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Sexuality-a matter of life and death: successful sexual rehabilitation of Men with Spinal Cord Injury in Nepal

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(Research)
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ABSTRACT

Sexual activity is an important aspect of activities of daily living. Traumatic spinal cord injury is well known for its notorious effect in altering sexual function and sex life among men. Despite abundant literature and knowledge on the extent of damage that Spinal Cord Injury (SCI) can cause on the sexual function of MWSCI and bio-medical interventions to address them, the sexual needs and concerns of most MWSCI remain largely unmet. There is equally growing evidence depicting health practitioners' unwillingness (attitude), lack of knowledge and skills in addressing sexual issues of MWSCI and the need for improving sexual rehabilitation services. In addition, there are very few qualitative studies exploring the sexual concerns and needs and the psychosocial impact on their health and well-being of MWSCI from their perspective. These studies identified the need for exploring sexual rehabilitation needs from the perspective of MWSCI.

This study explored the lived experiences and sexual concerns and needs of MWSCI and the attitudes of health professionals, family members and significant others in society from the perspective of Nepalese MWSCI. This study used a phenomenological methodology. Data were collected by conducting semi-structured interviews of 17 MWSCI who were purposively sampled with maximum variation. The main research questions were: 1) What are the sexual concerns and needs of MWSCI; and 2) What are the attitudes of health professionals, family members and significant others towards the sexuality of MWSCI.

Findings showed that various personal, social and economic factors in addition to impaired sexual function secondary to SCI play an important role in the sex life of MWSCI. The quality of existing health care services affected the overall outcome of SCI including sex life of these MWSCI. Most often sexual rehabilitation was not the priority of rehabilitation programs and when they did cover this issue the focus was on the bio-medical aspects of sexual functioning. In addition, medical interventions to address sexual functions such as erectile dysfunction and infertility appeared to be fragmented and inadequate. Most MWSCI felt a need to broach their sexual concerns early on with more information during rehabilitation and after returning to the community.

It is both surprising and illuminating to know how soon after injury men reported being curious about their sex life and sexual capacity. Indeed, sexuality after SCI is much more important than practitioners and society seem to have assumed. Many underlying sexual meanings, concerns and needs were identified and these typically extended beyond concerns about pleasure. Sexual function can be a matter of life and death for participants. In the absence of a social security safety net and previous income, these concerns focus on: maintaining family and community structures; ensuring ongoing care; and fear of dying without social supports. Sex can be seen as a ‘life line’ and recovery is determined by the social prejudices, family politics, and cultural pressures to have children and a wife for support. On the other hand, failure of the health care system to deliver the necessary SCI care including sexual rehabilitation adds to men’s fear of being unable to fulfil their prescribed masculine roles. The sociocultural and environmental impact on manhood forces some of these men to redefine their masculinity and overcome their reliance on traditional scripts for masculine identity that stress sexual prowess.

This research thus proposes an adapted protocol for sexual rehabilitation considering various factors and dimensions of sexual issues for the benefit of Nepalese MWSCI. These overall concerns and needs of MWSCI are grouped under five major themes: early and ongoing sexual concerns; loss and reconstruction of manhood; challenges to and failures of the health care delivery; sexuality as a matter of life and death; and the need for better SCI sexual rehabilitation.

Keywords

Men with Spinal Cord Injury, Sexuality, Sexual rehabilitation, Manhood, Phenomenology

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LIST OF ABBREVIATIONS

AD	Autonomic Dysreflexia
ADLs	Activities of Daily Living
AES	Abdominal Electrical stimulations
ASIA	American Spinal Injury Association
DHS	Department of Health Service
DPOs	Disabled People Organisations
ED	Erectile Dysfunction
EEJ	Electro Ejaculation
EHCS	Essential Health Care Services
GPHRC	Green Pastures Hospital and Rehabilitation Centre
HP	Health Post
ICF	International Classification of Functioning, Health and Disability
ICSI	Intracytoplasmic Sperm Injection
IIEF	International Index of Erectile Function
ILS	Independent Living Society
INF	International Nepal Fellowship
IPA	Interpretative Phenomenological Analysis
IVF	In vitro Fertilisation
KCAASS	Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale
MBI	Modified Barthel Index
MOHP	Ministry of Health and Population
MWSCI	Men with Spinal Cord Injury
NPC	National Planning Commission
NPCS	National Planning Commission Secretariat
PDE-5	Phosphodiesterase type 5
PHC	Primary Health Centre/Care
PVS	Penile Vibratory Stimulation
QOL	Quality of Life
SCI	Spinal Cord Injury
SCIAN	Spinal Cord Injury Association Nepal
SCIM	Spinal Cord independence Measure

SHP	Sub-health Post
SHS	Social Health Security
SRH	Sexual and Reproductive Health
TESA	Testicular Sperm Retrieval
UHC	Universal Health Coverage
WHO	World Health Organisation

LIST OF PRESENTATIONS

Ranabhat, M. K., Judd, J., Yau, M., & Plummer, D. (2015). Sexual concerns and needs of men with spinal cord injury: A literature review. *Association of Nepal's Occupational Therapist Forum*. Surkhet, Nepal.

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PRELIMINARY WORK INFORMING THIS RESEARCH

Wee, J., Ruttan, L., **Ranabhat, M.K.**, & Ng, E. (2009, November).*Sexuality education in SCI rehabilitation in Nepal – The Importance of Understanding Culture.*In A. Kovindha (Chair).The 8th ASCoN Conference conducted at the meeting of Spinal Injury Rehabilitation Centre, Kathmandu, Nepal.

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. doi: 10.1038/sc.2011.119

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CHAPTER 1

INTRODUCTION

1.1 Spinal Cord Injury

Spinal Cord Injury (SCI) is well known for its chronic disabling nature and was also regarded as an untreatable condition during ancient times. However, with the improvement in health care and rehabilitation services, life expectancy of people with SCI is gradually improving and is now comparable to the general population in some developed nations. With this increase in life expectancy more and more health issues and psychosexual problems associated with SCI have surfaced requiring further close attention.

Injury to the spinal cord anywhere within the neural canal from just below the foramen magnum to the cauda equina or injury of the cauda equina is known as SCI (Mittmann et al., 2005). A spinal cord or cauda equina injury can be suspected if there is a loss or impairment of reflexes, or sensation, or muscle strength, or a combination of these functions (El Masri, 2006). The level and extent of injury can be assessed by using The American Spinal Injury Association (ASIA) impairment scale, also known as the ASIA/ISCOS Classification, and recording these limiting factors will improve the reliability of assessment and/or allow appropriate comparison over time (El Masri, 2006). In MWSCI, sexual impairments range from: decreased sexual desire, erectile and ejaculatory dysfunction, lack of orgasm to infertility.

The level and extent of damage to the spinal cord, and completeness or incompleteness of the injury, determines the impact on physiological sexual responses such as erection, lubrication and ejaculation (Rathus, Nevid, Fichner-Rathus, Herold, & McKenzie, 2007). However, factors other than impairment could make these problems and sexual experiences unique for an individual. Chronic conditions like SCI affect the sexual activity of an individual distinctively, with no two individuals with the same diagnosis having exactly the same experience (Hattjar, 2012). Similarly, contextual factors (environmental factors: physical, social and attitudinal; and personal factors: education level, employment etc.) which comprises the right to a satisfying sex life (Sakellariou, 2006a) also vary from one person to other. Effective rehabilitation programs address both medical and social aspects of clients' sexuality however, from the South-Asian perspective there is a dearth of MWSCI sexuality literature. This phenomenological study is likely to be the first of its kind in Nepal and explores the sensitive sexual issues and concerns of men with SCI and it also identifies the perceptions of rehabilitation professionals and other significant people (family members: spouse or parents, partner, care givers, society) towards their sexuality and sexual concerns of men with SCI.

1.2 Background

1.2.1 Country profile: Nepal

The Federal Democratic Republic of Nepal is a landlocked country of 147,181 square kilometres. It is located in South-Asia between the Peoples Republic of China (to the north) and the Republic of India (to the south, east and west) as seen in *Click Nepal* (2016) (Figure 1.1). Based on gross domestic product per capita, Nepal is one of the poorest countries (ranked 156/185) in the world (World Bank, 2013). It has a total population of 26.4 million, a literacy rate of 65.9 (75.1% male and 57.4% female) and a disability rate of 1.94% (National Planning Commission Secretariat [NPCS], 2012). The life expectancy of Nepalese people increased from 63.2 years in 2001 to 69.2 years in 2015 (World Health Organization [WHO], 2016). According to the NPCS (2012), 81.3 % of people are Hindu, 9% Buddhist, 4.4% Muslim, 3.1% Kirat, 1.4% Christian, 0.5% Prakirti and 0.3% other religions. The country is geopolitically divided into 5 development regions, 14 zones as seen in *Click Nepal* (2016) (Figure 1.2) which is further divided into 75 districts consisting of as many as 130 municipalities and 3833 village development committees for administrative purposes (Central Bureau of Statistics [CBS], 2014).

Figure 2.1: Geographical location of Nepal

Figure 1.2: Administrative division of Nepal

1.2.2 Health Care Delivery system in Nepal

The Government of Nepal has formally adopted the model of "Primary Health Care" (PHC) for providing health care services as a signatory nation of "Alma Ata Declaration 1978" (Jha, 2014). This declaration had a goal of health for all by the year 2000 and has affirmed access to basic health services as a fundamental human right in 1978 (WHO, 1978). The PHC model was mainstreamed in Nepal through its endorsement in the 1991 National Health Policy (DHS, 2014a). In the Interim constitution of Nepal, 2007 as well as in the new constitution which was promulgated in 20th September 2015, health has been recognised as a fundamental right of the people. According to Article 35 of the new constitution:

1) Every citizen shall have the right to get basic health care free of cost from the state and no one will be restricted from emergency health care;
2) Everyone shall have the right to get information about his/her health care;
3) Every citizen shall have equal access to health care; and
4) Every citizen shall have the right to access to pure drinking water and sanitation (Constituent Assembly Secretariat, 2015, p. 15).

The Government of Nepal has: 8 central level , 3 regional; 3 sub-regional, 10 zonal, 78 district/other hospitals; and 208 PHC Centres; 1559 health posts ; and 2247 sub-health posts at village and municipality levels ([DHS], 2014a). The organisational structure and corresponding number of health facilities are illustrated in Figure 1.3 (DHS, 2014c).

According to the Department of Health Services (DOHS), the sub-health post is the first contact point of the basic health service, and each level above the sub-health post is the referral point in an institutional framework. Generally patients are referred from the sub-health post to the health post to primary health centre, then to a district, zonal hospital and finally, to the tertiary hospitals in the regions or capital city (DHS, 2014b). In addition there are 301 private, community and other types of hospitals and the number of these facilities in eastern, central, western, mid-west and far-western development regions are 68, 143, 59, 21 and 10 respectively (Government of Nepal, 2014). Two-thirds of these private hospitals have come into operation only in the last decade (Government of Nepal, 2014).

The Government of Nepal is optimistic about the progressive realisation of Universal Health Coverage (UHC) ([DHS], 2014a) to its citizens through improvement in old existing models of PHC. The interim plan (2007-2010) identified a lack of human resources and their mobilisation, poor physical infrastructure, the short supply of drugs and medical equipment, poor monitoring and political interferences as the challenges of the health care system in Nepal (National Planning Commission, 2007). The plan also identified the need to improve access to basic health services of the people in the marginalised sectors: Far-western and Mid–western development regions of Nepal. The National Health Insurance Policy of 2013 (DHS, 2013) and the National Social Health Insurance Policy of 2014 were developed with the objective of implementing insurance schemes and ensuring UHC by increasing access and utilization of quality health services (Government of Nepal, 2015b). The Social Health Security Development Board was formed by the Government in February 2015 to develop a legal framework and implement a Social Health Security (SHS) scheme (Government of Nepal, 2015a). Accordingly, the Government has already rolled out the first phase of the SHS scheme in three out of 75 districts. Similarly, the Nepal Health Sector strategy 2015-20 aims to provide basic health services through improvement in the quality of health services at lower level health facilities: sub-health posts, health posts, primary health centres, sub-district and district hospitals and referral to the appropriate service delivery centre from communities and lower level health centres to meet public expectations.

Organizational Structure of the Department of Health Services

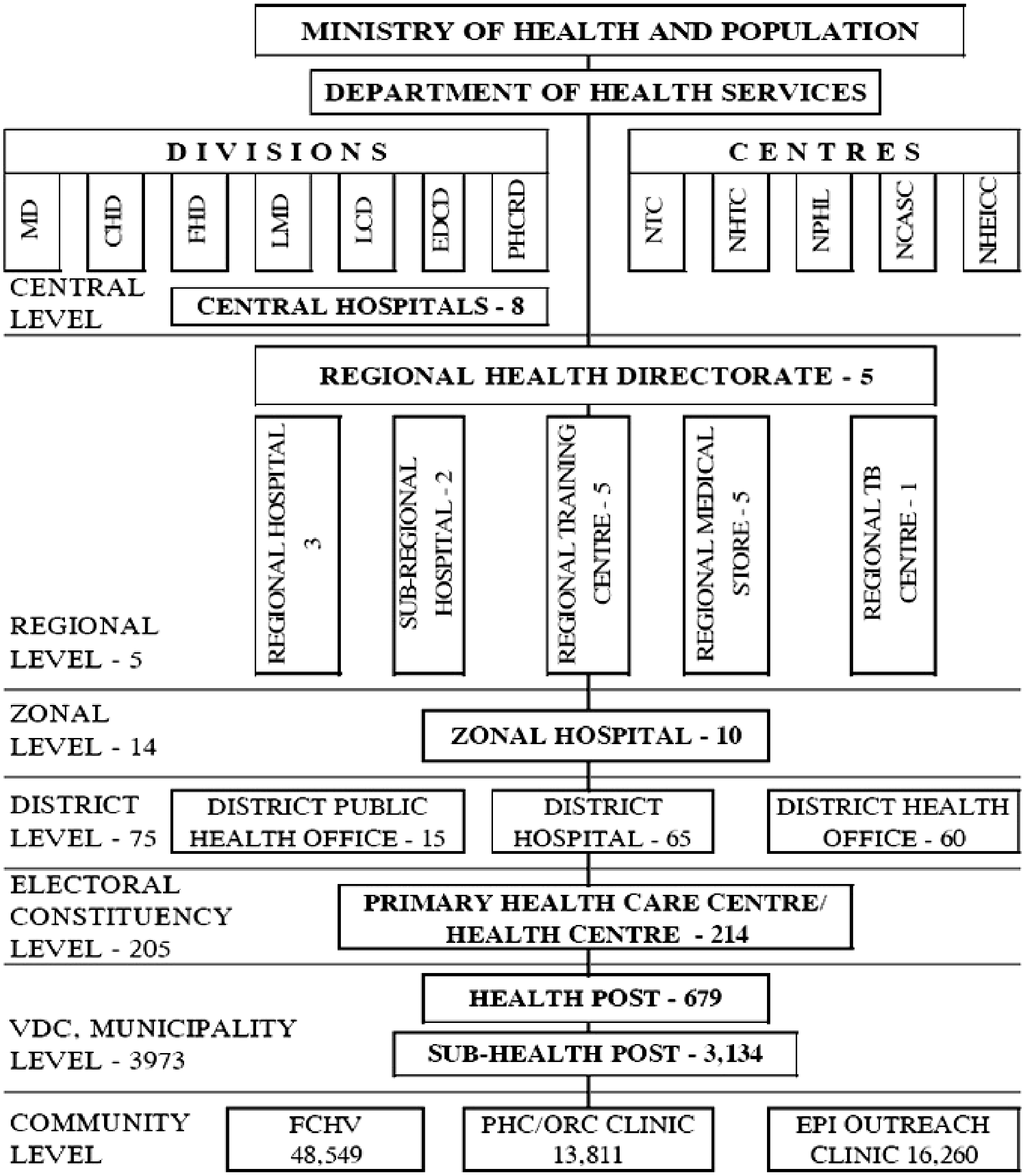


Figure 1b.1

Source: Administration Section, HMIS/MD, DoHS

Acronyms

MD	*Management Division*	*NHTC*	*National Health Training Centre*
FHD	*Family Health Division*	*NTC*	*National Tuberculosis Centre*
CHD	*Child Health Division*	*NCASC*	*National Centre for AIDS and STD Control*
EDCD	*Epidemiology and Disease Control Division*	*NPHL*	*National Public Health Laboratory*
LMD	*Logistics Management Division*	*FCHV*	*Female Community Health Volunteer*
LCD	*Leprosy Control Division*	*PHC/ORC*	*Primary Health Care Outreach Clinic*
PHCRD	*Primary Health Care Revitalization Division*	*EPI*	*Expanded Programme on Immunisation*
NHEICC	*National Health Education, Information and Communication Centre*		

Figure 1.3: Organisational structure of Department of Health Services

The Ministry of Health and Population [MOHP] (2015) will also restructure the health care delivery system (see Figure 1.4) as follows:

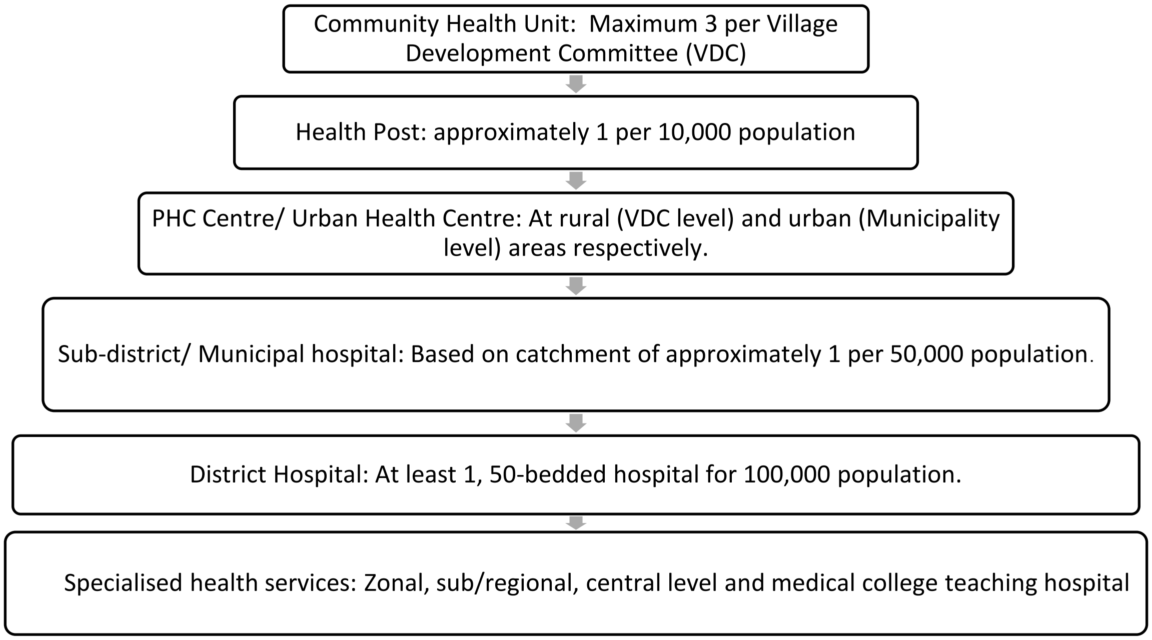


Figure 1.4: Referral hierarchy for Government Health Care Services

However, the Nepalese Government commitment to provide basic health care free of cost to its citizens is far from reality in the existing health system (Mishra, Khanal, Karki, Kallestrup, & Enemark, 2015) and PHC model. According to WHO (2006) Nepal's total health expenditure is just 5.1% of its gross domestic product which is considerably lower than America's (12.8%) – US$ 2636 per capita and global average (8.7%) – US$ 716 per capita and slightly above the South-East Asia Region (3.4%) – US$ 31 per capita. In addition, the share of the Government spending in health is just 30.5% which is also lower than the average spending of low-income countries in South-East Asia (34%) and significantly lower than Europe (76%) as a result of which private or out-of-pocket expenses in health are very high (69.5). A more recent WHO (2016) report on UHC also indicates that the goal of UHC is not feasible without increasing Government spending on health in those countries which spend less than 12% of their total budget on health. On the other hand, WHO's (2000) report on "Health Systems: Improving

Performance” shows the failure and end of its use of the PHC model as the delivery of healthcare services in low resource countries. According to this report, the failure is due to the lack of equipment, insufficient funding and inadequate training for healthcare workers and the unavailable and poor quality services at community level. People are often forced to bypass the primary-level services because they are not able to receive services at a lower level as a result the referral system in the PHC hierarchy. Similarly, the findings of various studies and government reports also showed that the resources and mechanism in the current health care delivery system was not adequate to meet the expectations and health needs of many people. According to Paudel (2008) the high ratio of available doctors, nurses, hospital beds and health care providers to population (18,439, 4,987, 2,349 and 2,071 respectively) is a major challenge in delivering basic health care services and this gap is even higher in rural Nepal. Similarly, a government report also acknowledged this gap stating that the current ratio of 0.17 doctors/1,000 population and 0.50 nurses/1,000 population is significantly less than the WHO’s recommendation of 2.3 doctors, nurses and midwives/1,000 population (MOHP, 2013).

On the other hand, although the share of private hospitals grew from 23% of total hospitals in 1995 to 78% in 2008 and the total bed capacity has reached twice that of public hospitals (RTI International, 2010) services are not distributed evenly throughout the country. The most developed region – the central region – has 48% of these hospitals, whereas the far-western region – the least developed region - has only 3% (Government of Nepal, 2014; RTI International, 2010). The Government’s unclear policy on partnership with the private sector, lack of clear provision for quality assurance and coordination has also limited the benefit of private sector engagement in health care. In addition, out-of-pocket expenditure is the mainstay of health care financing at both public and private hospitals except Essential Health Care Services (EHCS) in public health care facilities in Nepal (Government of Nepal, 2008). Out-of-pocket expenditure is about 5.5% per household which accounts for 74% of the total health care financing (Hotchkiss, Rous, Karmacharya, & Sangraula, 1998). The EHCS: prevention, clinic services, basic inpatient services, delivery services, a few essential drugs are provided free of cost at health posts, sub-health posts and primary health centres and to the target groups at district hospitals. Moreover, the services offered by private clinics and hospitals are not affordable for the poorest members of society. Furthermore, most people are not covered by health insurance (Mishra et al., 2015) as the Government SHS scheme is yet to roll out in the remaining 72 districts.

1.2.3 SCI incidence, age and gender in spinal cord injuries

Limited data is available regarding the incidence and prevalence of SCI in Nepal. A ten-year retrospective hospital-based study in the eastern region of Nepal reported that 896 SCI patients were admitted from 1996 to 2006 (Bajracharya, Singh, Singh, & Shrestha, 2007). This study reported a male (76.35%) to female (23.66%) ratio of 3:1 and a mean age of 41.74 and 38.56 years for men and women respectively (Bajracharya et al., 2007). In addition, the majority of the cases (93%) were from 7 of the 75 districts of Nepal and the rate of admission increased by a factor of 17 (from 10 to 167) during the study period. Moreover, the etiology of SCI among 896 patients showed that falls from heights were the most common cause of injury (37.86%), followed by falls from trees (21%), road traffic accidents (13%), agricultural injuries (8%) and other (19%) (Bajracharya et al, 2007). However, without conducting national surveys the incidence, prevalence and etiology of SCI cannot be accurately ascertained from the available data in countries like Nepal (Rahimi-Movaghar et al., 2013).

Based on the global incidence of traumatic SCI at 9-174/ million population and prevalence of 50-900/ million population, a Nepalese study projected SCI rates of 300-5000 and prevalence of 1500-25000 per year for the total population in Nepal (Scovil, Ranabhat, Craighead, & Wee, 2012). Similarly, a systematic review of the epidemiology of traumatic SCI in developing countries (including Nepal) reported the incidence of SCI as 25.5/million/year, ranging from 21-130.7/million/year, with 82.2% male cases, and for both sexes, a mean age of 32.4 years at the time of injury (Rahimi-Movaghar et al., 2013). Thus, based on Rahimi-Movaghar et al.'s (2013) study, the incidence of traumatic SCI could be as high as 600–3500 per year in Nepal. Indeed, the incidence of SCI could be much higher than this figure. The discrepancy in the incidence of SCI between global and developing countries could be due to a lack of documentation and under reporting of morbidity and mortality due to SCI.

1.2.4 Disability and SCI rehabilitation services in Nepal

Disability and rehabilitation services are neither highly developed nor widely available in Nepal. Civil society organisations such as non-governmental organisations (NGOs) and disabled people organisations (DPOs) are the main stakeholders. These organisations provide disability and rehabilitation services while services from government bodies are limited to community-based services and social schemes (Boggs, 2014). The availability of rehabilitation services such as providing assistive and adaptive devices; the number of the rehabilitation service providers; and the number of rehabilitation professionals are far below international sustainability standards. There is also a lack of comprehensive government policies for the delivery of these services (Boggs, 2014).

SCI rehabilitation is an emerging field in Nepal, with specific SCI rehabilitation services appearing to become available on a small scale from the mid -1990s. Currently, there are very few centres dedicated to SCI rehabilitation. Originally a tertiary leprosy referral centre (established 1957), Green Pastures Hospital was integrated into the general Green Pastures Hospital and Rehabilitation Centre (GPHRC) in 1997 (Brandsma, Schwarz, Anderson, & Herm, 2005). This Centre has allocated 12 out of 25 beds for SCI rehabilitation. The Spinal Injury Rehabilitation Centre (SIRC), established in 2002, is the facility that exclusively rehabilitates people with SCI. From August 2012, SIRC has been formally recognised by the Government as a 51-bed rehabilitation centre. Sainik Punasthaphan Kendra (SPK) is primarily the centre for the rehabilitation of army personnel. It is the only centre in Nepal run by the Government and is managed by the Nepalese Army. Other private rehabilitation centres' services are limited to medical care and physiotherapy management (Spinal Injury Rehabilitation Centre, 2014).

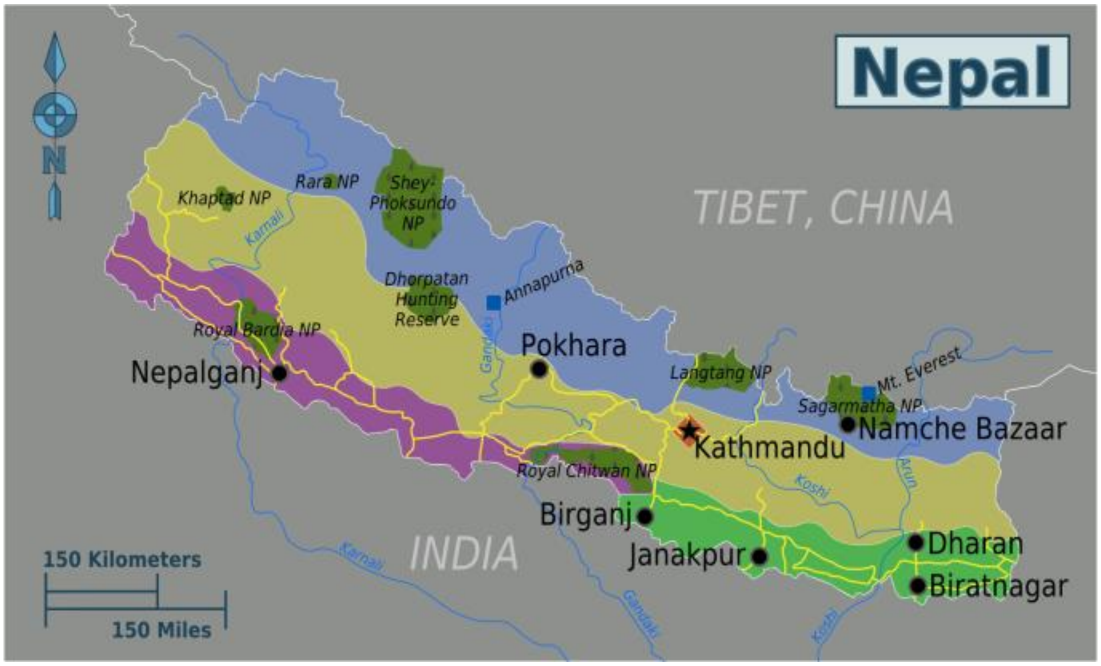


Figure 1.5: Geographical terrain and major cities of Nepal

Considering the catchment area, the current rehabilitation capacity of existing facilities and the increasing incidence of SCI, SCI rehabilitation services continue to be limited in Nepal. SIRC and SPK and most of the private facilities are located in the capital city, (Kathmandu), with GPHRC in the western region (Pokhara) therefore, leaving the eastern, mid-western and far western regions of Nepal without any SCI rehabilitation centres. Look at the map to find the city where the above rehabilitation centre are located as seen in *Nepal: Regions* (2016) (see Figure 1.5). According to Shah, Shrestha, and Subba (2013), the barriers to successful SCI rehabilitation in Nepal includes the lack of adequate and decentralised rehabilitation services; a lack of rehabilitation professional specialists with knowledge and awareness about specific disabling conditions such as SCI; and a lack of understanding of SCI in the general population. There is also a lack of proper referral mechanisms between the government health care system and rehabilitation service providers (Shah et al., 2013).

Even with limited SCI rehabilitation services in Nepal more people with SCI are surviving these days than before. In the late 1970s, health workers' considered the treatment of SCI patients to be 'wasteful' and a poor utilisation of scarce resources and patients were sent back home often without any rehabilitation (Hamilton, 1978). In addition, this lack of service resulted in a widespread sense of hopelessness in people with SCI, their families and society (Hamilton, 1978). Similarly, Wee and Schwarz (2004), also described that in Nepal people with SCI were often sent home to die, without receiving rehabilitation until recently. Yet, there are some encouraging signs of improvement in the survival rate and life expectancy of people with SCI in Nepal. Findings from a GPHRC follow-up study show more than three-quarters of people who were rehabilitated and discharged in the year 2007 continued to survive three years after their discharge (Scovil et al., 2012). In addition, in recent years more people living with SCI are being noticed actively participating in various self-help and support groups like the independent living society and SCI Association and working in private and public sectors in recent years than ever before. However, Nepalese people with SCI were found to live for fewer years than Canadians with SCI as life expectancy for the Nepalese general population is also already lower than for Canadians (by 15-20 years) (Wee & Schwarz, 2004).

1.2.5 Sexual issues in the cultural context of Nepal

The sexuality of people with disabilities is neither on the social agenda nor is it a rehabilitation priority in Nepal. For socio-cultural reasons, the sexual needs of people with disability remain invisible. Sexuality is a taboo topic in Nepal (Adhikari & Tamang, 2009; Mahat & Scoloveno, 2001; Regmi, Simkhada, & van Teijlingen, 2010) similar to that of other Asian countries (Agampodi, Agampodi, & Piyaseeli, 2008; Ali, Bhatti, & Ushijima, 2004). Conservative attitudes of the general population towards sexuality, arranged marriages and restriction of overt inter-relational behaviour between opposite sexes are a feature of Nepalese society (Wee, Ruttan, Ranabhat, & Ng, 2009). Although there is a gradual shift in the situation among adolescents, premarital relationships are still widely prohibited (Adhikari & Tamang, 2009). In addition, because of family system characterised by patrilocal marriage arrangements, young mothers in Nepal are under pressure to produce a son (Brunson, 2010). This in turn exerts undue pressure on men with SCI and couples with fertility secondary to SCI to have children, particularly a son.

1.2.6 Research on sexual functioning

Most of the studies on sexuality of MWSCI are focussed on biomedical aspects of sexual dysfunction and intervention, using mainly quantitative approaches. A few studies examined the benefit of sexual rehabilitation and knowledge, attitude, confidence, competence and comfort level of health practitioners on sexual rehabilitation of people with SCI. Very few studies were qualitative studies which explored the psychological and socio-cultural aspects of sexuality issues from the perspective of MWSCI. Most importantly, there was no single study that explored the sexuality issues of people with SCI in Nepal except a follow-up study which discussed sexuality issues briefly. In addition, there is also a dearth of literature on sexuality of MWSCI in the South-Asian region except for a very few quantitative studies from India. A narrative literature review which was published after the literature review of this study also claimed the paucity of qualitative study exploring the firsthand experience of people with SCI in India (Sunilkumar, Boston, & Rajagopal, 2015).

Men with SCI and who have sexual dysfunction appear to have decreased satisfaction with their sex life. Findings from most studies show that both men and women with SCI were less satisfied with their sex life after injury (Biering-Sorensen, Hansen, & Biering-Sorensen, 2012; Kennedy, Lude, & Taylor, 2006; Kennedy et al., 2010; Valtonen, Karlsson, Siösteen, Dahlöf, & Viikari-Juntura, 2006). Perhaps not unexpected, men with SCI were less satisfied with their sex life after injury compared to women with SCI (Biering-Sorensen et al., 2012; Sale et al., 2012; Valtonen et al., 2006). In addition, Quality Of Life (QOL) was better among people who were satisfied with their sex life (Sale et al., 2012). A study from The Netherlands reported that a satisfying sex life was a strong determinant of life satisfaction and life satisfaction in people with SCI deteriorated one year after the injury (van Koppenhagen et al., 2008). Moreover, men with SCI and erectile dysfunction also appeared to have low QOL (Mittmann et al., 2005). In a study conducted in the United States, most of the men with SCI (N= 199) reported that QOL would be enhanced with improvements in sexual function (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007). Additionally, recovering sexual function for improving QOL was ranked first and second by both men and women with paraplegia and quadriplegia respectively (Anderson, 2004). Most of the findings from the quantitative studies suggest the need for improvement in sexual function and sex life however there is a limit to how much sexual function can be maintained or improved with biomedical interventions and very little attention is paid to psychosocial and qualitative aspects of sexual issues to improve their sex life. For example, clinicians' competence in recognising men's adherence to the masculine scripts for sexual capacity or abilities has been reported as being an important skill for sexual rehabilitation (Burns, Mahalik, Hough, & Greenwell, 2008), and these authors argue the need for developing culturally appropriate guidelines incorporating these components.

Provision of sex education, counselling and therapy during rehabilitation has been found to hasten the process of acceptance of disability by enhancing sexual function (Cencora & Pasiut, 2012). Nevertheless, sexual need was still identified as a key unaddressed and unmet area (similar to occupation and pain relief needs) among people with SCI (Kennedy et al., 2006; van Koppenhagen et al., 2008). Partners of people with SCI and rehabilitation professionals also expressed the need for discussing sexual issues (Gianotten, Bender, Post, & Höing, 2006). About a quarter of participants of a (GPHRC's) follow-up study in Nepal expressed the need for more education on the topic (Scovil et al., 2012). Yet, only half of the married couples recalled receiving sexual education and half of those couples were not continuing their sexual relationship, citing decreased interest in sex, concerns for birth control (family planning), and the spouse's perception of their partner with SCI still being too ill (Scovil et al., 2012). Unfortunately, lack of skills, knowledge and comfort in addressing sexual issues with health professionals (working in SCI centres), appeared to make sexual rehabilitation more challenging. (Gianotten et al., 2006; G. Simpson, Anwar, Wilson, & Bertapelle, 2006). Similarly, in Nepal, the GPHRC SCI rehabilitation service evaluation identified that many staff felt inept to address the sexual problems of their SCI clients, and both staff and people with SCI felt uncomfortable discussing sexual issues openly (Yolland, Clark, & Craighead, 2006).

Most studies were either influenced by the medical model or the social model of disability. According to Üstün(2002) the medical model of disability 'calls for medical or other treatment or intervention, to 'correct' the problem with the individual' (p. 8) and the social model 'sees disability as a socially-created problem and not at all an attribute of an individual demanding a political response' (p. 9). Whereas, the biopsychosocial model of disability utilised in ICF synthesizes the biological, individual and social aspects of health incorporating 'what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects' (Üstün, 2002, p. 9). Most of the findings of quantitative studies on the biomedical aspect from India which shares a close sociocultural background with Nepal were comparable to the studies from other countries and the western world. However, all the qualitative studies were conducted in completely different sociocultural settings and the findings of these studies cannot be translated into a Nepalese setting. For all these reasons, a need for a qualitative study was realised to explore the biological, individual and social aspects of sexuality from the perspective of MWSCI in Nepal.

1.2.7 Statement of the problem

There is a knowledge gap about how Nepalese men with SCI perceive and manage their sexual issues of erection, ejaculation, orgasm, infertility and associated psychosocial problems. In addition, limitations in sexual activity, restrictions in participating in sexual activity and social and physical barriers and or facilitators in living a sexually satisfying life from the perspective of Nepalese MWSCI are also largely unknown. Furthermore, there is no information on how the attitudes of rehabilitation professionals, spouse, close relatives and other significant people accept and affect the sex life of MWSCI in Nepal.

1.2.8 Research questions

The research questions for this study are:

1. From the perspective of MWSCI, what are the men's sexual concerns and needs after SCI?
2. What are the perception of MWSCI about the attitudes of health professionals, spouse, family members and other significant people in Nepali society towards their sexual concerns and needs after SCI?

1.2.9 Significance of the problem and purpose of the study

GPHRC formerly a leprosy referral centre is probably the first organisation to offer rehabilitation services using a multi-disciplinary approach in Nepal. Although, this centre began to rehabilitate people with various conditions including SCI formally since 1997, psychosexual issues became part of its rehabilitation program only since 2006. Yet, formal (standarised) assessment tools such as the International Index of Erectile Function (IIEF) (Virseda-Chamorro, Salinas-Casado, Lopez-Garcia-Moreno, Cobo-Cuenca, & Esteban-Fuertes, 2013) are not utilised to measure the sexual abilities and outcome of sexual rehabilitation intervention (until data collection period) which could potentially compromise the health professional's ability to make the best decisions regarding the client. Similarly specific sexual rehabilitation approaches such as the PLISSIT model (P= permission giving; LI = Limited Information; SS = Specific Suggestions and IT = Intensive Therapy) (Annon, 1976) are also not followed. On the other hand, assessment tools such as the American Spinal Injury Association (ASIA) impairment scale to assess the level and severity of injury; the Modified Barthel Index (MBI) and the Spinal Cord independence Measure (SCIM) scale to assess functional independence; and Participation (P) Scale in assessing social participation etc. were routinely used. This could be due to the priority of MWSCI and or rehabilitation programs/professionals' priorities over other aspects of SCI rehabilitation than sexuality issues.

Reflecting on my work as an occupational therapist and sex educator as part of a multidisciplinary rehabilitation team in this setting I was left with queries such as how the MWSCI deal with issues around sexuality after returning to their homes and what impact does it have on their personal life and relationships. The centre also did not have a mechanism to follow-up sexual issues following discharge into the community and the situation and outcome of intervention mostly remained unknown. Apart from one study's claim about the usefulness of sex education for people with SCI in Nepal (Scovil et al., 2012) very little is known about the sexual issues of Nepalese people with SCI. A review of this study raises some important questions requiring further investigation into the following issues. What helps people with SCI to recall and use the information they received during sex education and counselling? What is a good time to provide information on sex-education? What mechanisms are in place to monitor the improvement in sexual performance and satisfaction during rehabilitation? What is the ease of access to information related to sexuality in the community? Is there a provision of follow-up services for sexually-related issues and if not, do people with SCI feel the need for it? What factors do they find as barriers or facilitators to living a sexually satisfying life? Is family planning a part of sex education for people with SCI and are they able to access the services from mainstream Sexual and Reproductive Health (SRH) facilities in the community? What kind of psychosocial issues do people with SCI face in their daily life because of the sexual problems they experience? What other concerns do people with SCI have regarding their sexuality while in the community?

Health professionals in Nepal do not have adequate exposure, training and understanding of sexual rehabilitation. The sexuality of people with disability is still not taught as part of professional education. El Masri (2010), the past president of the International Spinal Cord Society (ISCoS) argued that the relatively lower incidence of SCI combined with a lack of multidisciplinary expertise and resources outside spinal centres makes management of SCI complications and rehabilitation challenging even in a developed nation like England. This lack of multidisciplinary expertise and resources is even more challenging as it often results in inadequate management of various medical consequences including psychological, social, emotional, vocational, environmental and financial issues (El Masri, 2010). Until now there has been no specialised SCI unit in Nepal and the quality of SCI care in hospitals is compromised due to a lack of capacity to provide necessary SCI care. Lack of funding, infrastructure, training for staff, and lack of sufficient and adequately trained health workers in the hospitals is common in Nepal. SCI rehabilitation is an emerging concept and access to rehabilitation services is also limited. In this context, it is less likely sexuality issues would be the priority of health care and rehabilitation service providers. Further, sexuality is a taboo topic in some circles. On the other hand, it is essential “to recognize sexual concerns as a legitimate and important part of a well-balanced rehabilitation programme” (Ducharme & Gill, 1997). Furthermore, there are no previous studies informing the sexual needs and concerns of men with SCI in Nepal. The importance of contextualized knowledge on a sensitive issue such as sexuality cannot be overemphasized. Psychosocial issues may vary from one culture to another because of differences in cultural traditions and social beliefs (Rathus et al., 2007). A Greek study contended that some contextual social beliefs and values have a detrimental effect on the sexuality of men with SCI, and a holistic rehabilitation approach is preferred over a medical approach to address this issue (Sakellariou & Sawada, 2006).

Therefore, interviewing people with SCI and exploring their perceptions and lived experiences could potentially help health professionals in identifying, understanding and developing a strategy /strategies for addressing the contextual sexual problems. As a result of this research, there is an opportunity to improve rehabilitation services for men who have SCI in Nepal.

1.3 Research Design and Methodology

An outline of Research design and methodology is presented in this section, and further details are discussed in Chapter 3.

I chose a phenomenological, qualitative research design to explore the lived experience of MWSCI. A purposive and maximum variation sampling method was used in selecting participants in this study. A total of seventeen men with traumatic SCI, rehabilitated or undergoing rehabilitation at GPHRC took part in the study. Approval for conducting this research was obtained from GPHRC, INF, Nepal; Nepal Health Research Council (NHRC); James Cook University, Australia; including two consumer/ disabled people organisations (DPOs): the Nepalese SCI Association and the Nepalese Independent Living (IL) Centre. Data were collected through the use of face-to-face semi-structured in-depth phenomenological interviews and field notes. Interviews were transcribed verbatim and translated back into English for analysis. Then the data were analysed by using Interpretative Phenomenological Analysis (IPA).

1.4 Outline of Thesis

This chapter illustrates the background, significance and purpose, and aims of the study including key terms.

Chapter 2 presents the literature review on sexuality issues and sexual rehabilitation of MWSCI following SCI.

Chapter 3 outlines the research design and methodology, data collection process and analysis, and measures taken to improve trustworthiness of the study including ethical considerations.

Chapter 4 is the first of two findings chapters and discusses the impact of SCI, altered physical and sexual functioning, environmental (physical, social, attitudinal) factors and other personal factors on the manhood of MWSCI using these participants' lived experiences.

Chapter 5 is the second of the findings chapters and discusses the overall institutional SCI rehabilitation and community reintegration context in Nepal and ongoing sexual concerns and needs of MWSCI from the time of injury.

Chapter 6 presents the conclusions and limitations of the study and finally offers some recommendations for improving sexual rehabilitation and further areas of research.

1.5 Conclusion

This chapter outlined the background to and purpose of the study, the problem statement, the research design and methodology. Chapter 2 discusses the literature review undertaken for the study.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

2.1.1 Spinal Cord Injury (SCI) and sexual dysfunction

Injury to the spinal cord anywhere within the neural canal from just below the foramen magnum to the cauda equina or injury of the cauda equina is known as Spinal Cord Injury (SCI) (Mittmann et al., 2005). SCI is a chronic disabling condition often causing multiple health related problems including impairment of sexual function. A cross-sectional, multicentre , international SCI study (for developing the International Classification of Functioning, Disability and Health (ICF) for SCI) found a wide range of body structure and function impairments, limitations and restrictions in activity and participation: among 1052 participants, more than 20% reported body function and body structure impairment at 44% and 30% respectively (Kirchberger et al., 2009). Similarly, limitations and restrictions were experienced in 58% of activities and participation, and the overall environment was seen as either a barrier or facilitator (Kirchberger et al., 2009). Moreover, sexual and procreative functions and intimate relationships were among the more frequently reported concerns, yet these were more prevalent issues in the long term context than in the early post-acute stage (Kirchberger et al., 2009). In another study (Anderson, 2004) conducted in the United States of America (USA), recovering sexual function was ranked first by people with paraplegia and second by people with quadriplegia after arm and hand functions. Similarly, sexuality was ranked fifth (among the first two prioritized tasks) by participants in an Indian study (Nagarajan, Elango, Tharion, & Bhattacharji, 2012).

There are a few reasons for exploring the sexuality issues of men with traumatic SCI. Firstly, while regaining sexual function is essential for both men and women with SCI (Anderson, 2004; Nagarajan et al., 2012), more men appear to suffer from SCI than women and it appears to occur during the sexually and reproductively active period of life (Bajracharya et al., 2007; Rahimi-Movaghar et al., 2013). Unfortunately, most men with SCI also appear to have sexual dysfunction secondary to their acquired injury (Anderson, Borisoff, Johnson, Stiens, &Elliott, 2007b; Gianotten et al., 2006). Moreover, according to Ostrander, the psychological well-being of men with disabilities is affected to a greater extent than in women with disabilities (Ostrander, 2008) However, in the Nepalese context, little is known about sexuality issues in people with SCI; a small, follow-up study reported that more information on sexuality is needed (Scovil et al., 2012). In addition, Nepalese men with SCI highlight the difficulty in accessing and obtaining information about ongoing sexual issues after discharge from rehabilitation centres (Gautam H.K., Personal communication, Dec 15, 2013). Finally, there is a dearth of knowledge on sexual rehabilitation from the perspective of less resourced SCI settings and countries like Nepal and this deserves exploration.

This literature review will explore the sexual issues and concerns of men with SCI from various perspectives. Firstly, from a biomedical perspective it will examine the general sexual function problems after SCI, their prevalence and management. This review will also examine the effectiveness of various medical interventions available and their impact for enhancing clients' sexual lives. Finally, it will identify the factors to consider in the process of sexual rehabilitation. Thus, this exploration will recognize that a client’s personal and social factors make their sexual issues unique and also the difficulties in accessing and delivering sexual rehabilitation services. The extent of sexuality issues with reference to the reviewed literature is discussed in the following sections.

2.1.2 Literature search methods and plan

This literature search included both manual and electronic resources. MEDLINE (Ovid), and PROQUEST were identified as key electronic databases for this review. Databases were searched using a combination of keywords and Medical Subject Headings (MeSH) for Medline, and keywords and 'Thesaurus' for PROQUEST, containing relevant terminology on "spinal cord injury" and "sexuality" OR "sexual and reproductive health" of men with SCI. In MEDLINE (Ovid) data were searched using the "Ovid MEDLINE(R) 1946 to August Week 2 2014". Similarly, within ProQuest data-base: ProQuest Education Journals; ProQuest Health & Medical Complete; ProQuest Social

Science Journals; PsycARTICLES and PsycINFO were selected for searching articles. When limits such as: “humans”, "male", "all adult", "English language” and date from "2004 -Current" were applied, a total of 329 (136 from Ovid and 193 from ProQuest) articles were initially retrieved from 3041 articles (927 from Ovid and 2114 from ProQuest). Articles were excluded from the study if they met any of these exclusion criteria: editorials, reviews or meta-analyses; animal or in vitro studies; studies not related to sexual and reproductive health issues; articles published before 2004; languages other than English; mixed populations where more than 50% of participants were women or children and paediatric studies (participants below 18 years of age). After scrutinising for relevancy of title and abstract a total of 236 articles (84 articles from Ovid MEDLINE(R) and 152 articles from PROQUEST) were discarded and then 17 duplicate articles were removed, leaving 76 articles for appraisal. Further relevant information from a book, 13 articles from experts and reviewed article's reference list were also included in the continuum of the review process. Critical appraisal tools such as CASP were not used because of the exploratory character of the study and questions in the research.

2.2 General sexual dysfunction in SCI

2.2.1 Sexual desire in men with SCI

Despite a wide range of impairments in physical functions, and irrespective of the level and severity of their injury and cultural background, most men with SCI continue to retain sexual desire and interest in sexual activity. In a study (Javier et al., 2013) of Latin American men with SCI, sexual desire (Sexual Desire Inventory's [SDI] solitary subscale and dyadic subscale) was found to be similar to that of able-bodied men. In other studies, similar levels of sexual desire were expressed or maintained by most men with SCI across different cultures and/or countries: 86% in Finland, 92% in German; 93% in India (Dahlberg, Alaranta, Kautiainen, & Kotila, 2007; Reitz, Tobe, Knapp, & Schurch, 2004; Sharma, Singh, Dogra, & Gupta, 2006). Similar decreased levels in sexual desire also appeared across cultures and/or countries: 27% in India, 27.5% in Germany; 33.3% in Spain (Reitz et al., 2004; Sharma et al., 2006; Virseda-Chamorro et al., 2013). Regardless of whether there is a maintenance or decrease in sexual desire in men with SCI, the proportions appear similar; however, there is insufficient data from a broader South Asian perspective to say with certainty what effect the SCI has on overall sexual desire.

2.2.2 Erection and erectile dysfunction after SCI

An ability to achieve an erection after spinal cord injury depends upon the level and severity of damage to the spinal cord. Erections can be psychogenic and reflexogenic, which are controlled by a higher centre in the lumbar region and a lower centre in the sacral region respectively (Spencer, Jeffrey, Lois, Edward, & Sue, 2007). Thus, men with complete SCI at or below the T12 level can achieve psychogenic erection (while damage at or above the level of the lumbar centre impairs the T11-L2 pathway resulting in a loss of ability to achieve a psychogenic erection). Similarly, damage to the sacral erection centre impairs the S2-S4 reflex mechanism, resulting in a loss of ability to achieve reflexogenic erections. However, men with SCI can still achieve reflexogenic or psychogenic erections if the corresponding centres are intact, and men with an incomplete SCI may have both types of erection (Spencer et al., 2007).

After acquired injury, very few men with SCI are able to achieve a good erection naturally and this may result in psychological distress. A North American survey (using a general questionnaire) involving 199 men with SCI reported that although three-fourths (74.9 %) of the participants were able to achieve some kind of erection naturally (without the use of aids), erection in three-fifths (61.8%) of the participants were reported to be of short duration and unreliable, and only 13.1% were able to obtain an erection of longer duration (Anderson et al., 2007b). Similarly, only 11% of subjects in a Spanish study (using the International Index of Erectile Function-5 [IIEF-5] questionnaire), reported having no erectile dysfunction (ED) (Virseda-Chamorro et al., 2013). Moreover, only 1.1% of men (n= 89) with neurogenic bladders using intermittent catheterisation were able to achieve a normal level erection while the remaining participants had mild to severe ED (Ku et al., 2006). Further, a study from the USA contends that ED was the major factor of psychological distress in men with SCI (Barbonetti, Cavallo, Felzani, Francavilla, & Francavilla, 2012). These findings of a high prevalence of ED (ranging from 87% to 99%) among men with SCI and erection as a determinant of distress indicate the need for the management of both ED, and the resulting psychological distress.

2.2.3 Medical management of erectile dysfunction in men with SCI

Most often, ED secondary to SCI is a chronic condition requiring judicious and/or frequent treatment given that erection and ejaculation are desired by individuals (to enable them to engage in sexual activity). A North American study in which less than half of the participants (n=199) had sustained injury within the last 10 years found that two-thirds of participants had tried different artificial methods (medication and devices) to enhance their erections, with 37.1% able to achieve a lasting erection while 48% were able to ejaculate (Anderson et al., 2007b). In another study in which participants sustained their injury 10-45 years before, 78-94% of men reported penile vibration, drugs and intracavernous injections beneficial for obtaining erections and 56% of men reported using them for ejaculation (Biering-Sorensen et al., 2012). The use and results of wide-ranging artificial measures both in early post-acute and long term contexts in the above studies not only highlights the chronic nature of ED but also the importance of erectile function for men with SCI.

