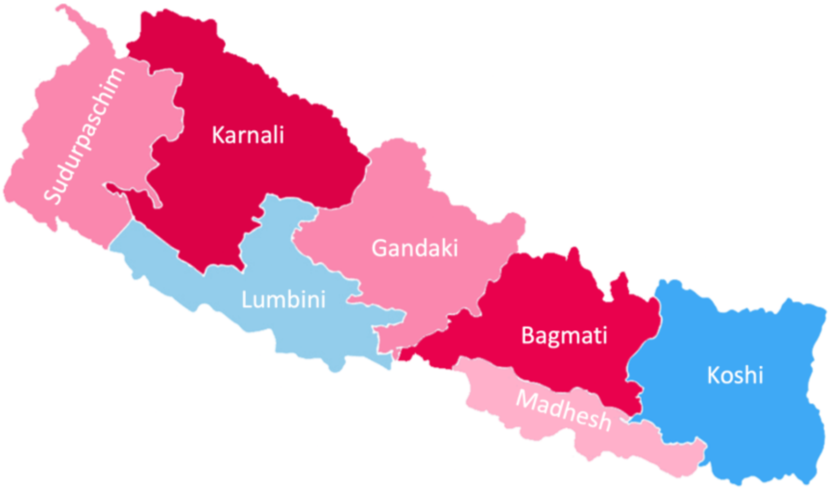


Figure 2: *Map of Nepal with seven provinces*

Reference: https://en.wikipedia.org/wiki/Provinces_of_Nepal , Photo Credit: Kinsu08

Nepal is the oldest country in Asia, dating back to the 7th century when the Kirantis were believed to be the rulers. Nepal had many small kingdoms previously. Prithvi Narayan Shah, King of Gorkha, conquered all the small kingdoms to make a single unified Nepal and made Kathmandu its capital. The Shah dynasty ruled Nepal from 1769 to 2008 A.D. On May 28, 2008, Nepal was declared a federal Democratic Republic where the President was the head of the country (Ministry of Foreign Affairs, Nepal, n.d.; Reyes, 2017).

Nepal is an independent landlocked country with an area of 147,181 square kilometres located in South Asia between two giant nations, China and India (Figure 1). Still, it is rich in natural resources and geographical diversities (plain terrain, hilly topography, and snow-capped mountains)(Embassy of Nepal, Abu Dhabi, n.d.; Government of Nepal, 2015, 2023). In 2015, Nepal was re-divided into seven provinces (Figure 2): Koshi Province, Madhesh Province, Bagmati Province, Gandaki Province, Lumbini Province, Karnali Province, and Sudurpashchim Province. The provinces are further divided into districts, districts into municipalities, municipalities into wards, and wards further into sub-wards. Out of 753 municipalities, 293 are urban, 460 are rural, and 65% of the population lives in urban municipalities (Embassy of Nepal, Abu Dhabi, n.d.; Ministry of Health and Population, Nepal; New ERA; and ICF, 2022). Nepal is also rich in culture and traditions; there are different tribes, ethnic, and social groups displaying their various festivals, customs, music, arts, and cuisines. There are 123 different languages spoken all over Nepal (Government of Nepal, 2023). These different geographical features, rural and urban habitation, and various languages and ethnicities may diversify the acute care experience of PWSCI. The acute care experience, for example, could be pretty different for a PWSCI (*Tamang* ethnicity, who has Nepali as a second language) from a remote mountain region who reached the tertiary acute hospitals three days after injury compared to a PWSCI (*Brahman,* Nepali is a first language) from an urban municipality who reached the same acute hospital within an hour.

1.3.2. Healthcare System in Nepal. Nepal's health practices incorporate beliefs, knowledge, and practices, including physicians who practice Western medicine, herbal doctors, nurses, pharmacists, health assistants, allopathic medication, traditional shamans, spiritual healers, medicinal herbs, household-based self-medication, and illegal traditions. Getting treatment from more than one practitioner is not uncommon for Nepalese until they are entirely cured. People also have deep-rooted beliefs about illness causation, like supernatural power, ghosts, evil eyes, witchcraft, evil spirits, and misfortune (Subedi, 2001). Some PWSCI, for instance, still go to traditional healers to be cleansed in the hope that they will be able to walk again, thinking that their disability is due to an encounter with evil spirits. Some Nepali people may also still believe that disability is a curse invoked by god or evil as a result of the misdeeds of a person, their family or ancestors (Aryal & Aryal, 2022). As a consequence, discrimination and stigma are prevalent for persons with disability in Nepali society (Aryal & Aryal, 2022). They are considered incompetent financially, and the family has low expectations of them (Aryal & Aryal, 2022). These beliefs can significantly affect the experience of PWSCI during acute hospital stay.

Health services are categorized as privately funded and state-funded. An increase in demand led to many private hospitals, nursing homes, private teaching hospitals, and colleges being established after the 1950s. However, these private health facilities are beyond the reach of poor or middle-class people (Marasini, 2020; Subedi, 2001). According to the WHO Global Health Expenditure Database, 51.3% of health expenditure in Nepal is out of pocket compared to 14.0 % and 49.8 % in Canada and India, respectively (Global Health Expenditure Database, n.d.).

There is at least one acute hospital in each district and one health facility in each rural municipality (previously named village development committee) run by the government of Nepal (Figure 3) (Government of Nepal, 2016). According to the Public Health Service Act 2018, Nepali citizens are entitled to free primary and emergency health services through state-funded hospitals ((Government of Nepal, 2018). In rural Nepal, female community health volunteers and health posts have provided free primary medical distribution and family planning services. They are regarded as a core of Primary Health Care (PHC) (Jones et al., 2015). Despite the government's continuous efforts, the challenges to free health services include more geographical access, competent human power, and the availability of needed medicine/services (Adhikari et al., 2019; Jones et al., 2015). The National Health Insurance Policy (NHIP) program has been actively running in 77 districts of Nepal since 2013, which provides insurance facilities to Nepali families charging a certain premium amount to decrease out-of-pocket expenses (Figure 4) (Khanal et al., 2023). A provision of 100,000 Nepalese rupees (NRP) as financial aid to PWSCI is also available but is limited to only certain tertiary hospitals in Nepal (Shresth, 2015). Most people are still unaware of this insurance provision, while PWSCI have to travel many days to reach these acute hospitals to access the benefits. The amount is insufficient to cover the expenses incurred during acute hospital stays, resulting in predominantly out-of-pocket expenses for hospitalization and rehabilitation (Shresth, 2015). This financial hardship may also contribute to the negative experience of PWSCI and their families. The challenges for NHIP include difficult topography, inadequate or delayed reimbursements, hospital drop-outs from the insurance program, insufficient monitoring of premium collections, more insurance reimbursement claims than premium collections, and disinterested service providers due to increased workloads and limited staff (Khanal et al., 2023).

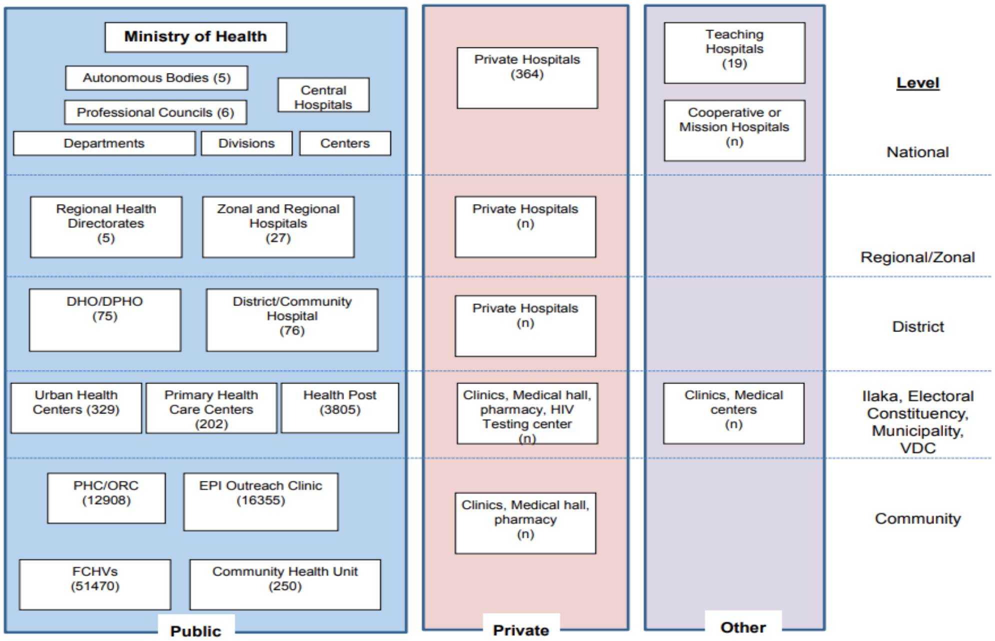
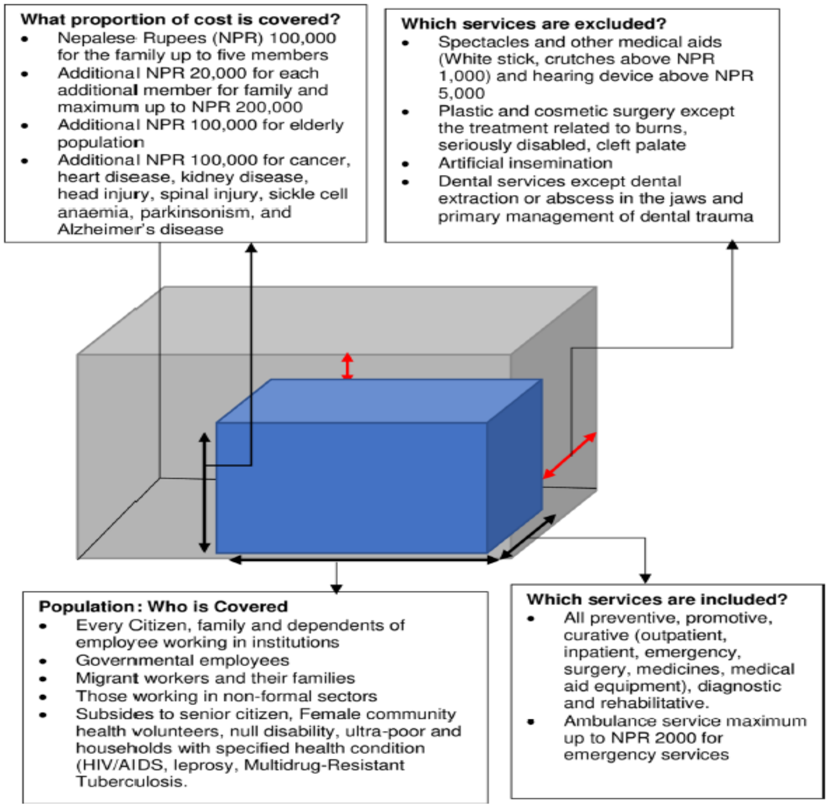


Figure 3: *Hierarchy of Health Service Delivery in Nepal*

Reference: (Health Facility Survey, Government of Nepal, 2016) (Diagram used with permission)



What proportion of cost is covered?
- Nepalese Rupees (NPR) 100,000 for the family up to five members
- Additional NPR 20,000 for each additional member for family and maximum up to NPR 200,000
- Additional NPR 100,000 for elderly population
- Additional NPR 100,000 for cancer, heart disease, kidney disease, head injury, spinal injury, sickle cell anaemia, parkinsonism, and Alzheimer's disease

Which services are excluded?
- Spectacles and other medical aids (White stick, crutches above NPR 1,000) and hearing device above NPR 5,000
- Plastic and cosmetic surgery except the treatment related to burns, seriously disabled, cleft palate
- Artificial insemination
- Dental services except dental extraction or abscess in the jaws and primary management of dental trauma

Population: Who is Covered
- Every Citizen, family and dependents of employee working in institutions
- Governmental employees
- Migrant workers and their families
- Those working in non-formal sectors
- Subsides to senior citizen, Female community health volunteers, null disability, ultra-poor and households with specified health condition (HIV/AIDS, leprosy, Multidrug-Resistant Tuberculosis.

Which services are included?
- All preventive, promotive, curative (outpatient, inpatient, emergency, surgery, medicines, medical aid equipment), diagnostic and rehabilitative.
- Ambulance service maximum up to NPR 2000 for emergency services

Figure 4: *National Health Insurance Program*

Reference: (Khanal et al., 2023) (Diagram used with permission)

1.4. SCI in Nepal

The prevalence and incidence rate of spinal cord injury still need to be determined in Nepal (Parajuli et al., 2020; Sharma, 2003; Shresth, 2015). Experienced spine surgeons, however, suggest that the incidence rate of SCI in Nepal is high and increasing compared to past years (Sharma, 2003; Shresth, 2015). Most retrospective studies are conducted in Nepal's central and eastern parts, while the western part is still uncovered (Parajuli et al., 2020). The most common causes of traumatic SCI in Nepal are falls (about 60 to 70%), followed by road traffic accidents (Parajuli et al., 2020). The falls are usually from trees, buildings, cliffs, and heights; however, falling from a tree is the most common (Parajuli et al., 2020; Shrestha et al., 2014; Willott et al., 2021). SCI was found to be 2 to 3 times more prevalent in males than females. The most common age group for traumatic SCI was below 30 (Parajuli et al., 2020; Shrestha et al., 2014; Willott et al., 2021). The comparison of various demographics of SCI in Nepal and a Western country is shown in Table 3.

This comparison highlights similarities in gender and age but reveals differences in the mechanism and level of injury between the two countries. The variations in these two characteristics of PWSCI between the Western country and Nepal may potentially contribute to disparities in their acute hospital experiences.

Table 1: *Comparison of Various Demographics of PWSCI in Nepal and the US*

Characteristics	**Nepal**[1]	**United States**
Gender (Men)	73.20%	79%
Mean Age	40 years	43 years
Mechanism of injury		
● Falls	59.99%	31.7%
● Motor accidents	16.98%	37.5%
● Burial[2]	7.12%	-
● Farm-related	4.22%	-
● Sports	-	8%
● Medical	-	3.7%
● Others	11.67%	3.8%
Level of Injury		
● Tetraplegia	37.36%	59.80%
● Paraplegia	62.67%	39.59%

References: (National Spinal Cord Injury Statistical Centre., 2024; Parajuli et al., 2020).

Notes: 1. In the context of Nepal, the above data were extracted from the systematic review (Parajuli et al., 2020). *2. Burial: buried in a pile of mud while digging it for home construction and decoration. In remote Nepal, the houses are made of mud and stone. Mud is also used to paint floors and walls.*

Trained paramedics in metropolitan areas in developed countries would typically reach the accident site within a few minutes via road or air ambulance and perform the needed intervention. The situation in Nepal is entirely different. No trained trauma squad can be quickly mobilized to the accident site due to rough and inaccessible terrain, limited SCI awareness, and lack of trained human resources (Paudel et al., 2022). The first respondents transporting patients from an accident or trauma site to the hospital are family, friends, or bystanders (Sharma, 2003;

Shrestha et al., 2022). Transportation methods include carrying the person on linen, riding on a bike, and being physically carried by 3 to 4 persons. Most people providing aid (about 96%) were not trained, and their handling may cause further neurological deterioration in the PWSCI (Sharma, 2003; Shrestha et al., 2022). Most of the PWSCI are referred to two or more other hospitals, and reaching the tertiary hospital takes more than 24 hours (Shrestha et al., 2022). Authors believe that, even in the emergency department of the acute hospital, handling patients with suspected SCI may not follow proper standards (Paudel et al., 2022). Patients are referred to different acute hospitals, i.e. private or government-funded, based on their economic status and affordability (Subedi, 2001) and sometimes to the closest distance from the accident site to the acute hospital. Most of the time, family members are the one who decides to choose among different acute hospitals (Based on communication with the SCI expert, Dr. Raju Dhakal, in Nepal). The choice between government and private hospitals, the location of acute hospitals in the capital city or various towns, the travel time to reach the acute hospital, and the handling and waiting times in the emergency department may result in varied acute hospital experiences among PWSCI as these may contribute to the timing of initial intervention in the acute hospital, potentially leading to different patient experiences and outcomes.

