

**Access to primary care for persons with spinal cord injuries in the greater  
Gaborone, Botswana**

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**Research assignment in partial fulfilment of the requirements for the degree:  
Master of Human Rehabilitation Studies**

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UNIVERSITEIT  
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STELLENBOSCH  
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1918 · 2018

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March 2018

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## Abstract

**Introduction:** People with SCI often have great need for health care services, but they report access challenges. Primary care access to people with SCI has not been explored in Botswana.

**Aim:** This study aimed to identify barriers and facilitators that users with spinal cord injuries experience in accessing primary care services in the greater Gaborone.

**Methods:** A quantitative, cross sectional, observational study was done. Data was collected with a structured questionnaire from 57 participants with traumatic and non-traumatic SCI. Descriptive analysis was done.

**Results:** The male to female ratio was 2.8:1. The mean age of participants was 40 (SD 9.59). Road traffic accidents caused 85% of the injuries. Most participants visited primary care facilities between 2 to 10 times in the six months before the study. Participants were satisfied with the services (63%) and felt that facilities were clean (95%) and well maintained (73.5%). Preferential treatment, respect, short waiting times and convenient hours facilitated an acceptable and adequate service. Availability was hampered by insufficient provider knowledge on SCI as indicated by 71.9% of participants, and shortage of consumables (80.7%). Structural challenges (42.1% could not enter the facility by themselves and 56.5% could not use the bathroom) and lack of height adjustable examining couches (66.7%) impeded accessibility. Cost was incurred when participants (64.9%) utilised private health services where public services failed to address their needs.

**Conclusion:** Primary care services were mostly affordable, acceptable and adequate. Availability and accessibility aspects created barriers.

**Key words:** Spinal cord injury, Primary care, Botswana, access, available, affordable, accessible, acceptable, adequate.

## Abstrak

**Agtergrond:** Spinaalkoord beserings veroorsaak 'n groter behoefte aan gesondheidsdienste. Tog ondervind persone met spinaalkoord beserings probleme met toegang tot gesondheidsdienste. Toegang tot primêre sorg vir persone met Spinaalkoord beserings in Botswana is nog nie ondersoek nie.

**Doel:** Die doel van die studie was om hindernisse en fasiliteerders te identifiseer wat persone met spinaalkoord beserings ondervind met gebruik van primêre sorg dienste in the groter Gaborone area in Botswana.

**Metodes:** 'n Deursnit, observasie studie is gedoen. Data was by 57 deelnemers met traumatiese en nie-traumatiese spinaalkoord beserings ingesamel deur middel van 'n gestruktureerde vraelys. Beskrywende data analise was gedoen.

**Resultate:** Die man tot vrou ratio was 2.8:1. Deelnemers se gemiddelde ouderdom was 40 (SD 9.59). Pad ongelukke het 85% van beserings veroorsaak. Deelnemers het primêre sorg fasiliteite tussen 2 en 6 maal besoek in die ses maande voor die studie. Hulle was tevrede met die diens (63%) en was van mening dat die fasiliteite skoon (95%) en goed onderhou was (73.5%). Voorkeur behandeling, respek, kort wag periodes en gerieflike ure het verder gesorg vir aanvaarbare en voldoende dienste. Besikbaarheid is negatief beïnvloed deur onvoldoende kennis oor die hantering van spinaalkoord beserings aan die kant van diensverskaffers, soos aangedui deur 71.9% van deelnemers, en 'n tekort aan verbruikbare produkte (80.7%). Strukturele beperkinge (42.1% kon nie op hulle eie die fasiliteite binnegaan nie en 56.5% kon nie die badkamer gebruik nie) en 'n tekort aan hoogte verstelbare ondersoek beddens (66.7%) het toeganklikheid beperk. 64.9% van deelnemers het ekstra koste aangegaan om privaat gesondheids dienste te besoek omdat staats dienste nie aan hulle behoeftes kon voldoen nie.

**Gevolgtrekking:** Primêre sorg dienste was oor die algemeen beskikbaar, aanvaarbaar en voldoende. Besikbaarheid en toeganklikheid van dienste het probleme geskep.