In general, Phosphodiesterase type 5 (PDE-5) inhibitors: Slidenafil, Tadalafil and Vardenafil, are all more or less equally effective in men with SCI for improving erectile function. Sildenafil was found to be more effective in improving erections in men with SCI having upper motor neuron (UMN) types of lesions than lower motor neuron (LMN) types of lesions (Khorrami et al., 2010), and in incomplete SCI (Ergin et al., 2008; Giuliano et al., 2007). Further, 90% of men with quadriplegia (n=60) using Slidenafil showed improvement of the erectile function in the International Index of Erectile Function- Erectile Function (IIEF-EF) domain score, and it was the most preferred choice of drugs over intracorporal injection (ICI) and a vacuum constriction device (VCD) (Moemen et al., 2008). Slidenafil was also found to be effective and safe in men with SCI over the long term (Lombardi, Macchiarella, Cecconi, & Del Popolo, 2009b). Tadalafil was also found to safely improve erections in men with SCI over the short term (Giuliano et al., 2006; Giuliano et al., 2007), and over intermediate and long term use (Lombardi, Macchiarella, Cecconi, & Del Popolo, 2009a). Similarly, Vardenafil was also found to be effective and safe for the management of ED in men with SCI (Giuliano et al., 2008; Giuliano et al., 2006).

Factors such as a client's preference, injury type, safety and effectiveness of an intervention, and availability and affordability of treatment need to be considered in the management of ED in SCI. In North America, Viagra (20.6%) was the most often used drug followed by different combinations of drugs and devices (12.6%) then penile injections (7.5%), Cialis (5.5%), penile ring (3.5%), vacuum device (3%), Levitra (2.5%), penile prosthesis (1.5%) and other (1%) (Anderson et al., 2007b). All PDE-5 inhibitors: Slidenafil (Viagra), Tadalafil (Cialis), Vardenafil (Levitra) were found effective and safe for obtaining an erection among men with both complete or incomplete SCI; further, there were significant therapeutic benefits in men with UMN lesions having reflexogenic erections than in men with LMN lesions and cauda equine (Lombardi, Macchiarella, Cecconi, & Del Popolo, 2009c; Soler, Previnaire, Denys, & Chartier-Kastler, 2007). In addition, in a randomized, blinded, crossover clinical trial, Tadalafil was found to be more effective than Sildenafil: it was able to sustain an erection up to 12-24 hours after its use in men with SCI (Popolo, Marzi, Mondaini, & Lombardi, 2004). On the other hand, Vardenafil in increased doses of 20mg improved the erection in men with SCI when 10mg administration did not produce an adequate erection (Kimoto et al., 2006). Moreover, men with SCI using a malleable penile prosthesis reported a good level of satisfaction (79.2%) and a low complication rate (16.7%) in addition to achieving the goal of urinary management by most (Kim, Yang, Lee, Jung, & Shim, 2008). Further, Lombardi et al. (2009c) contend that clinicians should consider a clients' purpose and preference for the use of drugs based on resulting benefits and feedback of each client such as duration and strength of erection, ejaculatory success, orgasmic function and the extent of side effects while selecting them as a treatment of choice. However, in the Nepalese context, penile injections, penile rings, vacuum devices and penile implants are largely missing from the choice of treatment, possibly due to a lack of resources and lack of affordability to clients.

2.2.4 Ejaculatory dysfunction in men with SCI and its medical management

Ejaculation is also an important sexual function for men from the perspective of gaining sexual pleasure and reproduction. Men with SCI and preserved ejaculatory function ejaculate naturally by masturbation and sexual intercourse and when impaired, attempt to ejaculate both naturally as well as use other artificial stimulating methods for different purposes. Seeking pleasure (for about one-third) and sexual intimacy (for about one-third) were the most common reasons for attempting ejaculation for men with SCI (Anderson et al., 2007b). Even though the majority of men with SCI in this study (80%, N= 199) attempted ejaculation following injury, only half (48%) were able to ejaculate and only half (46.2%) of those participants who were able to ejaculate, did so by natural stimulation (masturbation and sexual intercourse). In contrast, another study reported that most of the participants (91%, n=81, Canada and France) were able to ejaculate and only about one-third of the participants were able to ejaculate by natural self-stimulation (Courtois et al., 2008). Although this difference in men's ability to ejaculate in studied samples may be due to the differences in the level and severity of injury of the participants, ejaculation appeared to be of significant concern for most of the men in all studies. Whether this concern comes from the men's needs for maintaining sexual potency, masculinity and or sexual identity needs to be explored.

When natural stimulations were not successful in producing ejaculation, the most commonly discussed methods in the literature for achieving ejaculation are: Penile Vibratory Stimulation (PVS), medications combined with PVS, and Electro Ejaculation (EEJ).PVS is a noninvasive, economical and a safe method of ejaculation for men with SCI and ejaculatory dysfunction. PVS was found to be the most widely used method of achieving ejaculation and the third highest method after natural methods (Anderson et al., 2007b). Similarly, in another study, the use of PVS alone resulted in successful ejaculation in (70%) of men with SCI who were not able to ejaculate by natural methods (Courtois et al., 2008). Moreover, when PVS alone did not result in successful ejaculation, PVS combined with Midodrine also offered a safe and good result (Courtois et al., 2008; Soler, Previnaire, Plante, Denys, & Chartier-Kastler, 2007; Soler, Previnaire, Plante, Denys, & Chartier-Kastler, 2008). Further, semen retrieval results from case studies on the use of PVS combined with Abdominal Electrical stimulations (AES) are also promising (Goetz & Stiens, 2005; Kafetsoulis et al., 2006). The authors contend PVS combined with Midodrine and PVS combined with AES are potentially easier, economical and noninvasive. On the other hand, electro ejaculation - alone and in combination with drugs - is also one of the most prominent and reliable methods for obtaining ejaculation (McGuire et al., 2011) when natural methods and/or PVS fails.

2.2.5 Orgasm in men with SCI

Orgasm is another important aspect of SCI affected sexual life, however many men are still able to experience orgasm even after injury (Sipski, Alexander, & Gomez-Marin, 2006). According to Soler et al. (2008) orgasm is a cognitive interpretation of genital sensation and somatic responses, Autonomic Dysreflexia (AD) and ejaculation. In addition orgasm can occur alone or concomitantly with ejaculation (Sipski et al., 2006). Laboratory findings of blood pressure and heart rate during sexual climax both in able-bodied men and men with SCI were comparable, indicating the presence of orgasm despite lower rates of orgasm experiences among men with SCI (Sipski et al., 2006). Although there is a wide discrepancy in the literature about the proportion of men with SCI who could achieve orgasm naturally, about fifty percent of men with SCI were able to achieve orgasm in a laboratory setting while nearly two-thirds (64.4%) of men reported an ability to achieve orgasm (Sipski et al., 2006).

Overall, two-fifths to one-third of participants: 40.7% of participants in Anderson et al.'s (2007) study, 59% in Soler et al.'s (2008) study using PVS combined with Midodrine, 65% in Dahlberg et al.'s (2007) study, and 47% in Reitz et al.'s (2004) study were able to experience orgasm. However, men with UMN and incomplete lesions experienced orgasm more than any other types of SCI (Sipski et al., 2006; Soler et al., 2008). Moreover, 88.9% of the men who were able to experience orgasm were also able to ejaculate (Anderson et al., 2007b), while 84% of men who were able to ejaculate also experienced orgasm (Soler et al., 2008), indicating the close association between orgasm and ejaculation. Findings suggest that autonomic orgasm in men with SCI could be related to Autonomic Hyperreflexia (AHR) or AD, and educating clients to identify these bodily sensations (during sexual activity) through a guided questionnaire may help in recognizing orgasm (Courtois et al., 2011). If the proposed use of a self-ejaculation, self-exploration, and cognitive reframing approach could effectively enhance the perception of sexual sensations and climax experience then it could be used as a potential method in improving orgasm of men with SCI in the near future (Courtois et al., 2008). However, there is a need for caution. In Anderson et al.'s (2007b) study, about one-third (28.6%) of men experienced AD and of those, 16.1% reported interference (N=199) in their sexual activity while only 6% found it pleasurable.

2.2.6 Autonomic dysreflexia due to sexual activity in men with SCI

Autonomic Dysreflexia (AD) is a life-threatening condition requiring medical attention. AD is characterized by an abrupt and severe increase in blood pressure and a concurrent fall in heart rate triggered by a noxious stimulus (below the level of lesion) among people with SCI at the T6 level or above, who are also at risk of developing it particularly during sexual activity (Anderson, 2004; Courtois et al., 2012). In addition, men undergoing sperm retrieval have a significant risk of developing AD and silent AD during ejaculation (Ekland, Krassioukov, McBride, & Elliott, 2008). Similarly the use of both Midodrine and vibro stimulation techniques for enhancing ejaculation carry similar risks of developing AD (Courtois et al., 2012) particularly in tetraplegics (n=158 men with SCI) (Soler et al., 2008).

Medical management of AD secondary to sexual activity is equally important. There are cases where ejaculation has triggered the AD initially in men with cervical cord injury and high thoracic level injuries, although a combination of factors such as severe damage to descending autonomic pathways and bladder irritation could also cause AD (Elliott, 2010). In such ejaculation induced AD cases, Nifedipine appeared to be a safe drug of choice for its management, and oral Nifedipine rather than sublingual administration appeared safe to minimize cardiovascular risks. Moreover, the authors contend that long-term management of AD during sexual activity in men with SCI requires further consensus. Thus, the literature indicates the importance of health professionals' awareness about the signs, symptoms, causes and possible management of AD and the need for discussing AD during rehabilitation, with those who are at risk of developing it.

2.2.7 Infertility issues among men with SCI

Advancement in fertility care has not been able to adequately and appropriately benefit all couples with SCI, particularly those who are not able to conceive through sexual intercourse due to male related factors (such as decreased sexual desire, ED, ejaculatory dysfunction and poor semen quality) secondary to SCI in men. An American survey of 199 men with SCI found that in 14.1% of participants only, fertility was the reason for having their semen analysed, and in just 1%, fertility was the reason for engaging in sexual activity, while interestingly, 8% of participants fathered a child after injury (Anderson et al., 2007b). In addition, a retrospective analysis of data collected over 18 years indicated that most men with SCI had sperm concentrations similar to infertile men in the general population (Iremashvili, Brackett, Ibrahim, Aballa, & Lynne, 2011). However, the presence of various psychological symptoms in infertile couples with SCI appeared to be associated with low success rates of Artificial Reproductive Technology (ART) such as In Vitro Fertilisation (IVF) / Intracytoplasmic Sperm Injection (ICSI) and therefore adequate support and treatment even before proceeding with IVF/ICSI is essential (Karimzadeh, Salsabili, Akbariasbagh, & Mehrsai, 2006).

There could be many men with SCI in the community who would like to know their fertility capacity and the ability to father a child. An American study (n=253, 63% men and 37% women) found that both men's and women's decision on having children is influenced by SCI. They acquire information about pregnancy from SCI physicians (20%), SCI associations (15%), and primary care physicians (12%), internet (10%), peers (10%), communication medias (5%) followed by medical journals, and friends and family (4%) while 21% people did not seek any information (Pebdani, Johnson, & Amtmann, 2014). In addition, about half of the participants (women 54% and men 49%) had not completed their family planning at the time of their SCI, while roughly one-third (31% men and 35% women) who had not completed their family planning had one or more child or earlier pregnancy experience (Pebdani et al., 2014). Thus, it is essential not only to provide the correct information about reproductive health from the male's perspective during or after rehabilitation, but also to consider the appropriate channel and timing of the information.

When couples have difficulty in conceiving naturally because of problems with erection or ejaculation, there are many fertility care options available in terms of obtaining sperm and insemination. However, home insemination of partners (with a pregnancy rate of 43%, n=140) is a potential and economical method of achieving pregnancy in couples with male factor SCI and adequate total motile sperm count (Sonksen, Fode, Lochner-Ernst, & Ohl, 2012). Similarly, a pregnancy rate of 37.8% (31/82 couples with male factor SCI) obtained from intra-vaginal insemination (IVI) and intrauterine insemination (IUI) methods suggests that IVI and IUI should be considered prior to the use of other assisted reproductive technologies (ART) in couples with male factor SCI (Kathiresan et al., 2011). After erectile and ejaculatory dysfunctions, low semen quality is the third barrier for a man with SCI to becoming a father (Restelli et al., 2009). Hence, analysis of semen is essential for assessing fertility potential in men. Sperm can be obtained in most of the men with SCI easily through masturbation, PVS and EEJ so very few men will require expensive and invasive surgical sperm retrieval (SSR) (Brackett, Ibrahim, Iremashvili, Aballa, & Lynne, 2010). Semen obtained by masturbation in men with SCI also have higher motility than semen obtained by PVS and EEJ (Kathiresan et al., 2012). Thus, ART use, including the use of semen from masturbation should be encouraged in couples who fail to conceive naturally.

In men with SCI, PVS, AES, Medication, and EEJ are the most frequently used methods discussed in the literature for obtaining sperm required for insemination. Introduced in Ireland in 1998, PVS is a technique used for stimulating ejaculation by applying a probe at the base of the penis (McGuire et al., 2011). PVS alone has been found effective in achieving ejaculation in about half of the participants while PVS combined with Midodrine further achieved ejaculation in 12% of participants (Courtois et al., 2008). Similarly, PVS combined with AES (Goetz & Stiens, 2005; Kafetsoulis et al., 2006), and the use of two vibrators when one vibrator fails to stimulate an ejaculation in men with SCI and an intact ejaculatory reflex arc (Brackett, Kafetsoulis, Ibrahim, Aballa, & Lynne,

2007) were also found effective in obtaining ejaculation. Importantly, these authors contend that using PVS combined with AES or two vibrators is the safer, easier and more economical option than EEJ or surgical retrieval of sperm for fertility purposes. In addition, repeated ejaculation for at least 3 months with PVS at home has the potential for improving sperm characteristics for fertility purposes naturally and economically in men with SCI (Hamid, Patki, Bywater, Shah, & Craggs, 2006). Moreover semen in about 95% of men with SCI could be obtained by PVS and EEJ methods and used for achieving pregnancy by IUI in partners before considering the more expensive and most invasive ART, ICSI (Kafetsoulis et al., 2006).

EEJ can be used when a natural method of ejaculation (masturbation, sexual intercourse) and PVS fails to yield ejaculation. EEJ is a method of obtaining ejaculate through the use of a rectal probe applying gradually increasing electrical stimulation until ejaculation (McGuire et al., 2011). A 14 year retrospective review of hospital data in Ireland reported that electro ejaculatory stimulation was a safe and effective method of obtaining semen for insemination, with a 36% pregnancy rate (McGuire et al., 2011). Although repeated EEJ did not improve sperm quality (Das et al., 2006), obtaining second ejaculate in azoospermic men with SCI by EEJ, as opposed to PVS, is a sensible option prior to opting for surgical retrieval of sperm (Iremashvili et al., 2011). However, PVS is the treatment of choice for obtaining sperm, as the EEJ reduces sperm quality significantly (Salsabili, Ziaei, Taheri, Akbari, & Jalaie, 2006).

Cryopreservation, freezing of sperm, is an alternative to the use of fresh semen for some people who find difficulties in transporting semen and do not have sufficient time from retrieval to use (da Silva et al., 2010). However, freezing of sperm reduces the quality of sperm obtained by EE or PVS, both in able-bodied and men with SCI. In addition, the use of frozen-thawed sperm by ICSI also has a lower fertility rate than fresh ICSI (Kanto et al., 2009). On the contrary, Testicular Sperm Retrieval (TESA) and intracytoplasmic sperm injection provide good results (57.1% fertility rate and 30.2% pregnancy rate) in couples with SCI, when men are unable to ejaculate by EEJ or PVS (Raviv, Madgar, Elizur, Zeilig, & Levron, 2013). Moreover, cryopreservation of motile sperm for ICSI could prevent the discomfort and cost of repeated electro ejaculation (Chen et al., 2005)and TESA is the most invasive procedure. Thus, the use of cryopreservation and TESA for fertility in the SCI population should be used judiciously.

2.3 Qualitative aspect of sexual function in men with SCI

2.3.1 Manhood and SCI

Men with SCI often express concerns regarding their manhood. Greek men with SCI did not feel like real men as they experienced their manhood being compromised primarily due to a loss of autonomy and spontaneity in their sexual activity when they had to rely on a carer or partner for physical assistance (Sakellariou & Sawada, 2006). According to Ostrander's (2008) study, men with SCI appear to perceive themselves as less than a man following injury; they continue to emphasize their masculine identity and have difficulty in accepting their disability while continuing to compare life with and without injury. This notion is evident from the following statement of two participants:

> I just be looking at myself like a boy because if you're a man you say you make your own rules but a boy don't make his own rules. (Warren, 3 years since injury)
>
> You can't really defend yourself. It don't take your manhood from you, but it do take certain part of your manhood ... You know, someone get talking crazy to you, you talk crazy back, then the result come to well now I gotta get a gun because I can't sit here and fight him, so then you think, I gotta go get a gun and have to shoot this nigger. Go to jail, and worry about stuff like that or…I mean certain things is just really not the same. (Isaac, 10 years since injury) (Ostrander, 2008, pp. 79-78).

These men also expressed being a burden to their partners; however, shifting sexual pleasure from their own to their partner's sexual satisfaction potentially clashes with a perception of manhood, where high quality sexual prowess may cause further stress in men (Ostrander, 2008). In addition depression was more common among American men with SCI with a strong sense of sexual desire when they also hold traditional masculine norms stressing sexual prowess (Burns, Hough, Boyd, & Hill, 2009). Similarly, traditional Brazilian culture around the structure of sexual life emphasizes male domination and female submissive roles in sexual relations (masculine sexual activity and feminine sexual passivity), which causes men with SCI difficulty in understanding and complying with the notion of “manliness” after the injury both in terms of being socially active and performing traditional sexual roles (Mendes, Cardoso, & Savall, 2008). Nepal is also predominantly a patriarchal society, with a patrilineal tradition apparently emphasizing male domination and female submission when it comes to sexual relationships. Moreover, arranged marriages are the traditional system of beginning a sexual relationship and starting a family, while a premarital sexual relationship is not permitted culturally. Therefore, the Nepalese men with SCI may also experience similar hindrances in understanding and complying with the notion of "manliness" and this deserves exploration.

Lived experiences of men with SCI show that injury not only affects their sexuality but masculinity as well (Rapala & Manderson, 2005). Robert's (a person with SCI) autobiographical statements indicate that his sexuality and masculinity remained dormant for many years:

> Well, I was afraid to have intercourse for nine years. Simply because I was stopped by, that I can... wet myself (siezmoczy´ c).I can’t do all the positions, for example... I can’t lie down on the woman, yet, because I’m not that agile, but I can already do it from the side ... (Rapala & Manderson, 2005, p. 170).

Robert's fear about avoiding a sexual relationship appears to come from factors other than impairment of sexual function such as bowel or bladder accidents or inability to assume certain positions. At the same time, it appears that increased awareness of one's capacity and limitations combined with experience from trial and error appears to alleviate the fear over time.

To be able to perform sexually is often very important for men with SCI who strongly adhere to the traditional masculine script, stressing stamina and prolonged duration of intercourse as recognition of a man's sexual adequacy (Rapala & Manderson, 2005). This theme is evidenced by Robert as: “We started at ten or eleven, and finished at three and in the morning again...” (Rapala & Manderson, 2005, p. 175). Moreover, the authors also felt that the ability to socialize and attract women helps an individual to regain sexuality and masculinity to some extent. This was evidenced by Robert:

> I enter the shopping mall, all those pretty girls there they know who I am, I greet them politely, if they want to talk then we'll talk, if not, then no. Some of them stop me (zaczepiamnie??), how do I feel, how is everything ... They say, you're with another girl? I say, that's not my girlfriend, that's my nurse. Some of them don't believe me, "You sure change your girls" (Rapala & Manderson, 2005, pp. 175-176).

The notion of manhood and masculinity appear to play a significant role in coping with sexual problems for some individuals with SCI and sexual dysfunction. Therefore, awareness of these factors appears to be essential for both the individual and rehabilitation professionals, particularly when clients' adherence to manhood and masculinity is strong.

2.3.2 Sexual satisfaction in men with SCI

Satisfaction with sexual life in the SCI population may be influenced by various factors such as gender, level of injury, socio-cultural barriers and age. Firstly, findings from most studies show that both men and women with SCI were less satisfied with their sex life after injury (Biering-Sorensen et al., 2012; Kennedy et al., 2006; Kennedy et al., 2010; Valtonen et al., 2006). As expected, men with SCI were less satisfied with their sex life after injury compared to women with SCI (Biering-Sorensen et al., 2012; Sale et al., 2012; Valtonen et al., 2006). Similarly, a Brazilian study reported that sexual satisfaction in men with SCI decreased significantly after injury compared to both pre-injury as well as to able-bodied men (Mendes et al., 2008). Moreover, an Indian study reported that more than fifty percent of participants felt that their sex life was poorer after injury and one-third of participants were not satisfied with their current sex lives (Sharma et al., 2006). However, slightly more Indian women than men rated their sex life worse after the injury, 57% and 52% respectively, while significantly more women than men were unsatisfied with current sex life, 74% and 34% respectively (Sharma et al., 2006). This difference of more men expressing or experiencing sexual satisfaction than the women could be an interesting phenomenon, possibly explained by environmental factors such as social, cultural and physical accessibility nevertheless it warrants further research to investigate other underlying reasons within the eastern cultural context.

Decreases in sexual satisfaction between men with paraplegia and quadriplegia do not appear consistent. Men with cervical cord injury in a Swedish study were more satisfied with their sex life than the men with injury below the cervical level (Valtonen et al., 2006). In contrast, in a Finnish study men with paraplegia were more satisfied with their sex life than the men with quadriplegia (Valtonen et al., 2006). So it is possible that environmental factors such as social, political, economic, physical accessibility, sexual rehabilitation other than level of injury may be strong determinants of sexual satisfaction.

Sexual satisfaction in men with SCI did not appear to have a definite relationship with age. A Swedish study showed a negative association of increasing age after the SCI and injury at an older age (Valtonen et al., 2006). In contrast, another study of men with SCI over 50 years of age found that the median quality of life was high for men under and over sixty years, despite men under 60 years of age engaging in sexual intercourse three times more than men over 60. This discrepancy in more than half of the men over 60 years was mainly due to a shift in their interest from sexual intercourse to physical intimacy without intercourse (Lombardi, Macchiarella, Cecconi, Aito, & Del Popolo, 2008).

Men with SCI may need to overcome the social, personal and institutional hurdles for living a sexually satisfying life. According to Sakellariou(2006b), people with SCI experience various kinds of social barriers in their daily life such as: the social view of being independent is only when an activity is executed by oneself; seeing a person with a disability as childlike and having a need to be overprotective; the perception that people with disability lack sexual drives, and the sexuality of people with disability seen as a taboo. People with acquired disability could have similar misperceptions and prejudices towards disability as society (Groce, Izutsu, Reier, Rinehart, & Temple, 2009). Most of these negative attitudes and ignorance of individuals and health-care workers, and socially created barriers are more disabling than the actual impairments (Groce et al., 2009). In addition, sometimes the new and changed body image after injury creates an aesthetic anxiety due to the social ideals regarding the body beautiful and sexual attractiveness (Sakellariou, 2012). Despite this, it is also essential for an individual male with SCI to be able to make his own decisions and choose the preferred techniques and ways that will enable him to take part in sexual activities in comfort, simultaneously being in control of the care of one's body and sexuality (Sakellariou, 2012). For instance, Danish men with SCI were found to be more satisfied with their sex life when they were able to make their partner pregnant (Biering-Sorensen et al., 2012). Moreover, when couples with SCI are able to overcome individual and social barriers created by negative attitudes and are able to adopt more creative, less genitally focussed and mutually satisfying approaches in their sex life, they could potentially live an even more sexually satisfying life than before the injury (Ostrander, 2009). Further, there was a shift towards physical intimacy without focusing on sexual intercourse among adult men with SCI over 60 years of age compared to younger men (50-60 years of age), yet most men with SCI above 50 years of age were found to be satisfied with their sex life (Lombardi et al., 2008) On the other hand, a Swedish study found that people with SCI receiving adequate sexual counselling appeared satisfied with their sex life (Valtonen et al., 2006), indicating that insufficient or lack of a counselling service could act as an institutional barrier to living a sexually satisfying life.

2.3.3 Life satisfaction, quality of life, and sexual function among men with SCI

Impairment and disability in SCI is well known for its chronic nature causing various limitations in Activities of Daily Livings (ADLs) and restriction to social life participation. These limitations and restrictions in sexual activity often result in decreased sexual satisfaction and may influence the overall life satisfaction of men with SCI. Specifically, men with SCI and ED have a low Quality of Life (QOL) (Mittmann et al., 2005). A study from The Netherlands argued that life satisfaction in people with SCI deteriorated one year after the injury and sexual life was a strong determinant of life satisfaction (along with self-care and employment state) (van Koppenhagen et al., 2008). In addition, in a study conducted in the USA most of the men with SCI (N= 199) reported that their quality of life would be improved by improving their sexual function (Anderson et al., 2007b). Recovering sexual function in order to improve QOL was ranked first and second by both men and women with paraplegia and quadriplegia respectively (K. D. Anderson, 2004). Moreover, QOL was better among people who were satisfied with their sex life (Sale et al., 2012). However, a German study contends that satisfaction with sexual life and QOL may not be greatly dependent on preserving sexual functioning (Reitz et al., 2004). It can be inferred from these studies that most people with SCI engage in sexual activities regardless of the preservation of sexual abilities, and when they are unsatisfied with their sexual life, it appears to negatively impact their life satisfaction and QOL. This warrants a systematic identification and addressing of sexual needs and concerns of men with SCI in order to improve sexual satisfaction, life satisfaction and QOL.

2.3.4 Sexual rehabilitation in SCI and challenges

Sexual rehabilitation in SCI is a challenging task like many other acquired physical disabilities. An abrupt onset of physical disability combined with impairment of sensitive sexual issues, social stigma, and competence of health professionals in addressing the issues are some of the main factors that make working with SCI challenging. In many societies, there is often a lack of opportunity to obtain information about sexuality and reproductive health either at home or in school for young men compared to girls and women of their age (Groce et al., 2009). Moreover, young men with disabilities often have less opportunity to acquire appropriate information than other younger people who at least receive the information informally from their peers and other men’s comments and jokes (Groce et al., 2009). In developing countries like India, sex taboos such as partner is too ill for sexual activity a barrier to the sexual adjustment after SCI among couples with SCI (Sharma et al., 2006). For these reasons, The World Health Organization (WHO) recommends the mainstreaming of all programmes in addition to providing disability specific programs to ensure that all sexual and reproductive health programmes reach and serve persons with disabilities (Groce et al., 2009). In addition, WHO recommends improvement in attitudes and knowledge about disability through some essential activities such as in-service SRH training of service providers, pre-service training of health service professionals, and integration of existing training strategies and curricula (Groce et al., 2009).On the other hand, therapeutic interventions needs to be developed, based on further research findings considering various aspects of sexual health and SCI (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007a).

Sexual rehabilitation appears to be one of the most needed but least integrated areas of SCI rehabilitation (requiring meticulous attention and improvement). Sexual need was identified as a key unaddressed and unmet area among people with SCI, including occupation and pain relief needs (Kennedy et al., 2006; van Koppenhagen et al., 2008). Partners of people with SCI and rehabilitation professionals also have expressed the need for discussing sexuality issues (Gianotten et al., 2006). A prospective controlled pre and posttest evaluation from New Zealand revealed that the majority of multidisciplinary rehabilitation and disability staff despite having positive attitudes, did not have the skills required to address the sexual health concerns of clients (Simpson et al., 2006). Similarly, another study from The Netherlands also found that only 12% of health professionals were adequately trained to confidently address sexual issues with their clients (Gianotten et al., 2006). In addition, while a Brazilian study identified the lapse in the documentation of sexual function problems of clients receiving physical rehabilitation, the authors argued that this lack of data in clients' medical records could be due to ethical concerns for maintaining privacy (Spizzirri & Abdo, 2010). However, clinicians' skills in recognizing men's adherence to a masculine script for sexual potency is also expected to promote positive changes in sexual functioning of their clients, warranting further study and development of guidelines (Burns et al., 2008).

Co-existing or secondary conditions such as spasticity, low or high blood pressure, and medical management of these conditions along with sexual function may also appear challenging for physician/s. Use of antispasmodic drugs such as baclofen in the management of spasticity could interfere with sexual function in some cases although resulting sexual problems could be managed by reducing the baclofen dose and or by medications for ED (Elliott, 2010; Jones, Leslie, Bilsky, & Bowman, 2008). In addition, medications such as antidepressants, antispasmodics, antihypertensive, alpha blockers and anticholinergics or concomitant medical conditions could further worsen ED in SCI (Elliott, 2010). Moreover, there are cases where a family doctor has experienced difficulty in prescribing a PDE-5 inhibitor for the management of erectile and ejaculatory dysfunction in men with quadriplegia presenting with lower blood pressure (80-90/60 mm/Hg) (Elliott, 2010).

Organizing workshops at work on sexual health for health professionals increased the knowledge, skills and comfort level of staff in addressing sexual issues (Gianotten et al., 2006; Ostrander, 2009; G. Simpson et al., 2006). Even a one day sexuality training program using the PLISSIT model framework (in Queensland, Australia) was found effective in improving the knowledge, comfort and attitudes of health professionals at three months follow-up (Fronek, Booth, Kendall, Miller, & Geraghty, 2005). It was also found effective over two years follow up (using modified Knowledge, Comfort, Approach and Attitudes towards Sexuality Scale [KCAASS] and randomized controlled trial) (Fronek, Kendall, Booth, Eugarde, & Geraghty, 2011). Yet, Ostrander (Ostrander, 2009)argues that more frequent, well timed sexual education and therapy involving sexual partners should be a standard part of SCI rehabilitation, and a gender-specific approach to address both heterosexual and homosexual relationships needs to be developed. In addition, a Swedish study shows that people with SCI receiving adequate sexual counselling appeared satisfied with their sex life (Valtonen et al., 2006); therefore, the availability of an ongoing interdisciplinary service and sexual counselling to obtain necessary information is essential to promote the emotional well-being of clients (Hess, Hough, & Tammaro, 2007).

Further, setting organizational policies on professional boundaries, familiarity with the licensure laws and ethics codes, providing frequent, ongoing education programs on professional boundaries for health professionals and overall compliance for maintaining good boundaries are critical for the protection of both beneficiaries (people with SCI) and service providers, particularly those involved in sexual rehabilitation (Warren, Hamilton, & Roden-Foreman, 2013). The sexual concerns of men require a skilled and individualised sexual rehabilitation intervention. As such, physician/s and or a rehabilitation team should be able to provide necessary information about sexual and genital issues to people with SCI in a non judgemental manner, without taking a normative or directive attitude by listening to their client's sexual preferences or modes with great care in regards to professional ethics (Boyer, Novella, Laffont, Morrone, & Dizien, 2005).

2.3.5 Human sexuality: South Asian perspective and the Kamasutra

Created between the first and sixth century AD by Vatsyayana, the Kamasutra, an erotic Hindu text written in Sanscrit, is a rich piece of literature on love (Burton & Arbuthnot, 1963). As described by Bhattacharya (1975) and Trautmann (1971), it is an original work on human sexuality from northern India. According to Vatsyayana (in Kamasutra), although sexual desire is fundamental to humans - similar to - human sexuality is a socially constructed phenomenon rather than merely a biological need. Roy (1996) suggested that the Kamasutra is a work on Kama (desire) compiled in connection with the Dharmasastra (dharma -ethical norms) and Arthasastra (artha -means of livelihood). They constituted the three crucial dimension of a man’s life encompassing the totality of social existence (Roy, 1996). The objective of Vatsyayana in Kamasutra was to make Kama, or desire, legitimate by making it the subject of a sastra or through setting of rules based on principles and a basic knowledge of human sexuality (Roy, 1996).

The "Kamasutra" consists of 350 chapters divided into seven parts: the first "introductory" part deals with the objective of learning about Karma (desires), various life skills, daily chores and the importance of balance between virtue, wealth and love in people’s life; the second part "on sexual union" discusses variations in sexual relationships based on physical sizes of men and women, desires, love, duration, acts of sex, sexual positions, oral sex and foreplay; the third part is "about the acquisition of a wife" and deals with types of marriage, courtship, developing confidence; the fourth part "about a wife" illustrates the manner and roles of a woman or a wife at different periods; the fifth part is "about the wives of other people"; the sixth part is "about courtesans" and the last is "on the means of attracting others to one’s self" – and primarily discusses the use of various natural and artificial means (tonic medicines) with the specific objective to enhance sexual performance and satisfy a partner through the use of an artificial penis, or through making a bigger penis (Vatsyayana, 1963a).

Numerous translations and commentaries on the original are available today - having been compiled from different perspectives. The work was first translated into English by Sir Richard Francis Burton in 1883 and more recently in 2002 by Sudhir Kakar and Wendy Doniger (Doniger, 2003). In Doniger (2003)'s view the Kamasutra is more like a dramatic fiction sequence with seven acts resembling most classical Indian dramas revealing the existence of sophisticated knowledge on sex in third century Indiaat a time when the Europeans were "still swinging in trees, culturally (and sexually) speaking" (p.18). Her critique on Burton's translation is that Kamsutra is depicted as "orientalism, a simultaneously racist and romanticised set of European attitudes to colonised peoples" (p. 20). It has been portrayed little more thana text on sexual positions by most Americans and Europeans. On the contrary, it is a text with " modern ideas about gender and unexpectedly subtle stereotypes of feminie and masculine nature" and " relatively liberal attitudes to women's education and sexual freedom, and far more complex views of homosexual acts than are suggested by other texts of this period" ((Doniger, 2003, p. 18). She also argues that it is a text " about art of living-about finding a partner, maintaining power in marriage, committing adultery, living as or with a courtesan, using drugs-and also about the positions in sexual intercourse" and " as much about the control of men as about control of women" (p. 20).

Sex is innate and essential for reproduction, yet sex education appears to be vital in helping people to enhance their level of sexual pleasure. According to Vatsyayana, sexual intercourse is a mutual act requiring the appropriate use of knowledge and skills on the part of both men and women that could be learnt from the Kamasutra (Vatsyayana, 1963b). Puri (2002) agrees with Kapoor, director of the International Planned Parenthood Federation at the South Asian Regional Bureau (1993) that the Kamasutra and erotic temple carvings depict an in-depth knowledge and open attitude to human sexuality of the ancient Indian and South Asian people in the distant past, however, a limited understanding and a narrow mind-set on human sexuality at the present time is often a cause of embarrassment and unhappiness in South Asia today (Puri, 2002). It is both an irony and a pity that in India and South Asia where sexuality was perceived with so much open mindedness and sex education advocated as long as eighteen centuries ago, now features suppression and sex taboos. From this context it appears imminent to include sex education not only for people with SCI but also for the general population to enhance sex life and address the issues of inequalities of gender, class, sexuality, and ethnicity for the benefit of society as a whole.

2.3.6 Gender, sexuality and disability in Nepal

Women's position is subordinate to that of men in traditional patriarchal Nepali society (Dhungana, 2006; Poudel-Tandukar, Poudel, Yasuoka, Eto, & Jimba, 2008; Puri, Shah, & Tamang, 2010). The challenges for women's sexual and gender roles include and not limited to: an age-old traditional life style and family structure; social norms around rigid gender roles; societal expectation of marriage; gender norms of heterosexual, patriarchal society; policing of women's sexuality; and tight controlling of their outdoor mobility and sexual behaviour (Greene, 2015). Cultural values are constructed in such a way that sexual freedom, desire and pleasure are regarded basic and natural for men only (FWLD, 2008). In addition, social expectations construct a reality where "social roles for women emphasize their obligations but fail to establish or uphold their rights, or establish gender equality or reciprocity", creating a vicious cycle of inequality (FWLD, 2008, p. 12). Moreover, prevalence of "misconceptions that women's sexuality is inferior to that of men and the sexual roles of women are confined to satisfying their male counterparts" and exploitation of cultural and social values to justify them have further increased the violations of women's right to life and health (FWLD, 2008, p. 93). Further, " unequal power relations and lack of autonomy characterise the situation of married young women in many settings" and "gender norms stress male entitlement to sex, even if forced within marriage" in Nepal (Regmi, Simkhada, & Van Teijlingen, 2008). Thus, women experience obstacles and discrimination in all walks of their lives including suppression of their sexuality (Greene, 2015). van't Noordende, van Brakel, Banstola, and Dhakal (2016) found that marital problems and/or sexual abuse are even more evident in the case of women with conditions such as leprosy and visible/physical disability.

The United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (United States International Council on Disabilities, 2010) and CRPD article 23 –respect for home and the family and article 25 –health was ratified in 2008 by Nepal government.

These conventions clearly outline the rights of person with disabilities about their right to marriage; family; access to age-appropriate information, reproductive and family planning education etc.; and provision of quality and standard Sexual and Reproductive Health (SRH) services at free or affordable cost (as provided to other persons) without discrimination. Nevertheless, there has been no conscious effort from government institutions to fulfil these obligations. Access to health, education and employment opportunities is poor for the general population due to poverty. In addition to poverty, the physical limitations of disability, difficult and inaccessible geographical terrain and social stigma create further challenges to access these services for people with disabilities (Dhungana, 2006).

According to Khanal (2013) Nepalese women with disabilities do not have equitable access to pregnancy, maternal and child health care; about half of the participants (n=35) in her study were experiencing reproductive health problems; more than half of the participants delivered their child at home without any medical support; and about two thirds of the participants had never used contraceptives. A study on SRH of people living with disabilities in refugee camps also identified the need to protect and realise their rights to SRH and to overcome the existing barriers such as limited knowledge about the use of contraceptives, sexual violence from husband, forced sterilization, increase waiting time for accessing services and negative treatment from health workers towards unmarried pregnant women (Tanabe, Nagujjah, Rimal, Bukania, & Krause, 2015). Dhungana (2006) and Acharya (2012) argue that “disability does not stop a man [from] doing anything unless his physical and mental disability is severe. But the situation is just the opposite for disabled women. They face double discrimination because of their disability and their gender” (p. 23) and “sometimes a triple disadvantage because they are viewed as being part of the inferior sex and other biased cultural beliefs” (p.8) respectively.

However, in the absence of research about the situation of sexuality and position of men with disabilities in Nepal it is very difficult to conclude they are in a better position than their counterparts in the given socio-cultural setting and this warrants further investigation. However, it would seems reasonable to take a more balanced approach to address the issue of sexuality of both men and women with disabilities. Women With Disabilities Australia (WWDA, 2006) argues a need for more empirical work to reclaim the sexual experiences of people with disability to challenge and change negative public perceptions about sexuality and disability, and also to promote meaningful sexual relationships among people with disabilities. Through the provision of better access to information and education on sexuality and disability the stigma attached to disability and sexuality can be minimised (Esmail, Darry, Walter, & Knupp, 2010). However, even in a specialised rehabilitation facility, sex education is not provided to all clients and the information provided has been found to be inadequate (Scovil, Ranabhat, Craighead, & Wee, 2012). All of these contextual issues have wider and deeper consequences for the lives of people with disabilities.

Interestingly, along with political and social changes, emergence of new ideas about gender and sexuality is causing a shift in the social climate andthe deeply ingrained patriarchal traditions of contemporary Nepal (Greene, 2015) particularly on the rights of Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) community. In 2007 Supreme Court decision guaranteed ‘non-discrimination on the basis of sexual orientation and gender identity’, categorised gender variant people as third gender ensuring a right to a citizenship certificate based on their gender identity and issued a directive to address same sex marriages (Coyle & Boyce, 2015) . Nepal is the first country in South Asia and third country in the world to provide constitutional protection to LGBTI individuals as reported by Bhutia (2015, September 23). However, despite progressive legal standpoint in respect to LGBTI there is also a pressing need for corresponding changes in social attitudes toward sexuality and gender for the realisation of the established legal rights and equality in Nepali society (Greene, 2015).

2.4 Summary

Most of the studies on the sexuality of men with SCI suggest that general sexual functions such as sexual desire, erection, ejaculation, orgasm ability and fertility capacity are considerably affected in many individuals. Sexual desire tends to decrease in 27-33% of men with SCI. About 1-13 % of individuals appear to obtain good erections naturally and more than one-third (37%) of men were able to achieve long lasting erections (with the use of various artificial methods) in the studied samples. In addition, only one-fourth to one-third of the participants were able to ejaculate naturally while 48%-91% of participants appeared to be able to ejaculate after medical intervention. Similarly, only 41-65% of men with SCI were able to experience orgasm. Despite the introduction of highly effective PDE-5 inhibitors, advancement in medical and fertility care, and improvement in achieving an erection, ejaculation and orgasm for many, for significant others, these activities appear unattainable and challenging.

Improvements in general sexual function due to various medical interventions alone may not enhance the qualitative aspects of an individual's sex life. Sexual satisfaction after SCI in men is not entirely dependent upon physical components and the performative part of sexuality such as sexual desire, erection, ejaculation, orgasm, and sexual intercourse (Sakellariou, 2006b). Moreover, a German study argued that there is no significant correlation between preservation of: erectile function; ability to achieve orgasm; perform sexual intercourse and satisfaction in sex life after injury (Reitz et al., 2004). Rather, Sakellariou (2006b) contends that focusing only on the physical components and performative parts of these sexuality issues and overlooking social components of human sexuality in the medical model has failed to recognize environmental factors such as socio-cultural issues which are more disabling in the experiences of people with SCI than the impairment itself. Environmental barriers such as some social beliefs and attitudes, inaccessibility, lack of employment and inappropriate personal support were experienced as the social barriers limiting the right to a satisfying sexual life.

A growing body of knowledge on sexuality and fertility measures and an increasing research interest about men with SCI in this review comes mostly from the European and American continents' perspectives. Current literature suggests that there is a gap between the knowledge and the level of service delivery in sexual rehabilitation. More importantly, there is a dearth of knowledge on sexual rehabilitation from the South Asian perspective. Although existing knowledge from a biomedical perspective could be useful in the management of sexual function impairments contextual issues such as social and cultural: norms, values and beliefs, and the health care system may have different impacts on the sexuality of an individual. Hence sexual concerns and rehabilitation needs may vary accordingly and deserves exploration. In the context of Nepal, there appears to be a gap in providing sexual rehabilitation and sex education. Thus there is a need to find out: what are the sexual problems or challenges for men with SCI experience; what services do they need; how do they perceive their sexual rehabilitation and education and how do they want those sexual rehabilitation services to be delivered. In addition, it is also equally important to find efficient and effective ways to deliver this knowledge.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter outlines the research methodology and methods of the study. I chose a phenomenological, qualitative method to explore the sexual concerns and needs of MWSCI based on their accounts of their lived experiences. In this chapter I first discuss the methodological background of phenomenology and the rationale for choosing hermeneutic phenomenology to this topic. Then I will discuss the research methods; sampling and sample size; selection of the study setting and participants; ethical considerations; the data analysis process and conclusion.

3.2 Methodological background:

3.2.1 Phenomenology

Philosophies underlying specific research designs are known as methodologies (Dew, 2007). Qualitative methodology specifically phenomenology was used in this study. Phenomenology, in the scientific context was initially used by Immanuel Kant in 1786 (Spiegelberg & Schuhmann, 1982). Since then philosophical assumptions of phenomenology have changed across different philosophers. The main contributors were Franz Brentano (1838-1917) and Carl Stumpf (1848-1936) [the preparatory phase]; Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) [the German phase]; and Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961) [the French phase] (Spiegelberg & Schuhmann, 1982).

The common understandings of phenomenology are that it is the study of the 'conscious' lived experiences of people (Van Manen, 1990), and the essences of these experiences, not merely descriptions or analyses (Moustakas, 1994). The core of phenomenology is focussing the attention in the direction of consciousness for understanding the world (Sadala & Adorno, 2002). Thus, phenomenology identifies the meaning for several individuals about a concept or phenomenon under study and also looks for 'what all participants have in common’ by exploring their lived experiences (Creswell, 2007, p. 58).

3.2.2 Heidegger’s hermeneutic phenomenology

For Heidegger our being is ‘being-in’ the world so to begin our inquiry into the meaning of ‘being in’ our own case we must distinguish ‘beings’ from their ‘being’ and only then can we interpret our activities and the meaning things have for us by looking to our contextual relations to things in the world (Smith, 2013). He used the term ’Daesin’ [literally, ‘there-being’] to describe this unique nature of ‘human being’ (Smith et al., 2009b). For Heidegger (1962/1927) our access to ‘Dasein’ is possible through interpretation and his method of phenomenology is hermeneutic (Moran, 2000; Smith et al., 2009b). Heidegger suggests that the essence of human understanding becomes hermeneutic as people derive understanding of their everyday world through their own interpretation of it(Dahlberg, Drew, & Nyström, 2001). The objective of hermeneutic or interpretive work as Benner (1994) describes is the endeavour to “understand everyday skills, practices, and experience [and] to find commonalities in meaning, skills, practices and embodied experience; and to find exemplars or paradigm cases that embody the meaning of everyday practices”. Heidegger’s hermeneutic phenomenology requires both descriptive and interpretative endeavours. This is the approach I have used for describing and interpreting the meaning of participants’ voices and texts collected from the interviews.

3.3 Rationale for using qualitative and hermeneutic phenomenology

There are a few reasons for using a qualitative approach. Health professionals know or have very little access to firsthand experience of the sexual needs and concerns of MWSCI, and the roles of varied personal and contextual factors that help MWSCI to adjust to their life after SCI. Trieschmann (1988) suggested “from past research we know quite a bit about who will adapt to spinal cord injury, but we know very little about how they adapt” (p. 116). In addition, most often SCI rehabilitation and research activities are driven by medical and social models of disability. Unlike biopsychosocial models of disability that take account of biological, individual and social aspects of an individual, the medical and social model of disability view the disability as the result of a problem in the person (cause and effect of disease) and society respectively (Üstün, 2002, p. 9). In contrast with the medical model or pathogenesis paradigm, the salutogenesis paradigm pays attention to factors that promote health and wellness where its knowledge is ‘derived from understanding the world of the person’ (Stuhimiller, 2010, p. 78). Moreover, the health practitioner’s ability to facilitate the adjustment process is dependent upon their ability to identify the predictor of adjustment that is related to individual characteristics rather than injury or impairment itself (Frank et al., 1987). An individual’s unique personal, social and economic circumstances make up these characteristics (Harris, Patel, Greer, & Naughton, 1973). Further, ‘restoring health involves finding meaning in experience, that develop in response to altered functioning and are deepened through self- or social alienation and medical trivialization - and reclaiming connections that have become disrupted or lost (Stuhimiller, 2010, p. 77). Unfortunately, regaining physical and functional independence continues to be the focus of SCI rehabilitation (Hammell, 1992).

From my own personal experience and professional observations, SCI and sexual health rehabilitation practice in Nepal largely relies on the existing body of knowledge from the western world or cultural settings, and the outcomes valued by health practitioners. Finally, findings from the literature review of this study and a recent narrative literature review felt the need for further research based on the subjective accounts of MWSCI. This was “to identify the best possible outcomes for both treatment and rehabilitation”, as most researchers focussed on a biomedical perspective that relied on quantitative measurement of sexual function of MWSCI (Sunilkumar, Boston, &Rajagopal, 2015, p. 274).

The reason for choosing phenomenology and hermeneutics is that the methodology best matches the aims and objectives of this study. The objectives underlying the aim of this study were:

- to gain insights into the phenomenon from an “insider” perspective;

- to better understand the meanings, concerns and priorities that MWSCI attach to their sexuality;
- to favour the perspectives of the men themselves rather than the health professionals viewpoints;
- to understand the predictors of sexual adjustment and its process; and
- to understand how the social and cultural constructions of sexuality and disability impacts on the men's lives.

The pragmatic aim was to translate these findings into approaches to improve the lives of MWSCI and their significant others and to improve professional practice (including but not limited to Occupational Therapy) for MWSCI.

3.4 Research methods

3.4.1 Sampling and sample size

Purposive sampling was used in this study. According to Jirojwong, Johnson, and Welch (2011), purposive sampling is "handpicking participants for a study" (p. 212). This sampling method was selected as it aims to allow the researcher to select information-rich cases relevant to the research question. Initially, 15-20 participants who were able to share their lived sexual experiences specific to the aim of the study were screened from pre-identified lists and were invited to participate in the study. Pre-identified lists consisted of participants' details who have contacted the researcher (showing their interest to participate in the study) after learning about the research from the information sheet available at the hospital, the Spinal Cord Injury Association Nepal (SCIAN) and the Independent Living Society (ILS), Pokhara Nepal. According to Usher and Jackson (2014) in purposive sampling, recruitment of participants will continue until the data reaches saturation. Thus the decision about the number of participants or "sample size" was guided by the principle of saturation and participants were recruited until no new information was obtained.

A total of 17 participants were interviewed in this study. Among the 17 participants 10 were identified and referred International Nepal Fellowship (INF) Nepal staff, (Green

Pastures Hospital and Rehabilitation Centre [GPHRC], Partner for Rehabilitation, INF Surkhet Clinic, INF Dang Clinic, INF Nepalganj Clinic), 1 by SCIAN and 3 by ILS, and 3 were recommended by participants in this research using referral (Smith et al., 2009b) andsnow balling techniques (Biernacki & Waldorf, 1981; Penrod, Preston, Cain, & Starks, 2003; Smith et al., 2009b) respectively. At least twenty-five other participants were excluded from the study for two reasons: first informants were unable to trace or contact them making them unavailable for screening, and second to ensure that the sample included participants from varied backgrounds that had rich and diverse experiences relevant to the topic of investigation.

3.4.2 Selection of study sites

GPHRC-INF was selected as the research site based on the researcher's familiarity and professional experience with the organisation. The researcher/practitioner had observed and experienced the challenges of sexual rehabilitation in this facility during his tenure (1997-2011). A meeting led by the researcher with the hospital superintendent collectively identified the need to investigate the sexual concerns and needs of people with SCI. Later, the hospital superintendent also agreed to take the responsibility of providing field supervision for the researcher. Two Disabled People Organisations (DPOs): the SCIAN and the ILS were invited to participate in the research with the aim of assisting with facilitating the research participant recruitment process. Agreement from SCIAN and ILS was obtained before starting the field work for data collection. At the starting point of data collection, the decision to invite the Spinal Injury Rehabilitation Centre (SIRC) was contingent upon the availability of participants and the saturation of data from the clients who had received rehabilitation services from GPHRC-INF. Later, SIRC was not invited to participate as data reached saturation and adequate participants were available from GPHRC-INF for the purpose of this study.

3.4.3 Selection of participants: recruitment criteria

Participants meeting the following criteria were included in the study:

1. Participants should have reached 18 years of age at the time of study.

2. Participants must have a history of traumatic SCI (incomplete or complete, paraplegic or quadriplegic) and impairment of sexual function or limitation in sexual activity secondary to SCI.
3. Participants should be either undergoing rehabilitation at the time of study or they should have received rehabilitation services (in-patient or out-patient services) from GPHRC-INF after 2006. GPHRC-INF's clients from 2006 were included in the study as it marked the formal start of sexual rehabilitation at the centre; and
4. Participants should be able to give informed, voluntary consent and be willing to share their personal sexual experiences.

However, in cases of illiterate participants, the researcher read the consent form in the presence of a witness. Consent was then taken after ensuring that the participant had understood the objectives of the research and his right to withdraw from participating in the research at any time was explained.

3.4.4 Participant's selection strategy and process

Members of SCIAN and the ILS, and staff at GPHRC-INF and other INF programmes were individually oriented about the research and the participant recruitment process using the facts from the information sheet, interview guide consent form and checklist (see Appendix C). Both English and Nepali versions of information sheets, interview guides and consent forms were hand delivered to them. During the orientation, aims and objectives of the research, participant inclusion criteria, the voluntary nature of participation, sensitivity of the topic of research, and confidentiality issues were explained in detail. Staffs were requested to disseminate the information by word of mouth in addition to the distribution of information sheets and consent forms to men with SCI.

If the contacted individuals were interested in participating in the research then they were advised to contact the researcher at GPHRC personally or by making a phone call at the number listed in the information sheet. When potential participants contacted the researcher expressing their interest to participate in the research, participants were provided with an option for the researcher to call back minimizing their expenses in phone calls which were accepted by all. The researcher called the participants back and informed them about the research based on the information sheet. They were also advised of the inclusion criteria that the researcher had to consider in selecting the participants: the experience of people from different geographical areas, age group, injury level, religion, marital status, caste and ethnicity. The purpose of this explanation was aimed at reducing participants' disappointment in case some were not included in the study. When they confirmed their interest then brief information about date of accident, level of injury, age, marital status, religion, current sexual issues were obtained after taking verbal consent. They were informed that they would be contacted later to confirm their participation in the research and discuss a suitable time and venue for the interview. The conversation was concluded with acknowledgement of their interest to take part in the study.