There is no government-funded rehabilitation hospital in Nepal to date (Dhakal & Groves, 2019). Most acute government hospitals include physiotherapy treatment for PWSCI; otherwise, no dedicated rehabilitation resource is available (Dhakal & Groves, 2019). Most acute inpatient rehabilitation services are provided by private rehabilitation centres, with local non-governmental organizations (NGOs) and international non-governmental organizations (INGOs) also playing a role (Dhakal & Groves, 2019). However, most do not specialize in spinal cord injury rehabilitation (Dhakal & Groves, 2019). The Spinal Injury Rehabilitation

Centre (SIRC) is Nepal's only dedicated rehabilitation hospital for SCI, with 51 inpatient SCI beds and 10 for stroke and brain injury. While trekking, Mr. Kanak Mani Dixit, a renowned journalist with a fall-related SCI, realized the need for a rehabilitation hospital for PWSCI and established SIRC in 2002 (Dhakal & Groves, 2019). SIRC is a non-profit organization and admits about 300 PWSCI for treatment each year (Dhakal & Groves, 2019), with 11% being NTSCI and 89% being TSCI (unpublished SIRC patient statistics, 2023). SIRC is the primary referral site for SCI rehabilitation from acute hospitals nationwide. Patients from different geographical areas have diverse languages, cultures and socio-economic backgrounds (Willott et al., 2021). At this time, there are no published records regarding the referral rate of PWSCI from acute hospitals to SIRC versus other rehabilitation centres not specializing in SCI. The experience of PWSCI who are referred to specialized centres like SIRC may differ significantly from those referred to other private rehabilitation centres. For illustration, SIRC offers additional services such as multidisciplinary team intervention, vocational training and recreational facilities. These services may not be available in other private rehabilitation settings (Based on communication with the SCI expert, Dr. Raju Dhakal, in Nepal). The transition to the SIRC from the acute hospital might be easier than another rehabilitation centre, as SIRC has collaborated with major acute government hospitals in Nepal. Additionally, a SIRC staff is scheduled to regularly visit those acute government hospitals and communicate with PWSCI and their families to facilitate an easy transition process to SIRC (Based on communication with the SCI expert, Dr. Raju Dhakal, in Nepal).

1.5. Defining Quality of Care

Understanding the quality of care that PWSCI receives is essential as it helps guide their healthcare decision-making and practice and can improve patient health outcomes (Moreno et al., 2017). This understanding from the perspective of people with lived experience can be crucial in reflecting on what exactly is going on in the acute hospital and how a patient is being cared for. After reviewing the literature above, it became evident that there was a need to recognize all those gaps and identify a framework to guide the experience related to quality of care.

Different institutions, such as the Institute of Medicine, the European Commission, and the Council of Europe, give various definitions of quality health care. However, the framework provided by WHO is the most suitable for low- and middle-income-generating countries facing challenges in improving the quality of care (World Health Organization, 2018). It focuses on three main domains: effectiveness, safety, and people-centredness, with the following subdomains: timely, equitable, integrated, and efficient, as shown in Table 2 (World Health Organization, 2018, pp. 13)

Table 2: *Defining Quality of Care*

Defining Quality Healthcare

Quality health care can be defined in many ways, but there is growing acknowledgement that quality health services across the world should be:

- **Effective**: providing evidence-based health care services to those who need them.
- **Safe**: avoiding harm to people for whom the care is intended.
- **People-centred**: providing care that responds to individual preferences, needs and values.

In addition, to realize the benefits of quality of health care, health services must be:

- **Timely**: reducing waiting time and sometimes harmful delays for both those who receive and those who give care.
- **Equitable**: providing care that does not vary in quality on account of age, sex, gender, race, ethnicity, geographical location, religion, socio-economic status, linguistic or political affiliation
- **Integrated**: providing care that is coordinated across levels and providers and makes available the full range of health services throughout the life course.
- **Efficient**: maximizing the benefit of available resources and avoiding waste.

Reference: Handbook for National Quality Policy and Strategy (WHO, 2018)

There has yet to be a published national guideline for defining the quality of care in Nepal for SCI (based on communication with SCI expert Dr. Raju Dhakal in Nepal). The healthcare system in Nepal does not give sufficient attention to managing, caring and rehabilitating PWSCI (Shah et al., 2013). There are various challenges, such as the absence of formulation and implementation of proper policies, lack of awareness among the care providers and the general population, insufficient rehabilitative care training, specialized centres and the financial burden to the patients and families. (Dhakal & Groves, 2019; Shah et al., 2013; Shresth, 2015). Orthopedic surgeons lead most rehabilitation hospitals due to a lack of rehabilitation specialists, including physiatrists (Shah et al., 2013). Spine surgeons also advocate for the need for evidence-based practice in Nepal rather than assumptions for better outcomes for PWSCI (Shresth, 2015). There are additional issues, such as delays in surgery for patients with SCI, due to the unavailability of operating rooms and surgical implants (G. R. Dhakal et al., 2018, 2019). These issues raise the question of the effectiveness of treatment for PWSCI and might affect the experience of PWSCI in the acute hospitals of Nepal.

Chamberlain et al. (2015) mentioned that the mortality rates of SCI in low-income countries are three times higher than in high-income countries, which could result from low quality of clinical care in acute hospitals. In Nepal, there are high rates of secondary complications and mortality among patients with cervical SCI admitted to the intensive care unit (ICU) in tertiary care hospitals (Shah et al., 2013). In a research conducted by Ranabhat in Nepal, it was mentioned that quite a few PWSCI had incidents of pressure injuries while they were staying at the hospital and even discharged without receiving proper intervention or education regarding its prevention (Ranabhat, 2016), highlighting the importance of patient safety and the need to minimize harm to the patients that result from potentially preventable secondary complications such as pressure injuries. Reducing harm in SCI could be done by providing education about secondary complication prevention by the care team, as the WHO safety protocol suggests, preventing avoidable harm that could have an adverse effect on the individual to improve safety (World Health Organization, 2018). Patient education is vital to PWSCI in preparing them for community reintegration and facing their everyday challenges (May et al., 2006).

According to Sharma et al. (2018), Nepal lacks patient-centred practice, which might result from the continuous prioritization of disease-centred vertical practice in Nepal's health system. The recent data in Nepal shows that the surgical management rate for SCI is substantially increasing in Nepal (Parajuli et al., 2020). Many PWSCI undergoing surgery, however, are not counselled well and are excluded from decision-making, which could eventually make the post-rehabilitation phase challenging for them (Shresth, 2015). We know from the literature that patients who participate in the decision-making process demonstrate higher treatment adherence and satisfaction (Engkasan et al., 2015). Thus far, we lack empirical knowledge in the acute hospital regarding whether PWSCIs are included in patient-centred practice and, if so, how they are included.

These points mentioned above collectively reflect the need to study the quality of care, which includes effective evidence-based intervention, proper education for safety and patient-centred care from the perspective of PWSCI in the acute setting. No published literature in Nepal has incorporated the patients' experience related to the quality of care in acute or rehabilitation settings. Better outcomes of PWSCI require timely access to patient-centred evidence-based intervention, which is, unfortunately, a challenge for middle- and low-income generating countries. (Khosravi et al., 2022).

2. Why Did I Choose this Research Topic? The rationale of the Study

The Spinal Injury Rehabilitation Centre receives PWSCI from different acute hospitals from all over Nepal. I had numerous opportunities to hear PWSCIs'experiences, struggles, and success stories of recovery during my four-year tenure as a clinical physiotherapist for PWSCI at SIRC. Each patient had diverse perspectives on their care in the acute hospitals. Some patients had positive experiences, while others had negative ones. Some patients received thorough counselling before their spine surgery and were informed about what to expect, while others were not adequately informed. Some patients, for example, believed they would go home directly from the acute hospital immediately after surgery. That surgery would fully restore their paralysis, allowing them to resume their previous lives. They were unaware of the transition to the rehabilitation hospital and the extensive therapy required for recovery, which could take months or even years. Some patients were also not provided with information or basic techniques for preventing secondary complications, such as frequent position changes to prevent pressure injuries and joint movement to avoid contractures in paralyzed limbs. These anecdotal stories deeply affected me, prompting me to investigate the situation in Nepal's various acute hospitals. Upon searching the literature, I found that there are indeed various issues in the healthcare system with respect to PWSCI in Nepal. The identified issues were related to limited awareness about SCI among the general public and medical personnel, a lack of proper policy in Nepal’s healthcare system for SCI care, management and rehabilitation, ineffective strategies for preventing secondary complications, and limited involvement of patients in the decision-making processes for PWSCI (Dhakal & Groves, 2019; Shah et al., 2013; Shresth, 2015, Ranabhat 2016). However, those findings were predominantly from descriptive studies and did not provide a deep understanding of these issues through patient’s experiences. Furthermore, there were no published papers addressing the quality of care for PWSCI.

A study was conducted in Canada by Krysa et al. (2022) that explored the perception of care of PWSCI from acute hospitalization to inpatient rehabilitation. This study was based on acute hospitals and inpatient rehabilitation care sites across the province of Alberta (Krysa et al., 2022). This study concluded that the PWSCI were motivated to improve their functional outcome, desired to have more knowledge of SCI and rehabilitation, perceived a need for effective communication with the care team, and wanted to know more about the resources to facilitate the discharge process and reintegration to the community. However, the findings and conclusions drawn from this study in Canada may differ from those that can be gleaned in Nepal due to various social, cultural and developmental aspects. I, therefore, decided to undertake this qualitative research to gain a comprehensive understanding of the situation objectively and scientifically and to gain deeper insights from individuals who lived through this particular experience.

3. Statement of the Problem

The literature review on SCI in Nepal, combined with my personal clinical experience, shed light on various concerns regarding the acute care of PWSCI in Nepal. These concerns, as identified in the literature, coincidentally align with the three core domains, effectiveness, person-centredness, and safety, which define the quality of care provided by the WHO for middle and low-income generating countries.

We lack information about the positive and negative experiences perceived by the patients during acute care, including factors such as the frequency of doctor visits, available services, and resources in the hospital with respect to the effectiveness of care for PWSCI. Similarly, in terms of patient-centredness, there is limited understanding of how patients are involved in the communication and decision-making processes before spine surgery or transitioning to rehabilitation hospitals. As for patient safety, there is insufficient information on whether education sessions were provided in acute hospitals to prevent secondary complications such as pressure injuries and joint contractures, and if so, how effective these sessions were from the patient's perspective.

Therefore, recognizing these gaps in the literature, coupled with my curiosity and personal experience as a physiotherapist working with PWSCI in a rehabilitation setting, drove me to identify the need for this study and formulate the research question.

4. Research Question

What are the experiences of PWSCI related to quality of care during acute hospital stays in Nepal?

5. Objectives of the Study

- To understand the positive and negative experiences perceived by PWSCI during the acute hospital stay.
- To describe how PWSCIs are involved in decision-making and counselling in the acute hospital before spine surgery.
- To discuss how PWSCI are educated about secondary complications (e.g., pressure injuries and joint contracture prevention) and the patient's perspective on its effectiveness.

6. Research Methodology

Quantitative research is successful in investigating, analyzing, quantifying and replicating some phenomena. The study of some human phenomena, however, is unique, and the quantitative approach may not accurately answer the research question (Streubert & Carpenter, 2011). Therefore, for our study, we planned to use qualitative research methodology to understand the experience of PWSCI. Qualitative methods capture an individual's perception, experiences, culture, behaviours and knowledge instead of quantifiable aspects such as how many or how much (Tenny et al., 2017). Qualitative approaches facilitate the investigation of human life experiences by recognizing and honouring the importance of subjective experiences (Streubert & Carpenter, 2011). The essential characteristics of most qualitative research include a) accepting the fact that there exist multiple realities, b) the researcher is a research instrument and should stay committed to the participant's viewpoint, and c) reporting the findings in literary style with the participant's quotations (Streubert & Carpenter, 2011). There are various types of qualitative methods, with the most commonly used being ethnography, grounded theory, narrative research, case study and phenomenology (Creswell, 2007; Streubert & Carpenter, 2011; Tenny et al., 2017). In qualitative research, researchers follow various philosophical assumptions such as the study of knowledge and how the researcher knows what they know (epistemology), the nature of reality and its characteristics (ontology) and the methods used (methodology) (Creswell, 2007). The epistemological stance for this study is constructivism which believes that findings are constructed through interactions among the researcher, participants and their surroundings (Denzin & Lincoln, 2018). The ontological stance is that there exist multiple realities which are subjective and include the different perspectives of the participants as well as the researcher's own experience (Creswell, 2007; Denzin & Lincoln, 2018). The methodology used for this study is phenomenology.

Phenomenology is the study of the conscious lived experience of the participants (Streubert & Carpenter, 2011). This method helps us to explore and understand the particular phenomena, why and how the participants responded in a certain way as they lived those experiences every day. (Streubert & Carpenter, 2011; Tenny et al., 2017). There are various phenomenological philosophies and guidelines provided by many authors, e.g., Edmund Husserl, Martin Heidegger, Hans-Georg Gadamer**,** Max Van Manen and others (Streubert & Carpenter, 2011). Understanding these philosophical underpinnings is crucial to knowing the strengths, weaknesses and accurate interpretation of the approach that a researcher is following (Streubert & Carpenter, 2011; Tenny et al., 2017).

6.1. Max Van Manen's phenomenology approach

I used Max Van Manen's phenomenology approach to understand the experiences of PWSCI in acute hospitals. Van Manen's approach is considered a new phenomenology that combines the descriptive phenomenology of traditional approaches (e.g., Husserl) and interpretative phenomenology (Dowling, 2007). Even though phenomenology lacks a specific method, Van Manen suggested the researchers could use the following six methodological themes:

1. "turning to the phenomena which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomena through the art of writing and rewriting;
5. maintaining a strong and oriented relation to the phenomena;

6. balancing the research context by considering parts and whole" (Van Manen, 2016, pp. 30-31).

Our findings could provide a broader understanding of the phenomena by both describing and interpreting the participants' experiences. Similarly, we could use the above-mentioned methodological guidance provided by Manen to meet the objective of conducting this research, which is rarely provided in other approaches. Hence, these are the justifications for using Max van Manen's phenomenological approach.

I tried my best to follow the above guidelines. I started my project with a research question: What are the experiences of a PWSCI related to quality of care during acute hospital stays in Nepal? This question deeply interested me because of the different positive and negative acute care experiences of PWSCI while I was working as a physiotherapist at SIRC. These mixed stories from my patients made me curious to understand the acute care experience of PWSCI scientifically. Therefore, I was committed to conducting this research. Unlike other phenomenological research, which demands the bracketing of the researcher's experiences, my preunderstanding, beliefs, and presuppositions are not a hindrance to Van Manen's approach. He argued that ‘‘if we simply try to forget or ignore what we already ‘‘know,’’ we may find that the presuppositions persistently creep back into our reflections’’ (Van Manen, 1990, p. 47 as cited in Dowling, 2005). Our experiences, understandings, biases, assumptions, and prejudices should always be fully expressed and used as a starting point (Streubert & Carpenter, 2011). Van Manen believes that our own life experiences are immediately accessible to us. Hence, we should take advantage of this and use it as the starting point (Van Manen, 2016).

"The point of phenomenological research is to 'borrow' other people's experiences and their reflections on their experiences and their reflections" (Van Manen, 2016, p. 62). In this study, I used a semi-structured interview guide to investigate and ‘borrow’ the participants’ experiences.

Furthermore, using the selective or highlighting method suggested by Van Manen, I reflected on the essential themes that portrayed the essence of my participants' lived experiences.

According to Van Manen, “To write is to measure our thoughtfulness. Writing separates us from what we know, yet it unites us more clearly with what we know. Writing teaches us what we know and in what way we know what we know" (Van Manen, 2016, p. 127). Therefore, considering Manen’s words I wrote and interpreted my findings to clearly and better understand the care experience of my participants in the acute hospital. The more I wrote and re-wrote the findings and interpretation, the clearer I was about my participants’ experience. This might be because I went through the transcripts again and again and tried to dive deeper to understand what their experience really meant.

There is always the temptation to settle for superficial findings and preconceived assumptions or wander aimlessly if the researcher is not oriented to the research question or phenomena under study (Van Manen, 2016). There were many instances where I was about to conclude my findings. However, after peer debriefing and receiving feedback from supervisors, I gained a better understanding of PWSCIs’ experiences. I was also constantly aware of my research question and objectives, and I tried to be fully oriented towards them to explore the phenomenon.

We should constantly be aware of our overall question or goal and should move back and forth to balance between the part and the whole (Van Manen, 2016). It is easy to get lost in the text, so it is necessary to take time to go back and compare the part with the whole (Van Manen, 2016). At several points, I had to revisit my transcripts, participants' quotes and results to balance the research context.