## Introduction

### Background

Spinal cord injury (SCI) is a severely disabling condition, which can affect a person's physical, psychological, social and economic status negatively (Chang *et al.* 2012; Frantz & Mpofu 2006; Singh *et al.* 2014). SCI is also often associated with poorer health outcomes that may not only relate to complications and higher health care needs (Amatachaya *et al.* 2011; Chamberlain *et al.* 2015; Hitzig *et al.* 2008; Löfvenmark, Nilsson Wikmar *et al.* 2016; Oderud 2014), but also to general difficulties in accessing basic primary health care (Goodridge *et al.* 2015; Stillman *et al.* 2014; Stillman *et al.* 2017). In general persons with SCI utilise health care services less than they need to, while they often need these services more than the mainstream population (Ronca *et al.* 2017).

Health care provision in large parts of Africa is hampered by inequity, poor coverage and access, management challenges, high costs and ineffectiveness (Tanser, Gijsbertsen & Herbst 2006). Schneider *et al.* (2013) demonstrates that most African Union policies lack focus on the needs of individual vulnerable groups such as persons with disabilities. In South Africa the Ministry of Health's role in providing overall guidance on activities that contribute to improving levels of health has generally been characterised by good policies, but without equivalent emphasis on the implementation, monitoring, and assessment of these policies throughout the system (Coovadia *et al.* 2009). Lack of appropriate policies across Africa and poor implementation of the policies may therefore have contributed to non-equitable resource distribution in health care amongst other services.

Limited research could be identified on issues regarding needs of people with disability in general and SCI specifically in Botswana. Löfvenmark and colleagues have explored some of the issues and provide valuable information on the

epidemiology of and outcomes after SCI, as well as on the experience of living with SCI in Botswana (Löfvenmark *et al.* 2015; Löfvenmark, Hasselberg *et al.* 2016; Löfvenmark, Nilsson Wikmar *et al.* 2016; Löfvenmark, Norrbrink *et al.* 2016). One of the aspects that remains unexplored is the challenges that person with SCI may face when accessing primary care, a service that is fundamental.

Studies on barriers to accessing health services by people with disabilities including people with SCI in Botswana are limited. African studies, however, demonstrate general difficulty in utilisation of health care by persons with disabilities (Eide *et al.* 2015; Mulumba *et al.* 2014; Trani & Loeb 2012), but not necessarily primary care and not specifically by people with SCI. Van Rooy *et al.* (2012: 762) allege that “People living with disabilities experience unique difficulties when attempting to utilise conventional health facilities.” The challenges faced by people living with disabilities especially in developing countries are by and large a product of socially, medically, politically and structurally constructions rather than biophysical limitations (Rusvinga 2012). Access to primary care of people with SCI in Gaborone, Botswana therefore is worth being investigated.

Information gathered in this study might show deficiencies or efficiencies of health care service initiatives in providing equitable services to persons with SCI. Issues regarding health provision to persons with disabilities and accessibility of primary care to people with SCI could be identified. The results of this study might assist health care planners and providers in the greater Gaborone city area, to reflect on the deficiencies and successes of the services they render.

### Study problem

Having served in a SCI rehabilitation unit in Gaborone, the only one in the country, the general observation of the researcher is that clients with SCI fail to adequately utilise local primary care services after discharge from rehabilitation. In many

instances clients with SCI visit the rehabilitation unit with long standing undiagnosed and untreated ailments that they could not address at their primary care facilities. Anecdotal information also shows that persons with SCI find it hard to access disability related medication and consumables that should be sourced from primary care facilities. No information has been found on the actual impediments or enablers that hinder users with SCI from fully utilising the available primary care services in the greater Gaborone city area specifically and Botswana in general.

### Study question

What challenges and enablers do users with SCI in the greater Gaborone city area experience in accessing primary care?

### Study framework and literature review

#### **Spinal cord injury**

Incidence and prevalence studies on SCI differentiate between traumatic and non-traumatic SCI, but in both instances variation in figures are reported between and within countries. Based on a systematic review of the literature by Singh *et al.* (2014) New Zealand has at 49.1 per million per year the highest national traumatic SCI incidence figures, while Fiji (10.0 per million per year) has the lowest national figures. The estimated overall global-incident rate is 23 per million per year (Lee *et al.* 2014). Rahimi-Movaghar *et al.* (2013) summarised findings from studies done in developing countries in a systematic review and concluded that the incidence rate of traumatic SCI in developing countries is 25.5 per million per year. A traumatic SCI incidence figure of 13 per million per year were found for the only rehabilitation unit in Botswana (Lofvenmark *et al.* 2015).



Incidence rates for non-traumatic SCI varies between a low of 6 per million per year (Western Europe) to a high of 76 per million per year (Northern America). No figures could be found for the African region (New *et al.* 2014).