The depth of data were improved by including three kinds of information-rich participants: the first "typical" or "representative", the second "negative" or "disconfirming" and the third "exceptional" or "deviant" subjects (Miles & Huberman, 1994; Miles, Huberman & Saldana, 2014). This study referred to 'deviant' cases as 'variant' cases. In essence, all cases consisted of men with SCI and attention was paid to ensuring maximum variation sampling as the study unfolded. Maximum variation sampling is intended to capture both variant and negative cases.

3.4.5 Ethical considerations

Ethical approval was gained from Human Research Ethic Committee (HREC), James Cook University, Australia approval number H5985, International Nepal Fellowship (INF) Research Ethic Committee and Nepal Health Research Council (NHRC) Ethical Review Board reference number1443 for conducting this research (see appendix A).

Consent Taking

The researcher obtained informed consent from each participant when participants voluntarily agreed to participate in the study and be interviewed (Tina & Linda, 2012, p. 71), after providing adequate information about the study (reading the consent form). The information about the study included that their participation was voluntary, they had the right to stop at any point of the interview or withdraw from the research at any time without giving any clarification, and they could feel vulnerable and psychologically distressed after sharing personal and intimate sexual experiences. Participants also were informed about research aims and objectives, participant's selection criteria, research benefits and harm, arrangement for minimisation of harm, the use of pseudonyms for protecting participants' identities, measures taken to maintain the confidentiality of participants' information, and roles and responsibilities of the researcher and participants. Additionally, a copy of the information sheet with contact details was also provided to each participant before formalising the consent. Additionally, verbal consent for recording of the interview was taken just before the interview. In this study, at least one participant used his rights by choosing to skip an elaborative question without needing to give any clarification.

Benefit

All interviews were arranged at the convenience of the participants. The aim of working within the participants' preferences for time and place was to minimise disruption to their daily routine, to increase autonomy and provide privacy. Of the participants, 6 of the 17 participants chose their home for the interview primarily due to difficulty in travelling to the research sites. Each participant received a cash token of NRS 770 (Equivalent to 10 AUD) as an appreciation for their time away from home or work. In addition, travel and subsistence expenses were provided to the participants and their carers as per the GPHRC's financial policy to prevent undue burden to economically vulnerable participants. The researcher collected the signed receipts from the participants.

Reciprocity

At the initial stage of the interview, the researcher had routinely acknowledged the sexual concerns and needs of men with SCI and negative impacts they can have in their life due to other people's attitude towards the sexuality of men with SCI in general, as part of setting the background for the interview. This routine was repeated as per the interview guideline. During the interview, when participants invited the researcher's advice, the researcher reciprocated appropriately during and after the interview by providing information about relevant service providers who could possibly help in obtaining information and supporting them. In addition, at various occasions the researcher had to empathise with their situation, take pause and acknowledge the participant's hardship. As a result, many participants acknowledged the researcher for providing the information they needed although the researcher did not answer any of their queries. They also said that they were looking for someone with whom they could share their stories. Most participants expressed their gratitude for obtaining the opportunity to take part in the study and share their experiences. They felt that it was an opportunity to inform a wider audience about the issues people with SCI had to face in their everyday life. They looked at their participation as the opportunity to make a difference and some of the participants suggested using their real name. Some of the participants expressed their happiness and pride in being able to contribute to the study. At the end of the interview, the researcher acknowledged each participant for their valuable time and contribution to the study.

Minimising Harm

Before signing the consent form, each participant was advised of the sensitivity associated with the topic of research. All participants were informed about the possibility of feeling vulnerable and experiencing psychological distress after sharing their personal and private matters to the researcher. In addition participants were advised both verbally and in writing about the arrangement of free psychological support from GPHRC-INF in case of experiencing any kind of distress due to their participation in the interview. The participants were well informed about the meaning of voluntary participation and their right to make a decision in not participating in the research, and to stop the interview without giving any explanation at any time during the interview and withdrawing from research participation after the interview.

Privacy and Confidentiality

While conducting the interview at the participants' homes, they were requested to identify a safe and private area for conducting the interview in their home to ensure the privacy of the conversation. Family members of participants were asked to avoid listening to the conversation at all times during the interview and interrupting the participants except in emergency situations. Similarly, family members were asked to explain the situation to visitors coming to meet participants to prevent any external distractions. Similarly, when interviews were conducted at a research site they were conducted in a separate room to ensure privacy. Additionally, an advance verbal notice to management and written warning notice outside the interview venue was kept to ward of distractions and ensure privacy. As mentioned earlier participants were requested to select a pseudonym of their choice and it was used for de-identification of participants despite some participants' willingness to use their real name. Similarly, confidentiality of participants' information was maintained by not disclosing participants' information to anyone in the way that would disclose their identity and participants' real names were never used to record any information. Even the cash receipt for token money, transportation and subsidy allowances were signed by participants using their pseudonyms.

3.4.6 Selection of language: Nepali

Nepali is one of the most widely used official national languages in Nepal (National Planning Commission Secretariat [NPCS], 2012). All interviews were conducted in Nepali as all the participants including ethnic participants conversed in Nepali and felt comfortable to converse with me in Nepali. In preparation, the information sheet, interview guide and consent form were translated from English to Nepali by a professional translator and reviewed by the researcher after pilot testing on volunteers at GPHRC-INF for improving the ease of understanding in Nepali. The researcher as a native Nepali speaking occupational therapist also felt comfortable in broaching sexuality issues with participants due to previous professional experience in providing sexual education for men with SCI in the Nepalese context. When participants used slang or their local language to describe their experience, I used probing and elaborative questions to improve understanding of participants descriptions with an understanding that Nepalese people feel uncomfortable in using both formal and slang terms to describe sexual acts and sex organs. The participant's need for using local language, Sanskrit or English words to ward off their discomfort was acknowledged with humour and paraphrasing. Pigg (2012) describes the difficulties in finding “the true and best way to view sex, gender, and sexuality” in the Nepali context as educators themselves felt odd and were doubtful about the training using “the sexual words exercise" where the trainees had to use “formal” and “slang” terms “for body parts and sexual acts , in an activity that was meant to illuminate the valued attached to things sexual” (pp. 322-323).

3.4.7 Data collection and analysis

Data Collection Methods; Phenomenological Interview

Data on the lived experiences of men with SCI was collected through in-depth phenomenological interviews by using open-ended questions in a semi-structured format (Usher & Jackson, 2014). Further, when a participant’s description was unclear, clarifying and elaborating questions from an interview guide were used (Jirojwong, Johnson, & Welch, 2011) for probing the phenomenon of the study. According to Priest (2002), an audio recording of an interview is a widely used method for collecting data in a phenomenological study. Thus all interviews were recorded by using two digital recorders for retrieving and using the interview for data analysis by the researcher. In addition, notes were taken during the interview which helped the researcher to invite further clarification from participants by asking probing and elaborative questions.

Interview Transcription

The first few interviews were transcribed verbatim by the researcher using pen and paper. Verbatim transcription was challenging both in terms of the time it took to transcribe the data and difficulty in understanding the recorded transcripts due to background noises such as rain, running of electrical equipment etc. A verbatim transcription service was not available in the town where I was situated hence a decision to hire professionals on a contractual basis was taken. Prior to the recruitment of professionals for transcribing, two participants from the town transcribed the interviews themselves. They were paid for their work. Later two people were available for transcribing the interview however only one of them had Nepali typing skills hence further assistance in electronic typing of hand written data were obtained from a professional secretarial service provider in the town. The electronic transcriptions of data were further delayed due to the lack of human resources in the wake of a major natural disaster in the midst of field work. Nepal was struck by a devastating earthquake of 7.8 magnitude on April 25, 2015 and two major aftershocks of 7.3 and 6.8 magnitudes on May 12, 2015 that struck Nepal (Robertson & Koontz, 2015). The electronic verbatim transcription typed documents were cross-checked with interview recordings and edited by the researcher to ensure the quality of transcription. All transcribers including the secretarial service provider were advised of the need to maintain the confidentiality of the interviews and signed the consent form for not breaching the confidentiality of the information.

Interview Translation

Initially, the first few interviews were translated into English and were circulated to the supervisors and the researcher's ability to collect sufficient in-depth data from the participants was confirmed with constructive and critical feedback. In a subsequent meeting with the supervisor, a decision to translate all the interviews by the researcher was made considering the budget constraint, difficulty in finding a professional translator in the town and outside, occurrence of the natural disaster during field work and the amount of time it would take to ensure the true translation of the participant's meaning of their description in the interviews. Eight interviews were translated in English while still in the field by the researcher and the remaining nine interviews were translated after finishing the field-work which took more than two months.

3.4.8 Data storage

Data were protected both physically and electronically to maintain confidentiality. Interview recordings, verbatim transcripts, translated transcripts and electronic copies of interviews were saved under pseudonyms for the purpose of maintaining anonymity and each file was double password protected. Backup of each raw datum was created and saved in a computer, pen drive and Dropbox$^{©}$. Printed hard copies of transcripts, recorders and pen drives were not left unattended and always kept locked in a cabinet and locked in the room when not in use or unattended. Original electronic copies of all data were stored at James Cook University Research Data repository.

3.4.9 Trustworthiness

According to (Lincoln & Guba, 1985) in naturalistic/interpretative paradigms, reality is not singular and tangible rather it is assumed to be multiple and constructed. Further, in qualitative research or interviews "repeatability is not the essential property of the things themselves" and no two researchers will be able to reach the same findings following the same qualitative rigour due to underlying "differences in their philosophical and theoretical commitments and styles" (Sandelowski, 1993, p. 3). However, to ensure the validity of the study "research findings must invite the opportunity for critical reflection by consumers" (Whittemore, Chase, & Mandle, 2001, p. 535). Therefore, Whittemore et al. (2001) contend that it is essential to select criteria suitable to the ideals of the selected study which has "implications for both the research process and the research product" (p. 534). For example, Usher and Jackson (2014) suggested "statement of presuppositions, member checking, achieving representativeness and dependability, establishing an audit trial and transferability" as the criteria for maintaining the quality and rigour of the phenomenological study (p. 192). Some of these criteria which were deemed suitable to establish the trustworthiness this study findings are discussed in the separate sections below.

Credibility

According to Guba (1981) researchers should take account of various factors during and after the study to improve the credibility of a study and merit of the findings. He described them as: "while doing (during) the study, use prolonged engagement, persistent observation, and peer debriefing, do triangulation, collect referential adequacy materials, and do member checks, and after completing the study, establish structural corroboration or coherence, establish referential adequacy, and do member checks" (p. 84).

I spent between an hour and one and a half hours with each participant before proceeding with the interview which allowed both participants and myself to know each other well.

In addition, the inclusion of a questionnaire about personal information and life before SCI at the beginning of the semi-structured interview helped me understand the various social, cultural and economic issues that played an important role in their life before the injury. This was important for building rapport and trust before discussing sensitive and private issues of sexuality. As a result most participants provided detailed and in-depth information illuminating their lived experience. Discussion about field activities and issues that came across successive interviews was discussed with the research advisory panel fortnightly inviting critiques for enhancing insight into the phenomenon of the study. Discussion of two findings chapters with two peers one from occupational therapy and the other from the physical therapy discipline with SCI rehabilitation experience contributed to clarifying and refining the analysis. Peer examination/debriefing is a way of improving the researcher's honesty and deeper reflexive analysis (Lincoln & Guba, 1985).

Triangulation was utilised for establishing facts by being more 'wakeful' (Clandinin & Connelly, 2000, p. 182) that triangulation has limited value for meanings and highly individual experiences. Knafl and Breitmayer (1989) have identified as many as four ways of triangulation: triangulation of data methods, triangulation of data sources, theoretical triangulation, and triangulation of investigators (as cited in Krefting, 1991, p. 219). Different groups of MWSCI: married (with or without children), unmarried, arranged or love marriage, divorced, caste (at least one participant from 4 major caste systems), ethnicity, religion (Hindu, Buddhist, Christian, Muslim and Bone), geography (hilly or flat, urban or rural) were included by using a purposive maximum variation sampling method. In addition, parallel coding and interpretation of data by members of the research panel invited different perspectives of the data and coherence in the analysis of data.

Member checking was not used for a few reasons. It is associated with participants' embarrassment and withdrawal from the study; threat to the rapport; and loss of original valuable data (Carlson, 2010). It can also have ethical issues such as a harmful effect on the wellbeing of participants (Krefting, 1991). The research panel also raised the question about the authenticity of the procedure and dilemma that could result when participants disagree with a thesis which is based on my interpretation of their voices.

Miles and Huberman (1994) have identified four essential characteristics in assessing the trustworthiness of a researcher as a measurement tool and establishing the authority of the researcher and hence their credibility. In spite of being a novice researcher, I was equipped with most of these necessary skills prior to the field study. I had worked for many years in GPHRC in Nepal where the study was conducted. I also had firsthand experience of accessing rehabilitation services from this setting when I suffered a traumatic SCI in 2009. Thus, I had an understanding of SCI from the perspective of rehabilitation professionals as well as that of SCI clients. I undertook a separate phenomenological project during coursework on qualitative research to refine conceptual and theoretical knowledge in phenomenological study. In addition, to improve investigative skills I conducted a literature review on the study topic. Further, skills to conduct in-depth interviews were improved through my supervisor's coaching and mock interviews with colleagues and friends. Discussions about the researcher's presumptions were discussed with the research advisory panel and documented in the research proposal to minimise the bias and influence on research and this is discussed in a separate section in this chapter.

The following steps were taken to ensure that as far as possible, the data and analysis best represented the views of participants while minimizing undue influence of the researcher but at the same time, maximizing the insights that the researchers own person experiences brought to the project:

1. Interviews were open-ended and the direction they took was largely determined by participants. Gaining original diverse insights was important for the study.
2. Transcripts were reviewed at regular intervals by the supervisory team to ensure quality control over the data collection process, especially interviewing techniques. Attention was paid to the interview style; the use of clarifying questions; cross-checking facts; and verifying interpretations during the interview.

3. Continual comparative analysis at 3 principal stages was undertaken to ensure a coherent building of the knowledge-base. These stages were during the interview; preliminary analysis following the interview; full analysis after data collection was completed.
4. My own personal experience as both a rehabilitation professional and as a person who has experienced spinal cord injury myself were a strength of the project because of the insights and interpretative depth that this brought to the analysis.

Transferability

A complete and accurate picture of data generation conditions and process including an adequate description of the context of the study enables the reader to make a decision about transferability (Koch, 1996). Guba (1981) described usefulness of theoretical/purposeful sampling; and collection of “thick” descriptive data during the study and development of thick description of the contexts to facilitate the judgement of transferability to other contexts.

The context of this study has been described in detail in Chapter 1. In addition, an interview guide was used during the interview and it is available for reference to the reader (see appendix 2.a and 2.b). A purposive maximum variation sampling was used to select the participants in this study. The decision-making process during data collection and analysis, also known as the decision trail (Jirojwong et al., 2011), was utilised in the participant recruitment process by taking notes and maintaining a diary.

Dependability

Dependability is concerned with the consistency of study findings (Guba, 1981). Repeatability or uniqueness of this study is ensured by providing exact and thick descriptions of methods used in the data collection, analysis and interpretation as described by Krefting (1991). In addition, triangulation of data sources: data were collected from various groups of MWSCI using purpose and maximum variation sampling as described in credibility section of this chapter and parallel coding was done by supervisors. Further, findings were examined by two peers as described above in the credibility section and the research plan was closely supervised during its implementation by supervisors in the research panel. It is also known to improve the dependability of the qualitative research (Krefting, 1991).

Confirmability

According to Guba (1981) triangulation, reflexivity and audit can be used for establishing confirmability in qualitative study. For example, he suggested the use of at least two sources for every claim made by investigators except in negative cases. For establishing confirmability; credibility, transferability and dependability of the study are prerequisites. Thus, to establish confirmability of this study, an attempt to meet these pre-requisites has been made as described above in the corresponding sections.

3.4.10 Presuppositions

The following presuppositions for this study are based on the influence of Nepalese culture and social values on me as a fellow citizen, my previous clinical experience in SCI rehabilitation and the knowledge gained during the literature review. Presuppositions of previous clinical experience were that: erectile dysfunction was the main cause of blaming their wives for adultery by married Men with Spinal Cord Injury (MWSCI); and wives of MWSCI would not be open to sexual exploration such as trying different sexual positions due to cultural taboos. In addition, other assumptions were that: existing sexual rehabilitation services are inadequate for married MWSCI; and rehabilitation professionals do not attend to sexual issues of both now single and never married MWSCI and this could have created a lot of sexual anxiety in them; and now single and never married MWSCI may not have had the opportunity for sexual intimacy and relationship. Further beliefs were that: mainstream health professionals don’t attend to this area well; contrary to popular belief MWSCI are not asexual; attending to sexual needs should be as fundamental as other aspects of care; MWSCI have human rights including their emotional, sexual and relationship needs. The cultural assumptions were: that society ignores the sexual and intimacy needs of MWSCI. Following the literature review the researcher had assumptions such as Nepalese MWSCI may not have had a very good compliance with the use of erectogenic drugs due to inadequate education and feedback mechanisms to try out different drugs and doses and professionals do not feel comfortable in attending to sexual issues because of their lack of knowledge of sexuality of people with disability, time and priority for physical rehabilitation. However, the researcher was quite naive and unsure about the attitude of MWSCI about partner satisfaction, their perception of the attitude of health workers and family members towards their sexual needs and concerns and its effects on them.

3.4.11 Data analysis

A step by step Interpretative Phenomenological Analysis method designed for novice researchers as described by Smith et al. (2009a) was utilised for data analysis. According to Smith et al. "steps to analysis" involves: first, reading and re-reading of original data; second, initial noting; third, developing emergent themes; fourth, searching for connections across emergent themes; fifth, moving to the next case, and finally, looking for patterns across cases (Smith et al., 2009a). Then, a discussion in the context of the research objective, and findings with major themes and a clear outcome statement (Usher & Jackson, 2014) are compiled for dissemination.

Data Analysis Process

Verbatim transcription and translation of interviews in English allowed the researcher to become familiar with the data. Interviews were formatted into separate word documents with a margin left on the right side for initial coding and all files were kept in a separate folder. Formatted interview transcripts were read closely until becoming familiar with the content and gaining an understanding of the events and key issues as described by Thomas (2006). Transcripts were printed then text segments with meaningful units were highlighted after close reading and re-reading of interviews as described by Smith et al and Thomas (Smith et al., 2009a; Thomas, 2006). The first few transcripts were coded in parallel with an advisory team, compared and discussed. Professor Plummer strongly recommended coding intuitively instead of using an advance setting of codes for preventing pre-determined outcomes and reaching genuine discovery. He described it as:

> In my opinion you need to do coding intuitively and not set the codes in advance. In other words, I think it is better to end up with a code tree/classification instead of starting with a coding tree. Setting codes in advance can pre-determine the outcomes. In contrast, allowing the process to unfold without forcing it is more likely to be more flexible and responsive to the data and lead to unexpected and original findings that you were not (consciously) expecting and therefore to genuine discovery. (D. Plummer, personal communication, September 10, 2015).

The highlighted texts were thus labelled with one or more initial codes intuitively using one or two word summaries of key points and actual word(s) from the participant's quote(s) on the right side margin for all transcripts. According to Thomas (2006) in vivo coding (which uses the actual word(s) from the participant's, quote(s)) and inductive coding (the meaning of a statement that reflected something important or actual phrases) are lower-level or specific categories. It was also noted that some text segments were coded into more than one category (see Table 3.2), referred to as overlapping coding (Thomas, 2006).

After finishing the initial coding, original transcriptions were copied and pasted on word documents using simple qualitative analysis software known as DocTools (http://www.thedoctools.com). The codes from the hardcopy (of the transcripts) were entered into the word document, after selecting a corresponding section of the texts and quotes. Selected text, corresponding codes and participants' pseudonyms were extracted by running the macro function. The macro output table was sorted for grouping the same codes together in horizontal order. Smith et al. suggest that analysis of a large data focus of analysis should be in identifying emergent themes for the "whole group" and those themes are illuminated using individual participant's specific examples. A quick scan of the sorted coding revealed that a few codes were repeated several times, and others seldom repeated. Initial codes with similar meaning and patterns were arranged, and ordered, some codes fitted more as subsets of bigger categories (see Table 3.1). Such codes are described as upper-level or more general categories (Thomas, 2006). For example, most initial codes such as sexual concern, sexual needs and attitudes matched with the research aims and objectives.

Table 3.1: Themes and subthemes

General categories →	Sexual concern	Sexual needs	Social prejudices
↑ Sub categories ↓	Erectile dysfunction	Obtaining erection	Parents' attitude
	Ejaculatory dysfunction	Sexual pleasure	Parents-in-law's attitude
	Anorgasmia	Sexual satisfaction	Wife's attitude
	Infertility	Sexual intimacy	Friends' attitudes
	Satisfying partner	Drugs/medication	Peer's attitudes
	±Sexual desire/libido	Sex education	Health-worker's attitudes
	Attitude of others	Fertility information	Villagers' attitude

Further grouping and arrangement of codes also revealed large umbrella codes or major categories which connected several initial codes and emerged as a major theme (see Table 3.2). Smith et al. argue that using recurrence of themes across cases is a valuable tool in identifying an emergent or super-ordinate theme and a theme must repeat in "at least a third, or a half, or most stringently, in all of the participants' interviews" for labelling it as a recurrent theme Smith et al. p 107 (2009a).

Tables of demographic information and recurrence of themes across cases were developed. Table 3.3 shows demographic information such as age, marital status, geography, duration since injury, employment status and other variables to observe the specific and general trends. Table 3.4 presents the recurrence of some subsets of major themes and major themes such as presence (+) or absence (-) of sexual impairment, perceived sexual desire, sexual information and education, knowledge, use and impact of erectogenic drugs, concern over satisfying a partner, immediate and future infertility and partner concerns. It helped to see the linkage between various major themes for example SCI and sexual function impairment did not impact now single and never married men, and married men with SCI in the same way, employment, geography and accessibility impacted partnering and intimacy opportunities.

Table 3.2: Major themes

Umbrella codes →	Rehabilitation challenges	Community reintegration	Loss/reconstruction of Manhood
↑ Codes/Overlapping codes ↓	Rehabilitation information	Sexual concerns	Erectile dysfunction
	Referral issues	Accessibility issues	Infertility
	Mourning for loss	Provider role	Provider role
	Sexual concerns	Employment	Employment
	Rehabilitation priority	Family attitudes	Body image
	Staff knowledge and attitude	Social belief/prejudices	Social belief/prejudices
	Peers support	Support system	Sexual prowess
	Secondary complications	Secondary complications	Sexual relationship
	Rehabilitation cost	Sexual relationship	Mutual-understanding
	Sexual education	Relocation	Love/affection
	Rehabilitation duration	Follow-up services	Non-penetrative sexual activity

3.4.12 Demographics

Injury Type

Out of 17 participants 14 (83%) were paraplegic: 8 (47%) were complete paraplegic; 3 (18%) were incomplete paraplegic; 3 (18%) of them were not sure whether they had a complete or incomplete injury. The remaining 3 (18%) were quadriplegic: 1 complete; 1 incomplete; 1 unsure.

Age

Both mean and median age of participants was 35 with a standard deviation of 11.35, the youngest participant was 19 years old and the oldest participant was 58. One of the participants was under 20 years of age, 7 were in their early adulthood (20-35) and midlife (35-50) each and 2 were in the mature adulthood (50-80) stage of their life.

Sexual Orientation

Almost all participants identified themselves as heterosexual however 1 participant who is married and living with his wife and a son reported that he had sex with his male friend during his late adolescent period before getting married.

Education

Of 17 participants, two participants (12%) never attended school and were illiterate. Among the others 8 participants (47%) have completed a few years of schooling, 5 (30%) have completed 10 years of schooling of which 2 (12%) took admission into college for further study but one participant dropped out and one of them is currently pursuing his study. Only 2 (12%) participants have completed the Proficiency Certificate Level Study (12 years of schooling) and one of them is currently an undergraduate student.

Religion

Of the 17 participants, 11 (65%) were Hindu, 2(12%) were Buddhist, 2 (12%) were Christian, 1 (6%) was Muslim and 1 (6%) was Bon religion. Of the 2 Christian participants one of them is currently undergoing rehabilitation and has chosen to become Christian. He was Buddhist prior to changing his religion.

Socioeconomic Situation

The self-reported socioeconomic status condition of the 17 participants shows that more than half of the participants have a low socioeconomic status i.e. 9 (53%); followed by middle class 6 (35%), and 1 (6%) of lower middle class, and 1 upper middle class.

Marital Status

Out of 17 participants, 13 (77%) were married at the time of injury and 4 (24%) were unmarried. Out of 13 married participants two (15%) participants are single now as their spouses eloped/divorced them following the SCI. Of the 4 unmarried men, two were injured at a very young age and were children at the time of injury whereas two participants were in their late adolescent stage of their life and they have since experienced sexual relationships with their girlfriends.

Children

Among 13 married men with SCI, 10 participants had at least one child before the SCI. Of the 10 participants 9 are living with their spouse and family while only one of them is staying with his family and is single. He was not able to get married again because of social taboos however he was in a sexual relationship at least once following the injury. Of the three participants who do not have children one participant is a divorcee who is single. Out of two other participants one couple was not able to reproduce children because of pre-existing reproductive health conditions in the wife of the participant, whereas another couple was trying very hard to have children without any success until now.

Among 9 married couples, 6 of them have only one child and 3 of them have more than one child. Among 6 married couples with only one child, 4 of them have a son and two of them have a daughter.

Duration since SCI

Among the 17 participants, 3 participants were in a rehabilitation program of which one participant was injured more recently. Of the remaining participants, 5 were injured within the last 5 years, 5 were injured in the last 6 to 10 years and 5 were injured between 11 to 20 years ago and one participant was injured more than 20 years before.

Employment

Of the 17 participants, 3 (18%) participants are undergoing their rehabilitation at Green Pastures Hospital & Rehabilitation Centre. Among those 3 participants one of them is a student and he is hoping to continue his schooling. He is thinking to relocate/migrate to a place where he can find an accessible living environment for accommodation and schooling. However, two of the participants undergoing rehabilitation will most likely be unable to return to their previous occupations.

Out of 17 participants the remaining 14 participants who have completed their rehabilitation and have returned to their home: 5 (29%) are unemployed; 1 (6%) is a student; 1 (6%) is a retired Government worker and 7 of them have some form of employment. Among 7 participants who are working 3 (18%) of them are self-employed, 3 (18%) of them are working in the non-governmental sector and one (6%) is a government employee.

Relocation/ Migration

Among the 17 participants 3 were undergoing rehabilitation. Two of them will most likely continue to reside at their homes in the village following discharge, and one of them has expressed a strong desire to relocate to a new place to continue his schooling. Three more of the participants will return to their homes before making a decision to migrate, 7 (41%) out of 17 participants have already migrated or relocated for various reasons.

Four (24%) of the participants have moved either with their family or alone (in case of unmarried participants) to a new location for self-employment. Three of these participants have moved to district headquarters in a small or big city and one of them has moved to the business centre in the same village. In addition, one of these participants has started a job while continuing the family business. A fifth participant who is currently studying moved with his family when he was a child. The remaining two participants have moved to cities or a flatter area in search of better accessibility, one of which is a retired government worker and the second one after migrating has started working in a nongovernment organization.

Type of Housing

Of the 17 participants 12 are staying in their own/parents' home while 5 of them are staying in rented housing. Of the 5 participants who are staying in a rented home they have migrated from their home in the village, and 4 out of 5 are self-employed (running their own business or self-employed and one of them runs a family business as well as being employed at a nongovernmental organization) while the fifth participant is studying while his parents are finding employment in the city.

Geographical Distribution of Participants

Of the 17 participants, 4 were from mid-western regions and 13 were from the western regions of Nepal. These participants represented 2 out of 5 development regions of Nepal. At the time of the interview 4 participants were staying in a big city (3 of them had migrated to the city either for work, better accessibility or schooling), 2 participants were living in a small city (both had migrated for self-employment/running a business) while 3 participants were staying at the outskirts of the small and big city. One of the participants migrated for accessibility reasons and this participant has found employment at a nongovernment organization after migration. Similarly one of the participants migrated from the remote village in the hilly region to the slum area of the city for a better life and accessibility. Seven of the participants are staying in a remote village setting and all of them are from hilly regions except one who is from flat terrain. Only one of these participants has migrated to a business centre in the village for self-employment/running a business.

3.5 Conclusion/Summary

Hermeneutic phenomenology provided a suitable methodology for exploring the sensitive and private issues of human sexuality for MWSCI. All participants provided in-depth information by recalling and reflecting on their lived experiences. Initially transcribing and translating interviews appeared a time consuming and painful task for me, however the whole process provided more opportunities to become even more familiar with the participants' individual and shared perspectives which in turn made the process of coding, developing emergent themes, searching for connections, finding patterns and interpreting the findings meaningful and easier. In the process of data analysis, as a novice researcher I found using Smith et al.'s "steps to analysis" a helpful strategy.

Table 3.3 : Demographic information

Name	Interview date	Time since injury (Yrs.)	Age range	Region	Relocation	Remoteness	Injury level	Type of injury	Economic status	Marital status	Children	Education yrs.	Religion	Employed
Binod	13/03/2015	5	20-35	Mid-west	No	Semi urban	D-2	Complete	Lower class	Married	3	4-10	Hindu	No
Sirish	15/03/2015	20	35-50	Mid-west	Yes	Semi urban	L-3/L-4	Incomplete	Middle class	Divorce	1	10-12	Hindu	Yes
Birendra	15/03/2015	7	35-50	Mid-west	No	Semi urban	Mid-Thoracic	Complete	Lower class	Married	1	4-10	Hindu	No
Pradeep	7/04/2015	15	35-50	Western	Yes	Urban	T-12	Incomplete	Lower-medium	Married	2	10-12	Hindu	Yes
Nabin	13/04/2015	17	35-50	Western	Yes	Rural	T-9	Complete	Lower class	Married	1	10-12	Hindu	Self
Ram	2/05/ 2015	15	35-50	Western	No	Rural	T-6	Complete	Middle class	Divorce	0	4-10	Hindu	No
Bibek	4/05/2015	10	20-35	Western	Yes	Small city	T-8	Complete	Middle class	Single	NA	4-10	Hindu	Self
Dinesh	5/05/2015	10	20-35	Western	Yes	Small city	C-6 /C-7	Incomplete	Middle class	Married	0	4-10	Hindu	Self
Ashish	6/05/2015	11	20-35	Western	Yes	Urban	L-12	Complete	Middle class	Single	NA	10-12	Christian	No
Bharat	7/05/2015	31	50-80	Western	No	Urban	T-12	Complete	Middle class	Married	3	12-14	Hindu	Self
Som	22/05/2015	9	50-80	Western	Yes	Slum	T-3	Incomplete	Lower class	Married	0	4-10	Bon	Retired
Saroj	22/05/2015	8	20-35	Western	No	Urban	T-4	Complete	Middle class	Single	NA	12-14	Hindu	Yes
Kumar	28/05/2015	3	35-50	Western	No	Rural*	C-6/C-7	Complete	Lower class	Married	1	10-12	Buddhist	No
Prem	29/05/2015	1/12	20-35	Western	NA	Rural*	L-2	Complete*	Lower class	Married	1	Illiterate	Buddhist	No
Gaya	6/06/ 2015	5	35-50	Mid-west	No	Village	T-1/T-2	Complete*	Lower class	Married	1	Illiterate	Muslim	No
Arjun	10/06/2015	2	20-35	Western	No	Village**	C-5/ C-7	Complete*	Lower class	Married	1	4-10	Hindu	No
Anil	19/06/2015	1	1-20	Western	No	Village**	T-8/T-9	Complete*	Lower class	Single	NA	4-10	Christian	No

*** Unsure; ** No road access; **; NA Not applicable;**

Table 3.4: Concerns of Men with Spinal Cord Injury

Name	**Sexual desire**	**Erection**	**Active Sex**	**Sex life**	**Medical advice**	**Medicine Use**	**Medicine impact**	**Ejaculatory dysfunction**	**Anorgasmia**	**Infertility**	**Partner's satisfaction**	**Relationship**	**Negative attitudes**
Binod	+++	+	✓	Δ	x	x	NA	✓		NA	✓	Δ	✓
Sirish	+	+	x 1	Δ	✓	✓	++	✓	✓	✓	✓	Δ	✓
Birendra	+++	+	✓	Δ	x	✓	++	✓		✓	✓	Δ	✓
Pradeep	+++	+	✓	Δ	x	✓	++	✓		NA	✓	Δ	✓
Nabin	+++	-	x	Δ	x	x	NA	✓		✓	✓	Δ	✓
Ram	+++	+	x	Δ	x	x	NA	✓		✓	NA	Δ	✓
Bibek	+	+	x 1	Δ	x	x	NA	✓	✓	✓	✓	Δ	x
Dinesh	+++	+	✓	Δ	x	x	NA	✓	✓	✓	NA	Δ	✓
Ashish	NA	-	x	NA	x	x	NA	NA		✓	✓	No	x
Bharat	+++	-	✓	Δ	x	✓	x	✓		NA	✓	Δ	✓
Som	+++	+	x	Δ	x	x	NA	NA		✓	NA	Δ	x
Saroj	+++	+	✓	Δ	x	✓	++	✓		✓	✓	Δ	✓
Kumar	-	-	x	Δ	x	x	NA	NA		NA	NA	Δ	x
Prem	-	-	NA	Δ	x	x	NA	NA		NA	✓	Δ	✓
Gaya	++++	+	✓	Δ	✓	✓AD	++	✓		✓	✓	Δ	✓
Arjun	+++	+	✓	Δ	x	x	NA	✓		✓	✓	Δ	✓
Anil	NA	-	NA	Δ	x	x	NA	✓	✓	✓	NA	Δ	x
Yes	11	17	8	16	2	6	6	13	4	13	12	16	12
No/NA	2	7	7	1	15	11	11	4		4	5	1	5

- Absent; +Poor; ++ Improvement; +++ Intact; ++++ Better; NA Not applicable/No information;

X1 Number of sexual encounter; X No, ✓ Yes, Δ Changed

CHAPTER 4

MANHOOD

4.1 Introduction

This chapter primarily focusses on how sexual function impairments and physical disability following Spinal Cord Injury (SCI) challenge the manhood of Men with Spinal Cord Injury (MWSCI). These challenges are analysed at personal, family and societal levels based on concerns and needs of MWSCI. The participants' views on manhood are personal; however, humans are social beings so these views are also a reflection of their family members and societal views at large. The scope of this chapter is not to explore what manhood is in Nepalese society, but to view it from these MWSCI perspectives.

4.2 Defining manhood

Before analysing the data, various dictionaries and definitions were consulted to understand the general meaning of manhood. Interestingly the word "manhood" was not included in the medical dictionary. In the first cross-cultural study of manhood, anthropologist Gilmore contends that manhood is something that is achieved through struggle in the society (1990). He defined it as:

> *"... approved way of being an adult male in any given society. More specifically it is about why people in so many places regard the state of being a "real man" or "true man" as uncertain or precarious, a prize to be won or wrested through struggle, and why so many societies build up an elusive or exclusionary image of manhood through cultural sanctions, ritual, or trials of skill and endurance" (Gilmore, 1990, p. 1).*

Gilmore asserted that there is no conclusive answer to the question of whether there is a deep structure of manhood and a global archetype of manliness (Gilmore, 1990). He discussed the plurality of manhood and highlighted the influence of the socio-cultural environment in shaping the concept of manhood. Therefore, this chapter will explore how the event of SCI challenges the participants' manhood in Nepalese society.

According to The Penguin English Dictionary (2007), manhood means:

> *"The condition of being an adult male as distinguished from a child or a female;... the adult males of a country, etc...; manly qualities, such as physical strength and sexual prowess;... humorous a man's masculinity, as represented by his penis, I thought I was about to be deprived of my manhood" (Manhood. para. 1-4).*

Similarly, according to Merriam-Webster's Collegiate Dictionary (2012) ,manhood is defined as:

> *"The condition of being a human being; qualities associated with men: manliness; the condition of being an adult male as distinguished from a child or female; adult males: men; penis" (13c).*

4.3 Major themes

Three major themes concerning manhood following SCI emerged from the data: concerns about sexual dysfunctions; loss of manhood; and coping as a way of reconstructing manhood.

4.3.1 Concerns about sexual dysfunctions

Most men with SCI experience sexual dysfunction as a secondary issue to their acquired injury (Anderson et al., 2007b; Gianotten et al., 2006). Data from this study shows that most of the participants have experienced weakness or loss in their sexual functions: genital sensation; erection; ejaculation; fertility and orgasm (sexual pleasure) abilities whereas only a few MWSCI have experienced a decrease or loss of sexual desire. After SCI, most MWSCI appear to develop a lot of apprehension and grief about diminished sexual functioning, sexual performance and pleasure. Five subthemes: sexual desire: magic of the brain; loss of genital sensation; erectile dysfunction; concerns about loss of ejaculation and sexual pleasure; and infertility concerns were identified under the major theme sexual dysfunction and are analysed below.

4.3.1.1 Sexual desire: magic of the brain

Sexual desire is preserved in most (78%) MWSCI and it is correlated with age, severity of injury, level of desire and sexual experience before injury (Alexander, Sipski, & Findley, 1993). Similarly, participants' descriptions show that the decrease in sexual desire is associated with age, severity of injury, physical pain, erectile dysfunction and decrease in sexual pleasure after the injury. Increased levels of sexual desire were associated with an inability to fulfil sexual needs due to other impaired sexual functions and the perception that lifespan after SCI is limited or uncertain. In contrast with a decreased sexual desire preservation or increased level of sexual desire appeared to be associated with grief, frustration and feelings of worthlessness. Moreover, the availability of a partner was also linked with sexual desire. Of the17 participants in this study sexual desire has decreased in 2 participants, is absent in 3 participants and remained comparable to pre-injury level in 12 (71%) participants including increased sexual desire in two of the participants.

Ram who is single now becomes philosophical, and highlighted that sexual desire is not impaired by one's disability. He described sexual desire as a natural phenomenon:

> *Although a person may become handicapped, his/her feeling will not be handicapped. Every individual has a desire for sexual relationship. It is a rule of nature. (Ram)*

In this description below, Binod's awareness as well as fascination with the role of the brain in maintaining his sexual desire in the absence of genital sensation can be observed. He experiences an increase in his sexual desire and sexuality becomes even more important for him after SCI because of his perception that life after the injury is uncertain and limited. He described the role of his brain and influence of his perception about SCI life on sexual desire as:

> *Now after the injury although my linga (penis) does not have sensation, I have desire for sex because my brain still thinks about it... brain still continues to do the magic. In this situation there is even more increase in sexual desire and interest in sex because of thoughts of dying sooner or later (today or tomorrow). (Binod)*

Similarly, Pradeep also described experiencing an increase in sexual desire after the injury except when he was in physical pain. He noticed how sexual desire and performance expectation were exaggerated from not being able to fulfil the existing desires due to his sexual limitations. He described it as:

> *Courage and enthusiasm also needs to come together with the desire. After the injury, when there is physical pain, there is no such sexual desire. Physical pain affects the person psychologically as well... I had a lot of desire but the part of my body responsible for it was not working well as before. Desires and wishes were very high! How am I going to fulfil all those and what can be done? (Pradeep)*

He further described how memories of his past sex life, discrepancy in the sexual performance before and after the injury and perceptions of not being able to meet his sexual desires and needs led to feelings of apprehension, frustration and worthlessness. He described them as:

> *I used to get memories such as how I used to have sex before the injury; why did it happen? Recollection of many issues from the past used to worry me… I was not able to fulfil my sexual desire and needs… As a result, of this, there is a feeling of frustration. Because of unsuccessful sex life thoughts such as life is worthless; it has no benefit and importance were common. It also decreased the enthusiasm (Josh), interest (jangar) and energy level. (Pradeep)*

Similarly, Bharat compared and ruminated about his sex life before and after the injury. For Bharat both his inability to resume his sex life due to the lack of an erection and the accompanying feelings on not being able to fulfil his sexual wants due to his preserved sexual desire are the source of his unhappiness.

> *After the injury, I felt a big difference in my sex life because I am unable to have sexual intercourse. The reason for it is that following the SCI I am not able to obtain erection... I have sexual desire similar to that of a normal person but I am unable to fulfil my desire because there is no erection at all. I*

> *wish for it to work but there is no movement at all then I feel sad (khinna). Thoughts keep coming daily. That does not stop. (Bharat)*

The next example shows the loss of sexual desire in the early days which was followed by the gradual recovery of sexual desire when other issues such as education ceased to become a priority:

> *I also have lost my sexual desire... Gradually when I was achieving success in my studies then sexual thoughts started troubling me. (Saroj)*

Saroj further described his sexual tension and the association of his sexual desire with the availability of a partner as:

> *I have not had sex many times. It is obvious to get the desire for it after having a partner. (Saroj)*

Similarly, in Prem's description the early awareness of sexual desire of a married man with the availability of a partner can be observed. He described it as:

> *I do have desire but what can be done only with the desire since my legs and penis has no movement…I started to have this feeling about 10 days after my operation... my wife came about 9-10 days after the operation. When she came and I saw her then I started to think that we use to sleep like that and do that. I keep having memories of it thinking that now I cannot do it. (Prem)*

On the contrary, a few participants have experienced a decrease or lack of sexual interest or desire. In the next description, Prem's sexual apprehension triggered by his sexual desire and uncertainties about his ability to fulfil his wife's sexual needs due to his paralysis are apparent. He also highlighted a decline in sexual desire due to lack of erection. He described it as:

> *I keep thinking whether it can happen as mind desire or not... I have a feeling for her however I cannot do anything even when I sleep with my wife… but what I can do, I am in this state; my body is paralysed… Penis does not get erect so sometimes I lose my desire as well. (Prem)*

An unmarried participant, Bibek described his lack of interest in sex as:

> *I do not have real interest in sex now. Sometime I participate because of compulsion otherwise; I do not have such feeling or interest to do such thing. (Bibek)*

From his next description, it becomes obvious that lack of sexual pleasure similar to that of before the injury is the reason for his loss of interest in sex.

> *I had sexual relationship a few times after the SCI. I experience huge difference in the sex before and after the injury. Now, I do not get that much pleasure "good feeling" which I used to obtain before the injury... I do not obtain the sexual orgasm like before. I feel this difference because of my sexual experience prior to injury; otherwise I would not have felt this difference. (Bibek)*

Bibek further described that the lack of pleasure "good feeling" in his sex life as the reason for lack of motivation and interest in sex for him.

> *If we would have sensation then it would let us know that experience. That is why we cannot feel the good feeling that we experience in sex… We do not have the thoughts for having sex, interest for physical relationship which would usually occur once you have pleasurable sexual experience. However, there is not much interest now because of lack of such feeling. (Bibek)*

Kumar (a married man with severe injury who was unable to resume his sex life after the injury) described his loss of interest in sex in this way:

> *No. I have no interest in it! Not sure what has happened: for me feeling about sex is dead now. (Kumar)*

Kumar further describes the lack of sensation in addition to the lack of an erection and sexual pleasure as the reason for lacking sexual desire. He described it as:

> *In reality first issue is that, my own thing (Linga) does not work. That is a fact and it does not feel anything. You do not care about it when there is no any feeling (sensation) and anything else. On the contrary, it becomes boring… If sensation, feeling and emotions would have been there then sexual desire also*

> *would have been there… I have the same situation from the beginning that mal (penis) neither has any function nor it has any sensation. (Kumar)*

In this description, Sirish describes the gradual decline of his sexual desire with aging. He also makes comparisons of his sexual performance:

> *I feel that my desire/thirst regarding sex has been over now. When I was young, I used to imagine that if I could have sex like before then I would marry… I do not get such feelings like that anymore. Maybe it is due to my age. (Sirish)*

4.3.1.2 Loss of genital sensation

More than half of the participants expressed their concerns about the lack of genital sensation. These participants associated the lack of this sensation with diminished or lack of sexual pleasure, sexual desire, and sexual satisfaction. In this description, Gaya highlights lack of sensation as the reason for decreased sexual pleasure and interest in sex. The lack of sexual pleasure and his adherence to penetrative sex is clear:

> *My problem is that I do not feel. It would have been very good if I could feel that. If I would have sensation then I would have done 3-4 times out of my interest… I would have done it daily as before. (Gaya)*

Sirish also described that he is unable to appreciate sexual pleasure in the absence of sensation as:

> *Excitement that we get from inside of our body means capturing it even by our brain. It is possible only when there is sensation in the penis skin but we do not have that sensation. (Sirish)*

He further described the importance of sensation for regaining sexual satisfaction by highlighting the need for the development of an intervention to restore the sensation in this way:

> *When there is no sensation how can I obtain the satisfaction? Satisfaction is obtained only by wife. I feel that if there would have been sensation in the skin or development of technology that would help to gain the sensation for obtaining satisfaction it would have been good and quality of life of both couples also would be good. (Sirish)*

Binod also described that he is unable to obtain sexual satisfaction similar to that of before the injury due to the lack of sensation in his penis. He highlighted his desire to obtain sexual pleasure prior to that of his injury now. He described it as:

> *I had sensation in my penis before the injury. I used to get satisfaction from it. Now although I do not have sensation, I have desire for sex because my brain still thinks about it. Today, I feel for having that experience again. (Binod)*

Furthermore, in Bharat's experience his sex life is never going to be the same in the absence of sensation. He described it as:

> *Sensation did not return… There is sensation only up to the base of penis... It has affected greatly in sexual intercourse. It is not possible to have sexual intercourse normally. (Bharat)*

4.3.1.3 Erectile dysfunction

For MWSCI erectile function continued to be an important concern soon after the injury. Their concerns included lack of psychogenic or reflexogenic or both types of erection, difficulty and prolonged time to achieve erection, and lack of information for improving erection. Erectile dysfunction was the source of humiliation, sexual dissatisfaction, and anxiety about marriage prospects and infertility. For some participants, the loss of erection has resulted in a lack of opportunity to enjoy sexual intercourse. Some participants who achieved some amount of erection were not satisfied with their sex life because of their preoccupation with their sex life before the injury. More than half of the participants were preoccupied with the quality of the erections they achieved before the injury. A few participants who used erectogenic drugs were concerned about drug dependence, side effects, duration and the quality of erections.

For Prem, erection was the most important early concern after the ability to stand and walk:

> I am having a concern that whether my penis can have erection or not?...*I want to be able to stand on my feet in about one month time and walk, and get the erection as well. (Prem)*

Another participant, Bharat described being concerned about regaining his ability to achieve an erection from the very early days and he recalled checking his ability to achieve an erection as soon as his catheter was removed:

> *When catheter was removed I had a curiosity: whether I will be able to obtain erection or not; whether I will be able to have sex or not. During the time when catheter was removed I tried to touch and move it but nothing happened. (Bharat)*

Dinesh expressed his concern and dissatisfaction about the loss of spontaneity of erection as:

> *There is no instant erection... Prior to the injury penis used to become erect even when you touch her while sleeping together... In my case, I feel that lack of erection is the main issue... Erection occurs occasionally when there is spasticity and when there is little bit of feeling about it. (Dinesh)*

Gaya also expressed his frustration and humiliation with the lack of spontaneity of an erection and dissatisfaction with his sex life due to difficulty in achieving a reflexogenic erection as:

> *Now I have to stimulate manually for 5, 10, and 15 to 20 minutes to make it hard and do it. That is also an issue of humiliation now. Earlier, when I touch penis with the hand, it used to become erect and do that immediately. Then both of us used to get satisfaction from it. (Gaya)*

Young and unmarried MWSCI are concerned about the impact of erectile dysfunction on their marriage prospects. For example, in this description Bibek highlights his anxiety due to his lack of psychogenic erections as:

> *Erection is achieved only after stimulating manually for some time. Before the injury, there was spontaneous erection on seeing someone attractive and imagining about it. Now it does not happen so anymore.... I used to have tension because of that: I was worried thinking that whether it will affect my married life in future; whether I will be able to overcome this issue and fulfil this need or not. I still have such concerns sometime that: whether my family relationship will be in risk because of me. (Bibek)*

Similarly, another unmarried participant Ashish described his dilemmas and anxiety due to erectile dysfunction regarding marriage, his sex life and his fathering ability:

> *It is said that erection and sex is not everything. You need it as well. Isn't it? .... If someone comes in my life then I may have sex... mainly in the absence of erection how am I going to face it? That concerns me... If I got married whether it is possible to have children in the absence of erection or not? (Ashish)*

Ashish further highlighted the erectile concerns of young unmarried men like him and the lack of access to information for improving erections. He described that he and his peers would benefit if there were strategies to improve erections:

> *There are friends like me who also do not able to obtain erection. I would like to know what kind of solution: technology; medicine are there? You may know them and when the findings from the research are available then other friends with SCI also would be able to know about it. (Ashish)*

Married MWSCI also expressed similar needs:

> *I do not know how to achieve erection in people like me. I have not received any advices. It would be better to have such information. (Nabin)*

4.3.1.4. Loss of ejaculation and sexual pleasure

From the earlier sections in this chapter it is clear that loss of sensation and lack of erection are limiting factors in fulfilling sexual desire, obtaining sexual pleasure and satisfaction after injury. Additionally, in spite of impaired sexual functions most MWSCI expect to achieve sexual pleasure and satisfaction through traditional penetrative sex similar to that of before the injury. Further analysis of data reveals that the ability to ejaculate and perceive the sensation of ejaculation is also important for obtaining sexual pleasure and fulfilling sexual desires. Binod described that in addition to an erection, the feeling of ejaculation (without ejaculate) provided him with the sense of having sex and supported him psychologically. He also highlighted that the sensation of ejaculation provides him sexual pleasure and satisfaction comparable to that of before the injury. He emphasized the importance of the sensation of ejaculation in this way:

> *Sometimes, when I used to have ejaculation sensation during the sex, the feelings from it was similar to that of prior to injury and I used to feel proud about it. I used to get satisfaction in that way… This feeling also gave me support... Obtaining the feeling of ejaculation is important… I only have the feeling of ejaculation without ejaculating... In my experience, erection also has its own place in obtaining pleasure. I am aware that erection may bring pleasure in the partner, but I am not able to obtain the same pleasure from erection without ejaculation….The feeling that I am able to obtain during ejaculation is that I am having sex…. in my mind is a kind of sensation which reminds me about the experiences similar to that of before SCI. (Pradeep)*

Saroj also described lack of sexual pleasure and dissatisfaction in his present sex life as:

> *Now, it is not like before. There is no sensation as before. There is no enjoyment in sex life as before. There is no feeling. (Saroj)*

Similarly, Sirish describes the importance of sensation of the penis as well as ejaculation for obtaining sexual satisfaction and fulfilling sexual desire as:

> *For achieving a sexual satisfaction that will fulfil all our desire, it is necessary to ejaculate semen and to retain the sensation of friction on the outer skin of linga (penis). (Sirish)*

Most unmarried MWSCI have also attempted masturbating after injury before finding a partner for sex however their descriptions show that they could not derive any pleasure from it due to a lack of ejaculation. For example, Saroj described it as:

> *I attempted masturbating however there was rarely an ejaculation. I was unable to get pleasurable feelings from it. (Saroj)*

Bibek also described the lack of pleasure from masturbation as absence of 'good feeling'. A lack of motivation for continuing masturbating is understandable. He described it as:

> *If we could obtain the good feeling then we would have given priority to it and occasionally we would do such activity. Since there is no good feeling, there is no interest… in masturbating. I do not masturbate. (Bibek)*

4.3.1.5 Fertility or ability to father a child

Fertility capacity or ability to father children is a serious concern for most MWSCI. For more than half of the participants, either lack of ejaculation or lack of ejaculate was their concern for fertility purposes and, or pleasure. However, for all unmarried participants and childless and married participants who wanted more children, fertility was a major concern. For example, Dinesh echoed that desire for children as the main reason for sexual intercourse for him and his wife. His frustration due to infertility and stress in the couple's sex life is understandable. He also highlighted that for him the ability to ejaculate was important for fertility purposes:

> *My wife is not that much interested in sex. She is not that type of women who has desire for frequent sexual intercourse... if we could have a baby then she would be happy even if we do not have sex… I can have sex. I wish for ejaculation of semen and then have a child. When, I am not able to ejaculate after the sex, then I woe to myself. I am expecting for at least one child and*

> *wishing for it… I persuade her and ask her for having sex by telling her that if we have sex, there is a possibility for ejaculation and pregnancy… We have sexual intercourse but there is no ejaculation so we cannot have children. (Dinesh)*

He further expressed his frustration and grief at his inability to father a child blaming his destiny and God as:

> *Despite so much effort we are not able to have a child; I feel frustrated all the time. What is it? Why is so? Some of them have succeeded but why not mine. Is it because, that day has not come yet. I feel why it did not happen; maybe it is because I do not have that destiny. I also feel that how much grief has he given us and we got so much pain. (Dinesh)*
>
> *Since I am like this, if there is a child then there would be support for the future. I feel that if something happens to me then, it would be solace for her…We are in an anxious state as everybody has got children already. However, we are not able to have any children despite longing for it. (Dinesh)*

Gaya also describes anejaculation as the cause of his infertility. His effort and worries about reproducing, and also for pleasing his wife and the feeling of humiliation because he is unable to reproduce, all signifies the importance of his ability to reproduce and for him to fulfil his manly role as a husband. He described it as:

> *We are trying so hard but we cannot have a child. I have worries like... If I could ejaculate then we could have a child and it would be good for my wife... I feel shy because of it. (Gaya)*

In this description, the psychological impact of an ejaculation and erectile dysfunction on the sexual esteem and self-confidence of an unmarried MWSCI are obvious. Also notice how the fear of infertility has threatened his sense of manhood: a man is suitable for marriage if he is capable of having sex and reproducing.