Although Manens' method is widely referenced in health research (Creswell, 2007), it has some limitations. Firstly, the findings from this study cannot be generalized as it is not empirical analytic science (Van Manen, 2016). This means the findings from our study were specific to the participants at a particular time, so the results might vary if conducted by another researcher at another time. Therefore, the findings cannot be generalized to represent the acute care experience of all PWSCI in Nepal. Secondly, it cannot be used as a problem-solving as it does not provide any solutions to the problem (Van Manen, 2016). This study can provide recommendations and insights for improvement, but it does not offer robust solutions. For example, it does not provide specific measures to enhance the quality of care for PWSCI in acute hospitals.

6.2. Explicating the researcher's beliefs

In qualitative research, it is best to make clear thoughts about the topic as well as the personal biases of the researcher (Streubert & Carpenter, 2011). The sole purpose of this step is to bring our assumptions to consciousness regarding the topic and to ensure that the whole research process is bias-free from the beginning. Explicating personal biases enables us to understand our standpoint and facilitates the collection and analysis of data with honesty and openness (Streubert & Carpenter, 2011). My intersectional identity as a female from an upper caste, low-middle income-generating family, who is the first person to go to college, and my positionality as a physiotherapist who is an insider in this research, familiar with the research setting and experienced with PWSCI, could unintentionally or unconsciously interfere with the research process. For example, I might choose a research participant from a similar caste or geographical area, or my interactions and probing during the interviews could be biased. This could lead to overlooking particular perspectives. To best address these issues, I engaged in reflexivity, self-awareness, and transparency throughout the research process. According to Streubert & Carpenter (2011), the best way to address own's positionality is to write it down. So, I documented my assumptions that PWSCI were not involved in the decision-making process for their care and were not adequately educated about SCI and secondary complications prevention. I committed to being constantly aware of these assumptions throughout the research process, from data collection to data analysis and interpretation.

Working in a rehabilitation hospital as a physiotherapist, I interacted daily with PWSCI, who were referred from acute hospitals. I encountered some challenges in treating them, which led me to believe that PWSCI were not provided with enough information and counselling in the acute hospital to prepare them for rehabilitation. They had numerous expectations and unresolved queries regarding their prognosis. My intuitions, combined with the patient's stories, were somewhat supported by the literature reviews presented earlier. However, the available papers were primarily based on the quantitative approach and did not clearly address the aspects I was seeking. Hence, I planned to conduct this research to explore further what is happening in acute hospitals.

7. Thesis Outline

The goal of this study was to understand the experience of people with spinal cord injuries regarding the quality of care during their acute hospital stay. The available literature in Nepal did not investigate this topic enough and raised questions about the effectiveness, patient-centredness and safety of the PWSCI. The literature review and my personal experiences encouraged me to conduct this research.

Chapter 2 provides the details about the study, which consists of the introduction of the study, methods of data collection, analysis, results and discussion.

Chapter 3 addresses the trustworthiness of the study findings, strengths and limitations, future directions and personal reflection.

Chapter 2: Thesis Paper

Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal

1. Introduction

Spinal cord injury is a life-altering injury that often results in physical impairments, psychosocial issues, and decreased quality of life that generate financial burden to individuals, families, society, and the nation (Fehlings et al., 2017; Krueger et al., 2013). The rehabilitation phases of SCI are divided into 3 phases: acute, sub-acute, and chronic (Burns et al., 2017). The goals of the acute phase are to treat the underlying impairments, maximize the neuro recovery, prevent secondary complications, and prepare patients for further rehabilitation (Burns et al., 2017; Fehlings et al., 2017). Understanding the quality of care from the perspective of people with lived experience can be essential to reflect how a patient is cared for in an acute hospital and address the unmet needs to achieve a better outcome in the rehabilitation and community setting (Krysa et al., 2022). These experiences are well-studied in developed countries; however, this knowledge is lacking in developing countries like Nepal. There could be considerable discrepancies in the experiences of PWSCI between low-resource settings like Nepal and other Western countries, and conclusions cannot be directly drawn from those studies. Various factors such as high mortality rates (Chamberlain et al., 2015), significant out-of-pocket expenses, inaccessible topography, cultural beliefs, inadequate healthcare policies, shortage of trained human resources, limited availability of medical facilities, equipment, rehabilitation, services for PWSCI (Shah et al., 2013) contribute to these notable differences. Nepali people, additionally, strongly believe in traditional treatment options such as shamans, herbal medicines, and spiritual healers, often choosing to employ multiple methods simultaneously during illness (Subedi, 2001). They also believe disability is a consequence of evil past deeds and misfortune (Aryal & Aryal, 2022).

There are additional issues in Nepal with respect to SCI. There is no proper information (published literature, government surveys or reports, registry data) regarding the nationwide prevalence and incidence rate of SCI in Nepal (Shresth, 2015). It is accepted in developed countries that rehabilitation requires the participation and treatment of a multidisciplinary team such as doctors, nurses, physiotherapists, occupational therapists, psychologists, prosthetists/orthotists, social workers and peer counsellors for better outcomes. (Ahuja et al., 2017). In Nepal, however, there are a few schools for physiotherapy but none for physical medicine and rehabilitation physicians, occupational therapy and prosthesis/orthosis (Dhakal & Groves, 2019); therefore, that may contribute to limited multidisciplinary team intervention in acute hospitals. Many PWSCI in Nepal, for example, acquired pressure injuries while in the hospital, and some patients are discharged from the hospital without intervention or education related to pressure injury prevention (Ranabhat, 2016), potentially imposing risk to their health and safety. There is currently no information on the efforts by acute hospitals for secondary complication prevention in Nepal (Wee & Schwarz, 2004). Researchers, in addition, believe that Nepal’s healthcare system lacks patient-centred practice because the focus is still on ongoing disease-centred practice (Sharma et al., 2018). Data shows that 76.7% of PWSCI in Nepal are surgically managed (Parajuli et al., 2020); yet, despite this high rate of surgical intervention, some patients are not provided with sufficient counselling regarding what they should and should not expect after surgery (Shrestha, 2014). Evidence shows that involving patients and their families in the decision-making, planning, and evaluation of health services will help to prioritize their needs and provide guidance to ensure quality care (World Health Organization, 2018).

There was a requirement to establish a robust matrix that outlines the quality of care to comprehend these experiences considering the literature and the absence of studies that explored PWSCI's experience of quality of care during acute hospitalization in Nepal. Multiple organizations, namely the Institute of Medicine, the European Commission, and the Council of Europe, offer definitions of quality of care. This study adopts the framework outlined by the WHO. The WHO provided the framework for improving the quality of care for low- and middle-income-generating countries as it might be challenging to build policy and strategy in those resource-constraint nations (World Health Organization, 2018). It focuses on three main domains: effectiveness, safety, and people-centredness (World Health Organization, 2018). These domains are essential aspects of a patient's experience within the healthcare system.

2. Materials and Methods

2.1. Design

The understanding of the human experience demands the use of a qualitative approach rather than a quantitative approach (Streubert & Carpenter, 2011). This qualitative research study was conducted through in-person interviews with PWSCI at the SIRC, where the patients were referred from different private, government, and semi-government acute care hospitals across Nepal. This research utilized Max Van Manen's phenomenology approach to understand the experiences of PWSCI in acute hospitals. The reason for using Manen's phenomenology method is that it emphasizes both a descriptive and interpretive approach to understanding human experience (Dowling, 2007). The aim of conducting this research was to understand the experience by describing participants' experience and interpreting the findings, providing recommendations and improving the quality of care.

Unlike other phenomenological methods, bracketing prior experience is not recommended. Instead, the researcher's experience can be embraced and used as the starting point for the study (Van Manen, 2016). It is not easy for me to completely forget my assumptions based on my experiences. Therefore, using Manen's approach is appropriate for my study, where I used my experience as a starting point. Furthermore, Manen provided a clear and rigorous methodology to conduct the study, which is often not seen in other approaches. These methodological steps provided deep understanding, clarity, and trustworthiness to the findings. This approach is also widely accepted and used in the health sciences research.

2.2. Research Instrument

A group of SCI experts, including physiatrists, nurses, and people with lived experience, formulated and revised a semi-structured interview guide (Appendix A). The interview guide was prepared in English and then translated into the Nepali language (Appendix B). A pilot test was done with a person who had lived SCI experience in Nepal before the actual interview, and it was subsequently applied to the study participants. The Checklist-Consolidated criteria for reporting qualitative studies (COREQ), the 32-item checklist (Appendix C), was used to document crucial aspects such as the interview process and research team, analysis and findings, and to ensure the rigour of the study (Tong et al., 2007).

2.3. Research Setting and Sampling

The data collection was between January and March 2023 at the SIRC, Nepal. The SIRC is the only SCI-dedicated multidisciplinary non-profit and non-government rehabilitation centre that admits around 300 patients per year from all the regions of the country (Dhakal et al., 2021). According to unpublished SIRC patient data, 89% of TSCI and 11% of NTSCI patients were referred from fifteen different acute hospitals across Nepal in 2023.

Data collection was done using purposive sampling. Participants were purposively selected to have diversity in demographics, including the mechanism of injury (i.e., TSCI or NTSCI), level of SCI (i.e., cervical, thoracic, and lumbar), management approach (i.e., surgical vs. conservative), referring provinces and types of acute hospitals (i.e., government, semi-government or private). Including participants from various demographics allowed for a more comprehensive understanding of care experiences, as these experiences may differ depending on factors such as the type of injury. For instance, individuals with TSCI might have distinct experiences compared to those with NTSCI. In TSCI cases, the injury often occurs suddenly, leading to shorter acute hospital stays, whereas NTSCI may involve a gradual onset of the condition and potentially more extended hospital stays.

2.4. Eligibility Criteria

The inclusion criteria included PWSCI (tetraplegia or paraplegia), who were 18 years and older and were able to give voluntary consent to share their personal information. The participant needed to speak and understand Nepali and be directly admitted from the acute hospital to SIRC within six months of their SCI. Participants with significant memory and cognitive impairment were not included in the study.

2.5. Ethical Considerations

This study received ethical approval from the research ethics board of the University of Alberta (Study ID: Pro00120912), the ethical review board from the Nepal Health Research Council (NHRC), and the SIRC. For participants with low literacy levels, the interviewer or family members read the participant information and consent form for them. The written consent (Appendix D and E) was obtained from all the participants only after they had given verbal consent to participate in this study.

2.6. Recruitment

The nursing staff at the SIRC prepared a list of potential participants and then asked for verbal consent to release their information to the researcher. Only after the participants agreed, nursing staff handed over the list including potential participants to the researcher. The researcher then approached the participants, received verbal consent again, provided an information sheet and finally signed the consent form from the participants before the interview. The recruitment material (Appendix F) was posted on different sites at SIRC to call participants to the study. Peer counsellors provided study information after the weekly group therapy sessions at SIRC. Most of the participants were interested and directly contacted the researcher. Physiotherapists and other nursing staff helped in recruitment by introducing interested potential participants to the researcher.

2.7. Data Collection

Data were collected through interviews using a semi-structured format and open-ended questions, which is considered a gold standard in qualitative research (Streubert & Carpenter, 2011). The interview process started with more general questions and then specific questions. Probing questions were further used to obtain details and clarify the participants' descriptions. Field notes were taken during the interview. The interviews were scheduled according to the participants' availability in a private, sunny room and lasted 17 to 32 minutes. The interview was audio recorded using a Sony audio recorder, ICD-UX560 model. Reflection on the interviewer's biases and frequent reminders to participants that the experience is about the acute hospital, not of SIRC, as well as privacy protection, was considered before and during the interview process.

Before the interview, participants were contacted to build rapport, provide information about the study, and sign the consent form. Data collection continued until saturation was reached, which occurred after 24 participants were interviewed. Table 1 summarizes the participant demographics.

Table 3: *Participant Demographic Information*

Characteristics	Number	Characteristics	Number
Sex		**Age**	
• Male	17	• 18-28	8
• Female	7	• 29-39	5
		• 40-50	7
		• 51-61	3
		• Above 61	1
Education Level		**Level of Injury**	
• Illiterate	4	• Cervical	12
• Under 10th Grade	11	• Thoracic	7
• High School (Incomplete/complete)	5	• Lumbar	5
• Graduated	4		
Provinces		**Length of stay in acute hospital**	
• Koshi	6	• 15 days or less	10
• Madhesh	4	• 16 days to 1 month	7
• Bagmati	3	• 32 days to 1.5 months	5
• Gandaki	3	• More than 1.5 months	2
• Lumbini	3		
• Karnali	4		
• Sudurpaschim	1		
Mechanism of injury		**Acute Hospitals**	
• Fall from tree/height/cliff/house	17	• Private/non-government (5)	7
• Motor Vehicle Collision	5	• Government (2)	15
• Disease condition (tumour, spine tuberculosis, spine degeneration)	2	• Semi-Government (2)	2

Note: There were five different private hospitals, two different government hospitals and two different semi-government hospitals.

2.8. Data Analysis

The audio interview recordings were transcribed *verbatim* into Nepali transcripts. The transcripts were repeatedly checked with the audio recordings and corrected in case of errors. The data collection and analysis was an iterative process. Three data analysts independently coded the transcripts. One of the analysts used NVivo for data management, while the other two used manual methods for data analysis. All three analysts reviewed all 24 transcripts for data analysis. One of the analysts lacked experience in SCI, while the other two had prior experience working with PWSCI. Consequently, this was an advantage for the research team as the analyst without experience provided an outsider's perspective, potentially mitigating any personal positionality. The two analysts with the positionality expressed their biases fully and were aware of them throughout the data analysis process. The biases of analysts were as follows: PWSCI in acute hospitals were not provided with proper education regarding their condition and secondary complications. They were not included in proper counselling before surgery.

In this research, we used a selective or highlighting approach to isolate thematic statements from the interview transcripts, as suggested by Max Van Manen (Van Manen, 2016). The transcripts were first read repeatedly, and the phrases that stood out and portrayed the meaningful experience of the participants were highlighted and coded into meaning units. The meaning units were categorized afterwards into themes and sub-themes and then were put together with rich descriptions of the participants extracted from the interview transcripts. Moreover, experiences that were unique and could be valuable to report were not missed. Instead, they were incorporated into the results paragraphs rather than being grouped into separate themes or sub-themes. Each of the three analysts worked independently to identify codes and themes and came to their conclusions. Subsequently, after discussions and agreements over several Zoom meetings, the results were finalized. There were no significant disagreements; however, there was extensive discussion regarding the categorization of sub-themes into the main themes.

2.9. Language and Translation

All the interviews were conducted in Nepali language. The Nepali speakers (Srijana Gautam, Mandira Baniya and Prabita Shrestha) did the data analysis. It was first done in Nepali language to prevent the loss of data during translation and then the findings were translated into English. The translation was checked at the end by researcher Prabita Shrestha to see if the translation missed any vital information. The participants' quotes are in simple English. They may contain some structural errors which were intentional to accurately portray and preserve the participant's actual words, which could otherwise be lost if corrected.

3. Results

Five main themes and twelve sub-themes were identified, as shown in Table 4.

Table 4: *Themes and Sub-Themes*

1. Limited communication	**2. Limited education and knowledge**	**3. Limited participation in decision-making for care**	**4. Limited access to resources**	**5. The importance of providers' demeanour and conveyance of hope**
1. Patient and doctor meeting times were only during the medical rounds. 2. Patients obtained information about SCI only after asking.	1. Preventive measures and education for secondary complications like pressure injuries were recalled but not for other complications. 2. Patients were unaware of or dissatisfied with the reasons provided for delayed surgery. 3**.** The mismatch between participants' expectations of surgery and post-operative care and what they received.	1. Family members, rather than the patients, were often involved in counselling/interaction with the care team. 2. Limited participation of patients before surgery. 3. Co-decision-making in critical matters, such as the transition of care from acute hospital to rehabilitation, could often be limited and delayed.	1. Participants perceived that pre-existing relationships and connections favoured access to treatments. 2. Many patients admitted to government hospitals had minimal to no physiotherapy intervention.	1. Patients reported that the positive behaviours and demeanour of the care team mattered a lot to them and wanted to see more of it. 2. Patients felt hopeful and motivated when the surgeons showed interest in their care after surgery.

3.1. Limited communication

The participants expressed that they had limited communication with the care team. Families were more involved in communication with the care team than the patients most of the time. Participants were curious, confused and wondering what was happening to them, and many of them did not get answers. Many participants also did not know whether or not their family members were told about their condition, and yet they did not ask their family members about it. Some participants mentioned that they were not in the condition to ask the care team questions because of the seriousness of their condition.