According to the 2011 Population and Housing Census, there are 59103 persons with disabilities in Botswana of the total population of 2 024 904 (2.94%) (Hlalele *et al.* 2015). This figure is surprisingly low when compared to the global estimate of 15% (Mitra 2013). Among the most prevalent cause of disability was sight/visual impairment (40.7%), hearing impairment (17%), impairments of legs (11.7%), speech impairment (9.9%), mental health disorder (7.8%), impairments of arms (6.3%), and inability to use the body at 2.5%. Specific prevalence on disability caused by SCI was not found (Hlalele *et al.* 2015). The proportion of persons with impairments staying in the greater Gaborone could also not be found in a literature search.

The main cause of traumatic SCI globally (Singh *et al.* 2014), in Africa (Rahimi-Movaghar *et al.* 2013) and in Botswana (Lofvenmark *et al.* 2015) is road traffic accidents. While the global systematic review and the one done in developing countries shows falls as the second biggest cause of SCI, the study in Botswana by Lofvenmark *et al.* (2015) shows assaults as second biggest cause followed by falls in the third place. The main cause of non-traumatic SCI in developing countries including African countries are related to infections (EG Tuberculosis and HIV) and tumours, while in developed countries they were mainly caused by degenerative conditions and tumours (New *et al.* 2014).

Global studies (Rahimi-Movaghar *et al.* 2013; Singh *et al.* 2014), including Botswana (Lofvenmark *et al.* 2015) conclude that more males than females suffer traumatic SCI. They also concur that the injuries are most common in younger people and peaks at about 30 years of age.

## **Primary care needs after spinal cord injury**

People with SCI might have exaggerated needs of promotive, preventative and curative health care. They are at risk of developing secondary complications such as urinary tract infections (Amatachaya *et al.* 2011; Hitzig *et al.* 2008; Löfvenmark, Nilsson Wikmar *et al.* 2016; Oderud 2014), bowel problems (Hitzig *et al.* 2009) respiratory infections (Chamberlain *et al.* 2015; Hitzig *et al.* 2009; McKinley *et al.* 1999), autonomic dysreflexia (Hitzig *et al.* 2009; McKinley *et al.* 1999) pressure ulcers (Amatachaya *et al.* 2011; Löfvenmark, Nilsson Wikmar *et al.* 2016; McKinley *et al.* 1999; Oderud 2014; Saunders, Krause & Acuna 2012;), musculoskeletal and / or neuropathic pain (Amatachaya *et al.* 2011; Löfvenmark, Nilsson Wikmar *et al.* 2016; Oderud 2014), fractures (Amatachaya *et al.* 2011; McKinley *et al.* 1999) and depression (Hitzig *et al.* 2009; Oderud 2014). Furthermore Holtz and Levi (2010) are of the view that over time a SCI causes multiple organ vulnerability necessitating increasing health care provision. Persons with SCI also remain at risk for health conditions seen in the general population such as cardiac complications and hypertension (Chamberlain *et al.* 2015; Hitzig *et al.* 2009). Thus persons with a SCI might need to utilise health care services at primary level more than their uninjured counterparts.

## **Primary health care and primary care**

Health care delivery based on the Primary Health Care (PHC) philosophy might be the only way to deliver effective health care to many communities in developing nations (Tanser, Gijsbertsen and Herbst 2006, 691). "PHC has remained the benchmark for most countries' discourse on health precisely because the PHC movement tried to provide rational, evidence-based and anticipatory responses to health needs and...social expectations...features are person-centeredness, comprehensiveness and integration, and continuity of care, with a regular point of entry into the health system" (WHO 2008 xii). The primary health care model is

preferred for Botswana as well, “The health care system in Botswana follows a decentralised model, with primary healthcare as the pillar of the delivery system, supported by an extensive network of health facilities (hospitals, clinics, health posts, mobile stops) in the 27 health districts” (Sinha & Onyatseng, 2012: 110).