> *Whether to marry or not depends on if that gets erect and that thing [ejaculate] comes out or not... Yes. If ejaculate comes out then I will do it. If that does not come out then I am not of any use. (Anil)*

Other unmarried MWSCI described their concerns and anxiety about their fathering capacity as:

> *Well. This heartache was like... either I will be able to have children in future or not. (Saroj)*
>
> *Other curiosities are whether I am capable of having children or not? If I got married whether it is possible to have children in the absence of erection? (Ashish)*
>
> *Sometimes, I think that if there is a need for children in the future how could that be possible? (Bibek)*

Most of the participants including unmarried men had heard about artificial fertilization, particularly 'test-tube-babies' and they were anxious to know whether they will be able to reproduce by using it. For example, Ashish echoed most participants' views as:

> *Now test-tube-baby technology is here in Nepal. Whether I am capable of reproducing using this technology or not? (Ashish)*

4.3.2 Loss of manhood

Data from this study suggests that the perception of a loss of manhood appears to be exaggerated when MWSCI continue to adhere to traditional sexual relations (penetrative sex) and sexual prowess for their masculine identity. After SCI, men's ability to adjust to altered sexual functioning is limited if they continue to adhere to masculine norms focusing on sexual prowess (Burns et al., 2009). Most MWSCI in this study also find it difficult to accept the decrease or loss of sexual capacity and sexual performance. In addition, a decrease in their physical strength and inability to fulfil manly roles such as being the family provider also appear to threaten or add to the feeling of a loss of manhood. Further, MWSCI described experiencing various challenges or threats to their manhood due to the attitudes of members of the family and society towards MWSCI in addition to their own personal feelings of their loss of manhood. Furthermore, when MWSCI endorse the views of members of the family and society, the threat or loss of manhood is heightened. This section analyses and discusses the second major theme - challenges to or loss of manhood experienced by MWSCI under three subthemes. They are: loss of manhood due to erectile dysfunction and adherence to sexual prowess; and loss of manhood due to societal attitude and loss of manhood due to the inability to fulfil the traditional manly role of providing for the family.

4.3.2.1 Loss of manhood due to erectile dysfunction and adherence to sexual prowess

Major sexuality issues which have threatened or increased the feeling of loss of manhood among MWSCI are erectile dysfunction and sexual prowess. Descriptions of MWSCI revealing their difficulty in accepting erectile dysfunction, decreases in penetrative sexual performance and grief over loss of sexual pleasure from penetrative sex evidences both the importance of erections for MWSCI and their adherence to sexual prowess.

4.3.2.1.1 Erectile dysfunction

Desire for the intactness of the penis, particularly erectile function appears to be important for most MWSCI in ensuring their sense of manhood. The most common issues challenging or triggering the loss of manly feelings appear to be the association of manhood with the presence or absence of an erection and an adherence to a masculine script of manliness stressing sexual prowess. Other situations where an erection similar to that of before the injury is desired include obtaining sexual pleasure and sexually satisfying their partner from penetrative sex in order to strengthen their relationship or to prevent the partner from eloping. The nuances and subtleties in the following descriptions delineate the threat to or loss of manhood experienced by MWSCI.

The Nepali word “namard” means “neuter” or “unmanly” or a gender other than masculine and feminine or common. In this description, to what extent a lack of erection can threaten the sense of manhood can be observed. Arjun described the importance of an erection for his manhood as:

> *If there would have been a lack of erection, then I may have felt like that. I do not perceive myself as namarda (less than a real man) since I can get the erection. If there would have been no erection, then I would felt like being namarda… - however, I do not feel like that now. (Arjun)*

Bharat described how sexual dysfunction mainly the lack of an erection and penetrative sex following the injury affects the feeling of manhood among MWSCI. Notice his peers' humiliating shame (Schuetz-Mueller et al. 1995), fear of being labelled as a man "equivalent to having no penis" and "lacking that function", and the strategy used by his peers for demonstrating themselves as a real man. Conversely, Bharat also appears to be preoccupied by the idea that his peers are unable to obtain an erection and have sex reflecting the general attitude of people towards sexual abilities of MWSCI. He described them as:

> *Most of the peers feel shy. Even though they do not do that (have sex), and there is a lack of erection, they lie to others and say, 'I can have an erection whether you have it or not? ... They lie to fake their peers and make them feel that: 'they are complete; they are healthy, and they are normal persons', and they fear that their peers will tell them, they are equivalent to having no penis, they are in a category of lacking that function. I have noticed many friends telling me they can have sexual intercourse although they cannot do it and they ask me what about you. (Bharat)*

Additionally, Anil another participant refers to his penis in the absence of erection as "a dead thing". In this description, he portrays himself as less than an adult male because of his perception that it is not feasible to form a meaningful relationship with a person of an opposite gender in the absence of an erection. A decrease in his self-esteem (Cappelleri et al. 2005) and sexual esteem as a result of his erectile dysfunction is noticeable. It also shows his adherence to masculine norms based on sexual prowess. He described it as:

> *I also think that how the penis will be: whether there will be any erection or not? If it can become erect then a girl is needed again... Even if I get a girl*

> *what is the use? These days, penis is like a dead thing. I do not feel. How do I know? It never gets an erection. (Anil)*

4.3.2.1.2 Sexual prowess

In this description Bharat's adherence to sexual prowess for masculine identity before the injury and the feeling of being less than a "normal person" or subnormal after the injury are understandable. He describes his sexual functioning: sexual desire, erection and sexual performance particularly penetrative sex after the injury as less than that of a "normal person".

> *I had desire like a normal person: sometimes I had sex 4-5 times in a day at a gap of 1 or 2 days, sometimes 5-6 times including day and night… I did not have any problem and I had sexual intercourse like a normal person… After the SCI it is not like before. It is somewhat less. It becomes erect but becomes loose quickly. (Bharat)*

In the next description, Bharat's ongoing grief on the loss of his erection and stress on penetrative sex demonstrates his adherence to sexual prowess even after the injury. Also notice his priority for regaining an erection and resuming his sex life over his ability to walk.

> *I felt unhappy because of the thinking that my linga (penis) does not get erect. Such thoughts keep coming again and again. I wish I have a good one: even though I am not able to walk; I wished for my penis to work well so that I could have sex. (Bharat)*

Furthermore, the desire for obtaining a long lasting and strong erection also shows the adherence to sexual prowess. For example, Nabin described this feeling like many other participants as:

> *These issues continued to exist and I wish for effective solution of those issues …. If there would be some kind of medicine that would help to obtain strong erection for about half an hour without having any side effects. (Nabin)*

In this description, Bharat's grief and frustration at his inability to resume his sex life as before while continuing to have sexual desires similar to that of before the injury are apparent. His adherence to sexual prowess and his difficulty in adjusting to a sex life in the absence of an erection is described:

> *Now, it is not possible to have similar sex life as before. I feel a big difference because I am not able to have sexual intercourse. I continue to have sexual desire and thoughts as before and I want to have sex as many times as before. However, when there is no erection - how to do sexual intercourse? It is not possible… I feel sad. Thoughts keep coming daily. That does not stop… I had to suppress my wants. (Bharat)*

In this description below, Arjun reflects on his sexual capacity and performance before and after the injury and then dwells on his loss of pleasure, autonomy, virility and flexibility in his sex life. Yet, his adherence to phallo-centric sex is very clear:

> *Definitely there are differences. Before the injury, the body had sensation; the feeling of pleasure at that time was different... Earlier I was able to do it whenever I had the interest (man lageko belama). Now I have to depend on penis. I have to massage the body and do it with support. I cannot do it when I want to.] (Arjun)*

In this description Binod's sexual guilt and dilemma because of his increased sexual desire and adherence to sexual prowess are apparent. He described it in this way:

> *Before the injury, I use to have sex 2-3 times in a day ... now I am having sex only once. I feel ashamed… why it is like this now. Now too I look for it and imagine… Sometimes I ask myself, why am I thinking of doing it even in this injured state? However, I keep on getting the desire for it, and I invite her and do it (Binod)*

The descriptions of men with erectile dysfunction and strong adherence to sexual prowess show their susceptibility to a decrease in sexual confidence, and sexual esteem when they are unable to meet their original expectations in their marital relationships. Some of these men appear to feel insecure about their relationship and develop sexual jealousy and often blame their wives for being promiscuous.

Gaya describes his doubts and fears that his wife may have a sexual relationship with another man or elope in order to fulfil her sexual desire. He also highlights how lack of prolonged erection, and fear of not being able to sexually satisfy his wife has contributed to his sexual jealousy and self-humiliation. The resultant threat to his manhood is clear.

> *I feel that (less than a man) and humiliated because my situation is like this. I am worried that: I am like this; my linga (penis) does not get erect for a long time so she may have a love affair with other man and do wrong things. I am worried she may leave me and elope with another man. If my linga (penis) becomes erect and I can do that (sex) then she would not go. If I could satisfy her then why would she go? Her need will be fulfilled at home so she will not go to another place. (Gaya)*

Similarly for Arjun, like other married MWSCI has doubts and fears about the possible extramarital affair and elopement of his wife appears to be amplified by the rumours and incidences of promiscuity in society. His insecurity following SCI is palpable. He described it as:

> *Some women go out with another man when their husband in this situation. Women also do like that usually when their husband travel to other countries as a migrant worker. For example, some women… go out with their friends when there are functions in the village... Most of us have tension about our wives that: maybe the wife is having a relationship with another man... Those sorts of things come to the mind. (Arjun)*

Further, a peer supporter also highlighted that recently married and young MWSCI have similar issues. Pradeep described their concern and fear as:

> *Those who are young and recently married have concerns such as how they are going to satisfy their partner, and they feared that their partner may leave them because of it. There are such incidents (eloping) in the society as well. (Pradeep)*

Data from this study suggests that sex plays an important role in building trust, strengthening relationships, and the medium for expressing the feeling of love and affection particularly for men in arranged married relationships. However, the nuances and subtleties in the following few descriptions delineate the adherence of MWSCI to masculine norms stressing penetrative sex to claim their masculine identity or manhood. For example in this description Arjun highlights his adherence to sexual prowess by stating that sex is transient fun and a basic need which needs to be fulfilled again and again. Despite his diminished sexual performance his lack of appreciation for other aspects of the relationship is palpable. He described it as:

> *Sex is fun for a brief period while doing it; it does not last forever… For example, we need to keep eating; we eat when hungry. Similarly, having sex just once is not sufficient; we need to do it again and again… after having sex it does not fulfil your desire for another 5-7 days… it is not the thing that you would say I have enough of it. You have the desire to do it all the time. (Arjun)*

In Pradeep's view sex is an essential part of love and absence of sexual pleasure weakens the strength of a relationship. He described it in this way:

> *If there is no sexual satisfaction or you cannot obtain the pleasure and joy, then it will result in doubts and suspicions. That love that we express by saying "I love you" is also linked with that part (sex). (Pradeep)*

Similarly, Som also highlighted the importance of penetrative sex as:

> *There is love following sexual intercourse. Otherwise, there won't be love only through verbal talk. For having intense love in people, sex is also a medium. (Som)*

Another participant reflected on his sex life during the period between his marriage and injury and echoed that the lack of sexual intimacy with his wife added to his marriage failure. Relationship challenges and anxieties in a newly married couple in an arranged marriage (where the couples are usually strangers before marriage) is palpable. He described it as:

> *I had not had a sex after our marriage which also attracts each other and enhances your intimacy or love... We were newly married and we did not have opportunity for such activities. This lack also fueled our break up. We did not have feelings or love for each other in that short span of time. (Ram)*

4.3.2.1.3 Performance pressure

Experiences of most MWSCI who relied on penetrative sex to satisfy their partners show that they are pressured to perform well sexually. The most common reason underlying performance pressure or seeking sexual pleasure similar to that of before the injury is the concern for their partner's sexual satisfaction. Strengthening relationship; keeping a partner; fear that their partner may elope or look for other men to fulfil their sexual desires are the major motives of MWSCI underlying concern for their partner's sexual satisfaction. Similarly, both the overt and covert attitude of the partner and society at large also appear to contribute to sexual performance pressure among MWSCI. These men's adherence to masculine norms focusing on sexual prowess is understandable from the stress they put on sexual prowess to satisfy their partners and resulting sexual performance pressure.

For example, Pradeep stressed that for him his wife's sexual satisfaction was the priority irrespective of his sexual interest. He also highlighted that it was important to sexually satisfy his wife to strengthen their relationship. Pradeep described his sexual performance pressure and the need for satisfying his wife's covert sexual desire:

> *How I am going to give pleasure?... Sometimes, I used to participate in sexual activities in her favour after recognizing her sexual desire, even when I did not have such desire... I used to do so because I wanted to make her happier than me. I had to understand her feeling and interest. Isn't it?... I used to recognize her desire then I used to participate. I used to disguise in front of her as if I was also interested in it... since my interest is not only a big concern. It is important to understand and give a priority to her feeling to make the relationship strong. Isn't it? That's why for these reasons, I used to*

> *participate against my own interest but disguise as if I am interested in it without feeling tired of it. (Pradeep)*

Gaya also described that conflict in the relationship with his wife is mainly due to his inability to sexually satisfy her. The sexual performance pressure due to the fear of his wife leaving him and losing the only carer he has is palpable. He described it as:

> *I am doing it for satisfying my wife's desire. Injury has occurred in this young age. I have been in this condition, if she leaves me who will take care of me. That is why I am doing it… I feel that it would have been better if there would be erection as before. I could have done more and my wife would have been satisfied as before. Now, my wife is not happy (satisfied) as before. It has become loose so she hates me. She is angry. She gets annoyed. (Gaya)*

For Binod, rumours of wives cheating their husbands, and deterioration in his sexual performance after SCI made him think that his wife also may have a relationship with another man or elope. He further highlighted that these fears motivated or forced him to engage in sexual activity with his wife. He described it as:

> *I have heard rumours and seen relationship issues of other men's wives. When there are issues like that I used to have thoughts such as my wife also may engage in such immoral activities; go with other man and elope. Also, I cannot perform well, I was good at it (sex) before and I won't be that good now. I had thoughts like she could elope or she may have sexual relation with others came to me. That's why also I am compelled to take part in it (sex). (Binod)*

He further described t the fear of his wife cheating on him or eloping with another man and performance pressure as a result of it in this way:

> *Now, I feel that she is the only option, and I will not find anyone else, so I love her even more… I believe that she won't go out for it (sex). I feel that she may leave if I do not do like this and love her so I am going to provide more love from it. (Binod)*

In this description below, Gaya's psychological stress resulting from his diminished sexual performance and reliance on penetrative sex for maintaining a husband and wife relationship is clear. It shows the vulnerability of a relationship in such couples when they continue to focus on sexual prowess and virility. Gaya described his fear of his wife leaving him because of his erectile dysfunction:

> *I feel shy. If it does not become hard then I feel humiliation, thinking that how it was before and how is it now...I thought that there is a relation between man and women mainly because of from genitals; if it is not there then my wife will leave me and go away. I am doing it gradually from my side; I am not sure how it is in her opinion. I am trying very hard after the injury. It would be good if it could be like before. (Gaya)*

Gaya further continued and described his reliance on penetrative sex to fulfil his wife's desire as:

> *I am working with it and managing with that. When I am on top of her I do it 3-4 times. It is true that I can do as long as my wife wants it. I have that daring. That is the self-confidence however; I cannot do it in sitting posture. I do it by laying her down, I come on top bearing weight on my hands then my family holds and puts it inside and I do that. (Gaya)*

He continued and recalled his performance before the injury to show his sexual prowess as:

> *I have done 18 times without taking any medicine. I was fine before. I have done 18 times in a night. I had checked to see my capacity. If I would have sensation in my penis, then I think I would have done sex daily as before. (Gaya)*

Whereas, another participant Saroj described his need to use the medicine for improving his sexual performance to satisfy his partner as:

> *While having sex I am worried about things like if I do not use the medicine partner may not be satisfied because of not having erection for long time. If this happens then sex life will be very bad. Because of lack of long time erection I felt a bit awkward and difficult. (Saroj)*

He further highlighted his satisfaction with his performance to demonstrate his sexual prowess as:

> *I feel good. I feel okay because she does not know that I am using medicine for having sex with her. I have not told her because I have not had sex frequently with her. I have not disclosed it now. Although she knows my real life, she does not know that I am using medicine to become active in sex. (Saroj)*

Furthermore, MWSCI relying on the traditional masculine script stressing sexual prowess appear to experience performance pressure because of their partner's passive participation and hesitation to talk about sex openly when they also have a physical limitation. For example Saroj described it as:

> *Regarding that, she does not like to talk about that topic. ...You get the feeling that she may not be satisfied when she does not articulate her feeling openly, and because of my limitation, I am worried about urine leakage when I'm on top of her for a long time. (Saroj)*

In the next description, Saroj further described his analysis of the relationship with his partner and highlighted the need for more communication, his partner's active participation in sexual activities and appreciation of his physical need to overcome his physical limitations. He described it as:

> *First of all, Nepalese women are not open during the sex. That is a weakest point. It could be because I am not married... That means my sex partner could have considered my physical weakness and if she would take part in sex actively with me then I could have maintain the erection well. It is easy and convenient as well however, if I do it then although there is an erection; there is a problem of urine leakage when attention to water intake is not given (Saroj)*

4.3.2.2 Challenges or loss of manhood due to societal attitudes

Nepal is predominantly a patrilineal society, which places a high value on maintaining family lineage, and inheritance of property (Bennett, 1983; Brunson, 2010; Stone, 1978). Marriages are patrilocal as a result of which man enacts his son, husband and father role in the same family and an ideal of Nepalese society are focused around agnatically (Bennett, 1983). According to Cameron (1998,) Nepalese people also place high value on their “ijat” (honour, prestige, social worth) and issues of kinship, sexuality, labour, commensality, and birth in maintaining their patrilineal honour.

Bennett (1983, pp. 176-177) contended that to protect the agnatic solidarity of the joint family and patrilineal ideals, the young man’s family use public restraints on the husband/wife relationship as the man’s loyalty to his wife is perceived as a betrayal to the family hence he has to show his romantic affection and sexuality covertly whilst women use sex for having children and as an effective approach for obtaining the husband’s favour in the bedroom. Thus, together with the higher position of men there is a family and social pressure to maintain that manly status through fulfilment of those socially prescribed manly roles in traditional Nepalese society.

Evidence from this study also suggests that the occurrence of a sudden life-altering event of SCI along with impairment of sexual functions appears to aggravate the challenges in fulfilling socially prescribed manly roles and maintaining the achieved manly status. In addition to difficulty in the personal acceptance of altered sexual functions, capacity and performance, most MWSCI also had to overcome the challenges of acceptance from members of family and society. The challenges from the members of family and society include viewing a MWSCI as an asexual (unable to have sex and reproduce) and unproductive being.

The most common reasons for labelling MWSCI as asexual included that MWSCI are not able to have sex, fulfil the sexual needs of their partner and they are unable to father children. In some cases, the societal view of seeing MWSCI as asexual and unable to father children had resulted in divorce, or a decrease in the opportunity of partnering and marriage. Understandably for those MWSCI such a perception is a serious threat to their manhood.

4.3.2.3 Loss of manhood due to societal attitudes towards intimacy, partnering, fertility and marriage of MWSCI

There is a strong sense of dissatisfaction among MWSCI at the response of society towards their sexuality (intimacy, partnering, fertility capacity and marriage) needs. Through various nuances and subtleties, MWSCI are continuously reminded of the socially perceived inadequacies such as MWSCI not having sexual desires, and that they are unable to have sex and fulfil the sexual needs of their partners, and so marriage is not possible. In some men with diminished sexual functioning and the perceived inability to satisfy their wives their doubt and fear about the possibility of extramarital relationships and eloping of partners appear to be heightened because of both the negative societal attitude and rumours or incidences of women cheating on their husbands in the community in general. These societal views clearly undermine the intimacy; partnering and marriage needs of MWSCIs and abolish any hope for the satisfaction of their manly needs.

There are numerous situations where the manhood of MWSCI has been doubted and challenged by society as a result of which, in some cases, the marriage relationship has ended (wives of MWSCI have divorced or eloped), while some were not able to form a new relationship following SCI. For example Ram described that social perceptions regarding his sexual inadequacies were the main cause of his marriage failure.

> *We break up due to problems related to sexuality. People opinion was that I will not be able to have sexual intercourse. It became the main reason for divorce. When I was not able to walk, rather than my own difficulties perception of other people become the main issue. (Ram)*

Similarly, Nabin also described that people from his community tried to encourage his wife to elope with another man by portraying him as a worthless and hopeless case after SCI. Dread of SCI in the community is also understandable. He described it as:

> *Few people in the village had told negative things about me to my wife that: why are you waiting for him; what are you waiting for; your husband is of no*

> *use now; and your life is shattered now. Then they had advice and encourage her to leave me and marry with other man. They also had told her that they will find a man for her. (Nabin)*

In addition, people in the community also doubt the loyalty of the spouse of a MWSCI with the notion that MWSCI are not able to fulfil the sexual desire of their partners. Nuances in this description reveal that such social labelling adds to the sexual insecurity in MWSCI. Pradeep described his experiences as:

> *My sex life before the injury was successful. That is why our marriage relationship was going smoothly. There were no obstacles… issues of fidelity and trust… doubting and suspecting each other even when we had to remain away from each other… Similarly, villagers also were not concerned about my sexual abilities and fidelity of my wife. (Pradeep)*

Further, a lack of sexual pleasure and the young age of spouses also appear to induce such feelings. For example, in this description Pradeep describes that lack of sexual satisfaction causes sexual insecurity.

> *If there is no satisfaction, you cannot obtain the pleasure and joy and it will result in doubts and suspicions. (Pradeep)*

Pradeep further described that for him in addition to his diminished sexual functioning, his and societal doubt about his ability to satisfy his wife, and his wife's young age added to his stress.

> *At that period, I used to feel a little tense because the injury has hampered my sexuality and my wife was very young in her age. It added stresses. What will happen if I could not give pleasure? Relatives raised similar questions in the society. (Pradeep)*

Sirish also described that young women have more sexual desire, and they can achieve more sexual pleasure; when their sexual needs are not met they are more likely to leave MWSCI.

> *If we have SCI when our wives are very young 17-18 to 30-35 years old the age at which they have more desire for sex and sexual satisfaction… if*

> *husband gets SCI when she is young and she has a small baby, then she may also change her mentality. She may get extreme negative feelings such as what is the benefit of staying with him at this young age; I have only one child, so I will leave him and go (Sirish)*

Additionally, Saroj echoed that conflicts and divorce among married couples with SCI are increasing. His fear and concern regarding the success of his married life as an unmarried man is palpable.

> *There are many cases of people with SCI who are on the verge of getting a divorce. There are some cases where the wife has left. We have seen this in Nepal. (Saroj)*

Attitudes of family members, particularly negative attitudes of parents and parents-in-law towards MWSCI appear to have a detrimental effect on the marriage relationship. For example, in this description, Sirish describes that his parents-in-law perceived him as a useless person after SCI and they actively encouraged his wife to elope with another man.

> *My wife's parents told her that there is no use in staying with a person like this. Suddenly she eloped with another man after taking the advice from her parents. (Sirish)*

In this description, Sirish described that attitudes of the community particularly that of his peers were also obstacles to finding a partner for marriage. Also notice how attitudinal barriers present in society forces MWSCIs to give up their desire for marriage. He described it as:

> *I saw 2-3 girls for my marriage after regaining my parents' approval, but my friends from the village manipulated those girls. I was unsuccessful with my proposal because the girls were told by their friends: "How can you get married to such a disabled person? What is the benefit of getting married to him? Didn't you find any other boys?" Since then, I never thought about marriage. (Sirish)*

In cultures where arranged marriages still predominate, marriage provides a social sanction for intimate relationships and procreation (Majupuria & Majupuria, 2009). Traditionally, in an arranged marriage, parental approval of the relationship is required. In such marriages, the head of the household, parents, relatives or third parties, mediate the arrangement, identify a suitable candidate, and secure the primary candidate's agreement or expression of interest (Majupuria & Majupuria, 2009). For Sirish approval of his parents was first the step in his marriage however they did not approve it doubting his sexual capacity. He also highlighted that the negative attitudes of his parents made him anxious and fearful, thinking how society would respond to his feelings and needs. His frustration due to lack of support and acknowledgement for his needs from the parents is understandable. He described his marriage needs and frustration over his parents' disapproval as:

> *After coming back from rehab I told my parents that now you are there to help me, but I will need someone to look after and support me when I get old so I also need a life partner. In response, they told me if someone marries me then I will ruin her life. They thought: "what can he do after SCI as his penis does not get an erection?" Then I stopped talking about it to my parents... When my parents challenged me by saying: Why do you need to get married? What do you have to offer?... I became extremely frustrated... I felt that if my parents say this, then what would other people from my village say? (Sirish)*

In Nepal, cultural practices such as this, as well as the wider Nepali social environment, have a considerable impact on the formation of relationships. Adding to the complexity of this social fabric - life-altering events such as a SCI and the negative attitudes of family and society towards SCI will most likely decrease the support for and chance of an arranged marriage. Additionally, social and cultural sanctions on premarital relationships would further limit the partnering and intimacy opportunities for now single and never married MWSCI. For example Ram described his adherence to social values imposed by his family as:

> *My family had taught me that sexual relationship before marriage is immoral and sexual relationship must be restricted within marriage relationship. I became aware that premarital relationship creates hatred in the society. They*

> *have warned that they do not want to hear the blame from others such as your son has harassed someone's daughter and misbehaved. I was taught not to misbehave like that and I stuck to those values. (Ram)*

Growing up with such sociocultural values and dealing with the psychological trauma of divorce from his wife at a young age after SCI, Ram's partnering and intimacy needs are understandable. In the next description, Ram described his frustration and anger towards his community for their lack of understanding and indifference towards his sexual capacity, intimacy, partnering, marriage and sexual needs as:

> *A person with a disability also has a heart. Although physically disabled, he will not be mentally handicapped. He is also capable of loving others; is attracted to opposite sex, has desire, dreams and wishes to have a suitable partner. However, society underestimates our abilities and there is lack of understanding and attitude that he also needs someone to share his feelings, and you can get love from him. After SCI, my wife left me and if someone says there is a possibility of getting married again then it becomes a matter of joke in the society: how can people like you get married! (Ram)*

Ram continued and expressed his frustrations and resentment towards people who did not see a MWSCI as an eligible partner for marriage. In this description, he equates his lack of acceptance and value as a marriage partner to being a less desirable prospect for women than working in a brothel.

> *I feel that only 1 percent of people in Nepal have an understanding towards their boy or girlfriend with a disability. There is a lack of acceptance of a local person with disability as their life partner. Rather, they would choose to live a dreadful life in the brothels of Bombay, committing suicide in a foreign land and carrying unwanted, illegitimate pregnancies. (Ram)*

He then quoted the title of a Nepali song to express his intimacy needs and highlight the importance of having a wife in the family as:

> *I always remember a song by Narayan Gopal: "Love from a person makes so much difference in life" ("Eutava yktiko mayale kati farak pardachha*

> *jindagima") in the context of living a life. Similarly, if I have a wife in my home then… she would be a daughter-in-law for my parents… I also would get so much support. (Ram)*

Anil also highlighted the importance of having a wife in this way:

> *If I were not injured, I would have married in November last year… After seeing other patients' wives as care-givers, I felt that it would have been good if I had been married. I think that if I would have a wife, she would have taken care of me, and my father and mother would not have to take the trouble. (*

Furthermore, in his next description, Ram echoed his perception of social undesirability for sex because of his dependency and physical disability. A decrease in sexual esteem and body esteem (perceived attractiveness to others) by physical disability (George and Marita, 2002, p. 173) is clear. He also highlighted the lack of a partner and opportunity for sexual exploration for him.

> *Firstly, I feel that people may not be interested on it (sex) if a person is paralysed and dependent on others. Secondly you cannot say it is possible because there is no option to share this is how this can be done when there is no partner. Thirdly, you cannot say which position works for you as it is like an imaginary thinking of yourself. There is nothing that can be imagined beyond it. (Ram)*

Similarly, in this description, Som describes how the lack of acknowledgement of his sexual needs from his wife has challenged his sexuality and manliness. He noticed the nuances of feeling of being less than a man, loss of dominance and physical strength as:

> *Before the injury when I had a desire and persuade her for that, then she would not refuse for it. She used to let me finish the job before the injury... What can I say now: even though I have the desire; what can be done when she does not have the desire; you cannot insist on having sex. There will be pressure, threat and verbal warning against you thinking that a person like me also has such desire. If I would have been normal (laughs) then only I could*

> *have possibly used force, create a threat. She would not be ready for it, and I should not use the force as well. When you lose your power, then you will be unable to do anything. (Som)*

Som further described how the occurrence of SCI has restricted him in fulfilling his sexual desire. The feelings of loss of male dominance due to physical weakness following SCI and undermining of his sexual desire by his wife are understandable.

> *She gets over it by laughing (tyo ta haserai tardichha). After that, she does not come saying let's go for it (laughs). She does not come to my lap thinking that my husband is having a desire and I cannot pull her physically (laughs). She gets over it laughingly (hasoihasoma taridinchha). That is it… What can be done when she is not happy to have sex (yaun santosi naliyediyepaxi k garne)? I cannot insist or force her. (Som)*

In the next description, Som's feeling of being sexually undesirable is further evinced. His intention of keeping an extramarital sexual relationship to fulfil his sexual desire is understandable.

> *Suppose, let's say I have like this (sexual) desire and situation ... girls will not be having a desire for it. When girls are not interested, how it is possible. (Som)*

Ashish also described the frustration felt by his peers with disabilities in regards to no girl being willing to marry them, while their able-bodied friends are already married and have children:

> *When I talk with an unmarried friend he thinks that he may not get married; his friends are married, and they already have 2-3 children; he also could have earned money, got married and have children, but he does not have any girlfriend yet; he may not get married. (Ashish)*

Ram echoed that loneliness due to the lack of a partner can be a source of depression and self-harming behaviour. The lack of a partner for intimacy for him is understandable.

> *There is desire in every individual. Many individuals [with disabilities] develop depression because they think they are unable to have female friends; older ones (wives) also ended their relationships. They feel that they are alone on the planet. I have heard that people have committed suicide because of loneliness. (Ram)*

The impact of the social views of MWSCI as asexual can be so strong that even partners of MWSCI appear to neglect the sexual cues of their husband, as a result of which sometimes MWSCI are not able to express their sexual desire effectively and make sexual advances even to their wife. For example, Som described his sexual conversation and response of his wife as:

> *Sometime I bring up the sexuality issue jokingly but she does not. She does not have desire. Jokingly (laughs), I talk about it with a curiosity what she would say and she would do. I keep doing that as a naughty man. She also laughs, that's it. However, I do not say you should come and do it. I cannot insist her when she does not want it. Isn't it? It has not happened also. I tease her verbally and we laugh about it sometime by reminding about our past activities (laughs). (Som)*

For example, Ram highlighted that his wife left him mainly due to the social belief that people with SCI are unable to father children and he is still struggling to marry because of a social sanction on the marriage of people with a disability:

> *There were drastic changes in my family life, and I began a new life again with many struggles. There has not been the change in the existing view of society and neighbors such as he cannot have children; he should not get married after being a disable like this. I have experienced it in my life as well; I got a divorce from my wife because of my disability. (Ram)*

According to Stone "people are culturally induced to fear and avoid" childlessness, although a son is preferred for various economic, social and religious reasons "it is far better to have daughters than no children at all" for proving reproductive capacities particularly in the Brahmin and Chhetri populations in Nepal (Stone, 1978). MWSCI (as a member of society) conforming or endorsing such ideology are most likely to become consciously aware of these social nuances when people in society further cast doubt on their reproductive ability assuming that they become impotent after SCI. In this description, social undermining of Pradeep's ability to impregnate a woman or father a child adds to his struggle:

> *For example, in the society, there is a concept that everything becomes inactive following SCI. On the other side, if you can impregnate woman that is a success. After SCI to become successful in making your wife pregnant is a great achievement, but the society obliterates the fact and presumes that her husband is not capable of making her pregnant so it can be from other men. This is becoming a barrier in enjoying sex life and continuing a harmonious life for us. (Pradeep)*

In his description, Bibek reflected his parents' desire to see him get married and have grandchildren. Family and social pressure to have children is obvious. He described it as:

> *Yes, there is a pressure. Every parent wants to see their children having children and grandchildren... It is there in all people... I also keep hearing that I need to get married... Parents would always like to see their children wellbeing and progress. (Bibek)*

MWSCI view that impotency has the potential to damage sexual prowess of MWSCI and the sex life of couples with SCI. Pradeep described how negative social attitudes towards the sexual capacity of MWSCI affects the sex life of SCI couples as:

> *He has a desire for having sex with his wife but in a case of pregnancy the society can say that he does not have that capacity, this (pregnancy) could have happened from someone else. (Pradeep)*

Similarly in this description, Bharat, a disability activist, illustrated an account of couples with SCI and highlighted the impact of the family's and society's assumption about the sexual capacity of MWSCI on a couple with SCI. He described that the couple had to terminate the pregnancy despite their willingness to have a child due to family and social pressure:

> *I had a friend with SCI... told me that 'despite having the desire to have a child they were compelled to terminate pregnancy because of the fear of blame from family and society. Both family and society believed that I am not able to have sex because of the SCI and they raised question like with who did she had a sexual relationship and became pregnant. They gossiped about it and told: certainly she was made pregnant by another man; she is not a good woman; it would be better if she elope with the person who made her pregnant. (Bharat)*

4.3.2.4 Loss of manhood due to inability to fulfil provider role

Data from this study also strongly suggests that the ability to earn and look after the family needs is also a socially prescribed manly role which appears to be equally important for MWSCI in retaining their sense of manhood. In addition to the social viewing of MWSCI as asexual, they are also labelled as a person needing lifelong care, a burden to the family, that they are unproductive and better off dying. For many individuals the incidence of SCI in their lives threatens their ability to return to previous jobs or find occupations to earn their living or support their family.

In this description like many participants Pradeep's manly qualities, manliness and sexual prowess are challenged repeatedly by the villagers. His narration of villagers' perceptions *"he cannot do anything, he is of no use now, and he does not have any value and importance"* projects him to nothingness and an inability to fulfil his manly roles and responsibilities. Additionally, his provider role as a husband is also dismissed by viewing him as a person who need lifelong care. Furthermore, villagers were provoking his wife to elope by emphasizing her young age and projecting him as unable to fulfil any of her wishes and desires that directly challenges his provider role and his sexual capacity:

> *After SCI, the words/statements such as "he cannot do anything, he is of no use now, and he does not have any value and importance", were repeatedly*

> *used by villagers. Also, even my wife was told that there is no need to stay with him, as you are very young, and all your wishes and desires may not get fulfilled. First of all, there is no certainty whether he will survive or not. Second, even if he survives, you have to provide lifelong care for him. Whether you will go to work for earning or you will take care of him? (Pradeep)*

For Som, the news of a wife of MWSCI eloping because of the loss of her husband's productivity and dependency made him think about whether his wife would also do the same. He described it as:

> *While staying at the hospital, I heard that wife had left the husband thinking that he is not manageable, and he is not of any use. I felt sad in hearing it. People are like that; it is due to the affection to the money and not to the person. Isn't it? At that time, I had thought that whether my wife also would do the same thing for me?... I also had that feeling! Alas people can be like that! I understood that such attitudes could also be there. (Som)*

It was obvious for some participants that income generation appeared one of the early concerns. In this description, uncertainties including the inability to earn following SCI were negative thoughts for Nabin. The realisation of inadequacies to fulfil his manly roles; the inability to earn and to take care of himself and be self-sufficient is palpable. He described them as:

> *In this state I will be unable to continue farming and earn money. In addition, I do not have skills and job at my hand and there is no possibility to find other employment. I also do not have financial resources to run a business... How will I live and survive rest of my life? How am I going to earn the living and overcome the economic constraints? I am already poor. Life is shattered... I used to worry about my future. There can be other difficulties in life that I could be sick at any time; ... what I will do in that situation… how I will manage, such kind of negative thoughts use to worry me. (Nabin)*

Binod another participant, described that he had concerns about his children and family's wellbeing due to his limitation in earning opportunities following injury.

> *Immediately after the injury, at first I thought about my children... I was also thinking that, I do not have any income, what I can do to raise them, how am I going to look after the family?... I felt that if I would not have broken my back I would have: earned money; given better life to my family; prevent them from being in troubles; travel abroad and earned money. (Binod)*

Nabin in this next description describes his grief from his perceived inability to earn a living, fulfil his role as a son, father and husband and the social expectation of an adult man as:

> *If I were single, then it would not have caused so much sorrow but when you have a family with small kids, father, mother and wife in a village setting it is different. Before the SCI: my parents may have hoped that son will earn money and take care of them and wife also has left her parents' home for the sake of husband. In the Nepalese context, there is a belief that husband should be the breadwinner. (Nabin)*

Gaya presented an example of how important it is for a man to fulfil his provider role in the family. In this description, he highlighted that he goes begging to provide for his family however he maintained his self-esteem by making a temporal comparison and describing himself as a very hard working man before the injury:

> *I used to work very hard for earning a living. Now I cannot... How to arrange the food and live a life; it has been difficult. I beg for living because of paraplegia and I have to rely on others. My future is ruined now... They will give you depending on their will... I go for begging to the neighbouring community using wheelchair then they give me a small amount of rice, lentils. I bring that home and eat with the family after cooking. (Gaya)*

Whereas for Anil, whether to marry or not is contingent upon his ability to regain an erection and reproduce, in addition to his ability to earn. The importance of the ability to earn and fulfil the provider role even for unmarried men is clear. He described the impact of SCI on his marriage plan as:

> *Now whether to marry or not depends on my ability to obtain an erection and ability to ejaculate. Also, I do not have any income, so how will I look after my*

> *family and myself? However, if I get a job, and that happens (erection/ejaculation) then I will do it (marry). (Anil)*

Saroj also suggested that financial independence took priority over his marriage, family and social life. He described it as:

> *But it was only when I started to work and I achieved financial independence, that I started to think that I need to get married, I need to have children, and I need to live a life in the society. (Saroj)*

Additionally, society places a high regard on some occupations and it becomes important for the member of that society to achieve those career goals. However, when there is an event like SCI in people's life, it often becomes impossible to meet those socially approved career expectations. In this description, Saroj highlighted that he ended up in his current profession which is different from a career which is highly valued by his society and himself. He described his sense of unhappiness from it as:

> *They (friends) were selected in the Army service (Lahure): some in Indian Army; some in British Army... I grew up in a community with a principle that I need to earn some money by travelling to other developed countries for work so I focused more in joining the army... At present I have a different job. I have never imagined about it. Because of time and situation I was compelled to choose this option because there were no other choices. (Saroj)*

Another participant Ram highlighted his awareness about his parents' expectation that he should be earning. Nuances in this description also shows the place of men in his community who are able to travel abroad to earn and his realisation of his limitation to work and earn as migrant worker.

> *When my friends and other villager's son return to their home with earnings from foreign countries then they must be thinking their son also would have done the same thing if not injured. It must be painful for them but they do not express that to me. (Ram)*

Connell and Messerschmidt suggest that there exists a combination of the plurality of masculinities and the hierarchy of masculinities where hegemonic masculinity may not be normative for boys and men (Connell and Messerschmidt, 2005). Som in this next description also suggested that there are hierarchies of masculinities in society and he sees himself at a lower level in this men's hierarchy by comparing his education level, a position he held and his income capacity. He described it as:

> *Yes, I am a man. Talking about the man; they are earning 2-3 hundred thousand rupees either in the foreign country or people who are in a big position here. I am a man for the namesake only: I did not have higher education and higher position. At least, I got a government job. If it would have been a project job without pension, then my life would have been worst. I did that job sincerely until I was eligible for the pension. Now I have become like this. With that pension, I am maintaining my basic expenses such as food, medicine. (Som)*

Som continued and made a downward comparison of economic status to show his better position than other less fortunate people:

> *If I keep thinking that: I am weak; I could not do anything. What to do with feeling like that: you cannot see people at a higher level than you only; there are people in a less fortunate situation who needs to beg for a living. You need to take satisfaction from that as well. For example, I can feed myself, and I am satisfied with it. (Som)*

4.3.3 Coping as a way of social reconstructing of manhood

The data has revealed that MWSCI adhere to traditional masculine scripts that stress sexual prowess based on penetrative sex and fathering capacity in addition to providing for the family. However, there is also a gradual shift towards the traits or qualities with flexible gender characteristics such as the provider role, and focussing on relationships based on mutual understanding rather than exerting male dominance. Burns and Mahalik (2007) suggest that men who are able to establish their identity beyond their sexual prowess and are able to adopt flexible gender identity 'schemas' may adjust to their altered sex life better. To analyse the social reconstruction of manhood, first the contrasting views of different participants are discussed to see how personal and social factors have shaped their manhood and then the nuances and subtleties delineating negotiation and adjustment that are taking place within an individual or in common in the process of redefining or reconstructing their manhood are discussed.

In the context of a patrilineal male dominant society, MWSCI could experience feeling less manly because of being unable to utilize their male dominance. For example in this description Ram emphasized that his wife's subtle domination has the potential to challenge his manliness. He described that MWSCI are perceived as cowards and unmanly when they cannot tolerate the verbal pressure from their wives. He described it as:

> *While it does not hurt them so much by the comments of their parents, however, they are not able to bear the comment from their wives. When a wife says something to them, then they regard themselves as the coward and unmanly (Namarda) causing a feeling of self-guilt. Then conflict begins. (Ram)*

In contrast, Gaya stressed the need to find a way of negotiating with his wife without resorting to violence indicating his flexibility in letting go of his male dominance. He described it as:

> *Well, the advantage of the opportunity (situation) is that: I have broken spine; if she accepts it, then her life would be simple. I have to make her accept it. Gradually, I need to do it. She will not comply with scolding, arguing, and verbal abuse. That is what my issue is. What else should I say (smiles)? (Gaya)*

Manhood is sometimes associated with an ability to have multiple partners. However, in this description, Binod highlighted his increased loyalty and commitment to his wife following SCI:

> *I think that, if I had been all right I would have tried to have relations with other women. I used to get the thoughts like how would this or that woman is. She is mine, and now I think that I need to be good with her (wife). (Binod)*

There is also an association of the altered body image and a feeling of being less than a real man. In this description Dinesh acknowledged feeling less than a real man as a result of changes in his body image. His adherence to the masculine script that a man should be able to hide his emotions is clearly visible. He described it as:

> *I feel like my body has been reduced to a half. Everybody has their feeling. No matter whatever the amount of pain is there I take it to myself; I do not share. Sharing makes it even worse. I feel like I wish I would have been well and normal. (Dinesh)*

However, another participant tends to move away from such a traditional masculine script of manliness through the acceptance of his disability and resulting physical limitations. Saroj described that he has accepted his weakness resulting from SCI:

> *I do not feel less than a real man because my case is like that. I have already accepted that I am physically weaker than able bodied person so it is common to become slightly weak. I do not feel anything like that. (Saroj)*

In addition, some participants appeared to use a coping strategy such as acceptance of their disability particularly the limitations in their sex life as their destiny. For example, in this description Kumar accepts his loss as his destiny in this way:

> *In the beginning, I used to feel a little bit sad and unpleasant when I was not able to do that [have sex]. I do not feel anything like that now. I am able to accept my condition thinking that it is the nature of this injury that has made the situation like this and it was not in my destiny to take part in sexual activities... I do not take it seriously now. (Kumar)*

Nabin also blames his destiny as a way of coping with his grief. He described it as:

> *On being not able to fulfil her wants and desires, I feel heartache. She may also have her wants and sexual desires, but she is not able to express them. I do ask her, but what can be done, my destiny made me like this. (Nabin)*

He also highlighted the importance of accepting the loss for preventing negative thoughts. He described it as:

> *Sexual intercourse is not possible now because of my situation. I won't think about impossible things. I will not let myself develop negative thoughts for the things that are not feasible. (Nabin)*

In this description Ram described that he avoided dwelling on his marriage failure to reduce his grief and then he stopped eating nutritious foods which he perceived were increasing his sexual desire to suppress his sexual thoughts and desire.

> *If I think that my wife left me then it becomes more painful. However, those thoughts and feelings become less if I do not imagine about it at all. If I am able to marry again then it is also fine but it is not possible. I think that everyone has a desire for it... I have felt that there is more erection when you eat fish, meat, egg and milk products. I control my diet to overcome this problem. (Ram)*

Bibek becomes philosophical as a way of coping, and described life as a struggle that needs to be explored. He also emphasised that sex is a medium for temporary enjoyment and not essential to living a life:

> *Life is a struggle. Life is an experience. Sex is for occasional enjoyment… or, in my opinion, it is a medium used for self-satisfaction. There may be a difference of opinion, but for me, sexual relationship is not a big issue. It is not essential to have sexual relations to live a life. You need to struggle in life. Without struggle, life is incomplete. That's it. (Bibek)*

Participants have not only identified and explored the importance of the effective use of communication in helping their spouse to understand the sexual limitations of SCI but also in improving their sex lives. In this next description, Kumar described that he and his wife accepted the alteration in their sex life as their destiny. The importance of discussing sexuality issues between SCI couples and the role of communication is understandable:

> *What can be done: when it is not in your destiny, we have to accept it. We have to accept on this matter, we should not be concerned about it: neither you nor me. This issue depends on our mentality. We talked about it and agreed that both of us should not think anything about it. That is how both of us have solaced our mind. (Kumar)*

Arjun also becomes philosophical as a way of coping and highlights that human beings are capable of suppressing their desires and he advises married MWSCI to support their wives in building self-confidence to control their desires. He describes it as:

> *We need to give them (women) self-confidence. Wants and desires are there, but we need to be able to tolerate hunger, sleep deprivation and sexual desire in human life. It is not always the same in human life; we do not get what we want; we have to tolerate our thirst. (Arjun)*

Additionally, Binod described the use of verbal teasing and more open communication about sex by both of them can be observed. The increased intimacy from the wife's active participation and communication about sex is understandable. Binod described it in this way:

> *Sometimes she caresses me, and I ask her why you love me today. Then she tells me you are not coming today? Then I tell her my back is sore and then she turns away from me. Then, when I start fondling her, she returns to me (giggles). Then we start for a while (giggles). She then goes how much is your desire? You do not leave me even when you have a sore back (giggles). I pampered her by saying what to do darling; life is like this... I tell her that you women need like this. Then she says that of course we need it. Then, I tell her to find a man if you need everything. (Binod)*

On the other hand, some couples were able to continue their loving relationship they had prior to the injury despite the lack of sexual activity in their life after the injury. For example, Som highlighted that it is the love that has kept him and his wife sticking together despite the lack of sex in their life after the injury.

> *After the accident, the sexual relation was over... There has not been any change regarding love for each other since the beginning. Both of us continue to love each other… In fact, only sex is not there between us. Love is still the same. If we would not have the love same as before we would not be together until now. (Som)*

Nabin presented an example to demonstrate the strength of the relationship built on love and affection over the relationship stressing only sexual prowess:

> *Even sex requires love and affection. Some men become very close and love intensely during the sex and rest of the time after they physically abuse their wives. It is because of lack of love and affection for each other. Rather than that it is better to have love and affection to each other even if there is no sex. This will strengthen the relationship between the couples to make life easier and live a life. (Nabin)*

Nabin further illustrated the meaning of love and affection in his married life as providing her physical, emotional and financial support and gratifying her sexual needs. Furthermore, he also stressed interdependence, improving communication and understanding. He described it as:

> *For an example if my wife is doing a hard task then helping her to do that job… Buying special food for her; giving money in need; going for a movie; and fulfilling her sexual desire. Then inquiring about her problems and worries, showing concern and resolving them... You can make your relationship better by speaking in a proper manner and teaching her good things. (Nabin)*

He then offered an approach of enduring love and care for strengthening his relationship and highlighted the importance of exploring other pleasurable activities rather than focusing on short lived sexual pleasure. He described it as:

> *If there is intense love and affection, we can obtain pleasure from other activities... We can learn to obtain pleasure from many other activities… Sexual desire of people like us is of just 10-15 minutes so we should… be able to take satisfaction from other activities and make ourselves happy by sharing*

> *our joys and sorrows with each other and participating in various activities. That is love and affection. It is the greatest thing in our life so we should not limit our love only at the time of sex and it should be there in other times as well. (Nabin)*

Bharat described feeling frustrated due to the discrepancy between his sex life before and after the injury mainly about penetrative sex. His frustration from ongoing sexual desire, adherence to sexual prowess and the lack of an erection is understandable. In addition, notice how he uses the notion of being normal in terms of his preserved sexual desire and away from normal in terms of his decreased sexual performance.

> *It is not possible to have that sex life now. I was normal before. When it is not feasible, it is obvious to feel frustration. Isn't it? Now also thoughts and wants in my mind are same as before when I was normal. I want to have sex as many times as before. However, when there is no penile erection and no excitement how to do sexual intercourse. (Bharat)*

Bharat also highlighted that he had a feeling of being castrated when he realised that he had erectile dysfunction and he did not see any value in his life in the early days after the injury:

> *I had extremely bad and discouraging thoughts such as it is the end of my life. Thoughts and curiosities such as: I will not be able to have sex for rest of my life; what is the use of having this penis since it does not work anymore?... How am I going to fulfill my sexual desire?... I should say I became very discouraged. (Bharat)*

However, Bharat described that his bonding with his wife became even stronger after the injury as they both started sharing every aspect of their lives:

> *We had a good relation before the accident. After the injury, we became even closer as we started to share and discuss about our situation, family matters such as well-being of the family, schooling of children, handling social issues and plan things together that we were not able to do before... It was also due to love from the past. (Bharat)*

Similarly for most men who are single now and men who were never married penetrative sex is not a priority for varied reasons. They identified emotional intimacy focussing on qualitative aspects of sexuality such as loving and caring for each other and relationships built on mutual understanding and transparency over the traditional relationships focused on sexual prowess. Sirish describes that now he is able to derive sexual satisfaction from the companionship of his female friends although he relied on penetrative sex while he was young:

> *I had sex only once after the injury… Now my age for it is also gone… Now I have a best friend… She helps me a lot... Sometime she says "lets us sit together". When I talk with her and hold her hand I feel sexually satisfied. Of all the things in life… sexual feeling is the unique thing that we find in our one time life...I also have 1-2 friends who love me better than a wife and I do not talk about sex with them but… my inner sexual desires are fulfilled completely if we sit together. (Sirish)*

Ashish who has never been in a relationship echoed that sex is not everything in life, and mutual understanding, love and affection are important:

> *I feel like sex is not everything because, for example, if I have a girlfriend then she needs to be supportive of my weaknesses. Both sides need to sit together and make a decision beforehand. Isn't it? ...sex is not the only thing; love and affection give you encouragement. (Ashish)*

Bibek another unmarried participant also described that for him physical sexual relationship is not the priority as he is not able to derive any pleasure from it. He stresses that there are many aspects of life other than sex and he expresses optimism for fulfilling his sexual needs differently:

> *Sexual relationship is not every aspect of life. Although there is a sexual need, it is not everything... the need can be fulfilled by having sexual intercourse differently or from all other things. Sometime, I do have anxiety in my mind that it may create a problem. (Bibek)*

He continued and offered an approach of mutual understanding and transparency in the relationship to resolve the problems as:

> *If we can share well with our life partner, then it is not a big problem. If we can explain everything, such as our shortcomings and difficulties, then we can understand each other, and it is that is not a big issue... then it could be easier to engage in a physical relationship. (Bibek)*

Although Bibek considered the role of family in his marriage he appeared to move away from traditional arranged marriage practices stressing that marriage is a personal choice. He described his view on the marriage as:

> *There is a saying: "Adhuro Jeevan jiuneki madhuro Jeevan jiune", which means "married life is sweet and life without marriage is incomplete." However, it is your decision whether you want to live a sweet married life or remain single. It depends on how you perceive it: it does not mean you must get married. If you have a relationship with someone or have a girl or boyfriend, if the family is fine with it, then you can get married because you will have trust in the relationship as everything, including sexual issues, has been discussed beforehand. (Bibek)*

Participants' descriptions show that except two, all married men are continuing sexual activities. Some men are combining both penetrative and non-penetrative strategies to satisfy their partner. Many of these men experienced grief on not being able to enjoy penetrative sex as before because of their adherence to sexual prowess. On the other hand, many men who are unable to engage in sexual intercourse are also utilising non-penetrative sexual activities as a way of expressing their love, improving trust and an effort to fulfil their own and their partner's sexual needs irrespective of their adherence to sexual prowess for masculine identity. For example, Arjun highlighted that hugging and talking with his wife not only reduces his physical pain but also provides sexual pleasure for him despite diminished sexual functioning.