3.1.1. Patient and doctor meeting times were only during the medical rounds. Most participants reported interacting with the care team only during the bedside medical rounds, either in the morning or evening. The participants would wait for the doctors to interact or understand their condition the whole day. However, the medical team would usually visit them for a few minutes, speak among themselves in a language that was difficult to understand and leave without much interaction with the patients. The interactions mainly occurred in front of the visitors/families or other bystanders. The common topic of discussion between the patients and doctors was related to the latest medical reports, asking about the general wellness of the participants and doctors requesting them to move their legs.

P4: "*......They used to come in a group during rounds, talk among themselves and leave. We did not talk in a separate room....I did not get a chance to talk with them there."*

P8: " We did not interact much... they used to come (in the round) for one/two minutes and give some suggestions and leave, that's all happened there."

P17: "I did not understand them quite well… they used to speak rapidly during rounds. They did not talk with me personally or separately..."

P11: "All the interactions were in front of my sons at the bedside. They came during rounds and asked how I was feeling and then left."

P14: "No. Every counselling was in front of everyone, not in a separate room."

3.1.2. Patients obtained information about SCI only after asking. The participants shared that they had to ask the care team, family members or even some random people (especially if they are from the same ethnicity and share a common language) questions in an attempt to obtain information about their condition. They did not receive the information without asking.

P1: "Doctors did not talk with me. No direct interaction. After I came here (SIRC), I only talked to him over the phone. I was asking him questions, but he did not say anything directly to me."

P5: "There was a Tamang (ethnicity) brother. His wife was a patient there as well. She had a sister (a visitor). We asked them (to teach the exercise)."

P9: "They (the care team) did not say anything themselves. I was the one asking."

P18: "Apart from my family members, no one in the hospital gave me advice or information. Hospital staff also did not say anything."

3.2. Limited education and knowledge

The participants perceived that most of the time, they were in the dark; they often lay in bed in complete shock, lacked mobility, and were unaware of their medical condition, prognosis, and consequences. Most of the participants believed that the care team should share information with the patients rather than withhold it, while some believed that they should not be told everything early to prevent them from panicking.

Some participants believed in fate and misfortune more than the facts and information and also blamed themselves for their current condition. This behaviour of blaming self is not uncommon in the Nepali context.

3.2.1. Preventive measures and education for secondary complications like pressure injuries were recalled but not for other complications. Pressure injury prevention protocol was carried out well with most of the participants, but education on other secondary complications was not recalled. Nurses and doctors used to provide education about frequent position changes, the use of air mattresses, applying oil or lotion, and massage to the participants and their family members with respect to pressure injury prevention. The health care team also instructed patients to ask for help whenever required. Some participants, however, reported that they did not get any education on pressure injury prevention. A few incidents of pressure injuries (3 out of 24 participants) were reported by our participants as well. None of them were provided with reading materials or pamphlets regarding secondary complications or SCI information.

P5: "No, any such thing (secondary complication education) happened."

P11: "No! No! We did not have a pressure injury or get any information about it."

P16: "Yeah! They used to say, "You might get pressure injuries. If you have a pressure injury, then you will not be allowed to do therapy there, and it will be difficult to heal it, so be careful." I was being cared for daily."

P21: "I had a pressure injury while I was in the ICU. But, they healed it there and sent me here (SIRC)."

3.2.2. Patients were unaware of or dissatisfied with the reasons provided for delayed surgery. Anxiety and tension were created when the participant's spine surgery was delayed, cancelled, or did not happen at all. They also blamed delayed surgery for their bad prognosis. One participant also thought it would have been better for him if he had not undergone surgery. He felt he wasted much money on the surgery, which did not show any improvements. Most of the participants had concerns related to the timing of spinal surgery. Some participants had to wait for months for surgery but had no idea why surgeries were delayed; others had surgeries cancelled several times, and, in some cases, surgeries were cancelled and never rescheduled, or the doctors changed their minds. Those who were provided reasons like unavailability of surgeons or operating theatre were not satisfied with the reasons provided.

P5: "I also wondered why my surgery was delayed. Many thoughts came to my mind like I would have recovered and gone home if the surgery had been on time, but why do I have to go through all of these?"

P10: "I was kept in the emergency department for three days. That is why my surgery was delayed, and that is the reason for my present condition."

P15: "I felt like it was best if I had not done the surgery."

3.2.3. The mismatch between participants' expectations of surgery and post-operative care and what they received. Most of the active interactions of the care team with participants were just after the surgery. The most common statement from the doctors was, "Your surgery went well or was successful." They also talked about a referral to the rehabilitation hospital. Participants expressed that they did not get all the information regarding the prognosis and consequences after surgery. Participants "felt hurt" when they had to go to a rehabilitation hospital instead of home after surgery. They wondered why they were being referred to another hospital instead of going home directly from the acute hospital. They also felt good when they started seeing improvements because of the surgery; even undergoing surgery made them happy.

P3: "I thought after surgery I would be fine soon, but I did not like it when I was referred here."

P5: "While I was brought to the hospital, I thought it was just a minor surgery. I did not know I would be in this situation now."

3.3. Limited participation in decision-making for care

The overall experience of the participants was that most of the decisions for patients were taken by the family members without consulting or considering their opinions. The patients were hardly included in patient-centred care.

3.3.1. Family members, rather than the patients, were often involved in counselling/interaction with the care team. Care teams were more comfortable talking to the family members than the patients. They did not speak directly with the patients.

P3 “They did not tell anything to me but to my brother and sister-in-law.”

P10: “Those interactions happened with my brothers and wife. It was done outside. In fact, I am the patient, but it did not happen near me. I heard them talking outside only.”

P24: “Those things I do not know. What communications happened between my family and doctors, I have no idea.”

3.3.2. Limited participation of patients before surgery. Participants had no idea of what happened to them and what to expect. Most of the participants did not have proper interaction or talk with the surgeon before surgery. Family members or patients got answers about surgery only after they asked the questions to doctors.

P10: “My wife asked a doctor who was of the same ethnicity as mine, “Where is the surgery of my husband? What happened to him?” Then we got the answers in detail.”

P16: “They did not make me sit for a conversation to talk about my condition…just told me that I have to undergo surgery so that at least I could be in the wheelchair, which is their main goal. They said recovery depends upon therapy. Some recover from that, some may not.”

P18: “But those sorts of conversations never happened with me…They did not tell me anything about the surgery.”

P19: “Before surgery, they did not have any talk with me.”

3.3.3. Co-decision-making in critical matters, such as the transition of care from acute hospital to rehabilitation, could often be limited and delayed. The transition to a rehabilitation hospital or SIRC was often told to the patients by the surgeons after surgery just before discharge. The process did not involve co-decision-making. Patients often hear about these from other neighbouring patients or their families. SIRC staff who visit different acute government hospitals every week help patients transition to rehabilitation centres. Some doctors connect the patients to the visiting SIRC staff, and this makes the transition process smoother for some patients and their families in government hospitals.

P9: "My brother had told me about that already. Doctors suggested that to him."

(about the transition to the rehabilitation centre)

P13: "After surgery, just before the discharge, I knew about the transition to the rehabilitation hospital."

P19: "Yes! It would have been better if they had mentioned it before."

P24: "2 to 3 days after I was transferred to the ward, there was a man from here (SIRC) from the social department; he explained everything to me."

3.4. Limited access to resources

Participants perceived inequity in health care delivery. They had limited access to services like early surgery and physiotherapy services in government hospitals. Two participants transferred from the government hospital to a private hospital because there was a delay in planning the surgery and also for better care. They believed they did the right thing by moving from the acute government hospital to the private hospital. Some of the participants also encountered partiality in the treatment based on social status and affiliation with the hospitals or powerful people.

3.4.1. Participants perceived that pre-existing relationships and connections favoured access to treatments. Participants expressed that the one who has links or relations with high-status or politically powerful people has more advantage in the hospitals, either government or private, than other people in similar situations with no connections. Two of the participants communicated that because of their link to the hospitals and the doctors, they had higher advantages over others. In contrast, there was one participant who expressed her happiness when she got early treatment without any connections, influence or her status which was unusual in the government hospital setting. She felt fortunate when she compared her situation with her peers.

P1" In (hospital name removed) hospital, doctors and medical officers were my friends and the recognized people of my family. (Doctor's name removed) was my uncle. So it was easy for me. Everywhere, we need power and position. I also used it for my benefit. There is no way of compromising and not using those benefits in this condition."

P18: "In that hospital, as per my understanding, those patients who have links with high status and powerful people are treated as soon as they come to the hospital, but ordinary people like us are not getting the treatment and need to transfer to another place. Even though our cases are more critical than theirs and we should be the priority, those people are prioritized for surgery instead of us. There is the dirty political play of high-status people. It was all clear.

In (private hospital name removed) hospital, I did not notice those sorts of things. All the facilities that a patient deserves they get that easily there and it is good."

3.4.2. Many patients admitted to government hospitals had minimal to no physiotherapy intervention. Almost all the acute hospitals in Nepal have physiotherapy services. Early physiotherapy mobilization and intervention during the acute phase are essential to prevent various life-threatening complications (National Clinical Programme, 2018). Many participants in this study, however, did not receive physiotherapy services even though they had an extended hospital stay. The absence of physiotherapy treatment was primarily seen in government hospitals. The participants' interactions with physiotherapists were very minimal. Those who had physiotherapy sessions also mentioned that these were limited to 2 to 3 sessions throughout their acute hospital stay. Physiotherapists mainly taught the exercises, helped to put on the braces, and provided some information about SCI and secondary complications.

P8: "Did not teach me much. He (physiotherapist) used to come for like 5 minutes and teach exercises more specifically to my family than me."

P17: "No, no exercises there… nurses used to come for medications, but the physiotherapy treatment never happened."

P23: "The physiotherapist taught us to put on a brace and instructed me to move my legs. He came for 1-2 days. He also taught that to my family members."

P24: "Exercises. There? They did not do anything there."

3.5. The importance of providers' demeanour and conveyance of hope

Kind words, positive affirmations, and hope-filled conversations mattered a lot to the participants. Even small talk, such as asking about their wellness and a short visit by the care team, would boost their spirits. Despite the negative experiences of their acute hospital journey i.e., lack of proper interaction and knowledge sharing with the care team, almost all concluded that the positive behaviours of the care team were what mattered to them. By the end of the interview, they mentioned that everything was well, and they were happy with the overall acute hospital experience.

3.5.1. Patients reported that the positive behaviours and demeanours of the care team mattered a lot to them and wanted to see more of it. The patients were happy when the healthcare workers showed them kindness and talked with them. Many participants found nurses to be helpful and friendly. Some participants, however, expressed extreme disappointment in the attitudes and behaviour of nurses and other ground-level staff, such as housekeeping and recommended a change. Some participants reported some nurses to be rude, hesitant to perform their work, and not available when they wanted help. They desired to see more positive behaviours from nurses, doctors and ground-level staff.

P18: "After surgery, I received all the attention that a patient needed, including medicines, care, and supervision. They used to visit me frequently. They also used to ask how I was doing. They also asked and checked if I had any pressure injuries. I liked all these things about that (hospital name removed) hospital."

P6: "Some nurses showered us with good behaviour while some used to yell. When I said that, I wanted to pass stool or some other things. They used to say no, you are not, and were rude. Some were good, some were not. They might be so tired of doing the same thing every day."

P12: "Being an intellectual person, doctors should know how to counsel and interact with someone when they are a victim. I felt the doctors needed those types of counselling related to how to talk with empathy with the patients. I felt the need for those types of counselling once to them (care team)."

P23: "My negative experience was that the responsibilities that nurses should have done were lacking. I think that needs some improvement because that is their duty. The things that the patient asks, either medicine or whatever it is late to deliver. What I saw among the nurses is my negative experience."

P10: "They used to be there talking and asking me how I was doing. When they asked me, "Brother, how are you,' I felt like I would recover."

3.5.2. Patients felt hopeful and motivated when the surgeons showed interest in their care after surgery. Participants expressed their utmost happiness when doctors interacted with them after surgery. Even small talk, for example, "your surgery went well," made them feel delighted.

Some participants also felt more confident when the doctors asked about their condition and that motivated them, providing hope for recovery.

P2: "They had done everything very well. My condition was really poor. They improved my condition and did a great job. My surgery was successful. They used to care for me well and came on medical rounds morning and evening. They used to support, motivate, and tell me not to panic."

P10: "I was delighted because they performed the surgery. Then they also visited me after surgery and told me that the surgery had gone well, and I may be able to walk within three months."

P12: "My surgery was done by (Doctor's name removed) on the 30th. He came the next day and said, "Your surgery went very well, more than we expected. Whatever we saw in *the MRI, it was not that bad while we performed the surgery." He said it like that. I was so motivated after that conversation."*

4. Discussion

The primary objective of this study was to understand the overall experience of PWSCI regarding their acute hospital stay in Nepal. We found various issues in acute care settings with limited communication, education, participation, and resources. At the same time, participants reported that good behaviour and attitudes of the care team mattered the most, leading to the overarching theme that demeanour, kindness, and conveyance of hope mattered most to the patients despite limited communication, education, participation, and access to resources.

When the five main themes and 12 sub-themes were mapped to WHO's three core domains of quality of care (effectiveness, safety and person-centredness), the following findings were noted.

4.1. Effectiveness

Our findings, in terms of treatment effectiveness, suggested that acute care for PWSCI in Nepal appears effective to an extent but falls short in many areas. Some participants expressed that the treatments provided were effective as they had good recovery outcomes because of the skilled surgery team, the care team provided good services, and the facilities and services in the hospital were satisfactory and affordable. The main concern related to effectiveness, however, was delayed surgery, which was one of the negative experiences of many participants. They were disappointed when they had to wait in the emergency department for a long time without any intervention. Delayed surgery was reported to be expected in government hospitals. Patients were in a dilemma regarding the timing of surgery and why it was postponed or cancelled. Some participants, even when they were given reasons, were not convinced and took those reasons to be excuses. Some participants, as a result, transferred to private hospitals, and others waited for their surgery day. Some participants expressed that the possible reasons for this delay could be intentional because it was a government hospital with less monitoring, and surgeons preferred to leave early for private practice elsewhere. Similarly, they also expressed that the powerful connections of other patients with the doctors and political leaders put them in the top priority for surgery over the ones without connections. Whether these perceptions were accurate or not, there appears to be a need for a better understanding of these alleged healthcare inequities, which might have led to delays in intervention within acute hospitals. If these inequities are found to be accurate, they will need to be addressed by the government and authorized bodies.

The concern with delay in surgery expressed by our participants aligned with the findings of two studies by Dhakal et al. describing the timing of cervical and lumbar surgery, delays and neurological recovery following SCI in the government tertiary hospital of Nepal (Dhakal et al., 2018, 2019). No one out of 30 patients had cervical spine surgery within two days of admission, even though 40% of them arrived at the hospital within two days of injury. (G. R. Dhakal et al., 2019). Only 12.1% out of 91 patients had lumbar spine surgery within two days of admission, even though about 69% of them arrived at the hospital within two days of injury (G. R. Dhakal et al., 2018). The recommended surgery time is within 24 hours after SCI (Fehlings et al., 2017). The main reasons provided for the delay were the unavailability of the operating theatre and lack of finances for arranging the surgical implants (G. R. Dhakal et al., 2018, 2019). The authors highlighted the unacceptable practice in resource-constrained settings like Nepal. There was no neuro recovery of motor and sensory complete SCI patients after surgery, but the improvement was seen in the incomplete patients even though the surgery was delayed (G. R. Dhakal et al., 2019). In Canada, about 88% of patients with TSCI reach an acute hospital within two days of injury, and 80% of them have surgery within two days (Glennie et al., 2017). Despite the impressive data from Canada compared to Nepal, the reasons for delays were similar in both countries: unavailability of operating rooms, transportation delays from the injury site to acute hospitals, and the health condition of patients (Glennie et al., 2017). However, some of our participants expressed the same reasons for delayed surgery, while others had different reasons, like healthcare inequities and unavailability of doctors or surgeons.