Primary care, a cornerstone of PHC and effective healthcare delivery (Kringos *et al.* 2010), “brings promotion and prevention, cure and care together in a safe, effective and socially productive way at the interface between the population and the health system.” (WHO 2008: 41)

Primary care:

- Provides an entry point into the health system
- Address a wide range of health conditions
- Is supported by referral services
- Builds relationships between users and providers
- Focus on disease prevention, health promotion and cure
- Is provided by teams of service providers with biomedical and social skills
- Requires adequate resources (WHO 2008)

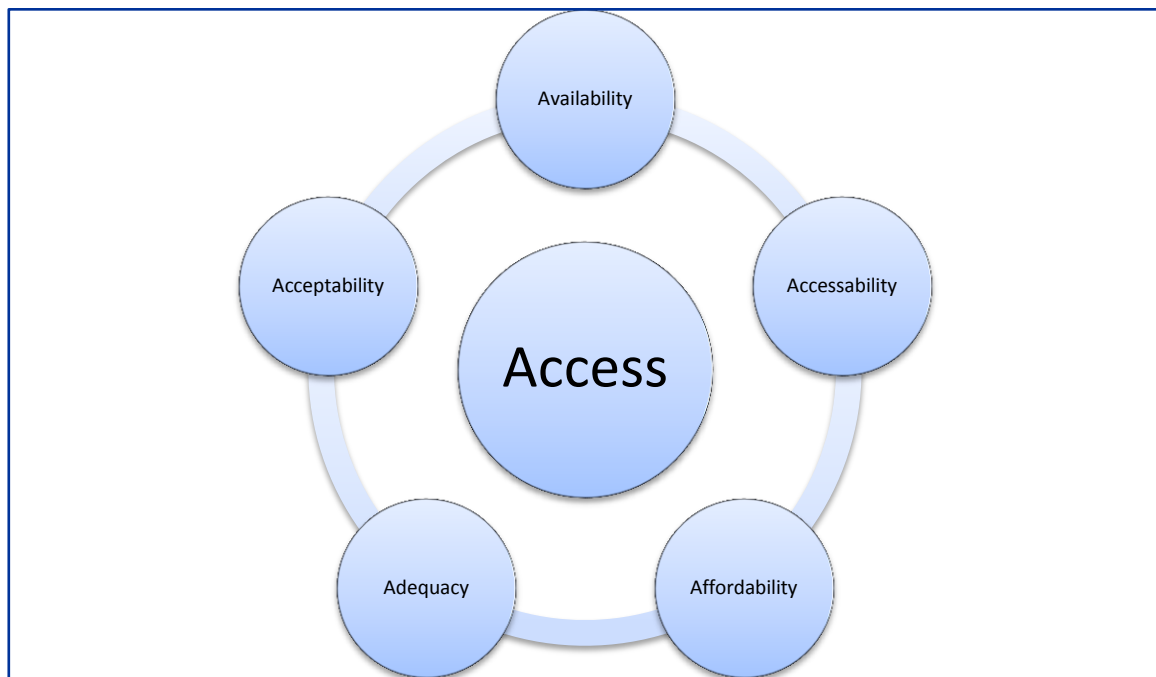
The focus of this study is on access to primary care.

### **Access to primary care**

#### **Framework for access**

Obrist and colleagues (2007) developed a comprehensive framework “to explore and improve access to health care in resource-poor countries, especially in Africa” (p1584); the ACCESS framework. The framework takes into account the supply side through policies, systems and services as well as the demand side through looking at the vulnerability context of the user, actual **access**, use, quality, health status, equity and patient satisfaction. The current study focusses on access specifically i.e. a

person has recognised an illness and seeks health care. According to the ACCESS framework five dimensions of access; availability, accessibility, affordability, adequacy and acceptability as presented in figure 1, impacts the course of seeking health care (Obrist *et al.* 2007). Each of the five dimensions will be defined and discussed separately.



**Figure 1: Health care access framework. Source: Adapted from Obrist *et al.* 20017**

**Availability of care:** According to the ACCESS framework a service is available if “the existing health services and goods meet clients’ needs” (Obrist *et al.* 2007: 1586). Thus the number and type of services and facilities, the number and skills of staff and medical and non-medical supplies meet the needs of users.

Studies from North America report that primary care services (Goodridge *et al.* 2015, Stillman *et al.* 2017; Stillman *et al.* 2014) that provided preventative and curative care to a greater or lesser extent to persons with SCI (Stillman *et al.* 2014) were physically available. However, the number of providers were not always sufficient and this

resulted in long waiting times (Goodridge *et al.* 2015), and requests to come back at another time (Goodridge *et al.* 2015).

Further availability challenges centred around service providers' knowledge and skills which were deemed insufficient to deal with the specific needs of someone with SCI and to understand the impact of SCI on over-all health (Goodridge *et al.* 2015; Stillman *et al.* 2014; Stillman *et al.* 2017).