> *Now, although I do not have sensation in my body and other things I can still get pleasure from having sex. When she embraces me in her arms: I feel like having no burning sensation; pain vanishes; and I experience joy while talking to her despite all the troubles. (Arjun)*

Nabin also highlighted the importance of expressing love in building trust and living a cordial relationship through non-penetrative sexual activities such as hugging and kissing. He described it as:

> *Trusting each other is love. Love is also hugging and kissing each other, helping each other in difficulties, making effort to fulfil each other's desires and living in harmony. (Nabin)*

Binod highlighted that he is now exploring more sexual issues and is using both penetrative and non-penetrative sexual activities to satisfy his wife in addition to having more interest in sleeping together with his wife:

> *Until my penis works I use it and when it did not work then I started thinking what will happen if I use hand instead. I was curious where it goes inside and gradually I got my interest in it… need to kiss more and stimulate… They will think that you still have not given up and their love for us will emerge… Earlier I did not have much interest in sleeping together however; nowadays after the injury I am keen to sleep together (Binod)*

For many participants in this study, it was observed earlier in this chapter that partner satisfaction was the priority and often it is the underlying reason to engage in sexual activity. Similarly, there are numerous inferences which show the increased appreciation of a partner's cooperation, mutual understanding, communication as a way of improving their sex life and relationship. For example, in this description Nabin described that he is able to partially fulfil sexual desire by engaging in non-penetrative sexual activities. He describes his concerns and strategies to satisfy his wife's sexual desire as:

> *During that period 25-30 per cent sexual desire can be fulfilled by sleeping together with wife, kissing her and asking her how her sexual wants and desire can be fulfilled. Until now we have fulfilled our sexual desire by touching various parts of the body: kissing her breasts; touching her thighs; using fingers to play with her vagina and lying over each other. (Nabin)*

Similarly another peer supporter also emphasized the importance of mutual understanding and cooperation by giving an example of sex positioning:

> *For positioning issues; firstly, both need to be prepared mentally, need to be able to convince the partner. The feelings, perception, experience and satisfaction is better when both the partners are mentally prepared and vice versa. (Sirish)*

In addition, despite popular belief and one of the participant's experience that Nepalese women are not open to sex, Binod described the sexual variation he and his wife used as:

> *Back side means anus. I also used to play there. She used to tell: it's enough, do not do anything there, if you want to do it, do it on this side otherwise do not do it. Then, I agree with her and stop doing that. That's how… I used to satisfy her and try to please myself... sometimes, I used to ask her to come on top after making the penis erect. She also does it from the top, and she used to stop by saying she is tired. Then I climb on top of her… when she says it is difficult to her, I used to stop. I then use my finger … I continue to do until she says no or enough. I used to ask her "are you satisfied or not?" She then said, "Yes I am." After masturbating her like that, I think that I can satisfy her. ... I take her in my arms and then sleep. (Sirish)*

Another participant further highlighted the importance of sharing sexuality issues 'shortcoming and difficulties' and understanding each other to strengthen the relationship. His optimism about his future relationship is clear. He described it as:

> *If we are able to share everything including our short comings and difficulties in our relation and understand each other well and then it is not a big problem. (Bibek)*

A peer supporter became philosophical and described life as precious and encouraged his peers to enjoy a sex life with mutual understanding. He described it as:

> *I tell to all my friends that we have this life for once... Therefore, for fulfilling your sexual desire do not use the force. You can neither obtain sexual satisfaction nor give satisfaction to your partner through the use of force. I*

> *advise them to involve in sexual activities with mutual understanding that are satisfying for both the couples. (Pradeep)*

4.4 Conclusion

Sexual desire was preserved in most MWSCI, increased in a few and decreased in a few MWSCI. Although sexual desire positively influenced sexual interest in MWSCI, most men were unable to fulfill their sexual desire due to lack of sexual pleasure from traditional sexual relations. Most MWSCI were not able to derive sexual pleasure because of an inability or difficulty in engaging in sexual intercourse due to erectile dysfunction, and lack of genital and ejaculation sensation (Mendes et al., 2008). Most of these men who were unable to fulfill their sexual desire were sexually unsatisfied and some of them eventually lost their sexual interest and desire. On the other hand, the majority of men who continued to sustain their desire and focus on penetrative sex have experienced frustration, shame and grief due to the discrepancy between actual and desired sexual performance (similar to that of before the injury). The contribution of strong sexual desire to the threat or loss of manhood among men with diminished sexual capacity and performance who also adhere to sexual prowess for their masculine identity is understandable.

The evidence in this chapter also helps to illustrate the adherence of Nepalese MWSCI to the masculine script of masculine identity that focusses on sexual prowess as one of the underlying cause of threat to or loss of manhood. Most MWSCI compared (ruminated) their sex life particularly penetrative sex pre and post-injury and wished for a good erection, ejaculation, and sexual pleasure as in pre-injury life despite various limitations and barriers to achieving an ordinary sex life. MWSCI who demonstrated poor acceptance and adjustment with impairment of one or more of these sexual functions - diminution of sexual performance and capacities further induced the feeling of loss of manhood when they continued to adhere to the traditional masculine scripts and marital relationship stressing sexual prowess. For example, married MWSCI who were not able to perform well sexually similar to that of before the injury were focussing on their partner's sexual satisfaction because of their doubt and fear that their partner may cheat on them or elope with other men to fulfill their sexual desires.

Of all sexual function impairment, erectile dysfunction and infertility challenged or induced the feeling of loss of manhood in MWSCI directly or through their endorsement of various social values and beliefs that were linked with these functions. Despite the societal portrayal of MWSCI as asexual and their personal feelings of dependence, loss of male dominance and the change in relationship dynamics, their ability to achieve an erection appeared to be one of the most important factors in providing a sense of their manhood. The ability to obtain an erection alone or engage in penetrative sex provided a strong sense of manhood or feeling of being a 'real man'. Very few men were successful in using the strategy of combining penetrative (penile-vaginal sex and manual stimulation) and non-penetrative sexual activities to satisfy their wives and demonstrate sexual prowess. On the other hand, most MWSCI either expressed the use of medication or emphasized the need for information and measures to improve erection rigidity and duration for satisfying their partners or wives rather than their own sexual pleasure. Similarly, fertility is also an important concern for most MWSCI. Childlessness and the lack of a son were related with a fear of lacking physical and economic support from the children later in their life. Inability to ejaculate, impregnate their wives and fathering a child after injury are associated with feelings of humiliation in married MWSCI whereas now single and never married MWSCI's marriage decisions were contingent upon their fertility capacity to reproduce. However, both married MWSCI with or without children, and now single and never married MWSCI continue to explore and express their optimism about trying out different artificial fertilization measures to reproduce.

Similarly, inability to fulfill the provider role after SCI also challenges the manhood of MWSCI. Most of the MWSCI in this study identified themselves as a provider for the family as a son, father and husband to their dependent parents, children and wives respectively. However, after SCI their inability to pursue their previous occupation, pursue a socially recognised career due to diminished physical capacity, lack of suitable employment opportunities, and unsuitable geographical and sociocultural environment, MWSCI find it difficult to fulfil their provider role. It was obvious why some men who felt they are unable to fulfil their provider role portrayed themselves as worthless (less than a man) on not being able to fulfill their manly role of son, father and husband. On the other hand, those who had some form of income and were able to provide for the family had better self-esteem and sexual esteem.

The data in this chapter further delineates how the response and attitudes of wife, parents and society adds to the threat to the manhood of MWSCI. There are numerous preconceptions about SCI that portrays MWSCI as asexual and unproductive. The prejudices that subtlety threatens manhood are: MWSCI do not have erections; they are not able to have sex and fulfill their wives' sexual desires; thus cannot reproduce; they need to be looked after and they cannot earn to fulfil the family needs. The strength of the impact on the MWSCI can be weighed from some of the examples where wives of MWSCI have divorced or eloped under the direct influence of their parents and society's pressure. Additionally, these negative attitudes have led to difficulty in finding a suitable partner for intimacy and marriage for single and never married MWSCI and potential partners for marriage have refused their marriage proposals. Further, men who subconsciously endorsed these views have experienced: increased sexual performance pressure; a shift in sexual satisfaction of their partner from their own, and an increase in their doubt and fear about partner cheating on them or eloping with another man to fulfil their sexual desire.

Until now the above discussion showed what kind of threats to the manhood of MWSCI exist and how they continue to reclaim their manhood based on their traditional masculine script stressing sexual prowess, fertility ability and the manly role (provider role) in the family. On the contrary, despite some men's assertion of being "less than a man" most MWSCI continue to adopt the behaviours which are generally regarded as less masculine without hesitation as a way of reconstructing their manhood. Shift from the scripted masculine ideals towards the reconstruction of new identities "beyond hegemony" is possible (Nolan, 2013). For example, some men who are able to accept their decreased physical strength rely on negotiation instead of verbal and physical aggression in exerting their male dominance. A few men who are able to accept their physical limitation and disability were able to view themselves equal to their able-bodied peers in all other aspects of life except the occasional need for physical assistance. Even men lacking an erection or partner for sex who are not able to fulfil their sexual desire use a strategy of self-control for suppressing sexual desire while men with some erectile difficulties, strong sexual desire and sexual prowess are able to effectively combine the penetrative and non-penetrative strategies to fulfil their own and their partner's needs. Similarly, most men who are not able to continue sexual intercourse appear to shift their focus to non-penetrative sexual activities and the qualitative aspect of the relationship. The cordial and loving relationship that existed before the injury was an important factor for an ongoing cordial relationship. Most now single and never married MWSCI view mutual understanding, transparency, and acceptance of weaknesses as the basis of partnering and marriage in contrast with a traditional arranged marriage. Therefore, SCI rehabilitation professionals' ability to identify their clients' individual specific sexual problems, concern, needs and knowledge on the contextual cultural traditions around sexuality and manhood is essential.

CHAPTER 5

HEALTH CARE SERVICES, COMMUNITY REINTEGRATION AND CHALLENGES OF SEXUAL REHABILITATION FROM THE PERSPECTIVE OF MEN WITH SPINAL CORD INJURY

5.1 Introduction

Data from this study reveals that Men with Spinal Cord Injury (MWSCI) experience numerous challenges in accessing health care and rehabilitation services, and reintegrating back into community life that have both direct and indirect impacts on their sexuality and sex life. Therefore, I strongly feel that it is important to understand these challenges so I first examined the health care delivery system (pre-hospital and hospital care and provision of SCI rehabilitation) from the perspective of SCI and challenges associated with community reintegration following institutional rehabilitation.

Then I analysed the data regarding the sexual concerns and needs of MWSCI simultaneously and chronologically in the order of early stage, rehabilitation stage and reintegration stage. For the purpose of this study, early stage is the period from the time of injury until before entering a dedicated rehabilitation program, and community reintegration stage is the time after returning to their home in their community following discharge from the rehabilitation facility. In addition, the perception of MWSCI about the attitudes of health professionals and other significant people (family members, partners, peers and society) towards the sexual needs and concerns of MWSCI and the impact of those attitudes on the participants' sexual issues are also discussed.

5.2 Major themes

For ease of understanding, various issues and concerns are discussed under three major themes: context of SCI rehabilitation in Nepal, sexual concerns and needs of MWSCI during the early and rehabilitation periods; and sexual concerns and needs of MWSCI during the reintegration stage.

The first theme includes the challenges associated with the health care delivery system with respect to SCI and community reintegration due to social prejudices towards SCI and the sexuality of MWSCI. The second theme discusses the sexuality issues during the early and rehabilitation stages. It also describes the strengths and weaknesses of sexual rehabilitation and attitudes of health professionals towards the sexuality of MWSCI. The third theme will illustrate the ongoing sexual issues in the community after discharge of MWSCIs. In addition, the impact of sexual rehabilitation services and social prejudices on the sexual adjustment process of MWSCI are also analysed in this section.

5.2.1 Context of spinal cord injury rehabilitation and community reintegration in Nepal

The major issues experienced by MWSCI during the early stage include: unsafe pre-hospital care; fear of dying, hopelessness and self-harming thoughts, lack of quality SCI care and a systematic referral mechanism. The unsafe pre-hospital care can further worsen the damage to the spinal cord affecting the functional and rehabilitation outcomes including sexual function. The fear of dying, hopelessness and self-harming thoughts initially as part of the adjustment process to the loss can be understood, however a prolonged presence of such feelings and thoughts can have a detrimental effect on the recovery and rehabilitation process.

The lack of a specialised multidisciplinary SCI centre (with a capacity to provide continuous and non-fragmented SCI care) as well as hospitals with adequate resources to provide the necessary care during the early stage of SCI is evinced from the data. In addition, there are numerous examples where a patient had to travel from one hospital to another stating that the hospital does not have the capacity to manage SCI cases which clearly demonstrated a lack of resources and an efficient referral system. Similarly, the occurrence of pressure sores while in the hospital, and discharging patients without treating or educating them about the prevention and care of pressure sores showed a lack of capacity and or negligence of the hospital. Rehabilitation referrals were also not consistent. All of these have contributed to a lack of hope in SCI patients and their families, and delay in their overall rehabilitation. One of our recent follow-up studies of SCI patients also found that pressure sores are a common cause of unplanned rehospitalisation in people with SCI (Scovil et al., 2012). All these are relevant because they add unnecessary expense to the already financially strained MWSCI and their families, and also complicate sexual rehabilitation.

On the other hand, most SCI patients are from remote villages relying on subsistence farming for a living (Prabhaka & Thakker, 2004; Singh et al., 2003), and about two-thirds of them are the main providers for their families (Shrestha, Garg, Singh, Singh, & Sharma, 2007). It also explains why the loss of income and an inability to look after the family threatened their manhood among MWSCI in the previous chapter. In addition, one or more family members need to accompany the patients from the time of injury to at least the rehabilitation stage leading to further loss of any income by other family members. Moreover, the health care delivery system in Nepal relies entirely on its citizens' out-of-pocket expenses for the treatment of most health conditions including SCI. Thus, injury leads to a loss of income and a blowout in expenses; all of these put pressure on families and relationships; and undermine manhood and sexual interest too. The pragmatic need to have children who can carry some of the burden and for the victim of SCI not to lose his wife because she, and whatever children they can produce, have so much personal, emotional and economic value is very apparent. It is not surprising that sex/reproduction/relationships become issues very early, because in many ways they are about both happiness and survival.

Good pre-hospital care is essential to minimise secondary SCI and complications (Ahn et al., 2011). However, people with SCI are usually taken to the primary health centres or hospitals on someone's back or a locally made sling on a bamboo pole carried between two men who are usually family members and neighbours often without stabilising the spine (Hamilton, 1978). This lack of resources and general awareness about SCI care in the community increases the risk of further worsening the SCI. For example, in this description of unsafe mobilization and transfer practice, delayed first aid/attention of trained health professionals in the community can be observed. Anil described it as:

> *A friend who happened to be across the hill at that time had come to my recue. People were called from various places using a mobile phone and I was carried for 2 hours in a locally made bamboo stretcher (Dhola). An ambulance was called there by telephone. I do not know what would have happened if the ambulance would not have come. It was a rainy season. (Anil)*

Birendra also described the delay in accessing a health professional's attention after SCI as:

> *Then people brought me home from the accident site and then only they took me to local (name omitted) hospital. (Birendra)*

Most participants had a fear of dying immediately after the injury. There was a gradual decline in the fear of dying after reaching the hospital followed by the hope of recovering. Understandably, survival and returning to normal life were the immediate concern after reaching hospitals. However, soon after hearing the chronic disabling nature of SCI grief over loss of physical functioning, depression and self-harming thoughts were prevalent in most of the participants. In this description Som described his fear and uncertainty about life immediately after the injury as:

> *I had a doubt and suspicion in the mind whether I will die or survive. (Som)*

Arjun describes his feeling of being relieved from the fear of dying soon after reaching the hospital, however his ongoing fear of dying is clear. He described it as:

> *After reaching the hospital I felt like I will not die immediately... I send my family back to home by counselling and giving them hope that I will be fine. I did not make them worried by telling I may die. (Arjun)*

Similarly Ram described his anxiety about the uncertainties and fear of dying due to his injury. His frustration from the lack of psychological support from health professionals is understandable. He described it as:

> *First one week following the accident was very difficult waiting for me. I felt that I may not survive and it is not worth living as well. During the treatment*

> *when doctor told me that there is no cure for it then I was extremely frustrated. (Ram)*

Ram further described his, subsequent feeling of hopelessness, depression and fear of dying as well as self-harming thoughts as:

> *… I also felt that injury was more than what I have thought... I lost my appetite. I felt that neither I can live a life like this nor survive. (Ram)*

Bharat also described his hopelessness and self-harming thoughts and his suicide attempt in the subsequent days after the injury as:

> *I also became hopeless... 3 months after the accident I also tried to commit suicide... I wanted to die instantly but no one will bring poison for me. To strangulate myself also I could not find a rope. I tried to commit suicide once. (Bharat)*

Saroj's preoccupation with self-harming thoughts due to a loss of independence and the fear of living a dependent life is understandable. He described it as:

> *I was dependent on the family for everything. I used to feel that if I have to survive in the care of my brothers and they have to do everything for me then there is no meaning of living a life. Immediately after the SCI, my heart-mind, mind was preoccupied with the feeling that it is better to die. (Saroj)*

A lack of resources in the hospitals, a lack of a specialised SCI centre and a good referral mechanism have caused unnecessary transfers between the hospitals adding further challenges to the acute management of SCI. For example, Anil described that he had to travel to the capital city due to a lack of services at the district hospital. He further added that he had to visit three different hospitals before receiving a definitive diagnosis and spinal fixation. A lack of good referral is clear. He described it as:

> *Staff at district hospital told that they cannot manage there. I was taken to Kathmandu from there at 6:00 pm in the evening in an ambulance. I reached Kathmandu next day early morning at 6:00 am after an overnight journey. In Kathmandu, I had to visit 3 different hospitals: Neuro; Bir and Teaching*

> *Hospital. Finally an operation was done at Neuro Hospital after one month. (Anil)*

Birendra described that he could not get good treatment despite travelling to a hospital in India. The lack of resources for effective acute SCI care in the region and a poor referral decision can be observed:

> *In the district hospital they could not provide treatment and they referred me to Lucknow, India. In Lucknow also they said it cannot be done here then I came back to Nepalganj, Bheri Hospital in Nepal. I stayed about a month there. My pressure sore became bigger while in the hospital. I could not get good treatment there as well. (Birendra)*

In addition, the occurrence of secondary complications such as pressure sores in the hospital itself suggests both negligence and/or a poor quality of SCI care. In this description, Kumar echoed the lack of the hospital's ability to treat pressure sores:

> *While I was at ICU (name omitted), I developed a bed sore on my back. Then I was sent to Green Pastures for the treatment of bedsore plus physical therapy and occupational therapy... I had to undergo operation twice during treatment of the pressure sores. (Kumar)*

In this description, about how the lack of pressure sore care and education, and information on rehabilitation services and rehabilitation referral from the hospital forces a person with SCI to live a bedridden life with worsening pressure sores at home for 14 months. Binod described it as:

> *I suffered injury while I was working in India. After 14 days of hospital stay, I came to my home. I was bedridden for 14 months after coming back to home... I went to the hospital in Nepalganj. I did not benefit from the consultation so I returned back to home on the same day then I developed three pressure sores because of lying all the time in bed. I went to Nepalganj (hospital) again where I spent 10 days doing nothing. After coming home I was bedridden again... pressure sores were becoming worst. (Binod)*

In the next description, Binod's loss of trust in the services of the hospital as well as hopelessness as a result of a lack of timely rehabilitation service due to a lack of rehabilitation referral from the hospital and information about rehabilitation can be seen. He described it as:

> *Birendra ... (name changed for confidentiality), a person with SCI like me, came to meet me 4-5 times... he spoke to INF staff then they (name omitted) came to meet me. Then I was advised to go to Kathmandu for bedsore treatment. I was not interested to go to Kathmandu as I was going to die anyway so I wanted to die at home. Then, they send me to Green Pastures Hospital. (Binod)*

On the other hand, another participant Arjun described that one of the admission criteria for rehabilitation in the centre which he had visited earlier, was that clients should not have big pressure sores. Notice the extended period of pressure sore healing time! High rehabilitation demand or limited rehabilitation capacity in another centre is understandable from the long waiting list. So by trying to address the pressure sores on his own, his situation was further complicated:

> *After coming back to home I developed 3 bedsores. In Kathmandu, they do not admit a patient with big bed sore... We thought it must be similar in Pokhara as well. We could not get that information and we decided to go for further treatment only after healing bed sores at home. Two of my bed sores healed at home while waiting for the response from hospital in Pokhara. My brother had entered my name in hospital waiting list by visiting there. We came here for treatment when they called us. Third bedsore healed after one and a half months treatment. I have just started trainings. (Arjun)*

Anil's description also suggests the high rehabilitation demand in the same centre. He described it as:

> *I was taken to the Green Pastures Hospital and rehabilitation Centre in Pokhara but bed was not available. I was then sent back to general Hospital. (Anil)*

A number of participants echoed a lack of: a good rehabilitation referral system; multi-disciplinary approaches in rehabilitation and adequate specialists in the facilities where they visited. For example, in this description, unsafe early mobilisation of the client due to poor referral instructions, lack of coordination between rehabilitation team members and a lack of adequate SCI expertise is understandable. Arjun described it as:

> *After seeing MRI report they said… It is not possible to operate; it is difficult… we cannot give any guarantee about the outcome as some people to whom we said they will not be able to move became better while some did not. We stayed there about 20-25 days... They (hospital staff) said you need to wear this brace and go to rehabilitation centre (name changed) where they will teach you to sit in wheelchair and other things. We went to rehab centre and they started to make me stand for two days. Then a part time spinal surgeon examined me and told that I need to bed rest for another 6 weeks. (Arjun)*

Anil also had a similar experience. He described his dissatisfaction and frustration over the post-operative rehabilitation services in the hospital. The lack of education about pressure sore prevention and SCI rehabilitation is also obvious. He described it as:

> *I stayed two months in a hospital in Kathmandu and then only I underwent spinal fixation... I took rest 2 weeks following the operation. Later, I was kept in a wheel chair directly. First three days I felt dizzy; I could not see; I felt nauseated; and I was unable to hear. I could not sit too long in the wheel chair. They put me in a standing frame 1-2 times and I became unconscious. I did not felt anything so it was of no use. They did not teach me about the different lying positions to prevent wound. At once, the big Doctor told to my father that this is what we can do; now it is your wish to take anywhere.*

He continued and repeated that his parents were forced to discontinue further rehabilitation risking his life because of the financial burden they already had:

> *... 600-700 thousand rupees was spent within two months...We had spent a lot of money there so when there was a discussion about where to go. Then a decision was made to go home whether or not I will survive. (Anil)*

Arjun also described that he had to discontinue his rehabilitation because of his inability to afford the expenses. He also expressed his concern about the loss of family income as his brother had to be away from work because he had to stay with him during rehabilitation:

> *My brother told that it is difficult for a person with our poor economic condition to stay there for 6 weeks. Bed charges were also expensive. Initially, I was put in a cabin. Cabin charge was 800 rupees and food was extra. After moving to general bed, bed charge was still 500 rupees. It was not affordable. During this period… there will be additional expenses on food for two people. My brother would not be able to return to home, and work to earn money if he was going to stay with me… then financially it was going to make difficult for all of us… we came home after 4-5 days thinking that we can go for rehabilitation in Pokhara after 6 weeks of rest at home. (Arjun)*

Only two-thirds of participants in this study had received direct rehabilitation referrals from hospitals at the end of their acute care phase whereas the remaining participants' rehabilitation was delayed on average by a year (See table 6.1). However, most accounts from participants consisted of positive responses about the rehabilitation services. Pradeep like many other MWSCI acknowledged the importance of engaging in therapeutic activities, exercises, and learning life skills, and he felt that it helped him to become free from negative attitudes, thoughts and even depression. He highlighted that the rehabilitation program helped him to sustain motivation, and regain hope and self-confidence:

> *After coming to rehab… I was free from negative thoughts and depression after participating in various activities such as games in occupational therapy department, exercises in physical therapy department… I got the motivation and feelings such as I can do something in my life even using wheelchair... I learned various skills such as: transfer... preparing meals... and I felt that*

> *although my life is like this I am also capable of doing something... and work by using hands. (Nabin)*

Binod also echoed the view of many other participants who experienced rehabilitation as a life changing event. He highlighted the independence he achieved in activities of daily living such as toileting, hygiene, personal mobility, and socialization:

> *... I stayed about 4-5 months in the rehab. Finally, my bedsore healed, I exercised for about a month. I was unable to go to the toilet, and take bath but after rehabilitation, I was able to do it independently. Before this, I use to think how it would feel to go to the road in front of my house, now I am able to go around in this wheelchair and chat with my friends. (Binod)*

Similarly, Ram highlighted that the health professionals' suggestions gave him hope for living and meeting peers provided him with role models for a SCI life. His frustration before meeting his peers and the increase in his self-confidence after meeting his peers is noticeable:

> *In rehab… I was advised that people with disability also can live a life and do something..., then I felt that I will be able to live further life. I met people like me and I thought they are living a life like mine then I felt that disable life is also a life otherwise I had a lot of frustration before seeing them... I came to know how to live a life after having a disability for example… I will be able to do activities of daily living such as toileting, feeding myself. I learnt them gradually and life is going on until now. (Ram)*

Being among other peers with SCI in the rehabilitation centre appears to promote the acceptance of their condition (disability), positive self-worth and a sense of identity. The benefit of having people with SCI in the same ward is that they become happy and grateful (Hamilton, 1978). Anil described that seeing other survivors and knowing that people with SCI can live longer increased his confidence:

> *I used to think that I will die however after coming to this Hospital I came to know that some people have lived for 15…some for 20 years. When I knew*

> *that people can survive that long after the SCI then my self-confidence has increased. (Anil)*

Another participant highlighted that both his peers' situations and psychological support from them helped him to remain hopeful:

> *I also got the opportunity to meet people like me with spinal and neck injuries and I realised that this condition is like this. They told me that you need to have more self-confidence to survive. (Kumar)*

Birendra also had a similar experience:

> *At the beginning… I also thought to the extent of what is the use of living a life like this. However, I did not felt so after seeing others life and talking with them. (Birendra)*

Nabin described his experience of meeting other people with SCI as:

> *After 19 days, I was referred to… rehab and… I met many people like me. I was not alone; there were other people with similar condition like mine. (Nabin)*

The period following discharge from the hospital or rehabilitation centre to their homes is a stressful time. It is a time when they begin to face the real outside world with remaining and new-found skills after the injury. The major challenges during community reintegration are an inaccessible home environment, public places, transportation, employment, difficult geographical terrain and negative societal attitudes towards SCI and their sexuality. In addition to the abrupt cessation of their previously free flowing, smooth life, the lack of opportunity to take part in social activities and events and the loss of income are inevitable. All of these factors also put pressure on families and relationships and create difficulties in adjusting their sex life; and also undermines their manhood.

A SCI follow-up study in Nepal found that the home environment was inaccessible for 80% of people with SCI using wheelchairs and 74% of those people using mobility aids were dependent on their carer for accessing the community due to physical terrain (Scovil et al., 2012). The inaccessible environment can limit participation in sexual activities as well. For example, for Bibek his inaccessible home, geography and transportation service resulted in the loss of his independence. It also affected his privacy and sex life. He described it as:

> *After the SCI, there were difficulties in every aspect for example toileting, moving around in the street and getting on and off the vehicle… I needed a friend or a carer for assistance that is a difficult situation… There are difficulties in ... sexual activities as well. Even when you have desire for physical relationship it is not possible because of lack of suitable environment. There are many such issues… many places are not wheelchair accessible. (Bibek)*

In the following description, the impact of an environmental barrier (social and physical) on the sex life of Ram can be observed. His concern for privacy as an unmarried man where there is a strict social and cultural sanction on premarital sexual relationships is understandable. Ram described it as:

> *I am staying in a remote village. I cannot get out of my room. I have less opportunity to meet people as well… If a person cannot come out of the room… because of inaccessible environment then we cannot participate in social gathering such as festivals, weddings, parties… meet people whom we like… Additionally, physical environment is a barrier because when a girl invites a guy to come inside her home but he may not be able to get in. Similarly when a boy invites a girl to his home… It is difficult to maintain privacy in such situation. (Ram)*

Ram stressed the impact of the lack of vocational skills, employment and financial independence in finding a suitable partner as:

> *I have an option of using phone to share my views with a girl and have an influence on them…but you need money for it… we are unable to earn so we are dependent on the family. To succeed in sexual activity you need to be secured financially and needs to have some skills to attract and impress a girl… For example if I am good tailor… can prepare a dress to impress her.*

> *People are greedy so you need to have something to lure them. People are selfish so if they can fulfil their one self-interest then they may be ready exchange one in favour of it… In my experience, if… you are psychologically and financially strong then you will have a confidence of making a girlfriend and fulfilling desire… Therefore, in my experience psychological, economical and geographical are three forms of barriers which have affected the sexual relationship of people with disability. (Ram)*

The societal attitude towards people with SCI is predominantly negative. They often portrayed MWSCI as useless, worthless, hopeless cases and needing lifelong care. In addition, MWSCI are perceived as unable to obtain an erection, fulfil the partner's sexual desire, reproduce, and are ineligible for marriage too. These social prejudices not only undermine manhood (see previous chapter) but also create difficulty adjusting with their sex lives and community reintegration.

The previous chapter has already provided a detailed discussion of how social prejudices view MWSCI as asexual and unproductive, challenging their manhood. The following few cases exemplify how some of those attitudes challenge the existing relationship and create difficulty in forming new relationships. For example, in this description, the threat to Pradeep's marital relationship is clear. He described that his villagers portrayed him as useless, worthless and unable to fulfil his wife's desire and even encouraged his wife to elope:

> *After SCI, in the village the words such as "he cannot do anything, he is of no use now, and he does not have any value and importance", were repeatedly used… During that time they tried to encourage my wife to elope … telling that there is no need to stay with him, as you are very young, and all your wishes and desires may not get fulfilled. First of all, there is no certainty whether he will survive or not. Second, even if he survives, you have to provide lifelong care for him. Whether you will go to work for earning or you will take care of him? (Pradeep)*

In addition to the villagers, the attitudes of close relatives such as parents-in-law also appear to play an important role in maintaining the marriage of a couple coping with SCI. For example, Sirish described that his wife eloped mainly because of her parents' pressure, stressing his inability to reproduce and a person always needing care. His parents-in-law's preference for having a grandson over a granddaughter is also palpable. He described it as:

> *Five months after my injury she left me and went to another house. Because her parents told her that: there is no benefit in staying with a man like this; instead of taking care of him it is better to elope; it is better to go to another home where you will be able to have more children, you have only one daughter here. (Sirish)*

Similarly, Ram described that the cause of his marriage failure was the negative attitude of his wife and her parents towards his disability from SCI:

> *I got a divorce from my wife because of my disability… Both my wife and her family thought that they cannot expect anything from a person with a disability like me, and I am not compatible with her life.*

Ram also echoed the need for changes in the social perception of SCI. He highlighted that the lack of understanding about SCI in the society as the reason for social prejudices towards SCI and their sexuality. The underlying cause of his divorce and barriers in finding a suitable partner for marriage are clear:

> *When I had to lose my life partner, I felt that people in the community are unable to understand, and they still hold the attitude such as when a person becomes a disable then they become handicapped in everything. If society becomes aware then, an individual with a disability also can give love and affection similar to that of an average person. I feel that it is a difference in the understanding and thinking of the society… There has not been the change in the existing societal view of society and neighbours such as he cannot have children; he should not get married after being a disable like this. (Ram)*

5.2.2 Sexual concerns and needs of men with SCI during early and rehabilitation stage and sexual rehabilitation

Although most participants were dealing with the fear of uncertainty, dying and going through the psychological trauma of sudden injury, many appeared to have concerns over their lost bodily functions such as the ability to walk, bowel and bladder function as well as sexual concerns. Early sexual concerns of MWSCI were loss of erection, ability to resume a sex life and the ability to father children.

Initially the experience of total dependence on the bowel and bladder management can cause a natural regression to infancy stage in people with SCI (Westie, 1987). The following two descriptions show how loss of bowel and bladder control can inhibit sexual thoughts among MWSCI. Yet, they had curiosity/concern about sex and reproduction at a very early stage despite everyone else's assumption that sex would be the last thing on their mind. These concerns relate to many important issues including fear of losing their wife, not having children, being left alone etc.

For Sirish although mobility, sensation and bladder function were his immediate concern, his sexual function became the priority for him soon after he regained control over his bladder function. He said that the main reason for having early concerns for his sexual function was fear of losing his wife and infertility. He described it as:

> *I had highest curiosity about ability to walk, after that I had a grief of having no sensation. It was only later I was curious about sex life. I did not think about sex life at all rather I used to think that at least if I am able to go for urine and stool myself then my family would not have to face the trouble... I was in a catheter when I went to Lucknow from the district hospital. I regained urine control within 18 days. At that moment, I was happy thinking that I am now able to control the urine. Now it is well, my wife will not leave me. I had a doubt that if urine was not controlled, urine will leak, semen won't ejaculate. After getting the control over urine, I felt ok intrinsically. (Sirish)*

Bharat also described that within 2-3 days after the injury he was curious and concerned about his ability to retain an erection, gain sensation and resume sexual intercourse as usual. He also highlighted that these issues concerned him more than being a paraplegic and wheelchair dependent.

> *In the first 2-3 days after the injury, I had a curiosity that whether I will have erection in my penis or not. After that, there was no sensation so what is going to happen: whether I will be able to have sex or not; whether sensation will be retained or not; I will able to continue a happy sexual life or not. These were the initial thoughts that came to my mind. I might be paraplegic, wheelchair user or I might die however, whether I will be able to make sexual intercourse or not... I thought it will be retained later. I did not have past experience. (Bharat)*

He further stressed that it was realistic for him to be concerned. His anxiety to find about his erectile function once his catheter was removed is understandable.

> *This curiosity kept coming to mind because Foley's catheter was inserted... so what will happen after removing catheter... I tried to touch and move penis but nothing happened... There was no reason for not touching and seeing it. (Bharat)*

In this description, Kumar's early sexual concern (erection) is obvious from his hope of retaining an erection (while still in his hospital bed) after meeting his wife. His apprehension at not knowing the extent of his loss in the early days of his injury is also understandable. He described it as:

> *At that time, in the beginning I used to think that if I get the opportunity to sleep with my wife whether that thing will work or not. I use to think that it would work like that of before. (Kumar)*

Despite the sexuality issue appearing early for many participants, none of them were able to raise the issue with health professionals and health professionals never raised the subject with them. Sexuality is a taboo topic in less resourced countries like Nepal (Scovil et al., 2012). In addition, most hospitals lacked the capacity to provide essential SCI care hence it is understandable why sexuality issues are neglected. This is very unfortunate. For example, in this description, Bharat (married man with children) described that his sexuality issues were neglected by health professionals. His expectation of health professionals providing sexuality information without asking them about it is understandable:

> *Health workers: doctor or nurse, nobody told me anything when I was hospitalized. When I stayed one and a half month at Bir Hospital at that time also nobody told me about it. When I was in Vellore (India) for 3 months at that time also they did not tell me. When I went to Western Regional Hospital... at that time also they did not tell anything to me. That aspect was neglected and nothing was talked about that aspect. I always had curiosity that whether I will be able to obtain erection some time later or not but nobody was giving right answer about it. (Bharat)*

During the rehabilitation stage, therapeutic activities and counselling helped most men to regain some hope for life as they continued to learn Activities of Daily Livings (ADLs) and life skills. In addition, peer support was extremely valuable. Priorities for regaining independence in ADLs such as mobility and bowel and bladder management were clear. Simultaneously, there was an emergent appreciation for the loss of sexual function and anxieties about their sex lives. In the previous chapter, most of these sexual concerns which were also important to their prospects of manhood in MWSCI have been already discussed. This section will focus more on sexual rehabilitation services and the health professionals' responses to the concerns and needs of MWSCI. Data from this study suggest that both MWSCI and health professionals feel reluctant to discuss sexual issues; there is a lack of competence in the sexual knowledge and skills of health professionals; and sexual rehabilitation is neither a priority nor adequate.

Pradeep described his sexual curiosities and concern he had during his rehabilitation period as:

> *Wow, there were a lot of queries. At that time, there were also a lot of desires within me (manma) such as how can it be and what can be done. (Pradeep)*

Similarly, Gaya described that he had his first sexual relationship with his wife in the hospital. His curiosity about erection and concern about sex life are clear.

> *I was able to do it after 5 months when I checked: how it would be: whether erection can be obtained or not. I did it by thinking that. My destiny was good so I did it 2-3 times in the hospital. Then I did it at home and everywhere I went. (Gaya)*

Very few participants in this study were injured quite recently. Arjun was not able to afford rehabilitation initially but is now in a dedicated SCI rehabilitation program. He stated that he started to think about his sex life after 4-5 months while he was at home.

> *I had curiosities after about 4-5 months. (Arjun)*

Anil an unmarried MWSCI had realised, perhaps for the first time that he was going to be paralysed for the rest of his life. His concern about achieving an erection amidst the uncertainties of his life, and bowel and bladder control is clear. He described his uncertainties about his future including sexuality as:

> *An issue that comes to my mind is how my life is going to be. Isn't it... After that, how the bladder and bowel control will be? I also think about how the penis will be… whether there will be any erection or not? If it can become erect, then a girl is needed again. (Anil)*

In this description, Bharat highlighted that none of the health workers introduced the topic of sexuality and it was the main reason for his hesitation to inquire about the subject himself. His hesitance and embarrassment is understandable in such an unsympathetic environment where even the health professionals didn't broach the matter. He described it as:

> *There is a hesitation to ask with anybody. Doctor and nurse never say anything about it. They provide medical treatment; physical therapy; occupational therapy but they do not say anything about sex life and sexual intercourse: whether it is possible in future or not; what to do and what not to do and how it is going to be for me. (Bharat)*

Similarly, in this description the reluctance of both Arjun and the health professionals can be observed. Nuances in this description provide difficulty in broaching sexual issues even among peers. A lack of subsequent follow-up visits for sensitive issues like sexuality is also clearly visible. Notice his answer "I do" in response to peer supporter's query about erection and sex, and his reflection later in this quote implying that his problems were not discussed:

> *I have not asked such questions with health workers and doctors. While talking with a staff like me, he asked me questions such as; whether I have an erection or not; whether I have sex or not. When I said I do, he told that you are doing well and having good experience. I had only that much conversation with him only. I did not ask with other staff. They also did not discuss about it; whether I have any problem like that. (Arjun)*

The data also revealed that very few married MWSCI had actively sought sexual information and advice from the health professionals. In addition, their experiences show the reluctance of staff to discuss sexual issues as well as a lack of sensitivity and competence to address the issue adequately. For example in this description Dinesh (married man with no children) described that he had sought information about his future sex life and ability to father children from rehabilitation professionals. Then he highlighted that preventing his wife from childlessness was the underlying reason for his concern about fertility and their sex life after the injury.

> *When they replied me I have got SCI then immediately a thought came in my mind that I do not have a child and I have a recently married 18-20 years old wife so it is necessary to have a child at least for her... So I asked them whether I can have a child or not? What information is there about the sex and how will be sex life? (Dinesh)*

However, in his next description the reluctance of the staff to discuss sexual issues is palpable as only limited information about one fertility alternative was provided and his concern about sexuality was not discussed. He described it as:

> *They told me that there is no guarantee on whether you can have a child or not. There is no medicine for it. Maybe there is something available in Nepal*

> *for example test tube baby is an option 9 months following the accident. Although there are some successful cases, we cannot say anything about you at the moment so you will be able to find out once you are there.*

Another participant, Bharat described that the privacy and confidentiality of information was not maintained by the staff when he raised his sexual concerns with them. His frustration due to the lack of staff competence in addressing sensitive sexual issues; humiliation and guilt feelings from the staff's attitude; and a lack of trust towards health professionals is understandable. He described it as:

> *"Nobody gave me proper advice about sexual intercourse and penile erection. It was neglected. They made fun of it when I inquired about my erection problem… I had come with the expectation of getting proper advice… staff disclosed that information to the other staff... Following that, there was no question of making further inquiries… I did not feel that I will get a correct answer from there... That was a confidential issue. I felt that they did not maintain the privacy of my personal life. They should not have done that... It hurt me greatly... I felt extremely dejected. I felt harassed. I will not talk to them even if I meet them again... I still feel that I should not have shared; why did I share?" (Bharat)*

On the other hand, Prem expressed his strong preference to discuss his sexual issues with a staff of the same gender. He highlighted the reason for feeling uncomfortable in discussing sexual issues with female staff as:

> *I feel that it would be good if male staff particularly male doctor from here...do it. I would feel very good about it... There are a lot of differences between the doctor and the nurse because they are female; they are like my own sister. Therefore, I cannot tell them about lack of movement in my penis... I feel awkward to tell them. I will have guilt feeling that what I did today... so I cannot.*

In the next description, Prem described his feeling of shame and guilt when he had to expose his private part to female staff during bladder care, and strategy he utilises to cope with it. At the same time he described it as “their job” implying that health professionals do not have to feel hesitation and shame. Nuances in this description also provide clues to why MWSCI have difficulties in raising sexual issues and creating a permissive environment by health professionals is important to help their client to express their concerns without losing face.

> *If I showed my penis (Mal) to them it is not comfortable... it is similar to showing to my own sisters. That is why I cannot show them. In the hospital they will make you unconscious and... if they see or do anything with it I do not know about it. They have to take care of it, it is their job. Now, I cannot ask them in front of my own eyes… They will cover your eyes still I feel very shy. Although they see it, it is equal to not seeing when your eyes are closed. I do like that always. When they come for any treatment or anything else then I do not see that ugly penis. If they must see it, they see it I cover my face. (Prem)*

The following descriptions by Gaya helped to illustrate the situation of the sexual rehabilitation he received during his rehabilitation. In this description, the health professional’s initiation in discussing the sexual issue, the couple’s counselling and provision of private rooms for privacy before his discharge can be observed. However the client’s concerns about erection appeared inadequately addressed. Gaya described it as:

> *In occupational therapy I was advised to see them together with my wife. A health worker asked me whether I am having sex with my wife or not and how. I told that I am doing it but it is not like before. My wife makes it hard by stimulating with her hand. I do it for 2-3 seconds and it becomes loose and inactive again... I was advised to lay down and ask my wife to come on top then do it… no one gave any advice from the beginning.... I asked with a doctor how the erection can be made strong. I was transferred to Ananda Niwas (minimal care unit/half way home)… and have sex. I stayed there for 15 days and we had sex there. It was not like before. (Gaya)*

Gaya's dissatisfaction with his erection and frustration on not obtaining proper advice or medicine to improve his erection are apparent. It is also clear that the other alternatives such as non-penetrative sexual activities are not a part of their education. He described it as:

> *I asked again whether there is medicine for it or not... I was not told or given any medicine which would benefit me. Doctor and staff told me that it will happen gradually. (Gaya)*

On further probing, Gaya said that his physician prescribed a medicine to improve his erection towards the end but he was not able to find that medicine in the market. It is clear from his description that sexual issues were the last priority in the rehabilitation program and he could not benefit from it. The evidence in this description also strongly suggests a lack of timely and supervised medication during rehabilitation can force MWSCI to self-medicate at home and side effects may outweigh any benefit and decrease the chance of any benefit. He described it in this way:

> *I could not try that medicine which was written by the Doctor at Green Pastures because I could not find the medicine in the rehab and outside while I was there. Then I was told to buy it in my hometown and use. I also lost that piece of paper… I took a medicine… from the local pharmacy near my home town. I think that medicine was hard (strong): I slept after taking it and it harmed me. It made me mad, it was not good. I thought I was going to die. I discontinued it because I was frightened… causes sedation. It causes tingling sensation gives an odd feeling. (Gaya)*

Additionally, a peer supporter also highlighted that the rehabilitation program is not able to address erection and ejaculation issues to the expectation of his peers with SCI. His frustration due to his inability to support his peers is also palpable. He described it as:

> *At rehab I get various questions from peers for satiating their concerns. Those who do not have erection and ejaculation, they ask questions particularly related to erection issue in first hand and ejaculation in the second: they wonder how and express their deep concern about it. When they have such*

> *questions, I do not see the suitable environment for getting answer to their concern yet. (Pradeep)*

In his next description, it can be observed that MWSCI are more open about their sexual issues with their peer supporter. The benefit of trained peer support during rehabilitation cannot be underestimated. He stated that the newly married MWSCI's concern for their partner's sexual satisfaction was due to their fear of losing their wife:

> *However, recently married and young men have concerns such as how they can satisfy their partner and they feared that their partner may leave them because of it. There are such incidents (eloping) in the society as well. (Pradeep)*

Of the four unmarried MWSCI, three of them were adolescent at the time of injury and they had had premarital relationships before the injury while one was still a child at the time of injury. Two of them had their sexual relationship with their girlfriend however their relationship did not continue because of the injury. For most of these men their immediate priorities were mobility and bowel-bladder management although they also had sexual concerns during the rehabilitation stage. For example, Saroj described that he was still mourning the loss of his ability to walk, and for him bowel and bladder management were immediate priorities coming before his sexual issue:

> *To think about sex life it is necessary to be free from other problems. At that time, I was a student and I was going through financial crisis. I was also in a pain for being unable to walk. I was concentrating on how to manage bowel and bladder problems. (Saroj)*

Anil, another unmarried MWSCI described that the regaining of bowel and bladder sensation was the precursor of his ability to obtain an erection. Nuances in this description explain his perception of being sexually undesirable, his inability to fulfil his provider role and sexual inadequacy from the lack of an erection.

> *Who will look after a person like this? You need to look after a girl's needs, as well as my needs, so who is going to do that? Even if I get a girl, what is the use?... If I would have the sensation of bowel and bladder then only erection could happen. I think it will not happen. (Anil)*

It is clear by now that sexuality is not a foremost priority for unmarried MWSCI nor in the rehabilitation program and it is most likely that these men will have to deal with their sexual issues alone, once it becomes a need after returning to their community.

5.2.3 Ongoing sexual concerns and needs of men with SCI during community reintegration

It is understandable that most MWSCI will have some level of independence and their immediate priorities are met on their discharge from the rehabilitation program. As MWSCI began to reintegrate into community life sexual issues also started to surface as they continued to explore their sex life in a relatively safe and private home environment. It is clear from the previous sections in this chapter that sexual issues were not discussed at all during early care and they were also not priorities of the rehabilitation program. In addition, in the community, MWSCI had to deal with their sexual issues alone because of the lack of institutional follow-up services and social support. For example, MWSCI were forced to self-medicate to improve their erection and sexual performance despite experiencing and fearing the drugs' side effects in the community. Similarly, wives of MWSCI were encouraged to elope by the family members and villagers and girls were discouraged to marry a MWSCI.

Men who adhered to the traditional masculine script stressing sexual prowess for masculine identity or manhood continue to worry about their diminished sexual functioning, and they were unable to focus on other qualities of the relationship and vice versa. For example, they shift the focus from their own to their partner's sexual satisfaction. Similarly, the sex lives of men who were not able to discuss and resolve their sexual issues such as: bladder incontinence; sexual positions; sexual preference and interest openly were stressful. Moreover, a decrease in self-esteem and sexual esteem due to an altered body image, diminished physical and sexual functioning appear to create a feeling of being sexually less desirable. On the other hand, infertility was a source of anxiety and fear for most couples with no son, childless couples, unmarried MWSCI amidst the social pressure to reproduce, lack of proper fertility information and services. As a result of all these factors, sexual and marital relationships were stressful.

Saroj described that for him sexual issues gradually became a priority after adjusting his social life and even more after finishing his studies.

> *Sexuality started to become an issue and troubled me when I was able to face other problems gradually. I started to think how to make my sex life successful. Life is incomplete without sex... I became tensed after starting my social life, studies... I began to worry more about my sex life after finishing my studies. (Saroj)*

Saroj further highlighted that he was concerned about his sexual performance, fertility capacity and partner's attitude towards him. The anxiety from the lack of information and education about his sex life after SCI is palpable. He described it in this way:

> *This heartache was like: from now onward how to make sex life successful; either I will be able to have children in future or not; how will be my partner; whether she will understand me or not; whether she will be open to me or not. Sex life may be successful but it will not be same as able bodied life. (Saroj)*

Ashish also described that for him his relationships with friends - both male and female – as the most important concern at this stage in his life:

> *... After re-starting school, I began making friends, and I came to know the importance of friendship. Otherwise, I knew only about family.... I have friends, and not having a girlfriend is not a big issue.*

However, in this description his emergent appreciation for his sexuality can be observed. For Ashish, lack of an erection was an issue. In addition, his anxiety due to a lack of information and education about his sex life after SCI is also understandable:

> *What can I say and how can I explain. If someone comes in my life and if I have sex then there may be a time and such situation as well. (Ashish) However, mainly in the absence of erection how am I going to face it? That*

> *concerns me a little bit. Although there may be solution to sexuality issues, I am not aware of that information. (Ashish)*

Ashish further echoed his and many of his peers' needs for information and advice in dealing with sexual issues.

> *There are friends like me who also do not able to obtain erection. I would like to know what kind of solution: technology; medicine are there? You may know them and when the findings from the research are available then other friends with SCI also would be able to know about it. (Ashish)*

Saroj echoed that sex taboos and myths about the sexual capacity of MWSCI in the wider society are a barrier now to seeking a professional's support for unmarried MWSCI like him. The lack of sexual education during his rehabilitation, follow up services in sexuality from the rehabilitation centre and mechanisms to provide support in the community is also clear. He described it as:

> *I have not asked with anyone yet... Yes, it is a problem in the context of Nepal. I feel that the health professionals' attitude will be different if a wheelchair user goes and asks them that: I have a girlfriend and I would like to have sex with her; how to take this medicine. The attitude has not changed in Nepal and doctors also do not think that a wheel chair user can have sex. In a radio program a doctor (name omitted) was telling that sex life after the SCI will be totally damaged. (Saroj)*

Even some married participants had no information about the erectogenic drugs and were not able to explore the potential benefit of it in their sex life. Nabin's concern for fulfilling his wife's sexual desire is understandable. He described it as:

> *There is no sensation, erection and ejaculation, and sexual intercourse is also not possible... These issues continued to exist... if there would be medicine which can help to obtain strong erection... ejaculation... It would be very nice... then we would be able to fulfil our wives' wants and desire. (Nabin)*

Some participants appeared to continue self-medicating despite fearing and experiencing side effects. For example, in this description Gaya's need for using erectogenic drugs amidst the fear of the side effects of drugs and a lack of access to health professionals is clear. He described it as:

> *Medicine from my local town... makes me mad, it is not good. I do not take medicine usually... I am trying. It would be better if it can be like before... if medicine does not harm then it is fine but life will be ruined if medicine causes loss, make me weak and mad. This is my experience. I am looking for anyone: doctor, health worker who can advise me what to do and what not to do to make it as that of before. (Gaya)*

Similarly, Bharat also described self-medicating and taking higher doses to improve erection strength despite experiencing and fearing side effects. He described it as:

> *I have used only Sildenafil Citrate time to time... when I took a 50 mg tablet I could feel the palpitation of my heart as if it is going to burst within 2-3 minutes... I was very scared and I became very apprehensive... erection lasted for about 5-6 hours and gradually declined and there was some effect until 10-12 hours. However, erection strength was not good enough for penetrating vagina... When I took 100 mg on the next day... then the same problem occurred. (Bharat)*

In the next description, Bharat described benefiting from his friend's advice to take the same medicine on an empty stomach. His hesitation to consult due to his lack of trust, and lack of local professional support is understandable from his previous descriptions. He described it as:

> *I consulted my foreigner friend... He advised me to take 50 mg in empty stomach. He told me that 50 mg in empty stomach will have an effect of 100 mg in full stomach... In doing so there was slightly more erection. I came to know that from my experience. (Bharat)*

Nuances and subtleties in all of the above descriptions showed that most unmarried MWSCI and very few married MWSCI have received information about sexuality during their rehabilitation. However, for both married and unmarried men and irrespective of when sexual issues started to become a priority, whether they had obtained some sexual education or not, erection is a major concern in the long term.