Another study finding related to concerns with the domain of effective care is the lack of rehabilitative care in the acute care hospital setting in Nepal. Rehabilitation requires the planning and intervention of a multidisciplinary team (Ahuja et al., 2017). It is expected that rehabilitation therapies will be started for PWSCI in acute care hospitals. Despite this requirement, Nepal lacks sufficient human resources, such as physiatrists and occupational therapists (Dhakal & Groves, 2019). Nevertheless, there has been a substantial increase in the number of physiotherapists recently (Dhakal & Groves, 2019), and most acute hospitals have physiotherapy departments. In fact, a study by Hamilton and Rai (1978) mentioned physiotherapy intervention for PWSCI in Nepal as far back as 46 years ago. Despite the increasing availability of physiotherapy in acute care hospitals in Nepal, our study revealed that many patients did not receive physiotherapy regardless of their prolonged hospital stays, particularly in acute government hospitals. This could be due to staffing shortages and the presence of multiple medical conditions or the severity of patients' conditions, making it inappropriate for rehabilitation therapies to be started.

4.2. Safety

Regarding the second WHO domain of safety, our findings suggested that it was potentially a concern in some aspects of the acute care hospitals of Nepal. Some of the participants were clearly explained about pressure injury prevention, and it was not prevalent during their acute hospital stay. Almost all of the participants, however, reported being unaware of other secondary complications after SCI, such as joint contractures and urinary tract infections. The possible reasons could be due to the short hospital stay after the surgery, or the participants might potentially have forgotten about it as they had to process much new information at that time. In fact, a previous study showed that recall by patients could be an issue after SCI. In this international comparative study, the authors tried to assess gaps and identify care processes in two countries, Nepal and Canada, with somewhat different socioeconomic status and healthcare systems (Wee & Schwarz, 2004). Out of the nine Nepali and eight Canadian PWSCI, only 2/9 patients in Nepal remembered the information provided on pressure injury management, and none in Nepal recalled the information regarding DVT, bowel and bladder, and joint contracture management in acute hospitals. On the contrary, 5/8 patients in Canada recalled information about pressure injury prevention (Wee & Schwarz, 2004). In our study, none of the participants indicated the use of informative, educational materials, such as posters, pamphlets, videos and others, to learn about secondary complications and their prevention. Developed countries like Canada have incorporated pressure injury education into SCI care, and patients are frequently educated and provided with educational materials (Wee & Schwarz, 2004). The majority of our participants mentioned that the information provided to them was difficult to understand. Moreover, they could not comprehend the information provided by the care team because it was provided in a hurry. They also expressed that they were nervous about asking again because they thought the care team might react negatively to that. How the education was provided; therefore, might have played a significant role in how patients might remember educational information. Moore (2007) concluded in his study that access to clear and appropriate information tailored for individuals with low literacy levels was one of the priorities of patients in Nepal. Further studies are needed to determine the exact reason(s) for the lack of recall of secondary complication education by our participants in order to address the safety issue directly.

4.3. Patient-centredness

As for the third WHO domain of patient-centredness, this is where many of our themes and sub-themes are matched. Our study found that the treatment provided in acute hospitals for PWSCI did not take patient preferences into account, and they were not involved in the decision-making process regarding their care. Participants expressed that one of their negative experiences was the lack of effective communication with the care team. They mentioned that they did not receive adequate explanations or information about their condition, SCI in general and the rehabilitation process, which may have impacted their ability to participate in the decision-making process. A study from India, a neighbouring developing country, concluded that factors like inadequate SCI education, low education level, and lack of patient education hindered pre and in-hospital care (Chhabra et al., 2018). We can assume that this may be similar in Nepal due to similar socio-economic factors, culture and religion. Some of our findings are also similar to those of Krysa et al. in Canada, where the authors highlighted the need for effective communication and information sharing by the care providers during the hospital stay for PWSCI (Krysa et al., 2022). Similarly, a study conducted in three different states of the US found that PWSCIs want to know about the prognosis of their condition as early as possible from their physician, irrespective of their demographic background (Kirshblum et al., 2016). These findings from developed countries align with those from our study despite differences in cultures and healthcare systems.

Another communication issue that many participants in our study expressed was that they did not even know the names of their surgeons and could not confidently ask them questions. This could have been influenced by a cultural factor in Nepal, where patients feel shy or embarrassed to ask doctors questions. Moore (2007) mentioned in his paper that the majority of doctors in Nepal came from higher caste systems and affluent families. In contrast, many patients in rural areas were illiterate and from lower socioeconomic backgrounds. These social differences and respect towards doctors may cause patients to refrain from speaking up even when they desire to do so. In fact, this was indeed the case for a few participants in our study. They felt more comfortable communicating with the doctors/nurses and others who shared their ethnicity, language or geographical area. Therefore, this ethnic and cultural issue appeared to have affected the acute care experience of our participants, negatively impacting patient-centred care.

Other cultural issues influenced participants’ experiences. Some participants strongly believed that accidents and SCI happened to them because of their misfortune, ill fate or bad luck. Some participants also reported that because of SCI, their families were going through a financial crisis and had to sell property for their treatment. They blamed themselves for their condition and expressed willingness to live their entire lives in such a condition. Such beliefs in Nepali culture are often associated with the idea that their current suffering is a consequence of evil deeds in their previous life. (Aryal & Aryal, 2022). This perception might be seen as a coping strategy to console themselves or a consequence of being provided limited information about SCI, its causes, consequences, and prognosis. It is not uncommon in Nepal to attribute illness to ill fate and misfortune (Subedi, 2001). Moore (2007) recommends in his study that the healthcare team should undergo training to effectively communicate with patients, taking into account their backgrounds, preferences and cultural beliefs. Interestingly, despite these cultural beliefs, participants still desired more communication and information from the medical teams regarding their SCI, as discussed above.

Some participants in our study also expressed that the care team interacted more with the family members than with the patients themselves, even though the patients wished to be part of the discussion. This could be attributed to cultural factors as well in Nepal, where the majority of the population still resides with their extended family. A follow-up study by Scovil et al. (2012) found that approximately 90% of the participants with SCI live with their family members. The authors of the same paper mentioned that the majority of the participants in their study could not access a wheelchair inside the house and could not use the toilet independently (Scovil et al., 2012). Similarly, the family members actively participate in pre-hospital SCI care and transportation to the acute hospital (Shrestha et al., 2022). These two contexts suggest that PWSCI frequently rely on their family members for both pre-hospital and basic day-to-day support within the community. These are common cultural practices in Nepal, where families are typically expected to care for their families, regardless of financial or other personal challenges. All these factors may contribute to the increased involvement of family members in the care of PWSCI compared to the PWSCI themselves. While the involvement of the family members in the care process is essential, the patients for whom the care is intended; however, should come first to be patient-centred.

Shared decision-making with patients is an expectation for patient-centred care. (Engkasan et al., 2015). None of our participants reported being involved in the decision-making process before undergoing spinal surgery. Similarly, the decision to transition to the rehabilitation center was also most often made by others for PWSCI. Moore (2007) highlighted that in Nepal, the practice was more doctor-centred than patient-centred, and patients accepted giving up control and entirely relying on the information or decisions provided by the doctors. However, patients were worried about their future. They wanted doctors to provide them with preventive education, treat them with respect in a friendly manner and collaborate as partners in their care (Moore, 2007). The author provided recommendations that doctors should address these issues and be flexible and willing to change the hierarchy of doctor-centred care (Moore, 2007). This study by Moore, notably, was conducted in the outpatient setting, which was different from inpatient SCI care in terms of complication, prognosis and long-term care needs. However, the recommendations related to doctor-patient relationships and cultural aspects could be equally applicable to this study. Of note, many participants in our study reported that because of their poor health condition, they could not ask questions and be involved in the decision-making process. These findings are consistent with a previous Swiss study (Scheel-Sailer et al., 2017). Appropriate shared decision-making with patients during acute care after SCI that takes into account their medical situation is certainly a complex area that deserves to be addressed in order to enhance patient-centredness and the acute care hospital experience of PWSCI in Nepal.

Interestingly, despite identified gaps and ample areas for improvement in PWSCI experience, in accordance with WHO domains in acute hospitals, participants generally perceived their overall experience as positive or satisfactory. They expressed contentment with other subtle aspects of care, such as early surgery due to their powerful connections, positive recovery outcomes, referral to SIRC, the care team's kind gestures and frequent doctor's visits. This might have been due to several factors. Firstly, individuals might have wanted to refrain from expressing only negative feelings and most probably preferred to share positive aspects of their care and the care team as well due to cultural values. Secondly, they might have had limited awareness of consumer rights or medical litigation, which is prevalent in Nepalese society (Moore 2007).

5. Recommendations

The findings from our study suggest that there are several areas for improvement in acute care for PWSCI in Nepal based on WHO domains of quality care. We found that all three domains, i.e. effectiveness, safety and people-centredness, were compromised.

The findings from our study can help policymakers, hospital administrations, and health professionals in Nepal understand the current state of care for PWSCI in the acute setting. They can make use of the patient's experience, identify the needs and address them on multiple levels to achieve better experiences for the patient. To address these issues and improve the quality of care, different actions could be initiated from various levels.

The health care team's role at the individual level could be involvement in evidence-based practice, conducting research and translating it into practice, promoting ethical practice, and frequent education sharing and training (World Health Organization, 2018). Prioritizing effective communication with patients and respecting their socioeconomic background, literacy levels and cultural beliefs is recommended at the individual level. Providing sufficient consultation time with the patients, including during the medical rounds, is also suggested.

Participants appreciated the compassionate and motivating behaviour of the care team, so these demeanours are expected to be continued by the care team.

Hospital administration could focus on situation analysis (through patient satisfaction surveys and interviews) and provide technical guidance in quality improvement in different ways such as clinical audits, monitoring safety guidelines, mortality reviews, competent management teams and operations (World Health Organization, 2018). The hospital could provide the arrangements to utilize different modes of communication or knowledge-sharing methods such as audio, video, pictorial formats or plain Nepali language. This is necessary to accommodate individuals with low education levels and could facilitate memorizing the information provided by the care team. The hospital could also develop its quality of care guidelines to ensure high-quality treatment for PWSCI. Focusing on patient-oriented research, its dissemination and utilization. Provision of training, motivation and incentives to the staff or department who demonstrate high quality of care. Addressing issues related to the unavailability of operating rooms and surgical implants should also be prioritized by collaborating with the government to mitigate surgical delays in government hospitals. Furthermore, hiring additional staff as needed is recommended to ensure PWSCI have access to all the available services in the hospital.

At the national level, identifying the key stakeholders and decision-makers for policy formation, defining quality of care metrics, and sufficient allocation of funding to support SCI care would be tremendously important (World Health Organization, 2018). Rewarding and accrediting the health professionals and hospitals that demonstrate high-quality performance. One of the primary concerns expressed by our participants is related to healthcare inequities. Implementing appropriate rules and regulations to monitor, avoid or address (if identified) any healthcare inequities could also be a crucial step in enhancing the quality of care experience for PWSCI at the national level.

The ultimate intention of this study was to enhance the acute care experience of PWSCI for better rehabilitation and community outcomes. Simply adopting the Western system of care for PWSCI in Nepal's acute setting without a clear understanding of the local culture and context may not be appropriate. More high-standard research, whether qualitative, quantitative or mixed, is needed to explore other perspectives on SCI care in acute settings, including those of the healthcare team, family caregivers and policymakers. This will provide a clearer understanding of the challenges and barriers in planning and implementing quality care for PWSCI in Nepal. Furthermore, the dissemination of the result is crucial to initiate change at any level. Therefore, I plan to publish my research in an open-access journal. I am also planning to present my work in various national and international conferences which include the relevant stakeholders.

Chapter 3: General Discussion

3.1. Trustworthiness and Rigour

The research team took various measures, in this study to ensure the trustworthiness and rigour of the study. The goal of trustworthiness and rigour is to represent the participant's experience accurately (Streubert & Carpenter, 2011). The following steps were carried out to ensure the trustworthiness of the research:

- Consulted during a one-hour Zoom meeting (23rd Jan 2023, 8-9 am MDT) with a qualitative research expert professor to get feedback and suggestions after the first few data collection sessions.

- Clearly presented the research process and findings and took feedback from the supervisors during the data collection process (21st Feb 2023, 8:30-9:30 am MDT).

- Consulted with a person with lived experience from the beginning regarding the research questions and interview guide.

- Used the COREQ checklist from the beginning to ensure all the important processes of research are reported.

- Extracted thick descriptions of the experience through the interview.

- Developed rapport with participants through prolonged engagement prior to the interviews.

- Reflected on personal positionality.

- Three data analysts worked independently on data analysis for a better understanding of the participant’s experience.

- Field notes were taken during the interview.

- Participant checking was done.

3.2. Summary and Significance

This is the first study to describe the experience of PWSCI in Nepal as related to the quality of care in acute hospitals. The unmet needs of the patients may prevent their optimal functioning and negatively affect their health in the long term. We used the three core domains: effectiveness, safety and person-centeredness, which defined the quality of care as described by WHO. Delayed surgeries, no or limited physiotherapy intervention, and inequity in healthcare based on socioeconomic status and political affiliations were more concerns in government hospitals than the private facilities. Participants mentioned that for secondary complication (pressure injuries) prevention, their care team provided most of them with sufficient education. Some participants, however, did not receive any information and developed pressure injuries, while no information was provided for other secondary complications prevention. Participants in our study reported that inadequate information was provided about their condition and limited participation in the decision-making process. Family members were relatively more involved in counselling and interactions with the care team. Despite the issues, PWSCI are generally happy with their care experience in the acute hospital, but they still crave change. These changes should be comprehensive at all levels, and cultural context should also be considered.

This thesis offers several implications for care teams. Firstly, there is a need to address the systems barriers that limit high-quality care provision in the acute hospital, for instance, multidisciplinary intervention, timely surgery, and improving on the few existing facilities, such as the availability of operating rooms. Secondly, there is a gap in providing sufficient information to patients and families regarding secondary complications prevention during acute hospital stays, which can be addressed by staff training for proper patient education and making it more memorable. Lastly, patients should be an integral part of information sharing and the decision-making process. The information presented should be in simple language and easy to understand. This will help patients better understand their condition and prepare them for future consequences.

3.3. Strengths and Limitations

3.3.1. Strengths

- Participants showed interest in participating and contacted the researchers themselves.
- SIRC staff helped in recruiting participants.
- There was a diversity of participants based on gender, acute hospital, age, educational background, type of injury, and surgical management.
- The interviewer was a local language speaker, i.e. Nepali.
- In-depth interviews were conducted to understand the participant’s experience.
- Data collection, transcription, and analysis were iterative processes.

- Two data analysts went through the transcripts independently and concluded data saturation, and three data analysts independently analyzed the data.

3.3.2. Limitations

Even though the interviews were held in a private room, there were some unavoidable noises passing by staff/visitors, and environmental noise, e.g., birds and airplanes, during the interview process. This caused difficulty in understanding some of the words from the recorder; however did not affect the data analysis and results.

Despite researchers' efforts to reflect and journal their positionality, there might still be potential biases during the interview, data analysis, and interpretation. However, several steps were carried out to mitigate this, such as constantly reflecting on their own biases throughout the process by journaling it, maintaining transparency, and using the COREQ checklist. The interviewer had a journal where assumptions were written down and constantly reviewed during data collection, data analysis, and interpretation. Constant reflection was performed on these assumptions to ensure they did not interfere with or get mixed with the actual data. Throughout the research process, transparency was maintained by frequently presenting the findings to the research team, discussing the results, receiving feedback, and implementing it. Similarly, the final results were also shared with two participants to get their feedback.

Persons with lived experiences were not involved in the data analysis and interpretation of the findings, which could have otherwise been very advantageous to our results. However, they were included in formulating the interview guide and conducting pilot testing before the interview.

3.4. Future Directions

There is a need to perform further research from the care team's perspectives to gain broader knowledge about acute SCI care for PWSCI. Similarly, PWSCI's families were more involved in the care process, and understanding their experience may uncover more invaluable guidance.

The engagement of policymakers and persons with lived experience throughout the research process, including data analysis and interpretation, could be helpful in the knowledge translation.

Further detailed investigation into specific domains such as patient-centredness, safety and effectiveness could be useful to uncover the quality of care experience in further detail.

3.5. Personal Reflection

It was sometimes challenging for me to think beyond my assumptions and be fully aware of my biases. I assumed that PWSCI were not involved in the decision-making process for their care and were not adequately educated about secondary complications prevention. I focused on the depth of the participants' experiences, despite these assumptions, without interfering with the process during the interview and data analysis. I was constantly aware of my positionality throughout the process and fully immersed in the participant's experience and its meaning without letting it shape my analysis. Also, the research team was made aware of my assumptions. We identified these results following robust steps to ensure the rigour of the data. One of the data analysts was an outsider with no affiliation with the research team and setting. Transparency in the research process was maintained throughout data collection, analysis and interpretation by frequently presenting the work to the research team and receiving feedback. Even though some of the findings were similar to my assumptions, I did not have a clear understanding of the whole picture. The findings from this study provided me with insights which I would not have otherwise gained. There were some interesting and surprising findings as well. For instance, participants were happy with small gestures from the care team, hospital services such as the provision of meals, and affordability. Similarly, not all participants were interested in knowing about their condition or prognosis.