African studies focusing on primary care access for persons with SCI specifically could not be identified. Studies that focussed on persons with diverse disabilities showed challenges with service availability that included lack of services and facilities (Eide *et al.* 2015; Mulumba *et al.* 2014), insufficient drugs (Eide *et al.* 2015; Mulumba *et al.* 2014; Van Rooy *et al.* 2012; Vergunst *et al.* 2015), insufficient equipment and supplies (Eide *et al.* 2015; Vergunst *et al.* 2015), lack of staff (Mlenzana & Mwansa 2012; Mulumba *et al.* 2014; Vergunst *et al.* 2015), lack of skills (Mlenzana *et al.* 2013; Mulumba *et al.* 2014; Van Rooy *et al.* 2012) and long waiting times (Cawood & Visagie 2015; Vergunst *et al.* 2015). Maart and Jelsma (2013) reported from a South African setting that only 2.5% of participants with disabilities who needed primary health care did not receive it. This positive finding was attributed to a high number of clinics in the study area.

**Accessibility of care:** A service is accessible when “the location of supply is in line with the location of clients” (Obrist *et al.* 2007: 1586). Accessibility refers to distance from the facility, transport and physical access of the health care facility. Especially important amongst a group of participants who are wheelchair users is physical access. The majority (73.8%) of American wheelchair users (n = 432) in a study by Stillman *et al.* (2017) experienced physical access challenges when accessing primary care services; as did the majority (99.1%) of a group with SCI (n = 108) (Stillman *et al.* 2014). These participants experienced challenges with physical access to the entrance door (Stillman *et al.* 2017; Stillman *et al.* 2014), the hallway (Stillman *et al.*

2017; Stillman *et al.* 2014), bathrooms (Goodridge *et al.* 2015; Stillman *et al.* 2014; Stillman *et al.* 2017) and examination rooms (Stillman *et al.* 2017; Stillman *et al.* 2014). In examination rooms a lack of height adjustable beds (Goodridge *et al.* 2015; Stillman *et al.* 2014; Stillman *et al.* 2017) combined with a lack of transfer equipment led to many participants (69.7% - Stillman *et al.* 2017 to 85.2% - Stillman *et al.* 2014) being examined in their wheelchairs.

In a Namibian study Van Rooy *et al.* (2012) demonstrated that physical access to the facility decreased accessibility of primary care services for people with disabilities. These challenges were confirmed by a rural South African study (Vergunst *et al.* 2015). Van Rooy *et al.* (2012) also found restrooms to be inaccessible or unavailable.

In Africa people, including those with disabilities, often walk or use a manually propelled wheeled device to access health care; often over considerable distances and muddy, sandy or rocky terrain (Mulumba *et al.* 2014; Van Rooy *et al.* 2012; Vergunst *et al.* 2015). Inaccessible roads and terrain, lack of transport, high cost of transport and inaccessibility of public transport all create barriers to health care access (Cawood & Visagie 2015; Löfvenmark Nilsson Wikmar *et al.* 2016; Maart & Jelsma 2013; Van Rooy *et al.* 2012; Vergunst *et al.* 2015)

**Affordability of care:** In an affordable service “the prices of services fit the clients’ income and ability to pay” (Obrist *et al.* 2007: 1586). Affordability refers to direct and indirect cost of health services including transport costs, time loss, cost of drugs, consumables and consultations. Van Rooy *et al.* (2012) identified costs of accessing health care, specifically transport cost, to be a significant factor limiting health care access of persons with disabilities in Namibia. Maart and Jelsma (2013) reported that persons with disabilities in South Africa also struggled to access rehabilitation services, due to costs.

**Adequacy of care:** When “the organization of health care meets the clients’ expectations” (Obrist *et al.* 2007: 1586) the service is adequate. Adequacy refers to the organisation of care in terms of the facilities hours as well as to cleanliness and maintenance of the facility and equipment. Scheffler *et al.* (2015) has shown how an appointment for a specific time, triage and extended service hours can improve adequacy of services at primary care facilities.

**Acceptability of care:** Obrist *et al.* (2007: 1586) defines acceptability as “the characteristics of providers match with those of the clients”. Clearer explanations are provided by other authors who state that an acceptable service is ethically sound, values respect for users, communication, and confidentiality, is culturally suitable and, sensitive to gender and life-cycle needs (Gilson & Schneider 2008; Levesque *et al.* 2013). Care should be rendered in a way that takes cognisance of the client’s cultural background and is in line with their expectations.