This indicated that MWSCI were not able to benefit from the potential benefit of existing sexual rehabilitation measures in the absence of the judicious use of erectogenic drugs and non-penetrative sexual activities.

For some MWSCI, bowel and bladder accidents during sexual activity is an ongoing source of embarrassment. A negative experience like this can have an effect on sexual interest and relationships particularly for single or never married MWSCI who do not have a committed partner. For example, Sirish described that despite following the instructions provided during his rehabilitation he was not able to prevent urine incontinence. He described it as:

> *According to the training we need to have sex after clearing both bowel and bladder. Although I cleared the bowel and bladder small amount of urine got leaked. That was the issue and then I have not had sex with anyone else. (Sirish)*

Whereas Saroj described that for him urine incontinence continues to be an issue due to a lack of his partner's appreciation of his limitation and an unwillingness to adopt woman on top sexual position. The lack of sexual information and education in the wider society and social influence on the women's passivity in sexual activity are understandable. He described it as:

> *It is in the same way how it happens in Nepal: man on top and woman on the bottom…. I feel that it would be easier and better if she comes on top… because… I will not have problem with urine. When I am on top, bladder gets pressed and I need to apply some effort also... so sometime urine gets leaked. (Saroj)*

In the previous chapter it has been observed how the social perception that MWSCI are unable to reproduce, challenges their manhood. On the one hand, because of social prejudices, the ability to reproduce could possibly help MWSCI to prove their manhood. On the other hand, unfortunately society further escalates the situation by doubting the character of the women in the case of a pregnancy. It is understandable why all single and never married MWSCI, childless married MWSCI raised their concern about their fertility and fathering ability. In addition, for some men with a pragmatic need to have a son for support later was even more important after SCI. The following data shows the ongoing fertility concerns and difficulties experienced by MWSCI in obtaining fertility information and services. For example, in this description Pradeep describes how the social prejudices towards the fertility capacity of MWSCI have added stress to his sex life that has already been complicated by sexual impairments:

> *At that period, I used to feel a little tense because the injury has hampered my sexuality and my wife was very young in her age. It adds further stresses. What will happen if I could not give pleasure? Similar questions were raised by relatives in the society. Even in that state we tried practically… Next issue is Society. Another aspect is that he has the desire, he has a good relationship with his spouse and somehow both the couples are sexually satisfied (obtaining/giving sexual satisfaction) but outside (their relation) behind the curtain there is a society. What that community is going to say?... He has the desire for having sex with his wife but in the case of pregnancy the society can say that he does not have that capacity, this (pregnancy) could have happened from someone else. (Pradeep)*

Whereas, Dinesh described his agony on not being able to reproduce and the pressure to reproduce in this way:

> *If we could have a baby then she would be happy even if we do not have sex.... Despite so much effort and desire for a child we do not have a child; I feel frustrated all the time… Why is so? Some of them have succeeded but why not mine. Is it because, that day has not come yet… maybe it is my destiny. I also feel that how much grief God has given us... Since I am like this, if there is a child then there would be support for future… I am expecting and wishing for at least one child … We are in an anxious state as everybody has got children already. However, we are not able to have any children despite longing for it… My wife says that anyhow we need to have at least one child. We need to have one even by using the test tube method. You are in this state, so we need to have a child at any cost for us as well as for others watching us. (Dinesh)*

Similarly, all participants bar one single and never married MWSCI described their fertility concerns and uncertainty about their ability to father children. For example:

> *Well. This heartache was like: from now onward how to make sex life successful; either I will be able to have children in future or not. (Saroj)*
>
> *Other questions are whether I am capable of having children or not? If I got married whether it is possible to have children in the absence of erection? (Ashish)*
>
> *Sometimes, I think that if there is a need for children in the future how could that be possible? (Bibek)*

Most of the participants had heard about artificial fertilization, particularly 'test-tube-babies'. For example, Ashish echoed most participants' views as:

> *Now test tube baby technology is here in Nepal. Whether I am capable of reproducing using this technology or not? (Ashish)*

Saroj further explored the issue of assisted fertility by weighing up some of the advantages and challenges. He expressed both sides of the issue:

> *I have also heard that if my ejaculate does not have the capacity to reproduce a child, then the quality of the ejaculate can be increased by taking advice from Doctors or a Sexologist… I also have heard that other people's ejaculate can be used to fertilize an egg. That is not a big issue; however, there could be some dissatisfaction about it, and there is a feeling in your mind 'why to do that?' (Saroj)*

Dinesh highlighted the need for a separate fertility clinic that is able to meet the specific needs of people with SCI in this way:

> *In a centre like Om Hospital people with various conditions go for seeking fertility assistance so it would be even better if there is a separate facility in Nepal for providing fertility assistance to people with the SCI similar to separate SCI rehabilitation centre. If there is a designated centre for the SCI then they would know the various issues of people with the SCI. (Dinesh)*

Data on fertility and concern about fathering children also indicates the need for including fertility information for both married and unmarried MWSCI during the rehabilitation period and improving the fertility clinicians' knowledge on the specific needs of MWSCI.

5.3 Discussion

5.3.1 Challenges of health care delivery system in spinal cord injury rehabilitation

According to The Edwin Smith surgical papyrus (1930) in ancient times, SCI was "an element not to be treated" (p 327). By the end of twentieth century, life expectancy of people with less severe SCI was already comparable to the general population due to an improvement in SCI care in developed countries like USA (DeVivo, Stuart, & Lammertse, 1999). On the other hand, complications secondary to SCI continue to pose management challenges as the life expectancy of people with SCI rises with availability of modern SCI care (DeVivo, Shewchuk, Stover, Black, & Go, 1992).Hence the role of rehabilitation and follow-up services to meet these challenges cannot be underestimated. Unfortunately in Nepal, health professionals still think that treating SCI patients is 'wasteful' or a poor utilisation of scarce resources and people with SCI often have to return to their home without any treatment/rehabilitation to die (Hamilton, 1978; Wee &Schwarz, 2004). Narratives of participants in this study show that the situation of SCI services still remains the same.

5.3.1.1 Pre-hospital care

Similar to that of other less resourced settings and developing countries pre-hospital care in Nepal is unable to provide the necessary care for people with SCI. There is a lack of pre-hospital care resources and inadequate expertise in most of the hospitals (Hamilton, 1978; Nguyen, Nguyen, Morita, & Sakamoto, 2008; Singh, Shrivastva, & Dulani, 2011; Singh, Sharma, Mittal, & Sharma, 2003). Good pre-hospital care is essential to minimise secondary SCI and complications (Ahn et al., 2011). In addition, immobilization and log roll are critical in preventing further damage to the spinal cord in suspected cases of SCI (Shooman & Rushambuza, 2009). Often in less resourced settings, the first responder involved in pre-hospital care from the site of the accident does not have basic first aid knowledge on spinal mobilization and transportation and there is added potential risk of further damaging the already injured spinal cord (Singh et al., 2003). In addition to poor pre-hospital care, the lack of an ambulance service is a common barrier for transferring SCI patients safely to the hospitals (Nguyen et al., 2008; Singh et al., 2011). In Nepal most SCI cases are first taken to the transport access point by a family member or relative in a locally made hammock or on their back through walking trails (Hamilton, 1978). Likewise, transfer to the hospital also takes place without proper immobilization of the spine in a non-specialist vehicle, which is often unsuitable for transporting SCI cases (Hamilton, 1978; Shrestha et al., 2007). Data from this study supports these findings.

5.3.1.2 Acute SCI care

Similarly, acute SCI care also has many challenges. Studies of the health care delivery system in Nepal revealed a lack of adequate health professionals and medical supplies in the primary and secondary level health care facilities (Mishra et al., 2015; Rai, Rai, Hirai, Abe, & Ohno, 2001). Little is known about the standard of acute SCI care in the hospitals of Nepal. Education to prevent secondary complications such as pressure sores, joint contractures, deep vein thrombosis, and instructions on bowel and bladder care is also not provided in these hospitals (Wee &Schwarz, 2004). There is also an absence of a specialized SCI unit, a pre-identified referral centre, a lack of proper referral mechanisms and knowledge and awareness about SCI rehabilitation (Shah, Shrestha, & Subba, 2013). This has resulted in unnecessary referrals and the development of pressure sores while in the hospital complicating overall SCI rehabilitation and outcomes. Particularly in the mid-western region of Nepal there were multiple referrals either due to lack of hospital resources in managing SCI, or a poor referral mechanism and these were common issues experienced by participants in my study. In these circumstances, it is clear why sexual education was not part of early SCI care.

5.3.1.3 SCI rehabilitation services

Further, accessing timely rehabilitation services is still a challenge for many people with SCI in Nepal. It can take 7 days to 9 years for accessing rehabilitation services in Nepal as compared to 18 to 300 days in Canada (Wee &Schwarz, 2004). Non-governmental organizations such as Green Pastures Hospital and Rehabilitation Centre in the western development region and Spinal Injury Rehabilitation Centre in the central development region are the only facilities offering multidisciplinary SCI rehabilitation service in a country of 26.4 million populations. In addition, the limited number of total beds available for SCI rehabilitation has also resulted in prolonged rehabilitation waiting times. Furthermore, factors such as poverty, lack of rehabilitation referral and access to information on rehabilitation services, were the main reasons for delayed rehabilitation in addition to limited and centralised rehabilitation services (Shah et al., 2013).

5.3.1.4 Financial burden of health care due to SCI

The poor quality of health care services has indirectly increased the cost of SCI care and rehabilitation. Despite there being a similar risk of developing pressure sores in developed and developing countries, an increased prevalence and incidence of pressure sores in the developing world are due to a lack of resources and services such as acute care, patient to nurse ratio, the supporting surface and education (Zakrasek, Creasey, & Crew, 2015). Compromise in the quality of early SCI care (Wee & Schwarz, 2004) in these circumstances is inevitable. Moreover, data from my study suggested that the occurrence and reluctance to treat pressure sores in the hospital and prolonged healing time also increased the overall rehabilitation duration and expenses. Further, in Nepal spinal surgery is conducted in general hospitals because of the lack of spine and spinal cord surgery specialty units (The University of British Columbia (n.d., para 4). There is also a lack of evidence demonstrating the benefits or harm of surgical management of traumatic SCI (Bagnall, Jones, Duffy, & Riemsma, 2009). Due to lack of appropriate post-operative rehabilitation and rehabilitation referral the participants in my study who had high cost surgery did not show any advantage over conservatively managed MWSCI.

Furthermore, out -of -pocket expenses for treatment hugely impacted on the financial situation of MWSCI and their families. Since 2014 the Ministry of Health and Population (MOHP) has initiated providing financial support of one hundred thousand rupees to MWSCI however, access to this support is limited to those receiving treatment from specific hospitals in the capital city and very few hospitals and health professionals are aware of this policy (Shrestha, 2014). Compared to the cost of SCI care and rehabilitation this one time support is negligible. All of these issues contributed to the delay in further rehabilitation, uncertainties and hopelessness in the patients and a blowout in personal expenses.

5.3.2 Sexual rehabilitation in SCI

Sexual health of MWSCI is neglected by the health practitioners and society at large similar to that of other people with disability. In many societies there is often a lack of opportunity to obtain information about sexuality and reproductive health either at home or in school for young men compared to girls and women of their age (Groce et al., 2009). In Nepal, sex and sexual health is still a taboo topic and formal sex education is not comprehensive enough even for girls (Menger, Kaufman, Harman, Tsang, & Shrestha, 2015). It is even truer in the case of young men with disabilities because they have less opportunity to acquire appropriate information than other younger people (Groce et al., 2009). Both mainstream and special school educators do not have adequate knowledge or the capacity to provide comprehensive sexual education on the topic of sexuality and disability (Taiwo, 2012). It is not surprising to know that even in a developed country like Australia 50% of participants with disability had not received any form of sex education (McCabe, Cummins, & Deeks, 2000). Most importantly motor function, bowel, bladder and sexual function are the priorities of both researchers and people with SCI (Simpson, Eng, Hsieh, Wolfe, & the Spinal Cord Injury Rehabilitation Evidence Research Team, 2012).

In addition, in developing South Asian countries like Nepal and India sex taboos such as a partner with SCI being too ill for sexual activity have been experienced as a barrier to a sex life after SCI (Scovil et al., 2012; Sharma et al., 2006). Further, the findings from these studies (Scovil et al., 2012; Sharma et al., 2006) identified the need for more information and education about sex. One surprising finding from a follow-up study in Nepal was that people with SCI reported birth control as the reason for not continuing sexual relations (Scovil et al., 2012) instead of pursuing their relationship and using contraceptive measures. In previous studies, unavailability and discrepancy in sexual pleasure with the use of condoms have been reported as the reasons for not using condoms (Puri & Cleland, 2006; Simkhada, van Teijlingen, Regmi, & Bhatta, 2010). Data from this study identified that for couples with SCI, accessing reproductive health services is difficult due to wide spread attitudinal barriers in the community, and pregnancy is often a matter of social disgrace for them because of the social belief that MWSCI are unable to reproduce. Sharma et al. (2006) argued that various cultural taboos, misconceptions and negative attitudes towards sex embedded in Hindu culture and religion undermines SCI rehabilitation in India. Nepalese are a predominantly a Hindu society and sexuality is continues to be a taboo. Thus, although sexuality was a strong concern from early on in many MWSCI it was not raised at all during their early care in hospital and it was also not raised or discussed consistently during their rehabilitation in Nepal.

In spite of the growing concerns of researchers, health practitioners and consumers about sexuality, it is unfortunate that health practitioners and individuals with SCI still find it difficult to broach the concerns of people with SCI. In The Netherlands, although two-thirds of neurosurgeons think that sexual health is their responsibility three-quarters of them were not doing it because of a lack of client's initiatives (36%); lack of knowledge (38%); and lack of time (26%) (Korse, Nicolai, Both, Vleggeert-Lankamp, & Elzevier, 2016). Medical students do not have adequate exposure to sexuality training particularly in respect to disability (Neufeld, Klingbeil, Bryen, Silverman, & Thomas, 2002). In Turkey, the reasons given by a nursing student for not being involved in sex education were patients not reporting (61.5%) or requesting information (57%); lack of knowledge (54%); lack of time (30%) (Cil Akinci, Yildiz,

& Zengin, 2011). In Western Australia 34% of practice nurses and allied health professionals were not interested due to discomfort (19%) and lack of knowledge (15%) (Hartshorn, D'Castro, & Adams, 2013). Health care practitioners in North America also agree that they are reluctant to discuss sexual issues and these issues are not addressed adequately (Esmail, Darry, Walter, & Knupp, 2010). Mc Grath and Sakellariou (2016) challenged the occupational therapy profession stating that despite the recognition of sexuality and sexual expression of people with disability, the profession continues to exclude sexuality from its practices. Further, a survey found that 86% of multidisciplinary health practitioners were poorly trained and 94% were less likely to be involved in addressing their clients' sexual problems. Doctors and nurses were more trained, comfortable, and willing to discuss sexual issues than a therapist (Haboubi & Lincoln, 2003). Furthermore, provision of training on sexuality topics targeting improving necessary skills and knowledge have been found to improve the willingness and involvement of health professionals in sexual health rehabilitation (Hartshorn et al., 2013). Until now there has been a lack of standardized clinical tools to measure the outcomes of sexual health in SCI therefore both qualitative and quantitative data including main issues should be used to measure the outcome (Abramson, McBride, Konnyu, Elliott, & Team, 2008).

During the rehabilitation stages, participants' early sexual concerns were overshadowed by their initial concerns for survival, mourning for the loss of a smooth flow of life, uncertainties about what lies ahead in the life, and other rehabilitation priorities. Physical functioning and regaining independence in basic activities of daily living (excluding sexual activity) was the priority of the rehabilitation program whereas mobility, bowel and bladder functions were the main concerns of MWSCI during the rehabilitation stages. Regaining physical functions such as arm and hand functions for quadriplegic participants, mobility (walking) for paraplegic participants and bowel/bladder functions including sexual functions were the priorities of both paraplegic and quadriplegic participants in both short and long terms (Anderson, 2004). Although access to sexual health interventions was desired by most people with SCI at about 6 months after discharge from their inpatient rehabilitation not everyone is ready for sexual adjustment during this stage (Fisher et al., 2002). Most

SCIs agreed that it is the best time for learning (May, Day, & Warren, 2006). Some men in my study complained that their health professionals did not broach their sexuality issues during the acute stage itself. Whereas, some believed early on that bowel and bladder sensation and control were precursors to regaining sexual function and when the catheter was removed that it was an opportunity for them to check whether their erection had been preserved or not. This could have been a perfect opportunity for health practitioners to raise sexual issues and establish the foreground for psychological preparation of the individual and couples with SCI in relation to sexual activity along with bladder care and training for its management. It was generally a missed opportunity. As a result, urinary incontinence continued to be an issue of SCI sex life (Sunilkumar et al., 2015). On the other hand, participants of a follow-up study from the rehabilitation setting of this current study indicated the need for more information on sexuality suggesting that the gap between the services provided for sexual rehabilitation and the services desired (Scovil et al., 2012).

Finally, the participants in this study raised issues such as confidentiality and privacy of sensitive information; lack of trust of the staff's capacity to address their sexual issues; lack of fertility information, referral advice and follow-up; and inadequate attention to their legitimate concerns. In general staffs who were usually involved in addressing sexuality issues of the participants in this study were the physicians, peer counsellors and occupational therapists. The consortium for Spinal Cord (2010) identified promotion of sexual health as the responsibility of all disciplines working with people with SCI and highlights the importance of the staffs' positive attitudes in addressing the sexual issues of their clients. However, the involvement and overall attitudes of other staff could not be ascertained from the perspectives of MWSCI due to a lack of information about these other disciplines. In addition, addressing sexual issues towards the end of the rehabilitation program and discharging them without adequate information, education and advice in a consistent manner similar to that of other rehabilitation priorities has resulted in limited benefits for MWSCI. Furthermore, rumination about sexual deficits, sex life and the search for information and advice about sexuality by MWSCI in this study strongly suggested a lack of follow-up services and support in the community. Such gaps between services provided during rehabilitation and expectation of clients is not uncommon (Tepper, 1992). Therefore, in the less resourced setting of developing countries, without improving the knowledge, attitude and competence of relevant staff in creating a suitable and safe environment to discuss sexuality issues from early on, health practitioners will not be able to identify and address the genuine sexual concerns and needs of MWSCI from the traditional rehabilitation approach.

5.3.3 Community reintegration challenges

Environmental (social and physical) barriers combined with the impairment of various body structures and functions make it difficult for people with SCI to reintegrate back into community life (Cieza et al., 2010). Provision of social support has been found to be associated with better health, adjustment, life satisfaction and functioning after SCI (Müller, Peter, Cieza, & Geyh, 2012). Even in highly resourced settings of developed countries secondary health issues (Middleton, Lim, Taylor, Soden, & Rutkowski, 2004; Tonack et al., 2008; Vogel, Krajci, & Anderson, 2002), decreased the opportunities for employment (Anderson & Vogel, 2002; Kang, Shin, & Kim, 2014; Kennedy et al., 2006; Tsai, Graves, & Lai, 2014), disruptions in sexual relations (Noreau & Fougeyrollas, 2000) and availability of accessible transportation continue to be ongoing challenges of SCI life although community needs such as skin care, mobility aids and accommodation are usually well addressed (Kennedy et al., 2006; Kennedy et al., 2010). Whereas, in rural and less resourced settings of Nepal, people with SCI often had to return to their home without proper treatment or rehabilitation due to insufficient resources in the hospitals, inadequate knowledge and negative attitudes about SCI care among the health practitioners are increasing the dread and hopelessness concerning SCI in the community (Hamilton, 1978). In addition, prevention of secondary health complications such as pressure sores and urinary tract infections have been identified as the ongoing needs of people with SCI in the communities of Nepal (Wee &Schwarz, 2004). Moreover, lack of: accessible home and community environments, vocational training and employment opportunities, and suitable mobility aids have been identified as challenges of community reintegration (Scovil et al., 2012). As a result of which community participation (measured by using p-Scale) has been found to be restricted moderately (Wee &Schwarz, 2004) to severely (Scovil et al., 2012). While people with SCI in Canada has been found to experience only mild restriction (Wee & Lysaght, 2009). The data from this study are consistent with findings of previous studies that difficult geographical terrain, inaccessible homes, public places, and transportation have been experienced as the barriers to successful community reintegration. Further, MWSCI's inability to return to previous occupations of subsistence farming and generate income from other employment due to physical limitations, environmental barriers and limited employment opportunities appear to threaten their provider roles.

Finances and sex life after the SCI are major sources of dissatisfaction among MWSCI globally. Data from this study showed that MWSCI and their family experience a blow-out in expenses after the injury because of out-of-pocket expenses for SCI treatment. This included an indirect increase in expenses due to poor services, personal loss of income after injury and the loss of another family member's income since as a carer (usually a close family member) had to accompany the person with SCI during early treatment and rehabilitation periods. In addition, a SCI follow-up study in Nepal found that about one-third of people with SCI did not have any income at all and only a half of married couples who had received sex education were continuing marital relationships (Scovil et al., 2012). In a comparable setting in India, about a half of the participants reported uncordial relationships and their sex life was worse than the pre-injury level (Sharma et al., 2006). Likewise, employment rates of people with SCI in less resourced countries are low 13% (Levy et al., 1998), 27% (Deconinck, 2003) and 35% (Prabhaka & Thakker, 2004). Even the MWSCI from developed countries such as Australia (Cobo-Cuenca, Sampietro-Crespo, Virseda-Chamorro, & Martín-Espinosa, 2015), and European countries are less satisfied with their sex life, financial and employment situation after SCI (Kennedy et al., 2006; Kennedy et al., 2010). Although a definite cause of wide spread ongoing self-harming thoughts among MWSCI from early on cannot be ascertained, the contribution from an escalation in expenses, inability to fulfil the provider role, a lack of social security safety net and ongoing sexuality issues after the injury cannot be underestimated.

Suicide rates are at the higher end among people with SCI particularly among MWSCI. A one year SCI follow-up study from Nepal found that 26% of participants (n=37) had died within 1 to 3 years following discharge and about a half of the (24) participants who were interviewed were also experiencing issues such as depressive moods, difficulty in sleeping and alcohol and other drug use (Scovil et al., 2012). The findings of this study revealed that pressure sores, infections and suicide (2 cases) were the most likely cause of death. This discrepancy is not simply a coincidence and death due to suicide could be higher than reported as a result of self-neglect. Macleod (1988) demonstrated that 9% (n=400) of people with SCI are susceptible to self-neglect an existential suicide or manifestation of an adjustment to disability, a major depressive episode and underlying cause of death from complications such as infection, pressure ulcer after SCI could be actually due to self-neglect or passive suicide. According to Macleod, patients deprived of their autonomy to live or die may choose self-neglect as a dignified way to end their life which is an option within their capacity for self-destruction. Even in developed countries like Australia, death due to suicide is higher among people with SCI than in the general population and is increasing as compared to death due to infection (Soden et al., 2000). A recent study from USA found that "being a male" with SCI is one of the highest risk factors for suicide among people with SCI in the early years after SCI (Cao, Massaro, Krause, Chen, & Devivo, 2014). The death rate (due to infection, passive suicide and suicide) among MWSCI is exceptionally high compared to female subjects (32% in male; 1% in female; n = 37; m= 25; f= 12) in Nepal (Scovil et al., 2012). The actual death due to suicide secondary to self-neglect or passive suicide is most likely to be even more. Data from this study strongly suggested that Nepalese MWSCI felt enormous psychosocial stress to prove their manhood because of their own sexual fixation on the traditional masculine scripts, family and social pressure to reproduce.

The contribution of all of the above factors (including poor health care and rehabilitation services, secondary health issues, and participation restriction in Nepal) in exaggerating social prejudices against SCI cannot be underestimated. Traumatic SCI in young adults often results in a permanent visible disability including sexual functioning and they experience more stigmas of asexualisation and social restrictions

(Esmail et al., 2010). In addition, the impacts of sociocultural barriers have been found to be more damaging than the physical impairment to people with disability (Mayers, Heller, & Heller, 2003). Data from my study showed that social prejudices such as: MWSCI are unproductive, require lifelong care, are unable to obtain an erection, fulfil sexual desire of partner and reproduce are widespread in the communities. It is not a surprise in these circumstances why some women are under pressure to leave or choose to elope and girls do not like to marry a MWSCI. It was also found that MWSCI were concerned and worried about some of these limitations and social prejudices long before they returned to their community. Amidst these social prejudices and diminished or altered sexual functioning following SCI the fear of MWSCI that a partner/wife would cheat on them or elope; and the feeling of loss or threat to manhood are legitimate.

In Nepal, the ability to reproduce and have children possesses a great social, cultural and religious significance (Bista, 2015). Satisfaction with sex life was significantly associated with ability to impregnate a woman among Danish MWSCI (Biering-Sorensen et al., 2012). Similarly, for more than fifty percent of people with SCI from multinational backgrounds show their greatest interest about fertility information (White, Rintala, Hart, Young, & Fuhrer, 1992). Whereas, it is a symbol of manhood or womanhood, family and social status and power, inheritance of generation and property, a sign of being not cursed due to a misdeed or sin in the previous life, children are essential for performing religious rites and rituals, and access to heaven (Bista, 2015). Further, infertile men and women are referred to as ‘Aputro’ or ‘Namarda’ and “Bahila” or “Banjhi” or “Aputri”, and infertile women experience physical, psychosocial, economical and marital consequences (Bista, 2015). All of these issues put pressure on families and relationships; and undermine MSWCIs’ manhood and sexual interests. It is very apparent that the pragmatic need to have children who can carry some of the burden around the home and in employment; and the pressure not to lose their wife who carries so much personal, emotional and economic value. It is not surprising that sex/reproduction/relationships become issues very early, because in many ways they are about both happiness and survival.

5.4 Conclusion.

Pre-hospital and hospital care plays an important role in the overall outcome of SCI. Yet, unsafe and delayed transfer to the primary care, development of secondary complications such as pressure sores, multiple referrals, and lack of timely rehabilitation referral were the main features of the health care delivery system in Nepal. This was due to a lack of resources, awareness about SCI care and rehabilitation among health professionals and the wider society. In addition, there was a lack of specialised SCI care facility with a capacity to provide integrated necessary SCI care. All of these factors and the limited capacity of the rehabilitation centre, the strict admission criteria and the prolonged healing time of pressure sores have also increased the overall rehabilitation time and expenses. Further, out-of-pocket expenses, the high cost of spinal surgery, the loss of family income due to carer requirements during early and rehabilitation periods has resulted in undue financial burden to the MWSCI and their families many of whom are already poor. The extent of the burden was so high for some of these men that they were forced to discontinue their treatment and rehabilitation with the risk of injuring their unstable spine and losing life. All of these put pressure on families and relationships; and undermine manhood and sexual interest too. Still most married MWSCI are curious/concerned about sex and reproduction at a very, very early stage.

Most MWSCI have sexual concerns about their ability to achieve an erection, resume a penetrative sex life, fulfil the sexual desire of their partner and being able to ejaculate in order to be able to reproduce. These functions were important to many men in order not to lose their manhood, the pragmatic need to have children who can carry some of the burden and not to lose their wife both of whom have so much personal, emotional and economic value. However, they were not able to raise their sexual issues with health professionals and their families amidst the uncertainty about life, physical rehabilitation priority (mobility, bowel and bladder function) while in the hospital and rehabilitation care. On the other hand, sexuality was not a priority of the rehabilitation program and was discussed mostly towards the end of the rehabilitation program. In addition health professionals were also reluctant to discuss sexual issues openly. The focus of sexual rehabilitation is not clear. As a result of which sexual rehabilitation was inadequate and ineffective. Some of the underlying reasons for this were: the client's preference to discuss sexual issues with staff of the same gender, fear of losing privacy and confidentiality of information (that has strong linkage with manhood) and a lack of trust in the competence and skills of the staff.

Further, back in the community, sexual issues continued to become a problem for most MWSCI. For unmarried MWSCI it became exacerbated with a gradual attainment of personal, social (education and friends) and financial independence. Similarly for other MWSCI it became more pronounced as they continued to explore their sex life. In addition to diminished sexual functioning, lack of or inadequate sexual rehabilitation during rehabilitation, lack of follow-up services and social support in the society all had contributed to difficulty in adjustment to their present sex life for most of these MWSCI. Lack of good sexual rehabilitation is evinced by most MWSCI's continued concern to improve their erection and anxiety about their ability to reproduce. In addition, they hesitated to consult health professionals because of sexual taboos and they were taking a risk in improving erection by self-medication. Similarly, social prejudices such as MWSCI are unable to obtain erection, have sex, fulfil partner's sexual desire and reproduce were extremely challenging. These social prejudices were strong enough to threaten manhood, ending SCI couple's relationship and preventing new marriages.

Finally, the benefit of existing sexual rehabilitation in improving the sex life of MWSCI cannot be underestimated. However, the experiences and concerns of MWSCI call for radical improvements in sexual rehabilitation. These concerns relate to many important issues including partner satisfaction, fear of losing their wife, not having children, being left alone in addition to diminished sexual functioning. Further, despite the issue appearing early for many participants, there seems to be little opportunity to raise the issue with family or professionals. The little opportunity they have during rehabilitation also has many limitations. In addition, client preference for a discussion with health care provider or the same gender and client confidentiality should also be respected. Further, a provision of follow-up services in the community to address ongoing sexual issues is also needed. Also, a social awareness program can be helpful to overcome social prejudices towards SCI and their sexuality.

CHAPTER 6

CONCLUSION

6.1 Introduction

This study explored the lived experiences of Men with Spinal Cord Injury (MWSCI) who had previously accessed rehabilitation services or who were currently undergoing rehabilitation at Green Pastures Hospital and the Rehabilitation Centre, Pokhara, Nepal. It is both surprising and illuminating to know how soon after injury MWSCI are curious about their sex life and sexual capacity. Indeed, sexuality after SCI is much more important than practitioners and society seem to have assumed. Many underlying sexual meanings, concerns and needs were identified and these typically extend beyond concerns about pleasure. Sexual function can be a matter of life and death for participants. In the absence of a social security safety net and previous income, these concerns focus on: maintaining family and community structures, ensuring ongoing care, and fear of dying without social support. Sex can be seen as a ‘life line’ and recovery is determined by social prejudices, family politics, and cultural pressures to have children and a wife for support. On the other hand, failure of the health care system to deliver the necessary SCI care including sexual rehabilitation adds to fears of being unable to fulfil prescribed masculine roles. The sociocultural and environmental impact on manhood forces some of these men to redefine their masculinity and overcome their reliance on traditional scripts for masculine identity that stress sexual prowess.

6.2 Main Findings

This study identified several important issues about the sexual needs and concerns of MWSCI. These are grouped under five major themes: early and ongoing sexual concerns, loss and reconstruction of manhood, challenges to and failures of the health care delivery, sexuality as a matter of life and death, and the need for better SCI sexual rehabilitation.

6.2.1 Sexual concerns of MWSCI

Sexual functions are early and ongoing legitimate concerns for MWSCI. It is much more important than what we have previously supposed. Even in the midst of concern for life/survival loss of physical function and functional independence many MWSCI have sexual concerns from the very beginning. These concerns were about the loss of genital sensation, the ability to achieve an erection, the fulfilment of sexual desire, sexual satisfaction of the self and partner, and their fertility capacity. In addition, the impact of sexual dysfunction is experienced differently depending on personal, social and environmental factors. Among married MWSCI, sexuality emerged early on as compared to unmarried MWSCI. They were curious and concerned about erection and genital sensation as early as 2-3 days after the injury. This was followed by the uncertainties around their ability to resume their sex life and/or reproduce. Timing of sexual exploration varied depending upon the residual sexual function, availability of a partner and suitable environment for it. The presence of their wife was a trigger for early sexual interest and exploration even in the busy wards of the hospital/rehabilitation centre. In addition, fear that their partner would leave if they were not able to fulfil their sexual desires and their need to have children was a key underlying reason for the early concerns of men who have not achieved family planning about their sex life.

Sexual desire was preserved in most MWSCI, however a few experienced a decrease in sexual desire and interest either due to their inability to resume penetrative sexual activity or derive pleasure from it. Underlying reasons were erectile dysfunction and the lack of genital and ejaculation sensation. On the other hand, in participants who perceived life as uncertain or limited, or who viewed sexual enjoyment as now or never and as an essential part of human life their desire was further increased amidst a decrease in sexual functioning, performance and pleasure. Some men also felt the need to suppress their sexual wants particularly when there was a perception of feeling sexually undesirable, or they lacked a sexual partner, or had a partner who was not interested in sex or their erectile dysfunction.

The ability to achieve an erection similar to the level of before the injury was one of the most important concerns for most men. The obvious reasons for desiring a good erection were to fulfil the sexual desire of themselves and their partner, sexual pleasure and fertility. SCI patients felt that the main reason for being able to pleasure their partner and reproduce was in order to prevent infidelity and a possible elopement, leaving them without a carer or support. In addition, the psychosocial impact of all of these, the lack of erection alone and adherence to a masculine identity stressing sexual prowess challenged or contributed to the feeling of loss of their manhood. As a result, most men with erectile dysfunction either were taking the risk of self-medication to improve their erection or were looking for information on ways to improve their erections after returning home. The benefit of improvement in sexual performance and sexual-esteem from using erection-enhancing drugs was undermined by the side effects they experienced and the fear they had about these. On the other hand, in some men the lack of information and intervention to improve erection has resulted in partial sexual satisfaction dependent on non-penetrative sexual activities in some men while some were forced to accept the loss as their destiny or suppress it and sexual activity was missing from their life.

Many men reported a lack of sexual pleasure due to an absence of genital and ejaculation sensation. The importance of having genital sensation was linked to: obtaining an instant erection, having the feeling of their penis – symbol of manhood, appreciating the feeling of sexual intercourse and deriving pleasure. For most men the sensation of ejaculation was important for sexual pleasure and their ability to ejaculate was important for reproduction. Sexual pleasure from the sensation of ejaculation was described as "it is a kind of sensation which reminds me about the experiences similar to that of before SCI"; or "I am able to obtain the feeling of having sex". Whereas, the lack of ejaculation sensation was described as: "cannot feel the good feeling"; "no enjoyment in sex life as before"; or "there is not much interest in sex now because of lack of such feeling". The overall impact of lack of these sensations and sexual pleasure was a decrease in sexual interest which was described as sex being "boring"; "lack of good feeling" and "satisfaction is only obtained by wife".

The ability to reproduce is another important early concern of childless young men, men who have not achieved family planning and also as a future concern for unmarried men. For this practical reason, ejaculation is a higher priority for fertility than for sexual pleasure among married men. However, uncertainty about their capacity to father children is a source of anxiety for both married and unmarried men. The underlying reasons for the majority of men's worries and anxiety about their fertility capacity came from social values of having children and the stigma attached to childlessness in Nepali society. Preference for a son was an issue mainly for ensuring support in their old age in the absence of a social security safety net. Among unmarried MWSCI the source of this anxiety was the effect that it would have on their marriage if they were not able to father children. With this awareness most of them looked for information on alternative ways to have children. The perception that MWSCI were unable to reproduce was often a reason why family and community members encouraged wives of MWSCI to elope and discouraged girls from marrying a MWSCI. Thus the ability to father children is a visible sign of being a man in their community and therefore MWSCI with diminished sexual functioning (lack of erection, and ejaculation) are under pressure to prove their manliness.

Despite early concerns about their sexual abilities and sex life it was not possible for most of the married MWSCI to explore these issues while they were either in the hospital or in the rehabilitation centre. Therefore, practical issues around their sex life particularly penetrative sex emerged after returning to their home. Very few married men and none of the unmarried men had had any opportunity to discuss sexual issues with health practitioners or to explore it in the private environment of a half-way home, as the services were not adequate enough to address their legitimate concerns about erectile dysfunction and fertility. Sexual matters were raised towards the end of the rehabilitation program by health practitioners only allowing a limited time for couples with SCI to explore and discuss these sensitive and private issues. Couples with SCI were not able to gather enough information before returning to their home. 'Assessment of sexual desire, perceived partner satisfaction, ability to please a partner, and knowledge of non-intercourse forms of sexual expression should be a routine part of clinical practice when assessing and treating sexual difficulties'

(Phelps, Albo, Dunn, & Joseph, 2001, p. 600). There was also no mechanism to follow-up sexual issues once discharged from the rehabilitation program. Family and social environments were also not very supportive. It is in this context that most MWSCI explored their sex life in their home in the community making it very difficult for them to adjust to their current abilities and sex life. All of these warrant the provision of well-designed individually tailored sexual rehabilitation services in hospitals, rehabilitation centres and follow-up services in the community.

6.2.2 Loss and reconstruction of manhood

Manhood in most MWSCI is mainly linked to the ability to achieve an erection, sexual performance or sexual prowess, ability to provide for their family, and their fathering ability. Also linked is body image and male dominance over women in a few men. In addition, family and social prejudices attached to infertility (childlessness), inability of men to fulfil a provider role in the family and overall social attitudes towards the sexuality of men with SCI (disability) strongly challenges manhood. Thus, men with erectile dysfunction and infertility who perceived themselves as unable to fulfil one or more of these functions or socially prescribed gender roles are at risk of feeling emasculated. The situation is further exacerbated when men adhered to the masculine identities stressing sexual prowess and when they perceive that they are not able to satisfy their partner sexually. Connell (1995) also suggested that manhood (masculine identity) is threatened when gendered performance breaks down for any underlying reasons (p. 54). Sexual dysfunction and infertility challenging manhood are illustrated in the earlier section of this chapter. The next section will discuss the importance of the provider role in maintaining manhood.

Poverty is wide spread in Nepal. Most MWSCI are the primary breadwinners of the family. In addition, most are already poor and their families rely on subsistence farming. Moreover, they are unable to return to previous occupations and find other paid work because of their physical limitations and environmental barriers. Further, most had less than ten years of schooling and did not have any other vocational or trade skills. Thus, most men become very aware that their provider role and the difficulties in fulfilling this role very early after the injury are an issue. Furthermore, they are also unable to choose the career of their aspirations or one that is highly regarded by their families and society. On the other hand, society portrays MWSCI as a person who needs care, is unproductive and unable to fulfil family needs. Data from the study showed that two-thirds of the now single and never married MWSCI who were able to find employment were also able to find a partner for sex and had better sexual esteem. In addition, financial independence took priority to partnering and intimacy for most participants including those who were not employed. Further, both participants undergoing rehabilitation and living in the community identified vocational skills, employment and financial independence as prerequisites for finding a suitable partner for a relationship and/or marriage. The ability to earn and look after the family is one of the important socially prescribed roles that provide them with a strong sense of their manliness and vice versa.

The impact of all of the above issues on manhood is such that men feel the need to reconstruct their sex life by changes to their gendered roles, redefining their masculinity and relationships. Often the dilemma for a married MWSCI is to stay with their spouse because they need a carer and in doing so to continue a relationship in which their traditional masculine identities (manhood) are compromised. Subsequently, there is a very slow but gradual shift towards the traits that are moving away from adherence to the traditional script of masculine identity that stressed sexual prowess. For example: a shift towards prioritising sexual satisfaction for their partner, a strengthening of their existing relationship, the formation of a new relationship based on mutual understanding over reinforcement of male dominance, and a focus on intimacy in their emotional relationships. MWSCI are able to shift their focus to non-penetrative sexual activities such as manual stimulation, lying against each other, verbal teasing to derive personal sexual pleasure with more understanding of their partner’s needs. MWSCI also are ready to accept childlessness or adopting a child in contrast to the social prejudices of childlessness and the family pressure to reproduce for maintenance of their family lineage. This is not an easy process as it involves a lot of negotiation between personal ego, self-reflection, balance of social prejudices and family politics. In addition, the existing model of the health care delivery has failed to recognise and address the specific biomedical sexual concerns, contextual sexual issues and the psychological impact on the manhood of MWSCI. As a result, the process of sexual adjustment as well as the social reconstruction of manhood after the SCI is disrupted. Further, in the absence of a well-designed sexual rehabilitation program, role model and social support this becomes a lonely journey.

6.2.3 Challenges or failure of health care delivery system in SCI rehabilitation

There are many challenges in the health care delivery system in relation to early SCI care and rehabilitation. These challenges are lack of: pre-hospital care resources, adequate expertise in hospitals, pre-identified referral centres, specialised SCI units, and a lack of proper referral mechanisms and knowledge and awareness about SCI rehabilitation. In addition, there is also a lack of proper management and education to prevent secondary complications such as pressure sores in hospitals. Accessing timely rehabilitation services is still a challenge for many people with SCI in Nepal due to lack of proper rehabilitation referral, access to information on rehabilitation services, and limited and centralised SCI rehabilitation services. All of these issues contribute to the delay in further rehabilitation, uncertainties and feelings of hopelessness in the patients. Furthermore, unnecessary expenses due to inappropriate referrals, pressure sore complications, delayed and prolonged rehabilitation, costly spinal surgery without proper post-operative rehabilitation, and out-of-pocket expenses for treatment hugely impacted on the financial situation of already poor MWSCI and their families.

6.2.4 Sexuality as a matter of life and death

For MWSCI, sexuality is much more than pleasure: it’s a matter of life and death. Sexuality literally offers MWSCI a life line. When MWSCI are in the hospitals they fear that if they go back to their home they are going to die and they have concerns about how they are going to survive for the rest of their lives. In addition, although reproduction and sexuality have different dimensions they are intricately intertwined with each other for maintaining marriage, their social life, and immediate support systems as well as their care in old age because of the social prejudices, family politics and the lack of a safety net. In addition, lack of appropriate follow-up services and peer support in the community are obstacles to successful community reintegration and adjustment with their sex lives. All of these contribute to their fear that their wives could leave them or elope if their sexual needs and need to have children are not fulfilled. Most participants are concerned about sexual satisfaction of the partners/wives and their ability to reproduce. With this awareness they participate in sexual activity either to satisfy their partner sexually or to produce children or both irrespective of their sexual desire or interest. Therefore, the fear of losing their only carer and support for the family and children is legitimate and real for them.

One of the major factors that affected the sex life, relationships and marriage of MWSCI was negative social attitudes towards their sexuality. Certain sociocultural barriers - beliefs and values of the participants' society can be as disabling as physical impairment (Sakellariou, 2006a; Sakellariou & Sawada, 2006). Men with SCI were perceived as unable to obtain an erection, unable to fulfil the sexual desires of their partner and unable to reproduce so their needs for fulfilling sexual desire, intimacy, partnering and marriage were undermined. In addition, they were also viewed as unproductive, people needing lifelong care and unable to fulfil their provider role in the family. These prejudices also pressured some women to elope with other men and potential partners to choose not to marry MWSCI. The role of parents-in-law was the most important factor that influenced their daughters to elope. There was an acknowledgement from the MWSCI who lost their wife after SCI that they were not able to fulfil the sexual desires of their spouses. It was also found that MWSCI were concerned and worried about some of these limitations and social prejudices long before they returned to their community. Amidst these social prejudices and diminished or altered sexual functioning following SCI the fear of MWSCI that a partner/wife would cheat on them or elope; and the feeling of loss or threat to manhood are legitimate.

All of these issues put pressure on families and relationships and undermine MWSCI manhood and sexual interests. It is very apparent that the pragmatic need to have children who can carry some of the burden around the home and in employment, and the pressure not to lose their wife who carries so much personal, emotional and economic value. It is not surprising that sex/reproduction/relationships become issues very early, because in many ways they are about both happiness and survival.

6.2.5 Need for a better SCI sexual rehabilitation

Sexual rehabilitation in MWSCI deserves much more attention from health practitioners and society than it has been given. Sex and sexual health is still a taboo topic in Nepal. In addition, MWSCI suffer the stigma of asexualisation and social restrictions in partnering and marriage. For example, a partner with SCI being too ill for sexual activity has been experienced as a barrier to a sex life after SCI. Data from this study identified that for couples with SCI, accessing reproductive health services is difficult due to wide spread attitudinal barriers in the community, and pregnancy is often a matter of social disgrace for them because of the social belief that MWSCI are unable to reproduce. Therefore, hospitalisation and the rehabilitation period offers a window of opportunity to address the early and legitimate sexual concerns of MWSCI and empowering these men and their families to deal with some of these widespread prejudices attached to sexuality of MWSCI. However, sexuality was not raised at all during their early care in hospital and it was also not raised or discussed consistently during their rehabilitation in Nepal.

During the rehabilitation stages, participants' early sexual concerns were overshadowed by their initial concerns for survival, mourning for the loss of their previously smoothly flowing life, uncertainties about what lies ahead, and other rehabilitation priorities. Some men in my study complained that their health professionals did not broach sexual issues during the acute stage itself. Whereas, some believed early on that bowel and bladder sensation and control were precursors to regaining sexual function and when the catheter was removed that it was an opportunity for them to check whether their erection had been preserved or not. This point could have been an ideal opportunity for health practitioners to raise sexual issues and establish the foreground for psychological preparation of the individual and couples with SCI in relation to sexual activity along with bladder care and training for its management. In addition, the participants in this study raised issues such as confidentiality and privacy of sensitive information, lack of trust of the staff's capacity to address their sexual issues, lack of fertility information, referral advice and follow-up, and inadequate attention to their legitimate concerns. Further, there is also a lack of follow-up services and support in the community. Therefore, improving the knowledge, attitudes and competence of relevant staff in creating a suitable and safe environment to discuss sexuality issues from early on including the development of a mechanism to follow-up these issues after discharge to the community is warranted.

6.3 Strengths and limitations of the study

Most participants in this study understood the importance of their participation in the study. They shared the details of their intimate and sensitive issues with the insight that sharing their experiences would help to improve sexual rehabilitation services in the future and would benefit themselves as well as other recently injured MWSCI. In addition, some of them even expressed their wish to share their experiences without maintaining anonymity to strengthen the validity of their experiences. Further, participants also expressed their gratitude to the study stating that it provided them an opportunity to share their experiences and feelings which they have carried with them for so long since their injury. As a result of which some participants described benefiting from that interview which I see as the increased awareness of their own situation as they reflected about their lives during the interview. At least one participant identified the researcher as a person who has lived through SCI and speculated that I too could have fertility issues as a result of the SCI.

There were a few limitations of this study which could not be avoided. Participants' responses particularly on staff attitudes towards their sexuality could have been influenced by social desirability or pressures. Underlying assumptions for this are that some of the participants were familiar to me since they were rehabilitated from the centre where I had worked in the past as a therapist and thus with a client relationship from the past this may have influenced the participant to give socially desirable answers or on the other hand may have enabled deeper reflections due to rapport that had been built before. In addition, MWSCI who were married after the injury could not be included in the study despite the use of purposeful sampling for some practical reasons. Given that two of the participants were known to be married after injury but were unable to be contacted. In addition, the search for such participants who were rehabilitated from other rehabilitation centres could not be extended because of the major devastating earthquake during the data collection period. Further, MWSCI who had not received rehabilitation from GPHRC were excluded. Therefore, experiences of MWSCI who were rehabilitated from other hospitals or rehabilitation centres and who have never accessed any SCI rehabilitation may be different.

6.4 Recommendations

Functional outcomes including sexual functioning following SCI is dependent on the quality of SCI care and rehabilitation. Findings from this study revealed some important limitations in early SCI care and were consistent with other studies such as the quality of pre-hospital care (Hamilton, 1978; Nguyen et al., 2008; Shooman & Rushambuza, 2009; Shrestha et al., 2007; Singh et al., 2011; Singh et al., 2003), development of secondary complications during hospital care or before entering the rehabilitation program (Aito, 2003; J. Wee & R. Schwarz, 2004), lack of proper referral mechanisms (Wee &Schwarz, 2004) and a SCI specialized unit (Aito, 2003) that has both direct and indirect impacts on the sexuality of MWSCI. Therefore, based on these findings (gap between current SCI services and services desired), I make the following general recommendations to improve the quality of early SCI care.

General recommendations:

1. Improvement in the pre-hospital care services.
2. Development of a specialised unit consisting of multi-disciplinary expertise and a capacity to provide all necessary SCI care and or identification of an existing referral centre that has the capacity to provide the necessary SCI care.
3. Development of a hospital and rehabilitation referral mechanism.
4. Pressure sore prevention and education should be emphasized from the start. Resources of acute care settings and capacity of health practitioners need to be improved through further skills development and education.
5. Provision of informed choice for surgical and conservative rehabilitation management of SCI.

Recommendations specific to sexual rehabilitation:

An individually tailored education and rehabilitation program is essential for addressing specific sexual needs of the people with SCI (Consortium for Spinal Cord, 2010). To achieve this goal, health professionals' knowledge on sexuality, understanding of the client's context, as well as their ability to create a nonjudgmental environment (where the client can raise their sexual issues without losing their dignity) is necessary (Consortium for Spinal Cord, 2010). In addition, the gender of the health professionals plays an important role in sexual rehabilitation where sexuality is a topic of social taboo. Even in developed countries like Australia both male and female staff are conscious of their own and the clients' gender while interacting and providing care with their clients (Wilson, Stancliffe, Parmenter, & Shuttleworth, 2011). Likewise, the importance of expert peers in sexual rehabilitation cannot be underestimated if they are adequately trained or work in close coordination with the rehabilitation team (Hammell, 2007). Most of the limitations inherent in the current sexual rehabilitation program and barriers experienced by MWSCI in adjusting to their sex life are consistent with previous studies while some of them are unique to the sociocultural setting of this study. For example, sex taboos and myths associated with people with SCI, men's adherence to the traditional script of manhood, the need to reproduce and loss of manhood as a result of social prejudices and family politics are unique to the Nepalese setting. Thus based on these findings, I make the following specific recommendations to improve sexual rehabilitation services in a low resource setting like Nepal:

1. Sexuality should be an integral part of acute care/rehabilitation and it should be introduced early (Sharma et al., 2006);
2. Sexual rehabilitation should be placed in a social and relationship context. It should not simply be a mechanical discussion of function;
3. Development of strategies to address the sexual needs of unmarried and under 18-year-olds is needed;
4. Sex education material: written materials such as flyers and brochures, videos, and websites need to be available;

5. Education and counselling of individuals with SCI, their partner/spouse and family members is important;
6. Provision of half way-homes should be continued with the aim of providing privacy for clients to explore their sex life;
7. Provision of institutional and community follow-up services; community awareness for alleviating sexual myths about SCI and disability; and
8. Sexuality training of relevant staff including peer supporters for improving staff attitudes, knowledge, skills and competence in handling sensitive issues and ensuring privacy; and initiating the discussion in a comfortable and private way. A simple model like the PLISSIT approach can be used (Annon, 1976). PLISSIT is an approach for giving the patient PERMISSION to speak about sexuality; giving them LIMITED INFORMATION to start with; move on to SPECIFIC SUGGESTIONS on a case-by-case basis when the time is right; and finally offer INTENSIVE THERAPY for those who need it (Annon, 1976).

Based on findings from this study, I have adapted the protocol for sexuality education and rehabilitation of SCI patients – proposed by GPHRC staff in collaboration with the NepalAbility team in 2008 (Wee, Ruttan, Ranabhat, & Ng, 2008) and recommend its use in the hospitals and rehabilitation settings of Nepal.