Another challenge was that some meaning units and themes were overlapping in more than one category. I tried my best to isolate and put them in the category that best describes those themes or units with the consensus of the research team.

References

Adhikari, S. R., Sapkota, D., Thapa, A., & Pandey, A. R. (2019). Evaluation of Nepal's Free Health Care Scheme from Health System Perspective: A Qualitative Analysis. *Journal of Nepal Health Research Council*, *16*(41), 372–377. https://doi.org/10.33314/jnhrc.v16i41.1584

Ahuja, C. S., Wilson, J. R., Nori, S., Kotter, M. R. N., Druschel, C., Curt, A., & Fehlings, M. G. (2017). Traumatic spinal cord injury. *Nature Reviews Disease Primers*, *3*(1), 17018. https://doi.org/10.1038/nrdp.2017.18

Aryal, R. P., & Aryal, B. (2022). Disability Stigma and Discrimination in Nepal: A Study of Pokhara Metropolitan City. *Asian Journal of Population Sciences*, 23–31. https://doi.org/10.3126/ajps.v1i1.43592

Burns, A. S., Marino, R. J., Kalsi-Ryan, S., Middleton, J. W., Tetreault, L. A., Dettori, J. R., Mihalovich, K. E., & Fehlings, M. G. (2017). Type and Timing of Rehabilitation Following Acute and Subacute Spinal Cord Injury: A Systematic Review. *Global Spine Journal*, *7*(3_suppl), 175S-194S. https://doi.org/10.1177/2192568217703084

Chamberlain, J. D., Meier, S., Mader, L., Von Groote, P. M., & Brinkhof, M. W. G. (2015). Mortality and Longevity after a Spinal Cord Injury: Systematic Review and Meta-Analysis. *Neuroepidemiology*, *44*(3), 182–198. https://doi.org/10.1159/000382079

Chhabra, H. S., Sharma, S., & Arora, M. (2018). Challenges in comprehensive management of spinal cord injury in India and the Asian Spinal Cord network region: Findings of a survey of experts, patients and consumers. *Spinal Cord*, *56*(1), 71–77. https://doi.org/10.1038/sc.2017.102

Creswell, J. W. (2007). Qualitative Inquiry and Research Design: Choosing Among Five Approaches. *Health Promotion Practice*, *16*(4), 473–475. https://doi.org/10.1177/1524839915580941

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2018). *The SAGE handbook of qualitative research* (Fifth edition). SAGE.

Dhakal, G. R., Bhandari, R., Dhungana, S., Poudel, S., Gurung, G., Kawaguchi, Y., & Riew, K. D. (2019). Review of Subaxial Cervical Spine Injuries Presenting to a Tertiary-Level Hospital in Nepal: Challenges in Surgical Management in a Third World Scenario. *Global Spine Journal*, *9*(7), 713–716. https://doi.org/10.1177/2192568219833049

Dhakal, G. R., Paudel, S., Dhungana, S., Gurung, G., & Kawaguchi, Y. (2018). Epidemiological Characteristics of Dorsal and Lumbar Spine Trauma Presenting to a Trauma Hospital in Kathmandu, Nepal: Formulation of a National Spine Policy. *Spine Surgery and Related Research*, *2*(4), 249–252. https://doi.org/10.22603/ssrr.2017-0087

Dhakal, R., Baniya, M., Solomon, R. M., Rana, C., Ghimire, P., Hariharan, R., Makower, S. G., Meng, W., Halpin, S., Xie, S., O’Connor, R. J., Allsop, M. J., & Sivan, M. (2021). *TEleRehabilitation Nepal (TERN) to improve the quality of life of people with spinal cord injury and acquired brain injury. A proof-of-concept study* [Preprint]. Rehabilitation Medicine and Physical Therapy. https://doi.org/10.1101/2021.06.21.21257001

Dhakal, R., & Groves, C. C. (2019). Rehabilitation in Nepal. *Physical Medicine and Rehabilitation Clinics of North America*, *30*(4), 787–794. https://doi.org/10.1016/j.pmr.2019.07.004

Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, *44*(1), 131–142. https://doi.org/10.1016/j.ijnurstu.2005.11.026

Embassy of Nepal, Abu Dhabi. (n.d.). *About Nepal*. https://ae.nepalembassy.gov.np/about-nepal/

Engkasan, J. P., Ng, C. J., & Low, W. Y. (2015). Who decides? A qualitative study on the decisional roles of patients, their caregivers and doctors on the method of bladder drainage after spinal cord injury. *Spinal Cord*, *53*(2), 130–134. https://doi.org/10.1038/sc.2014.199

Fehlings, M. G., Tetreault, L. A., Wilson, J. R., Kwon, B. K., Burns, A. S., Martin, A. R., Hawryluk, G., & Harrop, J. S. (2017). A Clinical Practice Guideline for the Management of Acute Spinal Cord Injury: Introduction, Rationale, and Scope. *Global Spine Journal*, *7*(3_suppl), 84S-94S. https://doi.org/10.1177/2192568217703387

Glennie, R. A., Bailey, C. S., Tsai, E. C., Noonan, V. K., Rivers, C. S., Fourney, D. R., Ahn, H., Kwon, B. K., Paquet, J., Drew, B., Fehlings, M. G., Attabib, N., Christie, S. D., Finkelstein, J., Hurlbert, R. J., Parent, S., & Dvorak, M. F. (2017). An analysis of ideal and actual time to surgery after traumatic spinal cord injury in Canada. *Spinal Cord*, *55*(6), 618–623. https://doi.org/10.1038/sc.2016.177

Golestani, A., Shobeiri, P., Sadeghi-Naini, M., Jazayeri, S. B., Maroufi, S. F., Ghodsi, Z., Dabbagh Ohadi, M. A., Mohammadi, E., Rahimi-Movaghar, V., & Ghodsi, S. M. (2022). Epidemiology of Traumatic Spinal Cord Injury in Developing Countries from 2009 to 2020: A Systematic Review and Meta-Analysis. *Neuroepidemiology*, *56*(4), 219–239. https://doi.org/10.1159/000524867

Government of Nepal. (2015). *Constitution of Nepal*. https://www.constituteproject.org/constitution/Nepal_2015.pdf

Government of Nepal. (2023). *Culture and society of Nepal*. https://mofa.gov.np/about-nepal/culture-society/

Government of Nepal. (2016). *Health Facility Survey 2015* (p. 468). https://dhsprogram.com/pubs/pdf/SPA24/SPA24.pdf

Government of Nepal. (2023). *Nepal profile*. https://mofa.gov.np/nepal-profile-updated/

Government of Nepal. (2018). *The Public Health Service Act, 2075 (2018)*. https://www.lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Public-Health-Service-Act-2075-2018.pdf

Hamilton, D., & Rai, T. (1978). Some experience with paraplegia in a small hospital in Nepal. *Spinal Cord*, *15*(4), 293–299. https://doi.org/10.1038/sc.1977.44

Jazayeri, S. B., Maroufi, S. F., Mohammadi, E., Dabbagh Ohadi, M. A., Hagen, E.-M., Chalangari, M., Jazayeri, S. B., Safdarian, M., Zadegan, S. A., Ghodsi, Z., & Rahimi-Movaghar, V. (2023). Incidence of traumatic spinal cord injury worldwide: A systematic review, data integration, and update. *World Neurosurgery: X*, *18*, 100171. https://doi.org/10.1016/j.wnsx.2023.100171

Jones, M., Saavedra, M., Medcalf, A., Momen, H., & Bhattacharya, S. (2015). *Health For All: The Journey of Universal Health Coverage*. Orient Blackswan.

Khanal, G. N., Bharadwaj, B., Upadhyay, N., Bhattarai, T., Dahal, M., & Khatri, R. B. (2023). Evaluation of the National Health Insurance Program of Nepal: Are political promises translated into actions? *Health Research Policy and Systems*, *21*(1), 7. https://doi.org/10.1186/s12961-022-00952-w

Khosravi, S., Khayyamfar, A., Shemshadi, M., Koltapeh, M. P., Sadeghi-Naini, M., Ghodsi, Z., Shokraneh, F., Bardsiri, M. S., Derakhshan, P., Komlakh, K., Vaccaro, A. R., Fehlings, M. G., Guest, J. D., Noonan, V., & Rahimi-Movaghar, V. (2022). Indicators of Quality of Care in Individuals With Traumatic Spinal Cord Injury: A Scoping Review. *Global Spine Journal*, *12*(1), 166–181. https://doi.org/10.1177/2192568220981988

Kirshblum, S. C., Botticello, A. L., DeSipio, G. B., Fichtenbaum, J., Shah, A., & Scelza, W. (2016). Breaking the news: A pilot study on patient perspectives of discussing prognosis after traumatic spinal cord injury. *The Journal of Spinal Cord Medicine*, *39*(2), 155–161. https://doi.org/10.1179/2045772315Y.0000000013

Krueger, H., Noonan, V., Trenaman, L., Joshi, P., & Rivers, C. (2013). The economic burden of traumatic spinal cord injury in Canada. *Chronic Diseases and Injuries in Canada*, *33*(3), 113–122. https://doi.org/10.24095/hpcdp.33.3.01

Krysa, J. A., Gregorio, M. P., Pohar Manhas, K., MacIsaac, R., Papathanassoglou, E., & Ho, C. H. (2022). Empowerment, Communication, and Navigating Care: The Experience of Persons With Spinal Cord Injury From Acute Hospitalization to Inpatient Rehabilitation. *Frontiers in Rehabilitation Sciences*, *3*, 904716. https://doi.org/10.3389/fresc.2022.904716

Lin, V. W., & Cardenas, D. D. (Eds.). (2003). *Spinal cord medicine: Principles and practice*. Demos.

Liverman, C. T. & Institute of Medicine (U.S.) (Eds.). (2005). *Spinal cord injury: Progress, promise, and priorities*. National Academies Press.

Marasini, B. (2020). Health System Development in Nepal. *Journal of Nepal Medical Association*, *58*(221). https://doi.org/10.31729/jnma.4839

May, L., Day, R., & Warren, S. (2006). Perceptions of patient education in spinal cord injury rehabilitation. *Disability and Rehabilitation*, *28*(17), 1041–1049. https://doi.org/10.1080/09638280500494744

Ministry of Foreign Affairs, Nepal. (n.d.). *History of Nepal*. https://mofa.gov.np/about-nepal/history-of-nepal/

Ministry of Health and Population, Nepal; New ERA; and ICF. (2022). *Nepal Demographic and Health Survey 2022: Key Indicators Report*. Kathmandu, Nepal: Ministry of Health and Population, Nepal.

Moore, M. (2007). What does patient-centred communication mean in Nepal?: International Perspectives. *Medical Education*, *42*(1), 18–26. https://doi.org/10.1111/j.1365-2923.2007.02900.x

Moreno, A., Zidarov, D., Raju, C., Boruff, J., & Ahmed, S. (2017). Integrating the perspectives of individuals with spinal cord injuries, their family caregivers and healthcare professionals from the time of rehabilitation admission to community reintegration: Protocol for a scoping study on SCI needs. *BMJ Open*, *7*(8), e014331. https://doi.org/10.1136/bmjopen-2016-014331

National Clinical Programme for Rehabilitation Medicine. (2018). *Integrated care pathway for the management of spinal cord injury*. Clinical Strategy & Programmes Division, Health Service Executive.

National Spinal Cord Injury Statistical Center. (2024). *Traumatic spinal cord injury facts and figures at a glance*. University of Alabama at Birmingham.

New, P. W., Cripps, R. A., & Bonne Lee, B. (2014). Global maps of non-traumatic spinal cord injury epidemiology: Towards a living data repository. *Spinal Cord*, *52*(2), 97–109. https://doi.org/10.1038/sc.2012.165

O’Sullivan, S. B., & Schmitz, T. J. (2006). *Physical rehabilitation* (5th ed.). F.A. Davis Company.

Parajuli, B., Acharya, K., & Shrestha, D. (2020). Epidemiology of traumatic spinal cord injury in Nepal: A systematic review. *Asian Journal of Medical Sciences*, *11*(6), 121–128. https://doi.org/10.3126/ajms.v11i6.30151

Paudel, K. P., Panta, S., Thapa, S. K., & Thapa, S. (2022). Traumatic Spinal Injury among Patients with Spinal Injuries Admitted to the Spine Unit of a Tertiary Care Centre: A Descriptive Cross-sectional Study. *Journal of Nepal Medical Association*, *60*(248), 335–339. https://doi.org/10.31729/jnma.6850

Ranabhat, M. K. (2016). *Sexuality: A matter of life and death: successful sexual rehabilitation of men with spinal cord injury in Nepal*. https://doi.org/10.25903/9CCK-RK92

Reyes, J. (2017). *Diagnostic Study of Local Governance in Federal Nepal 2017*. The Australian Government and the Asia Foundation Partnership in Nepal. Retrieved from The Asia Foundation (The Asia Foundation) (SCIRP).

Ropper, A., & Brown, R. (2005). *Adams and Victor's principles of neurology* (8th ed.). McGraw-Hill.

Scheel-Sailer, A., Post, M. W., Michel, F., Weidmann-Hügle, T., & Baumann Hölzle, R. (2017). Patients' views on their decision making during inpatient rehabilitation after newly acquired spinal cord injury—A qualitative interview-based study. *Health Expectations*, *20*(5), 1133–1142. https://doi.org/10.1111/hex.12559

Scovil, C. Y., Ranabhat, M. K., Craighead, I. B., & Wee, J. (2012). Follow-up study of spinal cord injured patients after discharge from inpatient rehabilitation in Nepal in 2007. *Spinal Cord*, *50*(3), 232–237. https://doi.org/10.1038/sc.2011.119

Shah, N., Shrestha, B., & Subba, K. (2013). Spinal cord injury rehabilitation in Nepal. *JNMA; Journal of the Nepal Medical Association*, *52*(190), 427–431.

Sharma, J., Aryal, A., & Thapa, G. K. (2018). Envisioning a high-quality health system in Nepal: If not now, when? *The Lancet Global Health*, *6*(11), e1146–e1148. https://doi.org/10.1016/S2214-109X(18)30322-X

Sharma, M. (2003). Acute Cervical Spine Injuries: Diagnosis and Management. *Journal of Nepal Medical Association*, *42*(148). https://doi.org/10.31729/jnma.641

Shresth, D. (2015). Traumatic Spinal Cord Injury in Nepal. *Kathmandu University Medical Journal*, *12*(3), 161–162. https://doi.org/10.3126/kumj.v12i3.13707

Shrestha, P., Shrestha, S., & Shrestha, R. K. (2014). Retrospective study of spinal cord injury patients admitted to spinal injury rehabilitation centre, Sanga, Banepa, Nepal. *Nepal Medical College Journal: NMCJ*, *16*(2–4), 169–172.

Shrestha, S., Shrestha, K., & Groves, C. C. (2022). Patient handling and transportation from site of injury to tertiary trauma centres in Nepal following acute traumatic spinal cord injury: A descriptive study. *Spinal Cord Series and Cases*, *8*(1), 79. https://doi.org/10.1038/s41394-022-00545-3

Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed). Wolters Kluwer Health/Lippincott Williams & Wilkins.

Subedi, M. S. (2001). *Medical anthropology of Nepal* (1st ed). Udaya Books.

Swain, A., & Grundy, D. (2002). *ABC of Spinal Cord Injury*. BMJ. https://unitedparalysis.org/files/27.pdf

Tenny, S., Brannan, J. M., & Brannan, G. D. (2017). Qualitative Study. *StatPearls Publishing*. https://www.ncbi.nlm.nih.gov/books/NBK470395/

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy* (Second Edition). Routledge, Taylor & Francis Group.