Admission (Acute settings)

↓

Confidentiality assurance: SCI assessment, education, treatment and rehabilitation information

(Sex education and information using PLISSIT approach e.g. sexuality brochures)

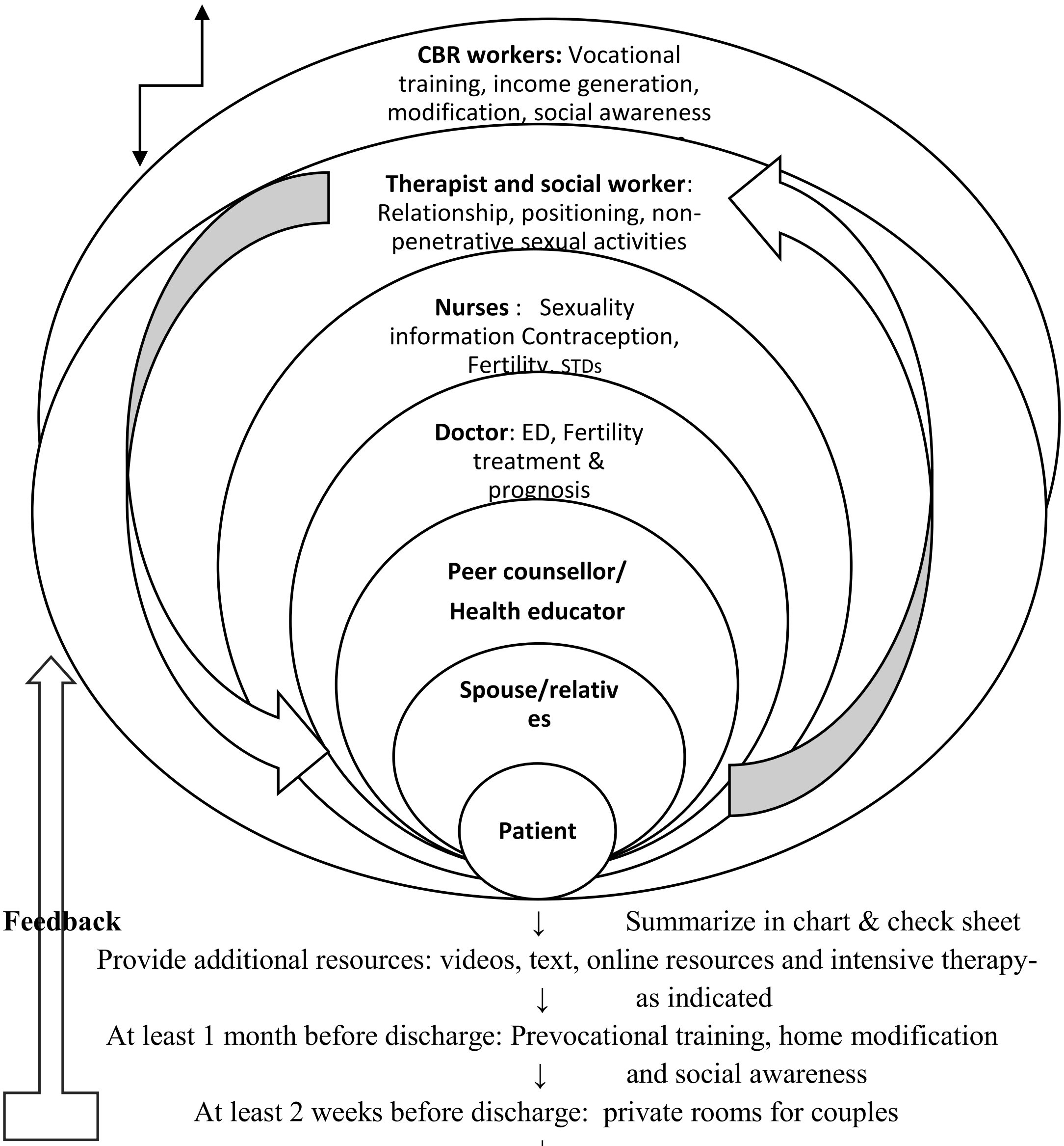
↓

Admission (Rehab settings)

Confidentiality assurance – Acute and chronic SCI assessment, education and rehabilitation

(Sex education, information and counselling using PLISSIT approach in the first 1-2 weeks: Patient/ spouse/patient and spouse/ other family members)

Contextual factors ↓ Summarise in chart and check list



Feedback ↓ Summarize in chart & check sheet

Provide additional resources: videos, text, online resources and intensive therapy- as indicated

↓

At least 1 month before discharge: Prevocational training, home modification and social awareness

↓

At least 2 weeks before discharge: private rooms for couples

↓

Discharge and follow-up as appropriate

Figure 6.1: Sexuality education and rehabilitation protocol for people with SCI

6.5 Future directions for study

Earlier studies suggested high death rates among MWSCI and this study revealed the presence of self-harming thoughts as well as a strong adherence of men to a traditional masculine script for manhood stressing sexual prowess and the provider role. Therefore, further research is needed to rule out whether the high death rate is from self-neglect because of psychosocial stress on manhood and identify the possible interventions for reducing poor outcomes. The findings from this study relied on the perceptions of MWSCI about the attitudes of their health practitioners, family members and significant others hence, a separate study to specifically identify and understand these attitudes would be beneficial. In addition, investigating and understanding sexual needs, concerns and attitudes of partners/spouses of MWSCI may benefit both health practitioners and consumers. Well-informed health practitioners may then be able to design an education program to address the needs and expectations of both the individual with SCI and their partner (family) and foster a better relationship and sex life based on mutual needs and understanding among SCI couples. Further, while I was collecting data for this study, health practitioners, social workers and peer supporters raised sexual issues among women with SCI hence a similar study to identify the sexual concerns and needs of women with SCI and their partners is indicated. Furthermore, collection of data by anonymous surveys at a national level would provide the opportunity to compare the results of current findings based on phenomenological interviews.

6.6 Conclusion

This chapter discussed the conclusions, strengths and limitations of the study. It presented recommendations for improving practice that were informed by the clients' specific and contextual sexual needs to facilitate the process of sexual adjustment, reconstruction of manhood and to minimise the psychological impact on men's health. In addition, an adapted sexuality education and rehabilitation protocol is proposed for use in the Nepalese setting. Finally, potential directions for future study on the neglected issue of sexuality of people with SCI are made.

This phenomenological study was thus able to explore biological, individual and social aspects of sexuality from the perspective of MWSCI. The findings of this study should inform and influence the behaviour and decision of the health care planner, policy makers, health professionals, people with SCI and their families and disabled people’s organisation in Nepal and South-Asia sharing similar sociocultural settings.

REFRENCES

Abramson, C. E., McBride, K. E., Konnyu, K. J., Elliott, S. L., & Team, S. R. (2008). Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. *Spinal Cord, 46*(5), 320-324. doi: 10.1038/sj.sc.3102136

Acharya, T. (2012). Gender, disability, and literature in the Global South: Nepali writers Jhamak Ghimire and Bishnu Kumari Waiwa (Parijat) (Master's thesis, Florida AtlanticUniversity). Retrieved from https://fau.digital.flvc.org/islandora/object/fau%3A3998/datastream/OBJ/view/Gender__disability__and_literature_in_the_Global_South.pdf

Adhikari, R., & Tamang, J. (2009). Premarital sexual behavior among male college students of Kathmandu, Nepal. *BMC public health*, 9(1), 241-241. doi: 10.1186/1471-2458-9-241

Agampodi, S. B., Agampodi, T. C., & Piyaseeli, U. (2008). Adolescents perception of reproductive health care services in Sri Lanka. BMC health services research, 8(1), 1.

Ahn, H., Singh, J., Nathens, A., MacDonald, R. D., Travers, A., Tallon, J., . . . Yee, A. (2011). Pre-Hospital Care Management of a Potential Spinal Cord Injured Patient: A Systematic Review of the Literature and Evidence-Based Guidelines. *Journal of Neurotrauma, 28*(8), 1341-1361. doi: 10.1089/neu.2009.1168

Aito, S. (2003). Complications during the acute phase of traumatic spinal cord lesions. *Spinal Cord, 41*(11), 629-635.

Alexander, C. J., Sipski, M. L., & Findley, T. W. (1993). Sexual activities, desire, and satisfaction in males pre-and post-spinal cord injury. *Archives of Sexual Behavior, 22*(3), 217-228.

Ali, M., Bhatti, M. A., & Ushijima, H. (2004). Reproductive health needs of adolescent males in rural Pakistan: an exploratory study. *The Tohoku journal of experimental medicine, 204*(1), 17-25.

Anderson, C. J., & Vogel, L. C. (2002). Employment outcomes of adults who sustained spinal cord injuries as children or adolescents. *Archives of Physical Medicine and Rehabilitation, 83*(6), 791-801. doi: 10.1053/apmr.2002.32742

Anderson, K. D. (2004). Targeting recovery: priorities of the spinal cord-injured population. *J Neurotrauma, 21*(10), 1371-1383. doi: 10.1089/neu.2004.21.1371

Anderson, K. D., Borisoff, J. F., Johnson, R. D., Stiens, S. A., & Elliott, S. L. (2007a). The impact of spinal cord injury on sexual function: concerns of the general population. *Spinal Cord, 45*(5), 328-337.

Anderson, K. D., Borisoff, J. F., Johnson, R. D., Stiens, S. A., & Elliott, S. L. (2007). Long-term effects of spinal cord injury on sexual function in men: implications for neuroplasticity. *Spinal Cord, 45*(5), 338-348. doi: http://dx.doi.org/10.1038/sj.sc.3101978

Anderson, K. D., Borisoff, J. F., Johnson, R. D., Stiens, S. A., & Elliott, S. L. (2007b). Long-term effects of spinal cord injury on sexual function in men: implications for neuroplasticity. *Spinal Cord, 45*(5), 338-348.

Annon, J. S. (1976). The PLISSIT model: a proposed conceptual scheme for the behavioral treatment of sexual problems. *J Sex Educ Ther, 2*(1), 1-15.

Bagnall, A., Jones, L., Duffy, S., & Riemsma, R. (2009). The benefits and harms of spinal fixation surgery for people with spinal cord injury due to trauma are not known at the moment.

Bajracharya, S., Singh, M., Singh, G. K., & Shrestha, B. P. (2007). Clinico-epidemiological study of spinal injuries in a predominantly rural population of eastern Nepal: A 10 years' analysis. *Indian journal of orthopaedics, 41*(4), 286-289. doi: 10.4103/0019-5413.36988

Barbonetti, A., Cavallo, F., Felzani, G., Francavilla, S., & Francavilla, F. (2012). Erectile dysfunction is the main determinant of psychological distress in men with spinal cord injury. *Journal of Sexual Medicine, 9*(3), 830-836. doi: 10.1111/j.1743-6109.2011.02599.x

Bennett, L. (1983). *Dangerous wives and sacred sisters: social and symbolic roles of high-caste women in Nepal*. New York: Columbia University Press.

Bhattacharyya, N. N. (1975). *History of Indian erotic literature.* Delhi, India: Munshiram Manoharlal Publishers.

Bhutia, J. (2015, September 23). Nepal becomes first Asian nation to include non-discriminatory laws for LGBT community. International Buiseness Times.

Retrieved from http://www.ibtimes.co.uk/nepal-becomes-first-asian-nation-include-non-discriminatory-laws-lgbt-community-1520845

Biering-Sorensen, I., Hansen, R. B., & Biering-Sorensen, F. (2012). Sexual function in a traumatic spinal cord injured population 10-45 years after injury. *Journal of Rehabilitation Medicine, 44*(11), 926-931. doi: http://dx.doi.org/10.2340/16501977-1057

Biernacki, P., & Waldorf, D. (1981). Snowball Sampling: Problems and Techniques of Chain Referral Sampling. *Sociological Methods and Research, 10*(2), 141-163.

Bista, B. (2015). Lived Experience of Infertility among Community Dwelling Infertile Women. *Journal of Nobel Medical College, 4*(1), 46-56.

Boggs, D. (2014). *Sustainability workshop III*. from Retrieved from http://www.sustainingability.org/case-studies/nepal/sustainability-workshop-iii/index.html

Boyer, F., Novella, J. L., Laffont, I., Morrone, I., & Dizien, O. (2005). Ethical Considerations when Providing Information on Genital and Sexual Consequences of Spinal Cord Injury. *Sexuality and Disability, 23*(4), 209-212. doi: http://dx.doi.org/10.1007/s11195-005-8928-x

Brackett, N. L., Ibrahim, E., Iremashvili, V., Aballa, T. C., & Lynne, C. M. (2010). Treatment for ejaculatory dysfunction in men with spinal cord injury: An 18-year single center experience. *Journal of Urology, 183*(6), 2304-2308. doi: http://dx.doi.org/10.1016/j.juro.2010.02.018

Brackett, N. L., Kafetsoulis, A., Ibrahim, E., Aballa, T. C., & Lynne, C. M. (2007). Application of 2 vibrators salvages ejaculatory failures to 1 vibrator during penile vibratory stimulation in men with spinal cord injuries. *Journal of Urology, 177*(2), 660-663.

Brandsma, J. W., Schwarz, R. J., Anderson, A. M., & Herm, F. B. (2005). Transformation of a leprosy hospital in Nepal into a rehabilitation centre: the Green Pastures Hospital experience. *Leprosy review, 76*(4), 267-276.

Breasted, H. J. (Ed.). (1930). *The Edwin Smith surgical papyrus : published in facsimile and hieroglyphic transliteration with translation and commentary in* *two volumes* (Vol. 1). [EBL version]. Retrieved fromhttp://jcu.summon.serialssolutions.com/2.0.0/link/0/

Brunson, J. (2010). Son preference in the context of fertility decline: Limits to new constructions of gender and kinship in Nepal. *Studies in family planning, 41*(2), 89-98.

Burns, S. M., Hough, S., Boyd, B. L., & Hill, J. (2009). Sexual Desire and Depression Following Spinal Cord Injury: Masculine Sexual Prowess as a Moderator. *Sex Roles, 61*(1-2), 120-129. doi: http://dx.doi.org/10.1007/s11199-009-9615-7

Burns, S. M., Mahalik, J. R., Hough, S., & Greenwell, A. N. (2008). Adjustment to Changes in Sexual Functioning Following Spinal Cord Injury: The Contribution of Men's Adherence to Scripts for Sexual Potency. *Sexuality and Disability, 26*(4), 197-205. doi: http://dx.doi.org/10.1007/s11195-008-9091-y

Burton, R., & Arbuthnot, F. F. (1963). Translator's introduction (R. Burton & F. F. Arbuthnot, Trans.). In W. G. Archer (Ed.), *The kama sutra of Vatsyayana* (pp. 85-89). London, England: George Allen & Unwin Ltd.

Cameron, M. M. (1998). *On the edge of the auspicious: Gender and caste in Nepal*: University of Illinois Press.

Cao, Y., Massaro, J. F., Krause, J. S., Chen, Y., & Devivo, M. J. (2014). Suicide Mortality After Spinal Cord Injury in the United States: Injury Cohorts Analysis. *Archives of Physical Medicine and Rehabilitation, 95*(2), 230-235. doi: 10.1016/j.apmr.2013.10.007

Carlson, J. A. (2010). Avoiding Traps in Member Checking. *The Qualitative Report, 15*(5), 1102.

Cencora, M., & Pasiut, S. (2012). Sexual rehabilitation after spinal cord injury. *Rehabilitacja seksualna po urazie rdzenia kręgowego, 20*(2), 12-31. doi: 10.2478/v10109-012-0011-4

Central Bureau of Statistics [CBS]. (2014). Administrative Division. Retrieved 6 March, 2016, from http://cbs.gov.np/atlas/general.html?page=administrative_division

Chen, S. U., Shieh, J. Y., Wang, Y. H., Lu, T., Ho, H. N., & Yang, Y. S. (2005). Successful pregnancy achieved by intracytoplasmic sperm injection using cryopreserved electroejaculate sperm in a couple both with spinal cord injury:

a case report. *Archives of Physical Medicine & Rehabilitation, 86*(9), 1884-1886.

Cieza, A., Kirchberger, I., Biering-Sørensen, F., Baumberger, M., Charlifue, S., Post, M. W., . . . Stucki, G. (2010). ICF Core Sets for individuals with spinal cord injury in the long-term context. *Spinal Cord, 48*(4), 305-312. doi: 10.1038/sc.2009.183

Cil Akinci, A., Yildiz, H., & Zengin, N. (2011). The Level of Comfort Among Nursing Students During Sexual Counseling to Patients Who Have Chronic Medical Conditions. *Sexuality and Disability, 29*(1), 11-20. doi: http://dx.doi.org/10.1007/s11195-010-9185-1

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: experience and story in qualitative research*. San Francisco: Jossey-Bass Publishers.

Click Nepal [Maps of Nepal]. (2016). Retrieved 25 July, 2016, from http://www.clicknepal.com/where-is-nepal.html

Cobo Cuenca, A. I., Sampietro-Crespo, A., Virseda-Chamorro, M., & Martín-Espinosa, N. (2015). Psychological Impact and Sexual Dysfunction in Men with and without Spinal Cord Injury: Quality of Life, Sexuality, and Spinal Cord Injury. *The Journal of Sexual Medicine, 12*(2), 436-444. doi: 10.1111/jsm.12741

Connell, R. (1995). Masculinities: Cambridge, Polity Press.

Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic masculinity rethinking the concept. *Gender & society, 19*(6), 829-859.

Consortium for Spinal Cord, M. (2010). Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for health-care professionals. *The Journal of Spinal Cord Medicine, 33*(3), 281.

Constituent Assembly Secretariat. (2015). *Constitution of Nepal*. Kathmandu, Nepal: Retrieved from http://www.can.gov.np/np/ncd.html.

Courtois, F., Charvier, K., Leriche, A., Vézina, J.-G., Côté, I., Raymond, D., . . . Bélanger, M. (2008). Perceived physiological and orgasmic sensations at ejaculation in spinal cord injured men. *Journal of Sexual Medicine, 5*(10), 2419-2430.

Courtois, F., Charvier, K., Vezina, J. G., Journel, N. M., Carrier, S., Jacquemin, G., & Cote, I. (2011). Assessing and conceptualizing orgasm after a spinal cord injury. *BJU International, 108*(10), 1624-1633. doi: http://dx.doi.org/10.1111/j.1464-410X.2011.10168.x

Courtois, F., Rodrigue, X., Cote, I., Boulet, M., Vezina, J. G., Charvier, K., & Dahan, V. (2012). Sexual function and autonomic dysreflexia in men with spinal cord injuries: how should we treat? *Spinal Cord, 50*(12), 869-877. doi: http://dx.doi.org/10.1038/sc.2012.83

Coyle, D., & Boyce, P. (2015). Same-sex sexualities, gender variance, economy and livelihood in Nepal: Exclusions, subjectivity and development. Retrieved from http://www.ids.ac.uk/publication/same-sex-sexualities-gender-variance-economy-and-livelihood-in-nepal-exclusions-subjectivity-and-development

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (Vol. 2nd). Thousand Oaks: Sage.

da Silva, B. F., Borrelli, M., Jr., Fariello, R. M., Restelli, A. E., Del Giudice, P. T., Spaine, D. M., . . . Cedenho, A. P. (2010). Is sperm cryopreservation an option for fertility preservation in patients with spinal cord injury-induced anejaculation? *Fertility & Sterility, 94*(2), 564-573. doi: http://dx.doi.org/10.1016/j.fertnstert.2009.03.022

Dahlberg, A., Alaranta, H. T., Kautiainen, H., & Kotila, M. (2007). Sexual activity and satisfaction in men with traumatic spinal cord lesion. *Journal of Rehabilitation Medicine, 39*(2), 152-155.

Dahlberg, K., Drew, N., & Nyström, M. (2001). *Reflective lifeworld research*. Lund, Sweden: Studentlitteratur.

Das, S., Dodd, S., Soni, B. M., Sharma, S. D., Gazvani, R., & Lewis-Jones, D. I. (2006). Does repeated electro-ejaculation improve sperm quality in spinal cord injured men? *Spinal Cord, 44*(12), 753-756.

Deconinck, H. (2003). The health condition of spinal cord injuries in two Afghan towns. *Spinal Cord, 41*(5), 303-309. doi: 10.1038/sj.sc.3101443

Department of Health Services. (2013). National health insurance policy 2013. Retrieved from http://p4h-network.net/wp-content/uploads/2013/10/2013_03_Nepal_Health_Insurance_Policy_fin.pdf

Department of Health Services. (2014a). Annual report 2070/71. Retrieved from http://dohs.gov.np/publications/

Department of Health Services. (2014b). Department of health services. Retrieved from http://dohs.gov.np/about-us/department-of-health-services/

Department of Health Services. (2014c). Organisation structure. Retrieved from http://dohs.gov.np/about-us/organization-structure/

DeVivo, M. J., Shewchuk, R. M., Stover, S. L., Black, K. J., & Go, B. K. (1992). A cross-sectional study of the relationship between age and current health status for persons with spinal cord injuries. *Paraplegia, 30*(12), 820-827. doi: 10.1038/sc.1992.158

DeVivo, M. J., Stuart Krause, J., & Lammertse, D. P. (1999). Recent trends in mortality and causes of death among persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 80*(11), 1411-1419. doi: 10.1016/S0003-9993(99)90252-6

Dew, K. (2007). A health researcher's guide to qualitative methodologies. *Australian and New Zealand Journal of Public Health, 31*(5), 433-437. doi: 10.1111/j.1753-6405.2007.00114.x

Dhungana, M. B. (2006). The lives of disabled women in Nepal: Vulnerability without support. Disability & Society, 21(2), 133-146. doi: 10.1080/09687590500498051

Doniger, W. (2003). The Kamasutra: It Isn't All about Sex. *Kenyon Review (Kenyon College, Gambier, OH), 25*(1), 18.

Ducharme, S. H., & Gill, K. M. (1997). *Sexuality after spinal cord injury: answers to your questions*. Baltimore: Paul H. Brookes Pub.

Ekland, M. B., Krassioukov, A. V., McBride, K. E., & Elliott, S. L. (2008). Incidence of autonomic dysreflexia and silent autonomic dysreflexia in men with spinal cord injury undergoing sperm retrieval: implications for clinical practice. *Journal of Spinal Cord Medicine, 31*(1), 33-39.

El Masri, W. (2006). Traumatic spinal cord injury: the relationship between pathology and clinical implications. *TRAUMA-LONDON-, 8*(1), 29.

El Masri, W. (2010). Management of Traumatic Spinal Cord injuries: current standards of care revisited. *Adv Clin Neurosci Rehabil, 10*(1), 37-39.

Elliott, S. (2010). Case study: Erectile dysfunction following spinal cord injury. *Journal of Sexual Medicine, 7*(12), 3808-3814.

Ergin, S., Gunduz, B., Ugurlu, H., Sivrioglu, K., Oncel, S., Gok, H., . . . Senocak, O. (2008). A placebo-controlled, multicenter, randomized, double-blind, flexible-dose, two-way crossover study to evaluate the efficacy and safety of sildenafil in men with traumatic spinal cord injury and erectile dysfunction. *Journal of Spinal Cord Medicine, 31*(5), 522-531.

Esmail, S., Darry, K., Walter, A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. *Disability & Rehabilitation, 32*(14), 1148-1155. doi: 10.3109/09638280903419277

Fisher, T. L., Laud, P. W., Byfield, M. G., Brown, T. T., Hayat, M. J., & Fiedler, I. G. (2002). Sexual health after spinal cord injury: A longitudinal study. *Archives of Physical Medicine and Rehabilitation, 83*(8), 1043-1051. doi: 10.1053/apmr.2002.33654

Forum for Women Law and Development [FWLD]. (2008). *Women and sexuality in Nepal: A study report.* Retrieved from http://fwld.org/publications/women-sexuality-nepal-study-report-2/

Frank, R. G., Umlauf, R. L., Wonderlich, S. A., Askanazi, G. S., Buckelew, S. P., & Elliott, T. R. (1987). Differences in Coping Styles Among Persons With Spinal Cord Injury: A Cluster-Analytic Approach. *Journal of Consulting and Clinical Psychology, 55*(5), 727-731. doi: 10.1037/0022-006X.55.5.727

Fronek, P., Booth, S., Kendall, M., Miller, D., & Geraghty, T. (2005). The effectiveness of a sexuality training program for the interdisciplinary spinal cord injury rehabilitation team. *Sexuality & Disability, 23*(2), 51-63.

Fronek, P., Kendall, M., Booth, S., Eugarde, E., & Geraghty, T. (2011). A longitudinal study of sexuality training for the interdisciplinary rehabilitation team. *Sexuality and Disability, 29*(2), 87-100. doi: http://dx.doi.org/10.1007/s11195-010-9177-1

Gianotten, W. L., Bender, J. L., Post, M. W., & Höing, M. (2006). Training in sexology for medical and paramedical professionals: A model for the rehabilitation setting. *Sexual and Relationship Therapy, 21*(3), 303-317. doi: http://dx.doi.org/10.1080/14681990600754559

Gilmore, D. D. (1990). *Introduction*. New Haven, Conn: Yale University Press.

Giuliano, F., Rubio-Aurioles, E., Kennelly, M., Montorsi, F., Kim, E. D., Finkbeiner, A. E., . . . Vardenafil Study, G. (2008). Vardenafil improves ejaculation success rates and self-confidence in men with erectile dysfunction due to spinal cord injury. *Spine, 33*(7), 709-715.

Giuliano, F., Rubio-Aurioles, E., Kennelly, M., Montorsi, F., Kim, E. D., Finkbeiner, A. E., . . . Vardenafil Study, G. (2006). Efficacy and safety of vardenafil in men with erectile dysfunction caused by spinal cord injury. *Neurology, 66*(2), 210-216.

Giuliano, F., Sanchez-Ramos, A., Lochner-Ernst, D., Del Popolo, G., Cruz, N., Leriche, A., . . . Casariego, J. (2007). Efficacy and safety of tadalafil in men with erectile dysfunction following spinal cord injury. *Archives of Neurology, 64*(11), 1584-1592.

Goetz, L. L., & Stiens, S. A. (2005). Abdominal electric stimulation facilitates penile vibratory stimulation for ejaculation after spinal cord injury: a single-subject trial. *Archives of Physical Medicine & Rehabilitation, 86*(9), 1879-1883.

Government of Nepal. (2008). *Nepal Health Sector Programme – Implementation Plan II (NHSP-IP 2): 2010–2015*. Kathmandu, Nepal.

Government of Nepal. (2014). *A report on census of private hospital in Nepal 2013*. (DDI-NPL-CBS-CPHN-2013-v1). Kathmandu, Nepal: Central Bureau of Statistics - National Planning Commission Secretariat Retrieved from http://cbs.gov.np/nada/index.php/catalog/45.

Government of Nepal. (2015a). Nepal Health Sector Programme 2010-15 (NHSPII), Fifth Joint Annual review (JAR). Retrieved from http://nhssp.org.np/jar/2015/Aide%20Memoire%202015.pdf

Government of Nepal. (2015b). Progress report on opportunites, challenges and strategic directions for the implementation of Nepal health sector programme - 2 2013/14. Retrieved 5 July, 2016, from http://nhsp.org.np/wp-content/uploads/2014/02/7.-Opportunities-2015-JAR-report-2015_02_18.pdf

Groce, N., Izutsu, T., Reier, S., Rinehart, W., & Temple, B. (2009). Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note. Retrieved 5 August, 2014, from http://www.who.int/reproductivehealth/publications/general/9789241598682/en/

Greene, S. (2015). Gender and Sexuality in Nepal: The Experiences of Sexual and Gender Minorities in a Rapidly Changing Social Climate. Retrieved from http://digitalcollections.sit.edu/cgi/viewcontent.cgi?article=3115&context=isp_collection

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *ECTJ, 29*(2), 75-91. doi: 10.1007/bf02766777

Haboubi, N. H. J., & Lincoln, N. (2003). Views of health professionals on discussing sexual issues with patients. *Disability & Rehabilitation, 25*(6), 291-296. doi: 10.1080/0963828021000031188

Hamid, R., Patki, P., Bywater, H., Shah, P. J., & Craggs, M. D. (2006). Effects of repeated ejaculations on semen characteristics following spinal cord injury. *Spinal Cord, 44*(6), 369-373.

Hamilton, D. (1978). Some experience with paraplegia in a small hospital in Nepal. *Paraplegia, 15*(4), 293-301. doi: 10.1038/sc.1977.44

Hammell, K. R. (1992). Psychological and sociological theories concerning adjustment to traumatic spinal cord injury: the implications for rehabilitation. *Paraplegia, 30*(5), 317-326. doi: 10.1038/sc.1992.75

Hammell, K. W. (2007). Experience of rehabilitation following spinal cord injury: A meta-synthesis of qualitative findings. *Spinal Cord, 45*(4), 260-274. doi: http://dx.doi.org/10.1038/sj.sc.3102034

Harris, P., Patel, S. S., Greer, W., & Naughton, J. A. (1973). Psychological and social reactions to acute spinal paralysis. *Paraplegia, 11*(2), 132.

Hartshorn, C., D'Castro, E., & Adams, J. (2013). ‘SI-SRH’ – a new model to manage sexual health following a spinal cord injury: our experience. *Journal of Clinical Nursing, 22*(23-24), 3541-3548. doi: 10.1111/jocn.12449

Hattjar, B. (2012). *Sexuality and occupational therapy: Strategies for persons with disabilities*. Bethesda, MD: The American Occupational Therapy Association, Inc. AOTA Press.

Heidegger, M. (1962). Being and Time. 1927. *Trans. John Macquarrie and Edward Robinson. New York: Harper.*

Hess, M. J., Hough, S., & Tammaro, E. (2007). The experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program. *Sexuality & Disability, 25*(4), 189-195.

Hotchkiss, D. R., Rous, J. J., Karmacharya, K., & Sangraula, P. (1998). Household Health Expenditures in Nepal: Implications for Health Care Financing Reform. *Health Policy and Planning, 13*(4), 371-383. doi: 10.1093/heapol/13.4.371

Iremashvili, V., Brackett, N. L., Ibrahim, E., Aballa, T. C., & Lynne, C. M. (2011). The choice of assisted ejaculation method is relevant for the diagnosis of azoospermia in men with spinal cord injuries. *Spinal Cord, 49*(1), 55-59. doi: http://dx.doi.org/10.1038/sc.2010.91

Javier, S. J., Perrin, P. B., Snipes, D. J., Olivera, S. L., Perdomo, J. L., Arango, J. A., & Arango-Lasprilla, J. C. (2013). The influence of health related quality of life on sexual desire in individuals with spinal cord injury from Colombia, South America. *Sexuality & Disability, 31*(4), 325-335. doi: 10.1007/s11195-013-9320-x

Jha, N. (2014). Revitalizing Primary Health Care and activities in Nepal. *Health Renaissance, 11*(3), 185-191.

Jirojwong, S., Johnson, M., & Welch, A. J. (2011). *Research methods in nursing and midwifery: pathways to evidence-based practice*. South Melbourne, Vic: Oxford University Press.

Jones, M. L., Leslie, D. P., Bilsky, G., & Bowman, B. (2008). Effects of intrathecal baclofen on perceived sexual functioning in men with spinal cord injury. *Journal of Spinal Cord Medicine, 31*(1), 97-102.

Kafetsoulis, A., Ibrahim, E., Aballa, T. C., Goetz, L. L., Lynne, C. M., & Brackett, N. L. (2006). Abdominal electrical stimulation rescues failures to penile vibratory stimulation in men with spinal cord injury: a report of two cases. *Urology, 68*(1), 204.e209-211.

Kang, E.-N., Shin, H.-I., & Kim, H.-R. (2014). Factors That Influence Employment After Spinal Cord Injury in South Korea. *Annals of Rehabilitation Medicine, 38*(1), 38-45. doi: 10.5535/arm.2014.38.1.38

Kanto, S., Uto, H., Toya, M., Ohnuma, T., Arai, Y., & Kyono, K. (2009). Fresh testicular sperm retrieved from men with spinal cord injury retains equal fecundity to that from men with obstructive azoospermia via intracytoplasmic sperm injection. *Fertility & Sterility, 92*(4), 1333-1336. doi: http://dx.doi.org/10.1016/j.fertnstert.2008.07.1776

Karimzadeh, M., Salsabili, N., Akbariasbagh, F., & Mehrsai, A. (2006). The psychological impact of infertility in the male able bodied and spinal cord injured population. *Sexuality & Disability, 24*(4), 185-193.

Kathiresan, A. S., Ibrahim, E., Aballa, T. C., Attia, G. R., Lynne, C. M., & Brackett, N. L. (2011). Pregnancy outcomes by intravaginal and intrauterine insemination in 82 couples with male factor infertility due to spinal cord injuries. *Fertility & Sterility, 96*(2), 328-331. doi: http://dx.doi.org/10.1016/j.fertnstert.2011.05.019

Kathiresan, A. S., Ibrahim, E., Modh, R., Aballa, T. C., Lynne, C. M., & Brackett, N. L. (2012). Semen quality in ejaculates produced by masturbation in men with spinal cord injury. *Spinal Cord, 50*(12), 891-894. doi: http://dx.doi.org/10.1038/sc.2012.71

Kennedy, P., Lude, P., & Taylor, N. (2006). Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. *Spinal Cord, 44*(2), 95-105. doi: 10.1038/sj.sc.3101787

Kennedy, P., Sherlock, O., McClelland, M., Short, D., Royle, J., & Wilson, C. A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months. *Spinal Cord, 48*(1), 15-20.

Kennedy, P., Sherlock, O., McClelland, M., Short, D., Royle, J., & Wilson, C. (2010). A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months. *Spinal Cord, 48*(1), 15-20. doi: 10.1038/sc.2009.65

Khanal, N. A. (2013). *Status of reproductive health and experience of motherhood of disabled women in Nepal.* SNV Nepal, Kathmandu, Nepal. Retrieved from http://www.socialinclusion.org.np/new/files/Neeti%20Aryal%20Khanal_1380089047dW5d.pdf.

Khorrami, M. H., Javid, A., Moshtaghi, D., Nourimahdavi, K., Mortazavi, A., & Zia, H. R. (2010). Sildenafil efficacy in erectile dysfunction secondary to spinal cord injury depends on the level of cord injuries. *International Journal of Andrology, 33*(6), 861-864. doi: http://dx.doi.org/10.1111/j.1365-2605.2009.01033.x

Kim, Y. D., Yang, S. O., Lee, J. K., Jung, T. Y., & Shim, H. B. (2008). Usefulness of a malleable penile prosthesis in patients with a spinal cord injury. *International Journal of Urology, 15*(10), 919-923.

Kimoto, Y., Sakamoto, S., Fujikawa, K., Tachibana, T., Yamamoto, N., & Otani, T. (2006). Up-titration of vardena fi l dose from 10 mg to 20 mg improved erectile function in men with spinal cord injury. *International Journal of Urology, 13*(11), 1428-1433.

Kirchberger, I., Biering-Sorensen, F., Charlifue, S., Baumberger, M., Campbell, R., Kovindha, A., . . . Stucki, G. (2009). Identification of the most common problems in functioning of individuals with spinal cord injury using the International Classification of Functioning, Disability and Health. *Spinal Cord, 48*(3), 221-229.

Koch, T. (1996). Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing, 24*(1), 174-184. doi: 10.1046/j.1365-2648.1996.17224.x

Korse, N. S., Nicolai, M. P. J., Both, S., Vleggeert-Lankamp, C. L. A., & Elzevier, H. W. (2016). Discussing sexual health in spinal care. *European Spine Journal, 25*(3), 766-773. doi: 10.1007/s00586-015-3991-1

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214-222.

Ku, J. H., Oh, S. J., Jeon, H. G., Shin, H. I., Paik, N. J., Yoo, T., & Kim, S. W. (2006). Sexual activity in Korean male patients on clean intermittent catheterization with neurogenic bladder due to spinal cord injury. *International Journal of Urology, 13*(1), 42-46.

Levy, L. F., Makarawo, S., Madzivire, D., Bhebhe, E., Verbeek, N., & Parry, O. (1998). Problems, struggles and some success with spinal cord injury in Zimbabwe. *Spinal Cord, 36*(3), 213-218. doi: 10.1038/sj.sc.3100574

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, Calif: Sage.

Lombardi, G., Macchiarella, A., Cecconi, F., Aito, S., & Del Popolo, G. (2008). Sexual life of males over 50 years of age with spinal-cord lesions of at least 20 years. *Spinal Cord, 46*(10), 679-683.

Lombardi, G., Macchiarella, A., Cecconi, F., & Del Popolo, G. (2009a). Efficacy and safety of medium and long-term tadalafil use in spinal cord patients with erectile dysfunction. *Journal of Sexual Medicine, 6*(2), 535-543. doi: http://dx.doi.org/10.1111/j.1743-6109.2008.01106.x

Lombardi, G., Macchiarella, A., Cecconi, F., & Del Popolo, G. (2009b). Ten-year follow-up of sildenafil use in spinal cord-injured patients with erectile dysfunction. *Journal of Sexual Medicine, 6*(12), 3449-3457. doi: http://dx.doi.org/10.1111/j.1743-6109.2009.01426.x

Lombardi, G., Macchiarella, A., Cecconi, F., & Del Popolo, G. (2009c). Ten years of phosphodiesterase type 5 inhibitors in spinal cord injured patients. *Journal of Sexual Medicine, 6*(5), 1248-1258. doi: http://dx.doi.org/10.1111/j.1743-6109.2008.01205.x

Macleod, A. (1988). Self-neglect of spinal injured patients. *Spinal Cord, 26*(5), 340-349.

Mahat, G., & Scoloveno, M. A. (2001). Factors influencing health practices of Nepalese adolescent girls. Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners, 15(5), 251-255. doi: 10.1016/S0891-5245(01)24751-8

Majupuria, I., & Majupuria, T. C. (2009). *Marriage customs in Nepal: ethnic groups, their marriage customs and traditions*. [Kathmandu]: Majupuria : available at International Book House.

Manhood. (2007). London, United Kingdom: Penguin. Retrieved from https://elibrary.jcu.edu.au/login?url=http://search.credoreference.com/content/entry/penguineng/manhood/0.

Manhood. (2012). Springfield, MA: Merriam-Webster.Retrieved from https://elibrary.jcu.edu.au/login?url=http://search.credoreference.com/content/entry/mwcollegiate/manhood/0.

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

Mayers, K. S., Heller, D. K., & Heller, J. A. (2003). Damaged Sexual Self-Esteem: A Kind of Disability. *Sexuality and Disability, 21*(4), 269-282. doi: 10.1023/B:SEDI.0000010069.08844.04

Mc Grath, M., & Sakellariou, D. (2016). Why Has So Little Progress Been Made in the Practice of Occupational Therapy in Relation to Sexuality? *The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 70*(1), 7001360010p7001360011. doi: 10.5014/ajot.2016.017707

McCabe, M. P., Cummins, R. A., & Deeks, A. A. (2000). Sexuality and Quality of Life Among People with Physical Disability. *Sexuality and Disability, 18*(2), 115-123. doi: 10.1023/A:1005562813603

McGuire, C., Maneckshа, R. P., Sheils, P., McDermott, T. E., Grainger, R., & Flynn, R. (2011). Electroejaculatory stimulation for male infertility secondary to spinal cord injury: the Irish experience in National Rehabilitation Hospital. *Urology, 77*(1), 83-87. doi: http://dx.doi.org/10.1016/j.urology.2010.07.477

Mendes, A. K., Cardoso, F. L., & Savall, A. C. (2008). Sexual satisfaction in people with spinal cord injury. *Sexuality and Disability, 26*(3), 137-147. doi: http://dx.doi.org/10.1007/s11195-008-9083-y

Menger, L. M., Kaufman, M. R., Harman, J. J., Tsang, S. W., & Shrestha, D. K. (2015). Unveiling the silence: women's sexual health and experiences in Nepal. *Culture, health & sexuality, 17*(3), 359-373.

Middleton, J. W., Lim, K., Taylor, L., Soden, R., & Rutkowski, S. (2004). Patterns of morbidity and rehospitalisation following spinal cord injury. *Spinal Cord, 42*(6), 359-367. doi: 10.1038/sj.sc.3101601

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: an expanded sourcebook* (Vol. 2nd). Thousand Oaks, Calif: Sage.

Ministry of Health and Population. (2015). *Nepal health sector strategy 2015-2020.*Retrieved from http://www.mohp.gov.np/images/pdf/NHSS_English.pdf

Ministry of Health and Population. (2013). *Human resource for health country profile for Nepal*. Retrieved from http://www.nhssp.org.np/human_resources/HRH%20profile%20%28QA%29.pdf.

Mishra, S. R., Khanal, P., Karki, D. K., Kallestrup, P., & Enemark, U. (2015). National health insurance policy in Nepal: challenges for implementation. *GLOBAL HEALTH ACTION, 8*(1), 1-3. doi: 10.3402/gha.v8.28763

Mittmann, N., Craven, B. C., Gordon, M., MacMillan, D. H., Hassouna, M., Raynard, W., . . . Tarride, J. E. (2005). Erectile dysfunction in spinal cord injury: a cost-utility analysis. *Journal of Rehabilitation Medicine, 37*(6), 358-364.

Moemen, M. N., Fahmy, I., AbdelAal, M., Kamel, I., Mansour, M., & Arafa, M. M. (2008). Erectile dysfunction in spinal cord-injured men: different treatment options. *International Journal of Impotence Research, 20*(2), 181-187.

Moran, D. (2000). *Introduction to Phenomenology*. Florence;New York;: Routledge.

Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, Calif: Sage.

Müller, R., Peter, C., Cieza, A., & Geyh, S. (2012). The role of social support and social skills in people with spinal cord injury--a systematic review of the literature. *Spinal Cord, 50*(2), 94-106. doi: 10.1038/sc.2011.116

Nagarajan, G., Elango, A., Tharion, G., & Bhattacharji, S. (2012). Perceptions of patients with spinal cord injury on future research in South India. *Social Care and Neurodisability, 3*(1), 20-26. doi: http://dx.doi.org/10.1108/20420911211207035

National Planning Commission. (2007). *Three years interim plan (2007-2010)*. Kathmandu: Government of Nepal Retrieved from http://www. npc. gov. np/en/plans-programs/detail. php.

National Planning Commission Secretariat [NPCS]. (2012). National population and housing census 2011: National report. Retrieved 24 June, 2014, from http://unstats.un.org/unsd/demographic/sources/census/2010_phc/Nepal/Nepal-Census-2011-Vol1.pdf

Nepal: Regions [File:Nepal-regions-map.png]. (2016). Retrieved 26 July, 2016, from http://wikitravel.org/en/File:Nepal-regions-map.png

Neufeld, J. A., Klingbeil, F., Bryen, D. N., Silverman, B., & Thomas, A. (2002). Adolescent sexuality and disability. *Physical medicine and rehabilitation clinics of North America, 13*(4), 857.

Nguyen, T. H. T., Nguyen, T. L. H., Morita, S., & Sakamoto, J. (2008). Injury and pre-hospital trauma care in Hanoi, Vietnam. *Injury, 39*(9), 1026-1033. doi: 10.1016/j.injury.2008.03.011

Nolan, M. (2013). Masculinity lost: a systematic review of qualitative research on men with spinal cord injury. *Spinal Cord, 51*(8), 588-595. doi: http://dx.doi.org/10.1038/sc.2013.22

Noreau, L., & Fougeyrollas, P. (2000). Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disability & Rehabilitation, 22*(4), 170-180.

Ostrander, R. N. (2008). Meditations on a Bullet: Violently Injured Young Men Discuss Masculinity, Disability and Blame. *Child & Adolescent Social Work Journal, 25*(1), 71-84. doi: http://dx.doi.org/10.1007/s10560-008-0113-5

Ostrander, R. N. (2009). Sexual pursuits of pleasure among men and women with spinal cord injuries. *Sexuality and Disability, 27*(1), 11-19. doi: 10.1007/s11195-008-9103-y

Paudel, N. R. (2008). *Health policy design and implementation in Nepal: A policy discussion.* Paper presented at the International Conference on ‘Challenges of Governance in South Asia’December.

Pebdani, R. N., Johnson, K. L., & Amtmann, D. (2014). Personal Experiences of Pregnancy and Fertility in Individuals with Spinal Cord Injury. *Sexuality and Disability, 32*(1), 65-74. doi: http://dx.doi.org/10.1007/s11195-013-9319-3

Penrod, J., Preston, D. B., Cain, R. E., & Starks, M. T. (2003). A Discussion of Chain Referral As a Method of Sampling Hard-to-Reach Populations. *Journal of Transcultural Nursing, 14*(2), 100-107. doi: 10.1177/1043659602250614

Phelps, J., Albo, M., Dunn, K., & Joseph, A. (2001). Spinal Cord Injury and Sexuality in Married or Partnered Men: Activities, Function, Needs, and Predictors of Sexual Adjustment. *Archives of Sexual Behavior, 30*(6), 591-602. doi: 10.1023/A:1011910900508

Pigg, S. L. (2012). Sexuality. In D. Fassin (Ed.), Companion to moral Anthropology (1 ed.). Somerset: Wiley. Retrieved from http://jcu.eblib.com.au/patron/FullRecord.aspx?p=837605.

Popolo, G. D., Marzi, V. L., Mondaini, N., & Lombardi, G. (2004). Time/duration effectiveness of sildenafil versus tadalafil in the treatment of erectile dysfunction in male spinal cord-injured patients. *Spinal Cord, 42*(11), 643-648. doi: http://dx.doi.org/10.1038/sj.sc.3101617

Poudel-Tandukar, K., Poudel, K. C., Yasuoka, J., Eto, T., & Jimba, M. (2008). Domestic violence against women in Nepal. *The Lancet, 371*(9625), 1664-1664. doi: 10.1016/S0140-6736(08)60723-0

Prabhaka, M. M., & Thakker, T. H. (2004). A follow-up program in India for patients with spinal cord injury: paraplegia safari. *The Journal of Spinal Cord Medicine, 27*(3), 260.

Priest, H. (2002). An approach to the phenomenological analysis of data. *Nurse Researcher, 10*(2), 50-63.

Puri, J. (2002). Concerning Kamasutras: Challenging narratives of history and sexuality. Signs, 27(3), 603.

Puri, M., & Cleland, J. (2006). Sexual behavior and perceived risk of HIV/AIDS among young migrant factory workers in Nepal. *Journal of Adolescent Health, 38*(3), 237-246. doi: 10.1016/j.jadohealth.2004.10.001

Puri, M., Shah, I., & Tamang, J. (2010). Exploring the nature and reasons for sexual violence within marriage among young women in Nepal. *Journal of Interpersonal Violence,* 25(10), 1873-1892. doi: 10.1177/0886260509354514

Rahimi-Movaghar, V., Sayyah, M. K., Akbari, H., Khorramirouz, R., Rasouli, M. R., Moradi-Lakeh, M., . . . Vaccaro, A. R. (2013). Epidemiology of traumatic spinal cord injury in developing countries: a systematic review. *Neuroepidemiology, 41*(2), 65-85.

Rai, S. K., Rai, G., Hirai, K., Abe, A., & Ohno, Y. (2001). The health system in Nepal - An introduction. *Environmental Health and Preventive Medicine, 6*(1), 1-8. doi: 10.1265/ehpm.2001.1

Rapala, S., & Manderson, L. (2005). Recovering In-validated Adulthood, Masculinity and Sexuality. *Sexuality and Disability, 23*(3), 161-180. doi: http://dx.doi.org/10.1007/s11195-005-6731-3

Rathus, S. A., Nevid, J. S., Fichner-Rathus, L., Herold, E. S., & McKenzie, S. W. (Eds.). (2007). *Human sexuality in a world of diversity* (2nd ed.). Toronto, Canada: Pearson Allyn and Bacon, Inc.

Raviv, G., Madgar, I., Elizur, S., Zeilig, G., & Levron, J. (2013). Testicular sperm retrieval and intra cytoplasmic sperm injection provide favorable outcome in spinal cord injury patients, failing conservative reproductive treatment. *Spinal Cord, 51*(8), 642-644. doi: http://dx.doi.org/10.1038/sc.2013.44

Regmi, P., Simkhada, P., & Van Teijlingen, E. R. (2008). Sexual and reproductive health status among young peoples in Nepal: Opportunities and barriers for sexual health education and services utilization. *Kathmandu University medical journal.* Retrieved from http://eprints.bournemouth.ac.uk/10147/1/KMUJ_Pramod_Sex_Reproductive_2008.pdf

Regmi, P. R., Simkhada, P., & van Teijlingen, E. (2010). “Boys Remain Prestigious, Girls Become Prostitutes”: Socio-Cultural Context of Relationships and Sex among Young People in Nepal. Global Journal of Health Science, 2(1), P60.

Reitz, A., Tobe, V., Knapp, P. A., & Schurch, B. (2004). Impact of spinal cord injury on sexual health and quality of life. *International Journal of Impotence Research, 16*(2), 167-174. doi: http://dx.doi.org/10.1038/sj.ijir.3901193

Restelli, A. E., Bertolla, R. P., Spaine, D. M., Miotto, A., Jr., Borrelli, M., Jr., & Cedenho, A. P. (2009). Quality and functional aspects of sperm retrieved through assisted ejaculation in men with spinal cord injury. *Fertility & Sterility, 91*(3), 819-825. doi: http://dx.doi.org/10.1016/j.fertnstert.2007.12.060

Robertson, J., & Koontz, H. (2015). *Magnitude 7.8 earthquake in Nepal & aftershocks: The USGS is providing up-to-date information*. Retrieved from http://www.usgs.gov/blogs/features/usgs_top_story/magnitude-7-8-earthquake-in-nepal/

Roy, K. (1996). Unravelling the Kāmasutra1. *Indian Journal of Gender Studies, 3*(2), 155-170.

RTI International. (2010). Overview of public-private mix in health care service delivery in Nepal (M. o. H. a. P. M. Healt Sector Reform Support Programme [HSRSP], Government of Nepal, Trans.). NC, USA.

Sadala, M. L. A., & Adorno, R. d. C. F. (2002). Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau Ponty's thought. *Journal of Advanced Nursing, 37*(3), 282-293. doi: 10.1046/j.1365-2648.2002.02071.x

Sakellariou, D. (2006a). If not the Disability, then what? Barriers to Reclaiming Sexuality Following Spinal Cord Injury. *Sexuality and Disability, 24*(2), 101-111. doi: http://dx.doi.org/10.1007/s11195-006-9008-6

Sakellariou, D. (2006b). If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury. *Sexuality & Disability, 24*(2), 101-111.

Sakellariou, D. (2012). Sexuality and Disability: A Discussion on Care of the Self. *Sexuality and Disability, 30*(2), 187-197. doi: http://dx.doi.org/10.1007/s11195-011-9219-3

Sakellariou, D., & Sawada, Y. (2006). Sexuality after spinal cord injury: The Greek male's perspective. *American Journal of Occupational Therapy, 60*(3), 311-319. doi: 10.1007/s11195-008-9103-y

Sale, P., Mazzarella, F., Pagliacci, M. C., Agosti, M., Felzani, G., & Franceschini, M. (2012). Predictors of changes in sentimental and sexual life after traumatic spinal cord injury. *Archives of Physical Medicine & Rehabilitation, 93*(11), 1944-1949. doi: 10.1016/j.apmr.2012.03.023

Salsabili, N., Ziaei, A. M., Taheri, M., Akbari, K., & Jalaie, S. (2006). Impact of Sperm Collection Methods on Sperm Parameters in Spinal Cord Injured Men and Compared to Normal Controls in ICSI Program. *Sexuality and Disability, 24*(3), 141-149. doi: http://dx.doi.org/10.1007/s11195-006-9015-7

Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS. Advances in nursing science, 16*(2), 1.

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. doi: 10.1038/sc.2011.119

Shah, N., Shrestha, B., & Subba, K. (2013). Spinal Cord Injury Rehabilitation in Nepal. *JOURNAL OF NEPAL MEDICAL ASSOCIATION, 52*(6), 427-431.

Sharma, S. C., Singh, R., Dogra, R., & Gupta, S. S. (2006). Assessment of sexual functions after spinal cord injury in Indian patients. *International Journal of Rehabilitation Research, 29*(1), 17-25.

Shooman, D., & Rushambuza, R. (2009). Importance of the log roll. *Emergency medicine journal : EMJ, 26*(7), 539.

Shrestha, D. (2014). Traumatic spinal cord injury in Nepal. *Kathmandu University medical journal (KUMJ), 12*(47), 161-162.

Shrestha, D., Garg, M., Singh, G. K., Singh, M. P., & Sharma, U. K. (2007). Cervical spine injuries in a teaching hospital of eastern region of Nepal: a clinico-epidemiological study. *JNMA; journal of the Nepal Medical Association, 46*(167), 107.

Simkhada, P., van Teijlingen, E. R., Regmi, P. R., & Bhatta, P. (2010). Sexual health knowledge, sexual relationships and condom use among male trekking guides in Nepal: a qualitative study. *Culture, health & sexuality, 12*(1), 45-58. doi: 10.1080/13691050903266080

Simpson, G., Anwar, S., Wilson, J., & Bertapelle, T. (2006). Improving the rehabilitative management of client sexual health concerns after neurological disability: evaluation of a staff sexuality training programme in New Zealand. *Clinical Rehabilitation, 20*(10), 847-859. doi: http://dx.doi.org/10.1177/0269215506072180

Simpson, L. A., Eng, J. J., Hsieh, J. T., Wolfe, & the Spinal Cord Injury Rehabilitation Evidence Research Team, D. L. (2012). The health and life priorities of individuals with spinal cord injury: a systematic review. *Journal of Neurotrauma, 29*(8), 1548-1555.

Singh, P. K., Shrivastva, S., & Dulani, R. (2011). Pre-hospital care of spinal cord injury in a rural Indian setting. *Rural Remote Health, 11*(2), 1760.

Singh, R., Sharma, S. C., Mittal, R., & Sharma, A. (2003). Traumatic spinal cord injuries in Haryana: an epidemiological study. *Indian J Community Med, 28*(4), 184-186.

Sipski, M., Alexander, C. J., & Gomez-Marin, O. (2006). Effects of level and degree of spinal cord injury on male orgasm. *Spinal Cord, 44*(12), 798-804.

Smith, D. W. (2013). Phenomenology. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Winter 2013 ed.).

Smith, J. A., Flowers, P., & Larkin, M. (2009a). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles, CA: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2009b). *Interpretative phenomenological analysis: Theory, method and research*. London: SAGE.

Soden, R. J., Walsh, J., Middleton, J. W., Craven, M. L., Rutkowski, S. B., & Yeo, J. D. (2000). Causes of death after spinal cord injury. *Spinal Cord, 38*(10), 604-610. doi: http://dx.doi.org/10.1038/sj.sc.3101080

Soler, J. M., Previnaire, J. G., Denys, P., & Chartier-Kastler, E. (2007). Phosphodiesterase inhibitors in the treatment of erectile dysfunction in spinal cord-injured men. *Spinal Cord, 45*(2), 169-173.

Soler, J. M., Previnaire, J. G., Plante, P., Denys, P., & Chartier-Kastler, E. (2007). Midodrine improves ejaculation in spinal cord injured men. *Journal of Urology, 178*(5), 2082-2086.

Soler, J. M., Previnaire, J. G., Plante, P., Denys, P., & Chartier-Kastler, E. (2008). Midodrine improves orgasm in spinal cord-injured men: The effects of autonomic stimulation. *Journal of Sexual Medicine, 5*(12), 2935-2941. doi: http://dx.doi.org/10.1111/j.1743-6109.2008.00844.x

Sonksen, J., Fode, M., Lochner-Ernst, D., & Ohl, D. A. (2012). Vibratory ejaculation in 140 spinal cord injured men and home insemination of their partners. *Spinal Cord, 50*(1), 63-66. doi: http://dx.doi.org/10.1038/sc.2011.101

Spencer, A. R., Jeffrey, S. N., Lois, F.-R., Edward, S. H., & Sue, W. M. (2007). Sexual arousal and response. In Eds (Ed.), *Human sexuality in a world of diversity* (2nd ed., pp. 125-127). Toronto, Canada: Pearson Allyn and Bacon, Inc.

Spiegelberg, H., & Schuhmann, K. (1982). *The phenomenological movement: A historical introduction* (Vol. 3rd rev. and enl.). The Hague; London: Nijhoff.

Spinal Injury Rehabilitation Centre. (2014). Spinal injury in Nepal. Retrieved May 14th, 2014, from http://techoutsolutions.com/sirc/?p=28

Spizzirri, G., & Abdo, C. (2010). Patients receiving physical rehabilitation: Records of sexual function before the introduction of erectogenic drugs. *Sexuality & Disability, 28*(1), 29-37. doi: 10.1007/s11195-010-9148-6

Stone, L. (1978). Cultural repercussions of childlessness and low fertility in Nepal. *Contributions to Nepalese Studies, 5*(2), 7-36.

Stuhimiller, C. (2010). Health, disorder and psychiatric enterprise: Reclaiming lost connections. In K. A. Brykczynski, P. Benner & G. Chan (Eds.), *Interpretive phenomenology in health care research: Studying social practice, lifeworlds, and embodiment* (pp. 75-90). Indianpolis, IN: Sigma Theta Tau International.

Sunilkumar, M., Boston, P., & Rajagopal, M. (2015). Views and attitudes towards sexual functioning in men living with spinal cord injury in kerala, South India. *Indian journal of palliative care, 21*(1), 12-20. doi: 10.4103/0973-1075.150158

Sunilkumar, M. M., Boston, P., & Rajagopal, M. R. (2015). Sexual Functioning in Men Living with a Spinal Cord Injury-A Narrative Literature Review. *Indian journal of palliative care, 21*(3), 274. doi: 10.4103/0973-1075.164886

Taiwo, M. O. (2012). Access to sexuality information among adolescents with disability. *IFE PsychologIA : An International Journal, 20*(2), 142-149.

Tanabe, M., Nagujjah, Y., Rimal, N., Bukania, F., & Krause, S. (2015). Intersecting Sexual and Reproductive Health and Disability in Humanitarian Settings: Risks, Needs, and Capacities of Refugees with Disabilities in Kenya, Nepal, and Uganda. *Sexuality and Disability, 33*(4), 411-427. doi: 10.1007/s11195-015-9419-3

Tepper, M. S. (1992). Sexual education in spinal cord injury rehabilitation: Current trends and recommendations. *Sexuality and Disability, 10*(1), 15-31. doi: 10.1007/BF01102245

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American journal of evaluation, 27*(2), 237-246.

Tina, M., & Linda, B. (2012). Consenting to what? Issues of access, gate-keeping and 'informed' consent. In M. Tina, B. Maxine, M. Melanie & J. Julie (Eds.), *Ethics in qualitative research* (2 ed., pp. 61-76). London, England: Sage.

Tonack, M., Hitzig, S. L., Craven, B. C., Campbell, K. A., Boschen, K. A., & McGillivray, C. F. (2008). Predicting life satisfaction after spinal cord injury in a Canadian sample. *Spinal Cord, 46*(5), 380-385. doi: 10.1038/sj.sc.3102088

Trautmann, T. R. (1971). Kautilya and the Arthasastra. *Statistical Investigation of the Authorship and Evolution of the Text.*

Trieschmann, R. B. (1988). *Spinal cord injuries: Psychological, social, and vocational rehabilitation*: Demos Medical Publishing.

Tsai, I. H., Graves, D. E., & Lai, C. H. (2014). The association of assistive mobility devices and social participation in people with spinal cord injuries. *Spinal Cord, 52*(3), 209. doi: 10.1038/sc.2013.178

United States International Council on Disabilities. (2010). Nepal ratifies crpd and optional protocol. Retrieved from http://usicd.org/detail/news.cfm?news_id=173

Usher, K., & Jackson, D. (2014). Phenomenology. In J. Mills & M. Birks (Eds.), *Qualitative methodology: a practical guide* (pp. 181-198). London, England: Sage.

Üstün, T. (2002). Towards a Common Language for Functioning, Disability and Health, ICF: Report number WHO/EIP/GPE/CAS/01.3. Geneva: World Health Organisation.

Valtonen, K., Karlsson, A.-K., Siösteen, A., Dahlöf, L.-G., & Viikari-Juntura, E. (2006). Satisfaction with sexual life among persons with traumatic spinal cord injury and meningomyelocele. *Disability and Rehabilitation: An International, Multidisciplinary Journal, 28*(16), 965-976. doi: http://dx.doi.org/10.1080/09638280500404362

van Koppenhagen, C. F., Post, M. W., van der Woude, L. H., de Witte, L. P., van Asbeck, F. W., de Groot, S., . . . Lindeman, E. (2008). Changes and determinants of life satisfaction after spinal cord injury: a cohort study in the

Netherlands. *Archives of Physical Medicine & Rehabilitation, 89*(9), 1733-1740.

Van Manen, M. (1990). *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Albany: State University of New York Press.

van't Noordende, A. T., van Brakel, W. H., Banstola, N., & Dhakal, K. P. (2016). The impact of leprosy on marital relationships and sexual health among married women in eastern Nepal. *Journal of Tropical Medicine, 2016*, 1-9. doi: 10.1155/2016/4230235

Vatsyayana. (1963a). Introductory (R. Burton & F. F. Arbuthnot, Trans.). In W. G. Archer (Ed.), *The kama sutra of Vatsyayana* (pp. 95-101). London, England: George Allen & Unwin Ltd.

Vatsyayana. (1963b). On the acquisition of dharma, artha and kama. In W. G. Archer (Ed.), *The kama sutra of Vatsyayana* (pp. 102-106): George Allen and Unwin Ltd.

Virseda-Chamorro, M., Salinas-Casado, J., Lopez-Garcia-Moreno, A. M., Cobo-Cuenca, A. I., & Esteban-Fuertes, M. (2013). Sexual dysfunction in men with spinal cord injury: a case-control study. *International Journal of Impotence Research, 25*(4), 133-137. doi: http://dx.doi.org/10.1038/ijir.2013.1

Vogel, L. C., Krajci, K. A., & Anderson, C. J. (2002). Adults with pediatric-onset spinal cord injuries: part 3: impact of medical complications. *The Journal of Spinal Cord Medicine, 25*(4), 297.

Warren, A. M., Hamilton, R., & Roden-Foreman, K. (2013). Invited grand rounds article—Up close but not too personal: Establishing appropriate boundaries with individuals following spinal cord injury. *Sexuality and Disability, 31*(4), 303-311. doi: http://dx.doi.org/10.1007/s11195-013-9317-5

Wee, J., & Lysaght, R. (2009). Factors affecting measures of activities and participation in persons with mobility impairment. *Disability and rehabilitation, 31*(20), 1633-1642. doi: 10.1080/09638280902736346

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.

Wee, J., Ruttan, L., Ranabhat, M.K., & Ng, E. (2009, November).*Sexuality education in SCI rehabilitation in Nepal – The Importance of Understanding Culture.*In A. Kovindha (Chair).The 8th ASCoN Conference conducted at the meeting of Spinal Injury Rehabilitation Centre, Kathmandu, Nepal.

Westie, K. S. (1987). Psychological aspects of spinal cord injury. *Clinical Prosth. Orth, 11*, 4.

White, M. J., Rintala, D. H., Hart, K. A., Young, M. E., & Fuhrer, M. J. (1992). Sexual activities, concerns and interests of men with spinal cord injury. *American journal of physical medicine & rehabilitation / Association of Academic Physiatrists, 71*(4), 225-231. doi: 10.1097/00002060-199208000-00005

Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in Qualitative Research. *Qualitative Health Research, 11*(4), 522-537. doi: 10.1177/104973201129119299

Wilson, N. J., Stancliffe, R. J., Parmenter, T. R., & Shuttleworth, R. P. (2011). Gendered Service Delivery: A Masculine and Feminine Perspective on Staff Gender. *Intellectual and Developmental Disabilities, 49*(5), 341.

Women With Disabilities Australia [WWDA]. (2006). Regulation of disabled women's sexuality. Retrieved from http://wwda.org.au/issues/sexualit/sexualit2006/

World Bank. (2013). International comparison program database. Retrieved 27 September, 2014, Retrieved from http://data.worldbank.org/indicator/NY.GDP.PCAP.PP.CD?order=wbapi_data_value_2013+wbapi_data_value+wbapi_data_value-last&sort=desc

World Health Organization. (2016). Life expectancy data by country. Retrieved 26th July, 2016, from http://apps.who.int/gho/data/view.main.SDG2016LEXv?lang=en

World Health Organization. (1978). Declaration of Alma Ata: report of the international conference on primary health care. *Alma Atta, USSR*.

World Health Organization. (2000). *The world health report 2000: health systems : improving performance* (Vol. 2000). Geneva, Switzerland: World Health Organization.

World Health Organization. (2006). World health statistics 2006. Geneva, Switzerland: World Health Organization. Retrieved from http://go.galegroup.com.elibrary.jcu.edu.au/ps/i.do?id=GALE|3FCY&v=2.1&u=james_cook&it=aboutJournal&p=AONE&sw=w.

World Health Organization. (2016). Tracking universal health coverage: First global monitoring report (Vol. 3). Beaverton: Ringgold Inc.

Yolland, N., Clark, R., & Craighead, I. B. (2006). SCI service evaluation. Green Pastures Hospital and Rehabilitation Centre: Pokhara, Nepal.

Zakrasek, E. C., Creasey, G., & Crew, J. D. (2015). Pressure ulcers in people with spinal cord injury in developing nations. Spinal Cord, 53(1), 7-13. doi: 10.1038/sc.2014.179

APPENDICES

APPENDIX A

A.1 Approval From Human Research Ethics Committee (HREC), James Cook University

This administrative form
has been removed

A.2 Approval From International Nepal Fellowship (INF) Research Ethic Committee Nepal Approval

This administrative form
has been removed

A.3 Approval From Nepal Health Research Council (NHRC) Ethical Review Board Nepal

This administrative form
has been removed

APPENDIX B: Institutional Agreement

B.1: Agreement with Spinal Cord Injury Association Nepal (SCIAN), Nepal

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has been removed

B.2 Agreement with Independent Living Society (ILS), Nepal

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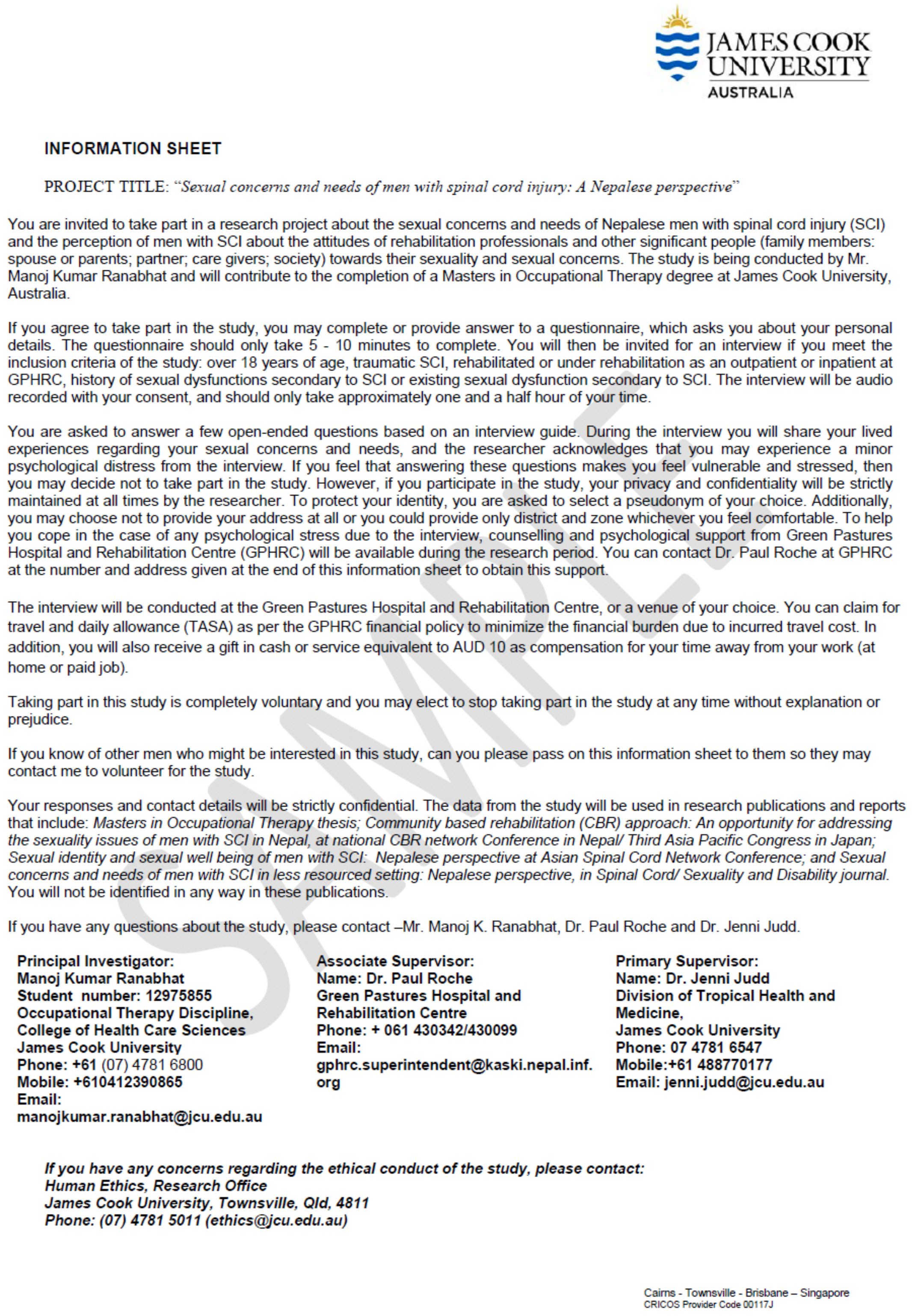
APPENDIX C: Information Sheets, Interview Guide, Consent Form and Check List

C.1.a Information Sheet English Version



JAMES COOK UNIVERSITY
AUSTRALIA

INFORMATION SHEET

PROJECT TITLE: "*Sexual concerns and needs of men with spinal cord injury: A Nepalese perspective*"

You are invited to take part in a research project about the sexual concerns and needs of Nepalese men with spinal cord injury (SCI) and the perception of men with SCI about the attitudes of rehabilitation professionals and other significant people (family members: spouse or parents; partner; care givers; society) towards their sexuality and sexual concerns. The study is being conducted by Mr. Manoj Kumar Ranabhat and will contribute to the completion of a Masters in Occupational Therapy degree at James Cook University, Australia.

If you agree to take part in the study, you may complete or provide answer to a questionnaire, which asks you about your personal details. The questionnaire should only take 5 - 10 minutes to complete. You will then be invited for an interview if you meet the inclusion criteria of the study: over 18 years of age, traumatic SCI, rehabilitated or under rehabilitation as an outpatient or inpatient at GPHRC, history of sexual dysfunctions secondary to SCI or existing sexual dysfunction secondary to SCI. The interview will be audio recorded with your consent, and should only take approximately one and a half hour of your time.

You are asked to answer a few open-ended questions based on an interview guide. During the interview you will share your lived experiences regarding your sexual concerns and needs, and the researcher acknowledges that you may experience a minor psychological distress from the interview. If you feel that answering these questions makes you feel vulnerable and stressed, then you may decide not to take part in the study. However, if you participate in the study, your privacy and confidentiality will be strictly maintained at all times by the researcher. To protect your identity, you are asked to select a pseudonym of your choice. Additionally, you may choose not to provide your address at all or you could provide only district and zone whichever you feel comfortable. To help you cope in the case of any psychological stress due to the interview, counselling and psychological support from Green Pastures Hospital and Rehabilitation Centre (GPHRC) will be available during the research period. You can contact Dr. Paul Roche at GPHRC at the number and address given at the end of this information sheet to obtain this support.

The interview will be conducted at the Green Pastures Hospital and Rehabilitation Centre, or a venue of your choice. You can claim for travel and daily allowance (TASA) as per the GPHRC financial policy to minimize the financial burden due to incurred travel cost. In addition, you will also receive a gift in cash or service equivalent to AUD 10 as compensation for your time away from your work (at home or paid job).

Taking part in this study is completely voluntary and you may elect to stop taking part in the study at any time without explanation or prejudice.

If you know of other men who might be interested in this study, can you please pass on this information sheet to them so they may contact me to volunteer for the study.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports that include: *Masters in Occupational Therapy thesis; Community based rehabilitation (CBR) approach: An opportunity for addressing the sexuality issues of men with SCI in Nepal, at national CBR network Conference in Nepal/ Third Asia Pacific Congress in Japan; Sexual identity and sexual well being of men with SCI: Nepalese perspective at Asian Spinal Cord Network Conference; and Sexual concerns and needs of men with SCI in less resourced setting: Nepalese perspective, in Spinal Cord/ Sexuality and Disability journal.* You will not be identified in any way in these publications.

If you have any questions about the study, please contact –Mr. Manoj K. Ranabhat, Dr. Paul Roche and Dr. Jenni Judd.

Principal Investigator:	Associate Supervisor:	Primary Supervisor:
Manoj Kumar Ranabhat **Student number: 12975855** **Occupational Therapy Discipline,** **College of Health Care Sciences** **James Cook University** **Phone: +61** (07) 4781 6800 **Mobile: +610412390865** **Email:** **manojkumar.ranabhat@jcu.edu.au**	**Name: Dr. Paul Roche** **Green Pastures Hospital and Rehabilitation Centre** **Phone: + 061 430342/430099** **Email:** **gphrc.superintendent@kaski.nepal.inf.org**	**Name: Dr. Jenni Judd** **Division of Tropical Health and Medicine,** **James Cook University** **Phone: 07 4781 6547** **Mobile:+61 488770177** **Email: jenni.judd@jcu.edu.au**

If you have any concerns regarding the ethical conduct of the study, please contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

C.1.b Information Sheet Nepali Version

जानकारी पत्र

परियोजनाशीर्षक : “मेरुदण्डकोपक्षघात भएका पुरुषहरुका यौन सरोकारहरु र आवश्यकताहरु : एक नेपाली परिप्रेक्छ”

तपाईलाई मेरुदण्डको पक्षघात भएका नेपाली पुरुषहरुको यौन सरोकार र आवश्यकताहरु विषयको अनुसन्धान परियोजनामा सहभागि हुन आमन्त्रण गरिएको छ। यस परियोजनामा पूर्नस्थापना पेशाकर्मीहरु र अरु महत्वपूर्ण व्यक्तिहरु (परिवारका सदस्यहरु : पत्नी अथवा अभिभावक, साथी, स्याहारकर्मीहरु, समाज) को मेरुदण्डको पक्षघात भएका व्यक्तिहरुको यौनिकता र यौन सरोकारहरुलाई हेर्ने धारणा/दृष्टिकोण प्रती मेरुदण्डको पक्षघात भएका व्यक्तिहरुको अनुभूतिपनि अन्वेषण गरिने छ। यो अध्ययन मनोज कुमार रानाभाटले गर्दैहुनुहुन्छ र यस अध्ययनले अष्ट्रेलियाको जेम्स कुक विश्वविद्यालयमा अकुपेशनलथेरापी विषयमा स्नात्तकोत्तरको डिग्रि पुरा गर्न योगदान गर्नेछ।

यस अध्ययनमा भाग लिन सहमत हुनु भएमा तपाईँले प्रश्नावली पुरा गर्न अथवा तिनको उत्तर दिन अनुरोध गरिनेछ जसमा तपाईँका व्यक्तिगत जानकारीहरु मागिएको हुन्छ। प्रश्नावली पुरा गर्न मात्र ५ देखि १० मिनेट लाग्नेछ। तत्पश्चात यदि तपाईँले समावेशी शर्तहरु : १८ बर्ष वा सो भन्दा बढी उमेर, मेरुदण्डको पक्षघात, हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्रको बहिरंग अथवा अन्तरंग बिरामीको रुपमा पुर्नस्थापित भइसकेको अथवा पुर्नस्थापनाको क्रममा रहेको, पुरा गर्नु भयो भने तपाईँलाई करिब डेढ घण्टा जति लामो अन्तरवार्ताको लागि आमन्त्रण गरिने छ।

अन्तरवार्ता निर्देशिकामाआधारित रहेर तपाईँलाई केहि खुलाप्रश्नहरुको उत्तर दिन अनुरोध गरिनेछ। अन्तरवार्ताको क्रममायहाँले आफ्नो यौन सरोकारहरु, अनुभवहरु र आवश्यकताहरु उल्लेख गर्नुहुनेछ। अन्तरवार्ताबाट तपाईँलाई सामान्य मनोबैज्ञानिक कष्ट हुन सक्नेछ भन्ने शोधकर्ता स्वीकार्नु हुन्छ। यदि यस्ता प्रश्नहरुको उत्तर दिंदा तपाईँलाई असुरक्षित अथवा तनावको महशुश हुन्छ भने तपाईँले यो अध्ययनमा भाग नलिने निर्णय गर्न सक्नुहुनेछ। तर यदि तपाईँले अध्ययनमा सहभागिता जनाउनु भयो भने शोधकर्ताद्वारा हर समय तपाईँको गोपनीयतापूर्ण रुपमा कायमराखिने छ। तपाईँको परिचयलाई गोप्यराख्न, तपाईँलाई आफ्नो रोजाइको कुनै छद्म नाम रोज्न अनुरोध गरिनेछ। यसका अतिरिक्त तपाईँले आफ्नो ठेगाना कत्ति पनि नखुलाउन पनि सक्नुहुनेछ अथवा यदि तपाईँलाई सहज लागेमा जिल्ला र अञ्चल मात्र भन्न सक्नुहुनेछ। अन्तरवार्ताको कारण कुनै पनि प्रकारको मनोबैज्ञानिक तनाव भएको खण्डमा अनुसन्धानको समयभरि तपाईँलाई हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्रबाट परामर्श तथा मनोबैज्ञानिक सहायता प्राप्त हुनेछ। यो सेवा लिन तपाईँले हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्रका साथी परामर्शदाता चेत प्रसाद अधिकारीलाई यस नम्बरमा सम्पर्क गर्न सक्नुहुनेछ + ०६१ ४३०३४२/४३००९९। परामर्श सहयोगको लागि समय लिइसकेपछि तपाईँलाई नेपालको गण्डकी अञ्चल, कास्की जिल्लाको नयाँ गाउँ, रामबजार -१५, पोखरा, स्थित हरियोखर्क हातामा रहेको हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्रमा आउन अनुरोध गरिन्छ।

अन्तरवार्ता हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्र अथवा यहाँको रोजाइको स्थानमा लिइने छ। यात्रा खर्चको आर्थिक भार न्यून गर्न हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्रको आर्थिक नीति अन्तरगत तपाईँले यात्रा र दैनिक भत्ता लिन सक्नुहुनेछ। यसका अतिरिक्त तपाईँको कामबाट समय निकालेको (घरको काम अथवा जागिर) क्षतिपूर्ति वापत तपाईँलाई अष्ट्रेलियन डलर १० बराबरको नगद अथवा सेवाको उपहार दिइने छ ।

यस अध्ययनमा सहभागिता पूर्णतया स्वेच्छिक हो र तपाईँले कुनै पनि समयमा विना कुनै व्याख्या अथवा पूर्वाग्रह यस अध्ययनमा भाग नलिन सक्नुहुन्छ।

यदि तपाईँले अन्य पुरुषहरु जो यस अध्ययनमा भाग लिन इच्छुक हुन सक्छन्, लाई चिन्नुहुन्छ भने कृपया यो जानकारी पत्र उनीहरुलाई दिन सक्नुहुन्छ ताकि उनीहरु यस अध्ययनमा सहभागिता जनाउनु मलाई सम्पर्क गर्नसकुन्।

तपाईँका प्रतिक्रियाहरु र सम्पर्क विवरणहरु पूर्णतया गोप्य रहनेछन्। अध्ययनबाट प्राप्त जानकारी अनुसन्धानका प्रकाशन र प्रतिवेदनहरुमा प्रयोग गरिनेछन्। यस्ता प्रकाशनहरुमा कुनै पनि अवस्थामा यहाँको पहिचान खुलाइने छैन।

अध्ययन सम्बन्धी कुनै प्रश्नहरु भएमा, कृपया, मनोज कुमार रानाभाट, डा. पल रोचे र डा. जेनी जुडलाई सम्पर्क राख्नुहोला ।

मुख्य शोधकर्ता :
मनोज कुमार रानाभाट
विद्यार्थी नम्बर : १२९७५८५५
व्यवसायिक चिकित्सा विभाग,
जेम्स कुक विश्वविद्यालय
मोबाइल : सिम कार्ड अध्ययनका लागि मात्र
इमेल:manojkumar.ranabhat@jcu.edu.au

सहायक सुपरीवेक्षक :
नाम : डा. पल रोचे
हरियोखर्क अस्पताल तथा पुर्नस्थापना केन्द्र
फोन + ०६१ ४३०३४२/४३००९९
इमेल:gphrc.superintendent@kaski.nepal.inf.org

प्राथमिक सुपरीवेक्षक :
नाम : डा. जेनी जुड
ट्रपिकल स्वास्थ्य र चिकित्सा विभाग
जेम्स कुक विश्वविद्यालय
फोन : ०७ ४७८१६५४७
इमेल:jenni.judd@jcu.edu.au

यस अध्ययनका नैतिक व्यवहारसँग सम्बन्धी कुनै प्रकारका सरोकारहरु भएमा, कृपया सम्पर्क गर्नुहोस् :
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

C.2.a Interview Guide English Version

Interview guide

The researcher will develop a rapport with the participant while obtaining personal information and make participant comfortable to talk on the topic of the interview.

Personal Information

Participant Number: ....

Please give a pseudonym of your preference to protect your identity in the study.
……………………………………………………………………………………………

Please provide the following details (as appropriate)?

Age: ....

Sex: ……………………………………………..

Sexual orientation: …………………………………………………………………

Marital status/
history:……

Number of children: ………. (……..son…….. daughter)

Family planning history (if relevant):
………

Education: ………………………………………………….....(Literate/ illiterate/highest level of education achieved)

Occupational history:
……

Religion: …………..

Are you living in rural or urban setting now?Please circle: Rural/ Urban

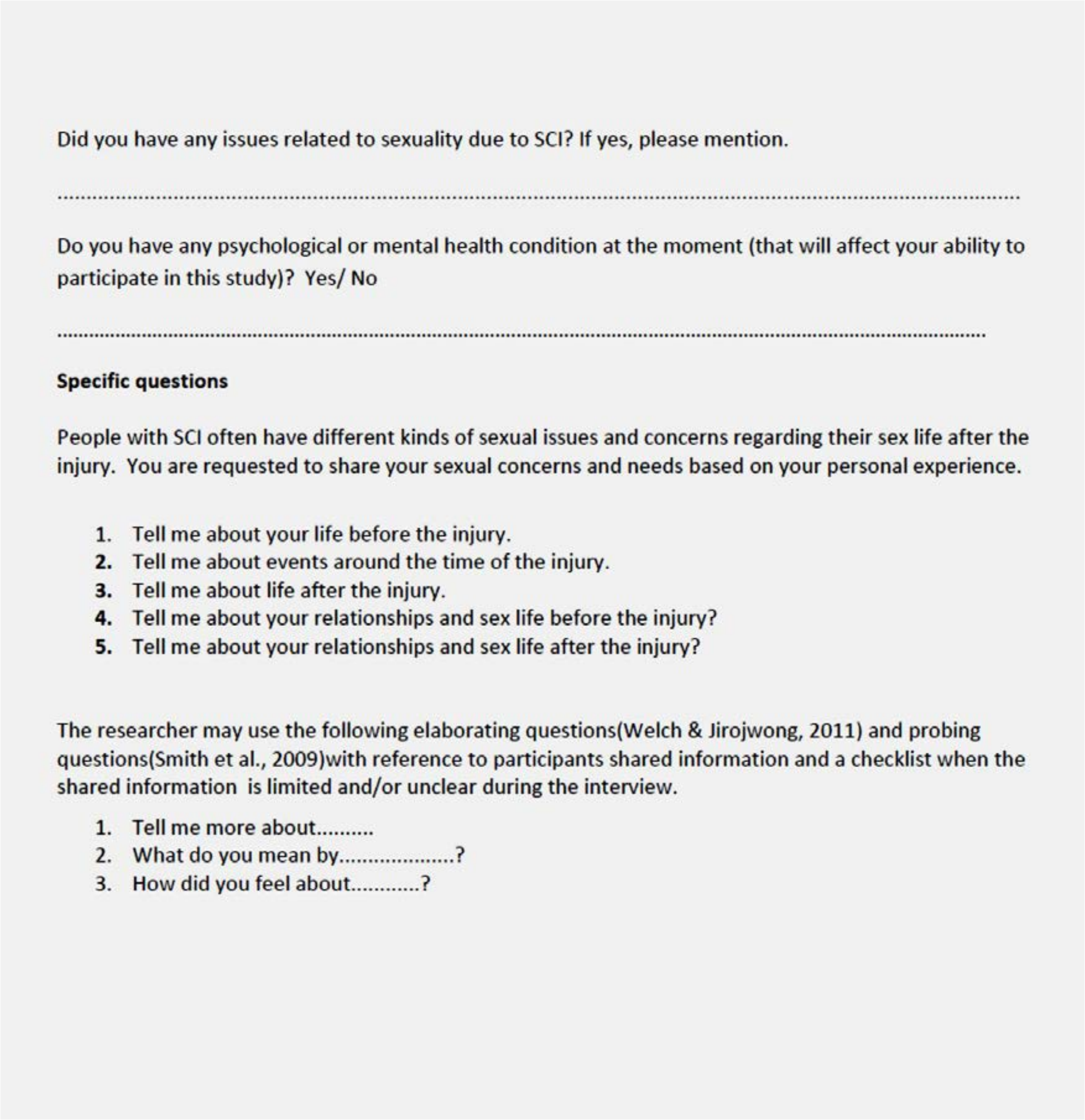
…………………………………………… (District)………………………………………………… (Zone)

Date of spinal cord injury: ……………………………..

Level of Injury: …………………………………………………………………………… (Complete/ Incomplete)

What is the cause of your spinal cord injury (SCI)?

……



Did you have any issues related to sexuality due to SCI? If yes, please mention.

....

Do you have any psychological or mental health condition at the moment (that will affect your ability to participate in this study)? Yes/ No

....

Specific questions

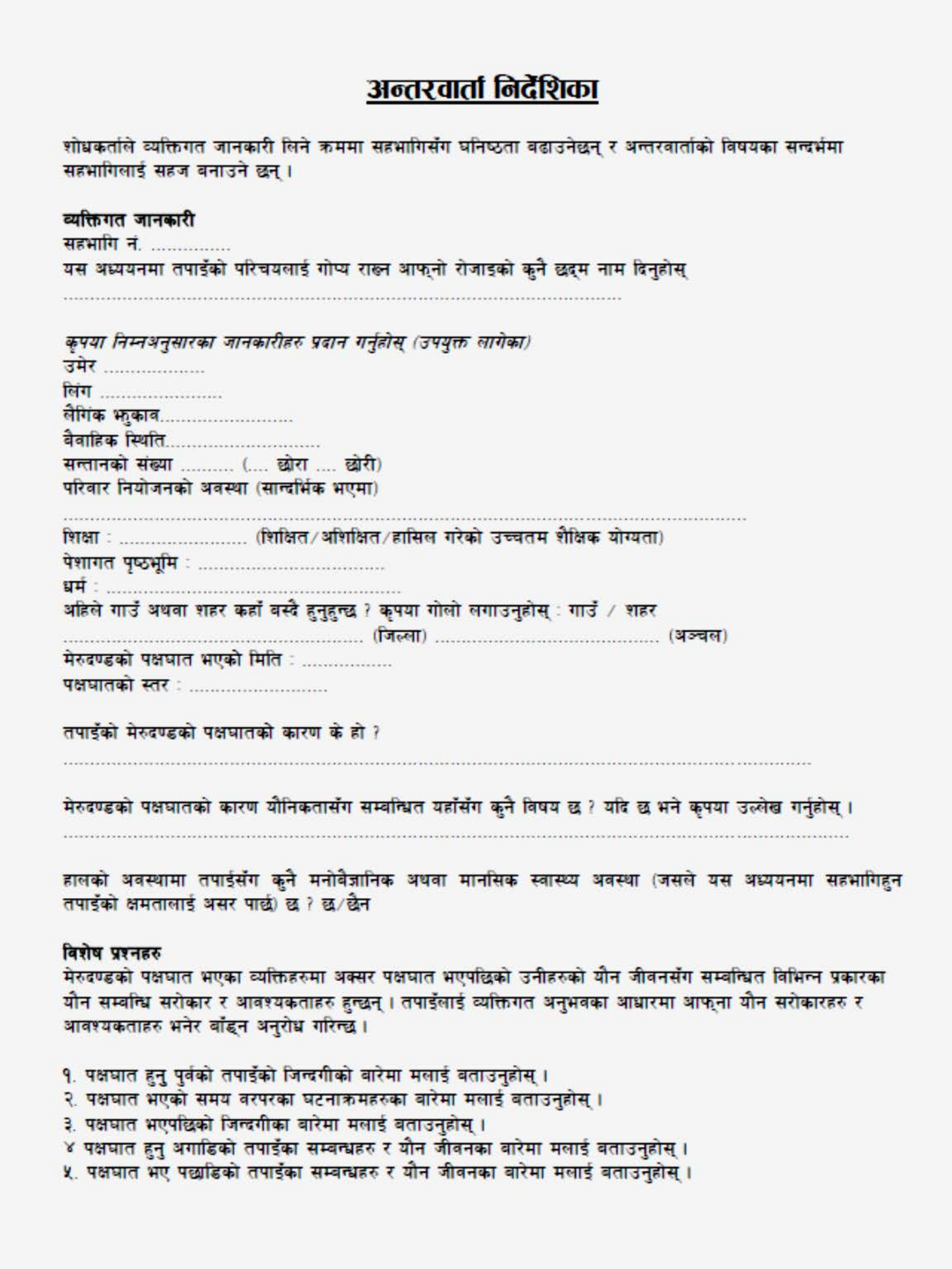
People with SCI often have different kinds of sexual issues and concerns regarding their sex life after the injury. You are requested to share your sexual concerns and needs based on your personal experience.

1. Tell me about your life before the injury.
2. Tell me about events around the time of the injury.
3. Tell me about life after the injury.
4. Tell me about your relationships and sex life before the injury?
5. Tell me about your relationships and sex life after the injury?

The researcher may use the following elaborating questions(Welch & Jirojwong, 2011) and probing questions(Smith et al., 2009)with reference to participants shared information and a checklist when the shared information is limited and/or unclear during the interview.

1. Tell me more about..........
2. What do you mean by....................?
3. How did you feel about...........?

C.2.a Interview Guide Nepali Version



अन्तरवार्ता निर्देशिका

शोधकर्ताले व्यक्तिगत जानकारी लिने क्रममा सहभागिसँग घनिष्ठता बढाउनेछन् र अन्तरवार्ताको विषयका सन्दर्भमा सहभागिलाई सहज बनाउने छन् ।

व्यक्तिगत जानकारी
सहभागि नं. ....
यस अध्ययनमा तपाईंको परिचयलाई गोप्य राख्न आफ्नो रोजाइको कुनै छद्म नाम दिनुहोस्
....

कृपया निम्नअनुसारका जानकारीहरु प्रदान गर्नुहोस् (उपयुक्त लागेका)
उमेर ....
लिंग ....
लैगिंक झुकाव.........................
वैवाहिक स्थिति.............................
सन्तानको संख्या .... (.... छोरा .... छोरी)
परिवार नियोजनको अवस्था (सान्दर्भिक भएमा)
....
शिक्षा : .... (शिक्षित/अशिक्षित/हासिल गरेको उच्चतम शैक्षिक योग्यता)
पेशागत पृष्ठभूमि : ....
धर्म : ....
अहिले गाउँ अथवा शहर कहाँ बस्दै हुनुहुन्छ ? कृपया गोलो लगाउनुहोस् : गाउँ / शहर
.... (जिल्ला) .... (अञ्चल)
मेरुदण्डको पक्षघात भएको मिति : ....
पक्षघातको स्तर : ....

तपाईंको मेरुदण्डको पक्षघातको कारण के हो ?
....

मेरुदण्डको पक्षघातको कारण यौनिकतासँग सम्वन्धित यहाँसँग कुनै विषय छ ? यदि छ भने कृपया उल्लेख गर्नुहोस् ।
....

हालको अवस्थामा तपाईसँग कुनै मनोवैज्ञानिक अथवा मानसिक स्वास्थ्य अवस्था (जसले यस अध्ययनमा सहभागिहुन तपाईंको क्षमतालाई असर पार्छ) छ ? छ/छैन

विशेष प्रश्नहरु
मेरुदण्डको पक्षघात भएका व्यक्तिहरुमा अक्सर पक्षघात भएपछिको उनीहरुको यौन जीवनसँग सम्वन्धित विभिन्न प्रकारका यौन सम्वन्धि सरोकार र आवश्यकताहरु हुन्छन् । तपाईंलाई व्यक्तिगत अनुभवका आधारमा आफ्ना यौन सरोकारहरु र आवश्यकताहरु भनेर बाँड्न अनुरोध गरिन्छ ।

१. पक्षघात हुनु पुर्वको तपाईंको जिन्दगीको बारेमा मलाई बताउनुहोस् ।
२. पक्षघात भएको समय वरपरका घटनाक्रमहरुका बारेमा मलाई बताउनुहोस् ।
३. पक्षघात भएपछिको जिन्दगीका बारेमा मलाई बताउनुहोस् ।
४ पक्षघात हुनु अगाडिको तपाईंका सम्वन्धहरु र यौन जीवनका बारेमा मलाई बताउनुहोस् ।
५. पक्षघात भए पछाडिको तपाईंका सम्वन्धहरु र यौन जीवनका बारेमा मलाई बताउनुहोस् ।

अन्तरवार्ताको अवधिमा प्राप्त जानकारीहरु सिमित र/अथवा अस्पष्ट भएको खण्डमा, जानकारी पत्र र जाँच सूचीमा आधारित रहेर शोधकर्ताले निम्नानुसारका व्याख्यात्मक प्रश्नहरु (Welch &Jirojwong, २०११) र प्रष्ट पार्ने प्रश्नहरु (Smith et al., २००९) प्रयोग गर्न सक्नेछन् ।

१. .... का बारेमा मलाई थप बताउनुहोस्
२. .... भन्नाले के भन्न खोज्नु भएको हो ?
३. .... बारेमा तपाईंले कस्तो महशुश गर्नुभयो ?

C.3.a Consent Form English Version

JAMES COOK
UNIVERSITY
AUSTRALIA

This administrative form
has been removed

C.3.b Consent Form Nepali Version

This administrative form has been removed

C.4.a Check List English Version

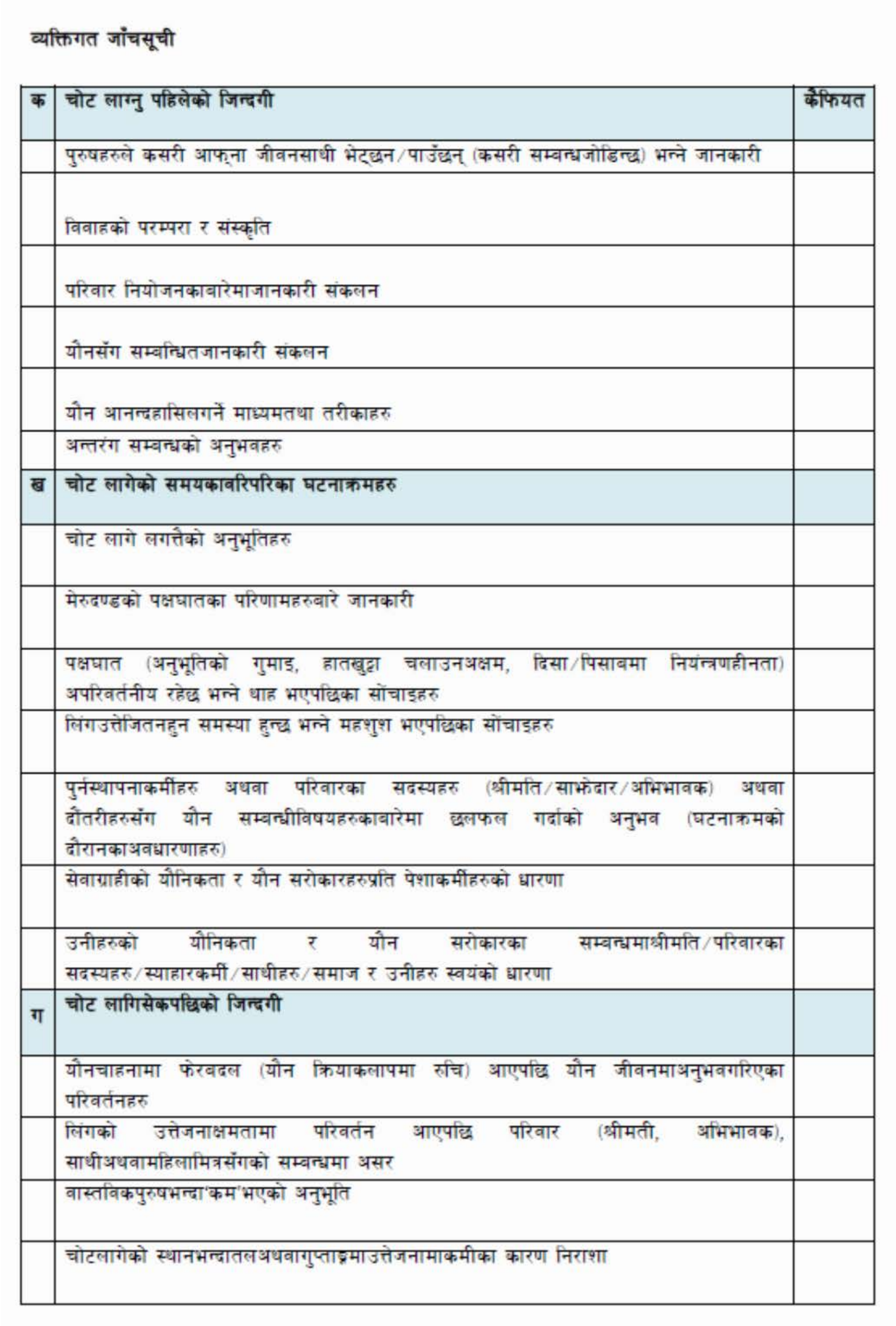
Personal checklist

A	**Life before the Injury**	**Remarks**
	Information on how menmeet/find (get into relationship with) their partner/spouse	
	Marriage customs and culture	
	Obtaining Information about family planning	
	Obtaininginformation related to sexuality	
	Means and ways of obtaining sexual pleasure	
	Intimate relationship experiences	
B	**The events around the time of the injury**	
	Thoughts immediately after the injury	
	Information about the consequences of SCI	
	Thoughts after realizing that paralysis (loss of sensation, inability to move limbs, bladder/bowel incontinence) was irreversible	
	Thoughts after realizing that obtaining erection was an issue	
	Experience (perception around the events) on discussing sexual issues with rehabilitation professional/s or family member (spouse/ partner/ parents) or peers	
	Attitudes of professionals towards client's sexuality and sexual concerns	
	Attitudes of spouse/family members/ care giver/friends/ society's and client's own attitude towards their sexuality and sexual concerns	
C	**Life after the injury**	
	Changes experienced in sex life afteralteration in sexual desire (interest in sexual activities	
	Effect of changes in capacity to have an erection on the relationship with family (spouse, parents), partner or a girl friend	
	Feeling of 'less' than a real man	
	Frustration due to lack of sensation below the level of injury and or in genital	
	Masturbation	
	Impacts experienced in sex life after altered ability to ejaculate	
	Changes experienced in sex life after alteration in orgasm capacity	
	Adaptation in sex life	
	Partner's satisfaction	

	Concerns about capacity to father a child	
	Sexual rehabilitation/s services (counselling/education).	
	Obtaining information regarding sexual concerns	
	Use of devices/medicines for enhancing sex life	
	Access (ease of availability and affordability) to the device/drugs	
	Desired changes in the sexual rehabilitation service	
	Social beliefs and cultural values about sexuality	
	Opportunity to socialize and finding a potential partner/s	
	Feelings on not being perceived as potential sexual partner/ life partner	
	Advice to othermen with a recent SCI	

It is expected that participants will provide the above information while telling their stories in a free flowing manner during the interview (without needing much clarification and or probing). However, the researcher may seek further elaboration and or clarificationtowards the end of the interview to enrich the text data using the above checklist, when shared information is not clear.

C.4.a Check List Nepali Version



व्यक्तिगत जाँचसूची

क	**चोट लाग्नु पहिलेको जिन्दगी**	**कैफियत**
	पुरुषहरुले कसरी आफ्ना जीवनसाथी भेट्छन/पाउँछन् (कसरी सम्वन्धजोडिन्छ) भन्ने जानकारी	
	विवाहको परम्परा र संस्कृति	
	परिवार नियोजनकाबारेमाजानकारी संकलन	
	यौनसँग सम्बन्धितजानकारी संकलन	
	यौन आनन्दहासिलगर्ने माध्यमतथा तरीकाहरु	
	अन्तरंग सम्वन्धको अनुभवहरु	
ख	**चोट लागेको समयकावरिपरिका घटनाक्रमहरु**	
	चोट लागे लगत्तैको अनुभूतिहरु	
	मेरुदण्डको पक्षघातका परिणामहरुबारे जानकारी	
	पक्षघात (अनुभूतिको गुमाइ, हातखुट्टा चलाउनअक्षम, दिसा/पिसाबमा नियन्त्रणहीनता) अपरिवर्तनीय रहेछ भन्ने थाह भएपछिका सोंचाइहरु	
	लिंगउत्तेजितनहुन समस्या हुन्छ भन्ने महशुश भएपछिका सोंचाइहरु	
	पुर्नस्थापनाकर्मीहरु अथवा परिवारका सदस्यहरु (श्रीमति/साझेदार/अभिभावक) अथवा दौंतरीहरुसँग यौन सम्बन्धीविषयहरुकाबारेमा छलफल गर्दाको अनुभव (घटनाक्रमको दौरानकाअवधारणाहरु)	
	सेवाग्राहीको यौनिकता र यौन सरोकारहरुप्रति पेशाकर्मीहरुको धारणा	
	उनीहरुको यौनिकता र यौन सरोकारका सम्वन्धमाश्रीमति/परिवारका सदस्यहरु/स्याहारकर्मी/साथीहरु/समाज र उनीहरु स्वयंको धारणा	
ग	**चोट लागिसेकपछिको जिन्दगी**	
	यौनचाहनामा फेरबदल (यौन क्रियाकलापमा रुचि) आएपछि यौन जीवनमाअनुभवगरिएका परिवर्तनहरु	
	लिंगको उत्तेजनाक्षमतामा परिवर्तन आएपछि परिवार (श्रीमती, अभिभावक), साथीअथवामहिलामित्रसँगको सम्वन्धमा असर	
	वास्तविकपुरुषभन्दा'कम'भएको अनुभूति	
	चोटलागेको स्थानभन्दातलअथवागुप्ताङ्गमाउत्तेजनामाकमीका कारण निराशा	

	हस्तमैथुन	
	विर्यनिकाल्ने क्षमतामा फरक परेपछि यौन जीवनमाअनुभवगरिएका असरहरु	
	चरमोत्कर्षको क्षमतामा फरक आएपछि यौन जीवनमाअनुभवगरिएका परिवर्तनहरु	
	यौन जीवनमाअनूकुलन	
	(यौन) साथीको सन्तुष्टि	
	बच्चाको बाबु बन्न सक्ने क्षमताबारे सरोकार	
	यौनिकपुर्नस्थापना/सेवाहरु (परामर्श/शिक्षा)	
	यौन सरोकारहरु सम्बन्धीजानकारी हासिल	
	यौन जीवनमा बढोत्तरीकालागि साधनहरु/औषधिहरुको प्रयोग	
	साधनहरु/औषधिहरुमापहुँच (सहजउपलब्धतार बहनयोग्यता)	
	यौन पुर्नस्थापना सेवाहरुमा इच्छित परिवर्तनहरु	
	यौनिकताकाबारेमा सामाजिकविश्वास र साँस्कृतिकमान्यता	
	समाजमा घुलमिल हुने र सम्भावित साथीपाउने अवसर	
	सम्भाव्य यौन साथी/जीवन साथीको रुपमानलिइने सम्बन्धमा सोंचाइ	
	मेरुदण्डको पक्षघात भएकाअन्य पुरुषहरुलाई सल्लाह	

अन्तरवार्ताको दौरानमासहभागिहरुलेआफनाकथाहरु सुनाउँदाधेरै प्रष्टीकरण अथवा सोधखोज विनामाथिउल्लेखितजानकारीहरु प्रदानगर्नेछन् भन्ने अपेक्षागरिएकोछ । यद्यपि, अन्तरवार्ताको अन्त्यतिर थपजानकारीहरु हासिलगर्ने उद्देश्य सहित शोधकर्ताले माथिको जाँचसूचीप्रयोग गर्दै थपव्याख्याअथवा स्पष्टताको लागिआग्रहगर्न सक्नेछन् ।