Wee, J., & Schwarz, R. (2004). An international comparative study assessing impairment, activities, and participation in spinal cord injury rehabilitation–a pilot study. *Asia Pacific Disability Rehabilitation Journal*, *15*(2), 43-53 https://www.researchgate.net/profile/Joy-Wee2/publication/228849394_An_International_comparative_study_assessing_impairment_activities_and_participation_in_spinal_cord_injury_rehabilitation-A_Pilot_Study/links/00b4953c94885db286000000/An-International-comparative-study-assessing-impairment-activities-and-participation-in-spinal-cord-injury-rehabilitation-A-Pilot-Study.pdf

Willott, A., Dhakal, R., Groves, C., Mytton, J., & Ellis, M. (2021). The demographics and traumatic causes of spinal cord injury in Nepal: An observational study. *Trauma*, *23*(4), 330–337. https://doi.org/10.1177/1460408620941342

World Health Organization. (2021). *Global Health Expenditure Database: Country profile*. Retrieved from https://apps.who.int/nha/database/country_profile/Index/en

World Health Organization. (2018). *Handbook for national quality policy and strategy: A practical approach for developing policy and strategy to improve quality of care*. World Health Organization. https://iris.who.int/handle/10665/272357

Ziu, E., & Mesfin, F. B. (2024). Spinal shock. In StatPearls [Internet]. Treasure Island, FL: StatPearls Publishing. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK448163/

Appendices

1. Appendix A: Interview Guide (English)

Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal.

Interview Introduction

Thank you for giving us your time to participate in this research. You are free to ask questions about anything you do not understand. You do not have to answer any questions if you find yourself uncomfortable. Your participation is entirely voluntary, and you can stop at any time. We will record this interview so that we can listen to it again and take notes, but we will make sure that your name and other personal information are kept confidential. The interview might take 30 to 60 minutes. So, shall we start? Do you have any questions?

We are first going to ask a few questions about yourself and your injury if you are comfortable answering:

1) What gender would you define yourself as?
2) What is your age?
3) Where are you from? (Province)
4) What is your education level?
5) How have you been affected by spinal cord injury?
6) In which hospital did you receive your acute care?
7) How long did you stay at the hospital? (Date of admission and discharge if possible)

Interview Guide

- **Can you please tell me a bit about your SCI story, what happened, when, how it happened, and your journey to the hospital?**
- **Can you please explain to me what happened after you reached the hospital?**

1) **Patient-centredness**

a. What was your interaction with care providers at the hospital? (Hint: frequency of visit, amount of time spent, do you think you received the best available treatment?)

i. Doctors
ii. Nurses
iii. Physiotherapists
iv. Other healthcare workers
v. Can you describe an example of positive interaction between you and a healthcare provider? Negative, if any?

b. Please explain to me from the beginning how you and your caregivers were included or participated in providing the care for you.

i. How did you feel? Please explain. (Do you think you got all the information that you needed to know?)

c. Please explain to me about your surgery from the beginning and how it went.

i. How and what did your care provider explain to you and your family before surgery?
ii. Who was the care provider who explained this to you?
iii. How long was the pre-surgery counselling session?
iv. Do you think that was enough or effective?
v. If not, what can be done to make it effective?

d. Explain to me your transition from the acute hospital to the rehabilitation centre.

vi. What do you understand about rehabilitation?
vii. When did you know you were being referred to another hospital for rehabilitation (before or after surgery)?
viii. How did you feel?
ix. Who explained that?
x. Did you feel prepared? Why? Why not?
xi. What helped you feel prepared?
xii. What was missing?
xiii. What would you recommend for others?

xiv. What education, resources, or other support before your discharge?
xv. What types of care providers were helpful in your transition?
xvi. Was your family involved?
xvii. Do you think that was the right time for your transition, or was it too early or late?

2) Patient Safety

a. Were you given all the information you needed to understand your condition and treatment?

i. Was the information easy to follow/understand?
ii. What did you do to learn more about your condition and the treatment you were receiving? (hint: search on the internet)
iii. What information would you have liked to have received?
iv. What types of information would be useful for others in the future?

b. Did your nurses, doctors, and caregivers provide you with information so that you do not develop complications like bed sores or stiffness in your joint in the acute hospital?

If not, did you have any complications? Please explain. Would you like to have received such information?

If yes:

i. Who provided you with the education?
ii. Do you think that was effective? Explain how?
iii. What do you think can be done to make it more effective?

3. Effectiveness

a. Can you please explain to me your overall experience in the hospital following your SCI?

i. What was your positive experience?
ii. What was your negative experience?

b. How would you describe the overall quality of care you received during your hospital stay?

i. What did you like the most and want them to do more often?
ii. What are the things that need to be changed? What are your suggestions?
iii. What could have been better?
iv. Do you think the services that you get from the hospital are similar to other countries? Have you tried to search for that?
v. Is there anything else you want to tell us about your stay?

2. Appendix B: Interview Guide (Nepali)

अध्ययनको शीर्षक: नेपालमा तीव्र अस्पताल बसाइको समयमा हेरचाहको गुणस्तर सम्बन्धी स्पाइनल कर्डमा चोट लागेका बिरामीहरूको अनुभव।

अन्तरबार्ता को परिचय

सर्भप्रथम आफ्नो अमुल्य समय खर्चेर यस अनुसन्धानमा भाग लिनु भएकोमा हामी आभारी छम। एस अन्तरबार्ता लिदै गर्दा केहि नबुजेको खण्डमा प्रशन सोध्न सक्नु हुने छ। आफु लाई अप्ठ्यारो लागेको र उत्तर दिन मन नलागेको प्रस्न को जबाफ नदिन नि पाउनु हुन्छ। यस अध्ययनमा भाग लिनु तपाईंको छनौट हो र जुन समय मा पनि छोड्न सक्नु हुन्क्ष ।

हामी यो अन्तरबार्ता रेकोड़ गर्ने छम तर तपाईको परिचय खुल्ने खालको कुनै पनि कुराहरु मेटाइनेछ र सबै कुरा हरु सुरक्छित राखिनेछ । यो अन्तर्वार्ता अधिकतम ३० देखि ६० मिनेट हुनेछ। के हामी अब सुरु गर्दा हुन्छ ? केहि प्रस्न छ भने सोध्नु होला।

सर्बप्रथम तपाईलाई तपाईको बारेमा र तपाईलाई लागेको चोटको बारेमा केहि प्रस्नहरु गर्नेछु:

1. आफुलाई कुन लिङ्ग भनेर चिनाउन चाहनु हुन्छ ?
2. तपाइको उमेर कति हो?
3. कुन प्रदेश बाट हुनुन्छ?
4. तपाइको सैक्षिक योग्यता/पढाई कति सम्म छ?
5. स्पाइनल कर्डमा चोट लागेर तपाइलाई के कस्तो असर परेको छ?
6. प्राथमिक उपचार कुन अस्पतालबाट प्राप्त गर्नु भयो?
7. यस अगाडीको अस्पतालमा कति समय बस्नु भयो ? (भर्ना गरेको र छुटेको मिति)

अन्तरबार्ता

- के तपाई मलाई आफ्नो मेरुदण्डमा लागेको चोट बारे अझै बृस्तृतमा सुनाउन सक्नु हुन्छ? कहिले भएको थियो, के भएको थियो त्यो दिन? कसरी चोट लग्यो र कसरी अस्पताल सम्म पुगनु भयो?
- अस्पताल पुगी सके पछि के के भयो?

1. बिरामीलाई समाबेस/ सग्लगन गरिएको उपचार

1. **तपाइको अस्पतालमा स्वास्थ्यकर्मीहरु संगको घुलमिल कसरी बयान गर्नु हुन्छ? (डाक्टर संग भेटेको समय, संख्या, राम्रो उपचार पाउनु भएको जस्तो लाग्छ कि के सोच्नु हुन्छ?)**

- डाक्टर
- नर्स
- फिजियोथेरापिस्ट
- अन्य स्वास्थ्यकर्मी
- कुनै राम्रो क्ष्यन अथवा चित्त नबुजेको क्ष्यन याद छ स्वास्थ्यकर्मीहरु संगको भने भन्नु होला।

2. **कृपया मलाई सुरु देखि भन्नु होला कसरी तपाई र तपाई को परिवार/ कुरुवा लाई तपाइको उपचार मा समाबेस/ सग्लगन गरिएको थियो?**

- तपाइलाई कस्तो अनुभव भयो? कृपया सबै बताउनु होल। (तपाई ले पाउनु पर्ने सबै सूचनाहरु पाउनु भयो जस्तो लाग्छ कि लाग्दैन?)

3. **कृपया आफ्नो सल्यक्रियाको बारेमा सुरु देखि बताई दिनु होला।**

- स्वास्थ्यकर्मीहरु ले तपाई र तपाइको परिवार/ कुरुवालाई कसरी र के भनेर सल्यक्रिया अगाडी सुझाब दिनु भयो?
- प्रमुख सुझाब दिने, बुजाउने स्वास्थ्यकर्मी को हुनुन्थ्यो?
- सल्यक्रिया अगाडी सुझाब दिने कार्यक्रम कति समय चल्यो?
- तपाइको विचारमा के लाग्छ, के त्यो सूचना पुग्ने गरि दियिएको थियो र कत्तिको मदत पुग्यो तपाइलाई?
- एदी दियिएको थिएन भने तपाइको विचारमा के गर्यो भने अझ उपयोगी हुन्छ?

4. **अस्पताल देखि पुर्नस्थापना केन्द्र सम्म को सराई /यात्रा लाई कसरि बयान गर्नु हुन्छ? पुरा बताउनु होस।**

- पुर्नस्थापना भनेको के बुझ्नु भएको छ?
- तपाइलाई थप उपचार/पुर्नस्थापना को लागि अर्को अस्पतालमा सराई /यात्रा हुदैछ भन्ने बारे जानकारी कहिले पाउनु भयो? (सल्यक्रिया अघि कि पछि)
- कस्तो अनुभव भयो त्यो सुन्धा?
- कसले जानकारी दिनु भयो त्यो बारे?
- तपाई तेस्को लागि तयार हुनुन्थ्यो जस्तो लग्यो कि लागेन? किन?
- के कुराले हजुर तयार हुनुहुन्छ भन्ने महसुस गरायो?
- के कुरा को कमि महसुस भयो?

- भबिस्यमा अरु को लागि के सुजाब दिन चाहनु हुन्छ?
- तपाई अस्पताल बाट बिदा/डिस्चार्ज हुनु अगाडी के के कुराको ज्ञान दिनु भयो, केहि पढ्ने बुझ्ने सामग्री दिनु भयो कि कसरि साहयोग पाउनु भयो?
- कुन स्वास्थ्यकर्मीहरुको सहयोग तपाइलाई तेस समय मा महत्वोपुर्न/ उल्लेखानिए लाग्यो?
- के तपाइको परिवार लाई समाबेस गरिएको थियो?
- तपाइको विचार मा के लाग्छ त्यो सहि समय थियो कि,चाडो भयो कि ढिलो भयो?

2. <u>बिरामी को सुरक्क्ष्या</u>

1. **के तपाइलाई आफ्नो स्वास्थ्य सम्बंदी सम्पूर्ण जानकारी तथा उपचार को बिधि बारे जानकारी दियिएको थियो?**

- के त्यो जानकारी तपाइलाई बुझ्न सजिलो थियो?
- तपाइले आफ्नो स्वास्थ्य अवस्था र पाई रहेको उपचार को बारेमा थप जानकारी पाउन के गर्नु भयो? (नेट मा खोज्ने, अरु डाक्टर लाई सोध्ने)
- के कस्तो जानकारी पहिले पाएको भए झन् राम्रो हुने थियो जस्तो लाग्छ ?
- भबिस्यमा तपाई जस्तै बिरामी को लागि केके जानकारी चै सुरुमै प्रधान गरे राम्रो जस्तो लाग्छ तपाइलाई ?

2. **के तपाइको को नर्स, डाक्टर अथवा कुरुवा ले तपाइलाई कसरि स्पाइनल कर्डमा चोट लागे पछि आउने अन्य समस्या जस्तै बेड सोर, जोर्नी जाम हुने बारे जानकारी दिनु भएको थियो?**

   यदि जानकारी दिईएको थिएन भने तपाइलाई केहि समस्या देखा पर्यो कि परेन? कृपया बृस्तृतमा भन्नु होल। तेस्तो जानकारी पाउनु भएको भए राम्रो हुने थियो जस्तो लाग्छ?

   यदि जानकारी दिईएको थियो भने:

- कसले दियो ?
- के तपाइलाई त्यो जानकारी उपयोगी लाग्यो, कसरी ?
- तपाइको विचार मा तेस्लाई अझ उपयोगी बनाउन के गर्न सकिन्छ?

3. <u>प्रभावकारीता</u>

1. **के तपाई मलाई आफ्नो आस्पताल बसाई बारे समग्रमा कस्तो अनुभव भयो बताउन सक्नु हुन्छ?**

- कस्तो अनुभव सकारात्मक रहयो?
- कस्तो अनुभव नकारात्मक रहयो?

2. **तपाइले अस्पतालमा रहदा पाउनु भएको स्वास्थ्य सेवाको गुणस्तर समग्र मा भन्नु पर्दा कस्तो थियो?**

- के कुरा चाई धैरै राम्रो लाग्यो र पछि भबिस्यमा नि उपलब्ध भइ रहे/ गरि रहे राम्रो जस्तो लाग्छ?
- के कुराचाई परिवर्तन गरे राम्रो जस्तो लाग्छ? तपाइको सुझाब पनि भन्नु होला।
- के कुराचाई भैदिएको भए अझै राम्रो हुने थियो?
- तपाईको विचार मा तपाइले अस्पताल बाट पाउनु भएको सेवाहरु अन्य देश संग मेल खान्छ कि फरक होला ? के एस बिषयबारे खोजने कोसिस गर्नुभयो?
- तपाइको आफ्नो अस्पताल बसाई बारे अरु केहि कुरा बाढ्न/ बताउन चाहनु हुन्छ?

3. Appendix C: COREQ Checklist

Table: Consolidated criteria for reporting qualitative studies (COREQ) checklist

Items	Guide questions/description	Answers
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Srijana Gautam
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Bachelor of Physiotherapy
3. Occupation	What was their occupation at the time of the study?	M.Sc. Student
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	Qualitative study course completion
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Yes, through prolonged engagement
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All the research information through the participant information form
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	No affiliation with the research setting i.e., SIRC or acute hospital.
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Phenomenology
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Face-to-face interview
12. Sample size	How many participants were in the study?	24

13. Non-participation	How many people refused to participate or dropped out? Reasons?	None
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	SIRC
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Two participants had spouses present at the participant's request
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Diversity in demographic data
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Prompts and guidance provided. / Yes, pilot tested.
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes, audio recording
20. Field notes	Were field notes made during and/or after the interview or focus group	Yes
21. Duration	What was the duration of the interviews or focus groups?	17 to 32 minutes
22. Data saturation	Was data saturation discussed?	Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data codes	How many data coders coded the data?	Three
25. Description of the coding tree	Did authors provide a description of the coding tree?	Yes
26. Derivation of themes	Were themes identified in advance or derived from the data?	Derived from the data
27. Software	What software, if applicable, was used to manage the data?	NVivo by one coder
28. Participant checking	Did participants provide feedback on the findings?	Yes, a total two participants
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes/Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes

31. Clarity major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

4. Appendix D: Participant Consent Form (English)

UNIVERSITY OF ALBERTA

Title of Study: Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal.

Principal Investigators: Dr. Raju Dhakal, MD, Spinal Injury Rehabilitation Centre (SIRC), Sanga, Nepal Tel: 011-660847/848

Research Coordinator: Srijana Gautam, Student, M.Sc. in Medicine, Department of Medicine, University of Alberta, Phone No: +9779849607600, +1825-888-0076

Why am I being asked to take part in this research study?

We want to understand the experience of people with spinal cord injury about the quality of health care in acute hospitals before they get referred to this rehabilitation centre. This form contains information about the study so that you can decide whether you wish to take part or not. Before you read it, a member of the study team will explain the study to you in detail. You are free to ask questions about anything you do not understand. You will be given a copy of this form for your records.

What is the reason for doing the study?

This study will help us know about your different experiences related to your stay in acute hospital after your spinal cord injury. We do not know much about this. Therefore, the reason for doing this study is to better understand how persons with SCI experience care in acute hospitals in Nepal which will help to improve the care in the future.

What will I be asked to do?

You will be asked to take part in an interview at the Spinal Injury Rehabilitation Centre (SIRC) at your convenience time. The interview may take 30- 60 minutes. During this interview, we will ask questions about you, your experience with healthcare workers, and other concerns during your acute hospital stay. The interview will be audio-recorded using a secure device. We will also take notes on the paper during the interview process. Any personal information related to you will be removed and all your information will be stored safely.

What are the risks and discomforts?

TThere are no physical risks associated with this research study. There may be emotional distress from sharing your experiences from a sensitive period of life. In this case, you will have access to a peer counsellor and clinical psychologist for your help. In case of any emergency, there will be a nursing and medical team available 24 hours a day. Please note that it is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

There may not be any direct benefit to you from participating in this study. However, this study will help the researchers to learn more about your experience with the quality of health care in acute hospitals. Hopefully, this information will help to improve the quality of care for patients with spinal cord injuries like yours in the future.

Do I have to take part in the study?

Participating in this study is your choice. Whether you decide to participate or not or change your mind during the interview, this will in no way affect the treatment you are receiving from your doctors or therapists. You can feel free not to answer any questions that you find uncomfortable. You can also withdraw your data after the interview is over. We will delete the audio recordings or any other related documents.

Will I be paid to be in the research?

You will not be paid for your participation.

Will my information be kept private?

Your information will be kept private. During the study, a researcher will collect information about you in a private room. We will remove all your personal identifying information and assign it with codes. No data relating to this study that includes your name will be released to the staff at SIRC, previous hospital, anyone outside of the researcher's office, or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private. By law, data will be stored for a minimum of 5 years after the end of the study.

What if I have questions?

If you have any questions about the research now or later, please contact us:

Principal Investigators: Dr. Raju Dhakal, MD, Spinal Injury Rehabilitation Centre (SIRC), Sanga, Nepal Tel: 011-660847/848

Research Coordinator: Srijana Gautam, Phone No: +9779849607600, +1825-888-0076

If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at 780-492-2615. This office has no affiliation with the study investigators.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study at any time.
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

____

Name of Participant

________________________________ ______________________

Signature of Participant Date

SIGNATURE OF PERSON OBTAINING CONSENT

________________________________ ______________________

Name of Person Obtaining Consent Contact Number

SIGNATURE OF THE WITNESS

____

Name of Witness

___________________________________ _______________________

Signature of Witness Date

A copy of this consent form has been given to you to keep for your records and reference.

5. Appendix E: Participant Consent Form (Nepali)

सहभागी सहमति फारम

अध्ययनको शीर्षक: नेपालमा तीव्र (एक्युट) अस्पताल बसाइको समयमा हेरचाहको गुणस्तर सम्बन्धी स्पाइनल कर्डमा चोट लागेका बिरामीहरूको अनुभव ।

प्रमुख अन्वेषक: डा. राजु ढकाल, एम.डी, स्पाइनल इन्जुरी पुनर्स्थापना केन्द्र (SIRC), साँगा, काभ्रे नेपाल । टेलिफोन: ०११-६६०८४७/८४८

अनुसन्धान संयोजक: सृजना गौतम, बिद्यार्थी, चिकित्सा विभाग, अल्बर्टा विश्वविद्यालय । फोन नम्बर: ९८४९६०७६००, +१८२५ -८८८ -००७६

मलाई किन यस अनुसन्धान अध्ययनमा भाग लिन भनिएको छ ?

हामी स्पाइनल कर्डमा चोट लागेका मानिसहरूलाई यो पुर्नस्थापना केन्द्रमा रिफर गर्नु अघि तीव्र (एक्युट) अस्पतालहरूमा स्वास्थ्य सेवाको गुणस्तरको बारेमा अनुभव बुझ्न चाहन्छौं । यो फारममा अध्ययनको बारेमा जानकारी समावेश गरिएको छ जसले गर्दा तपाईंले भाग लिने वा नलिने निर्णय गर्न सक्नुहुन्छ । तपाईंले यसलाई पढ्नु अघि, अध्ययन टोलीको सदस्यले तपाईंलाई अध्ययनको विस्तृत व्याख्या गर्नेछ । तपाईंले नबुझेको कुनै पनि विषयमा प्रश्नहरू सोध्न स्वतन्त्र हुनुहुन्छ । तपाईलाई तपाईको रेकर्ड को लागी यो फारम को एक प्रतिलिपि दिइनेछ ।

अध्यय गर्नुको कारण के हो?

यो अध्ययनले हामीलाई तपाईंको स्पाइनल कर्डमा चोट लागेपछि तीव्र (एक्युट) अस्पतालमा तपाईंको बसाइसँग सम्बन्धित विभिन्न अनुभवहरूको बारेमा जान्न मदत गर्नेछ । यसबारे हामीलाई धेरै जानकारी छैन । तसर्थ, यो अध्ययन गर्नुको कारण भनेको स्पाइनल कर्डमा चोट लागेका व्यक्तिहरूले नेपालका एक्युट अस्पतालहरूमा हेरचाहको अनुभव बारे राम्रोसँग बुझ्नु हो जसले भविष्यमा हेरचाह सुधार गर्न मदत गर्नेछ ।

मलाई के गर्न सोधिनेछ ?

तपाईंलाई तपाईको अनुकुल समय मिलाएर स्पाइनल इन्जुरी पुनर्स्थापना केन्द्रमा अन्तर्वार्तामा भाग लिन अनुरोध गरिनेछ । यो अन्तवार्ता अधिकतम ३० देखि ६० मिनेट हुनेछ । यो क्रममा, हामी तपाईबारे, चिकित्सकहरुसँगको अनुभव र आन्य हेरचाह अनुभवहरुको बारे मा प्रश्नहरु सोध्नेछौं । तपाईसंगको

अन्तरबार्ता सुरक्षित माध्यमबाट रेकर्ड गरिनेछ। हामी अन्तरबार्ता गरि रहदा केहि कुराहरु कागज मा पनि टिप्ने छौ। तपाईको परिचय खुल्ने खालको कुनै पनि कुराहरु मेटाइने छ र सबै कुराहरु सुरक्षित राखिनेछन्।

जोखिम र असुविधा के हो?

यस अनुसन्धानसँग सम्बन्धित कुनै भौतिक जोखिमहरू छैनन्। जीवनको संवेदनशील अवधिबाट आफ्ना अनुभवहरू व्याक्त गर्दा भावनात्मक पीडा हुन सक्छ। यस अवस्थामा, तपाईसँग तपाईको मदतको लागि साथी सल्लाहकार र मनोवैज्ञानिकको पहुँच हुनेछ। कुनै पनि आपतकालिन अवस्थामा, त्यहाँ एक नर्सिङ र मेडिकल टोली दिनको २४ घण्टा उपलब्ध हुनेछ। कृपया ध्यान दिनुहोस् कि अध्ययनमा हुन सक्ने सबै जोखिमहरू जान्न सम्भव छैन तर अनुसन्धानकर्ताहरूले अध्ययन सहभागीलाई कुनै पनि ज्ञात जोखिमहरू कम गर्न सबै उचित सुरक्षा उपायहरू अपनाएका छन्।

मलाई के फाइदा छ?

यस अध्ययनमा भाग लिएर तपाईलाई कुनै प्रत्यक्ष लाभ नहुन सक्छ। यद्यपि यो अध्ययनले अनुसन्धानकर्ताहरूलाई तीव्र अस्पतालहरूमा स्वास्थ्य सेवाको गुणस्तरको बारेमा तपाईंको अनुभवको बारेमा थप जान्न मदत गर्नेछ। आशा छ, यो जानकारीले भविष्यमा तपाई जस्तै मेरुदण्डमा चोट लागेका बिरामीहरूको हेरचाहको गुणस्तर सुधार गर्न मदत गर्नेछ।

मैले अध्ययनमा भाग लिनुपर्छ?

यस अध्ययनमा भाग लिनु तपाईंको इच्छा हो। तपाई अन्तरबार्तामा सहभागी भए पनि नभए पनि, बीचमा छोड्ने विचार आए पनि जे निर्णय गर्नुहुन्छ, यसले तपाईको डाक्टर वा चिकित्सकहरूबाट प्राप्त गरिरहनुभएको उपचारलाई कुनै पनि हिसाबले असर गर्दैन। तपाईलाई असहज लाग्ने कुनै पनि प्रश्नको जवाफ नदिई स्वतन्त्र महसुस गर्न सक्नुहुन्छ। अन्तर्वार्ता सकिएपछि तपाईले आफ्नो डाटा पनि निकाल्न सक्नुहुन्छ। हामी अडियो रेकर्डिङ वा अन्य सम्बन्धित कागजातहरू मेटाउनेछौं।

मलाई अनुसन्धानमा भाग लिए बापत केहि भुक्तानी गरिनेछ ?

तपाईको सहभागिता को लागी भुक्तान गरिने छैन।

के मेरो जानकारी गोप्य राखिनेछ ?

तपाईको जानकारी गोप्य राखिनेछ। अध्ययनको क्रममा, एक शोधकर्ताले तपाईको बारेमा एक निजी कोठामा जानकारी सङ्कलन गर्नेछ। हामी तपाईको सबै व्यक्तिगत पहिचान जानकारी हटाउनेछौं र कोडहरुसंग नियुक्त गर्नेछौं। यस अध्ययनसँग सम्बन्धित कुनै पनि डाटा जसमा तपाईंको नाम समावेश छ, त्यो जानकारीहरु स्पाइनल इन्जुरी पुनर्स्थापनाका वा अघिल्लो अस्पतालका कर्मचारी, अनुसन्धानकर्ताको कार्यालय बाहिरको कसैलाई, वा अनुसन्धानकर्ताहरूले प्रकाशित गरेको कर्मचारीहरूलाई जारी गरिने छैन। कहिलेकाहीं, कानूनद्वारा, हामीले तपाईंको नामको साथ तपाईंको जानकारी जारी गर्नु पर्ने हुन सक्छ। त्यसैले हामी पूर्ण गोपनीयताको ग्यारेन्टी दिन सक्दैनौं। यद्यपि,

हामी तपाईको जानकारी गोप्य राखिएको छ भनी सुनिश्चित गर्नका लागि सबै कानूनी प्रयास गर्नेछौं । कानून अनुसार, डाटा अध्ययन समाप्त भएपछि न्यूनतम ५ वर्षको लागि भण्डारण गरिनेछ ।

यदि मसँग प्रश्नहरू छन् भने के हुन्छ ?

यदि तपाईंसँग अहिले वा पछि अनुसन्धानको बारेमा कुनै प्रश्नहरू छन् भने, कृपया हामीलाई सम्पर्क गर्नुहोस् ।

प्रमुख अन्वेषकः डा. राजु ढकाल, एम.डी., स्पाइनल इन्जुरी केन्द्र, साँगा, काभ्रे, नेपाल टेलिफोनः ०११-६६०८४७/८४८

अनुसन्धान संयोजकः सृजना गौतम, फोन नम्बरः ९८४९६०७६००, +१८२५ -८८८ -००७६

यदि तपाईसँग यस अनुसन्धान सहभागीको रूपमा तपाईको अधिकारको बारेमा कुनै प्रश्नहरू छन् भने, तपाई +१७८० -४९२ -२६१५ मा अल्बर्टा विश्वविद्यालय अनुसन्धान नैतिक कार्यालयलाई सम्पर्क गर्न सक्नुहुन्छ । यस कार्यालयको अध्ययन अनुसन्धानकर्ताहरूसँग कुनै सम्बन्ध छैन ।

म यस अध्ययनमा मेरो सहमतिलाई कसरी संकेत गर्छु ?

तल हस्ताक्षर गरेर, तपाईंले बुझ्नुहुन्छ ।

क) तपाईंले माथिको जानकारी पढ्नुभएको छ र तपाईंले नबुझेको कुनै पनि कुरा तपाईंको सन्तुष्टिको लागि व्याख्या गरिएको छ ।

ख) तपाईंले अनुसन्धान अध्ययनमा भाग लिनुहुनेछ ।

ग) तपाईंले कुनै पनि समयमा अनुसन्धान अध्ययनलाई स्वतन्त्र रूपमा छोड्न सक्नुहुन्छ ।

घ) तपाईंले अध्ययनमा रहेर आफ्नो कानुनी अधिकार त्याग्नु हुन्न ।

ङ) तपाईंले यस अध्ययनमा भाग लिएर अनुसन्धानकर्ताहरू र संलग्न संस्थाहरूको कानुनी र व्यावसायिक दायित्वहरू परिवर्तन हुँदैनन् ।

....

सहभागीको नामः

....	....
सहभागीको हस्ताक्षर	मितिः
....	....
सहमति प्राप्त गर्ने व्यक्तिको नामः	सहमति प्राप्त गर्ने व्यक्तिको हस्ताक्षर

……………………………… ………………………………

साक्षीको नाम साक्षीको हस्ताक्षर

यस सहमति फारमको प्रतिलिपि तपाईलाई तपाईको रेकर्ड र सन्दर्भको लागि राख्नको लागि दिइएको छ ।

6. Appendix F: Recruitment Material (English)

Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal.

You are being invited to participate in our study with the title, **'Experience of patients with spinal cord injury regarding the quality of care during acute hospital stay in Nepal.'** You would be asked to give an interview that may last between 30 to 60 minutes. We will ask you a few questions related to your injury and the care you received in the acute hospital.

You can participate in our research and help us to understand more about your care experience if you are:

- Person with Spinal Cord Injury with the date of injury no more than six months.
- Age is 18 years or older.
- Able to speak and understand Nepali.
- Is directly admitted from the acute hospital and residing in the Spinal Injury Rehabilitation Center.
- Able to give voluntary consent and be willing to share personal information.

You may not be eligible if you have a problem remembering the events or cannot explain your experience.

If you wish to know more about this research study and want to participate, please contact

Principal Investigators: Dr. Raju Dhakal, MD, Spinal Injury Rehabilitation Center (SIRC), Sanga, Nepal Tel: 011-660847/848 Email: medicaldirectorsirc@gmail.com

Research Coordinator: Srijana Gautam, Student, M.Sc. in Medicine, Department of Medicine, University of Alberta, Email: srijana1@ualberta.ca

7. Appendix G: Recruitment Material (Nepali)

अध्ययनको शीर्षक: नेपालमा तीव्र अस्पताल बसाइको समयमा हेरचाहको गुणस्तर सम्बन्धी स्पाइनल कर्डमा चोट लागेका बिरामीहरूको अनुभव।

तपाइलाई हाम्रो अनुसन्धान **' नेपालमा तीव्र अस्पताल बसाइको समयमा हेरचाहको गुणस्तर सम्बन्धी स्पाइनल कर्डमा चोट लागेका बिरामीहरूको अनुभव '** मा भाग लिन को लागि आमन्त्रण गर्दछौं। तपाइलाई अन्तर्वार्तामा भाग लिन सोधिनेछ जुन ३० देखि ६० मिनेटको हुनेछ| यो क्रममा, हामी तपाइँ बारे र पहिलेको अस्पतालसंग सम्बंदित अन्य हेरचाह अनुभवहरुको बारेमा प्रश्नहरु सोध्नेछौं।

तपाई हाम्रो अनुसन्धानमा सहभागी भएर हामीलाई तपाइको यस भन्दा आगाडी को अस्पतालको अनुभव बारे बताउन सक्नु हुनेछ यदि तपाई:

- स्पाइनल कर्डमा चोट लागेर ६ महिना नकटेको व्यक्ति हुनुहुन्छ भने।
- उमेर १८ वा माथि हुनुहुन्छ भने।
- नेपाली राम्रो संग बुझ्न र बोल्न सक्नु हुन्छ भने।
- सिधै अस्पताल बाट यस स्पाइनल इन्जुरी पुर्नस्थापना केन्द्रमा भर्ना भएर बसीरहनु भएको छ भने।
- आफैले यस अनुसन्धानमा भाग लिन स्वीकृति दिन सक्नुहुन्छ र आफ्नो व्यक्तिगत कुरा हामीसंग बाढ्न समर्थन दिनु हुन्छ भने।

यदि तपाईलाई बिर्सिने समस्या छ अथवा आफ्नो अनुभव बाढ्न गारो हुन्छ भने तपाइले यस अनुसन्धान मा सहभागी हुन पाउनु हुनेछैन।

यदि तपाईं यस अनुसन्धानको बारेमा थप जान्न चाहनु हुन्छ अथवा सहभागी हुन चाहनु हुन्छ भने, कृपया हामीलाई सम्पर्क गर्नुहोस्:
प्रमुख अन्वेषक: डा. राजु ढकाल, एमडी, स्पाइनल इन्जुरी रिह्याबिलिटेसन सेन्टर, साँगा, नेपाल टेलिफोन: ०११-६६०८४७/८४८, इमेल: medicaldirectorsirc@gmail.com
अनुसन्धान संयोजक: सृजना गौतम, ९८६०३१२८४१, इमेल: srijana1@ualberta.ca