Studies showed positive and negative findings on acceptability (Goodridge *et al.* 2015; Mlenzana *et al.* 2013; Stillman *et al.* 2014; Stillman *et al.* 2017). Participants in the qualitative study by Goodridge *et al.* (2015) explained that they wanted to be heard by health care providers (Goodridge *et al.* 2015). They also felt they had to be vigilant and pro-active and not unquestioningly accept the opinion of care providers in order to protect their health interests (Goodridge *et al.* 2015).

Van Rooy *et al.* (2012) describe nurses to be rude and demonstrate a failure of clients with disabilities to fully utilise the available health care services due to staff attitude. Other studies also found attitudinal barriers including a lack of compassion, patience, courtesy and respect that impacted service acceptability negatively (Mlenzana & Mwansa 2012; Mulumba *et al.* 2014). Furthermore, Mlenzana and Mwansa (2012) and Mulumba *et al.* (2014) identified communication challenges in Zambian and Ugandan studies respectively. Persons with disabilities indicated that doctors did not always listen to them and did not always provide clear explanations.

## **Persons with spinal cord injury satisfaction with primary care**

Obrist *et al.* (2007) identify patient satisfaction as one of the ways to measure service outcomes. In general person with disabilities are more often dissatisfied with health care service than their non-disabled peers (Trani *et al.* 2011). Both studies by Stillman and colleagues (2014 & 2017) found that the majority of participants were satisfied with primary care access; with 13.7% (Stillman *et al.* 2017) and 17.6% being dissatisfied (Stillman *et al.* 2014).

### Aim

To identify barriers and facilitators that users with spinal cord injuries experience in accessing primary care services in the greater Gaborone city area, Botswana.

### **Objectives**

- To determine perceived availability of primary care services
- To determine perceived accessibility of primary care services
- To determine perceived affordability of primary care services
- To determine perceived acceptability of primary care services
- To determine perceived adequacy of primary care services

### **Methodology**

#### Study Design

This cross sectional study was quantitative, observational and descriptive in nature. As stated by Joubert *et al.* (2007) a descriptive study can quantify the extent of a health problem. In this study, problems encountered by people with SCI in the community of the greater Gaborone city area, with regard to primary care access, was observed, described and quantified.



## Study setting

Worldpopulationreview.com states that Botswana has a population of 2.04 million of which 232 000 resides in the capital city of Gaborone. According to <http://www.greatergaboronecity-region.info/Gaborone> the official website of the Gaborone city area Gaborone has been expanding rapidly since its establishment and even now is growing into the nearby villages. Gaborone and the neighbouring areas are referred to as the greater Gaborone city area.

Primary public facilities including health posts, clinics, primary and district hospitals provide primary care to most of people in the country for a consultation fee of 5 Pula (6 Rand). The choice of facility depends on whichever is the nearest to the patient. These facilities are managed by the district health management team (DHMT). Primary care is also provided through private facilities for profit, most of the patients who utilises private facilities would be on medical aid. However from the researcher's observation patients tend to use public facilities for first contact even if they have medical aid.

There is a single public hospital, Princess Marina hospital (PMH), in the city, which serves as a referral facility for the southern part of the country; it therefore is not managed by the DHMT. Greater Gaborone DHMT has 39 Public clinics which include some facilities in the South west and Kweneng west Districts while the neighbouring DHMTs of South West and Kgatleng have 8 and 27 clinics respectively including Health posts and two District hospitals. There are also two private hospitals and a number of Private clinics in the area being studied. PMH houses the only SCI rehabilitation unit in the country. Established in partnership between the government of Botswana and a Swedish NGO 'Spinalis foundation' the unit is called Botswana Spinalis SCI rehabilitation unit. The unit is a 12 bed ward and only provides care for clients with traumatic SCI. Following discharge clients are expected to source primary care as well as SCI health related products from their

local primary health care facilities. These comprises mostly of clinics, health posts and a limited number of mobile stops.

Clients with SCI who live in the southern and the northern part of the country are usually referred at the practitioner's discretion to the orthopaedic department of Princess Marina hospital. Since the hospital currently has no spine surgeon or neurosurgeon referrals to the two private hospitals in Gaborone are often made. A very limited number of clients are referred for surgical procedures to neighbouring South Africa. Following surgery those referred to South African private facilities would undergo acute rehabilitation before returning to Botswana. Users with traumatic SCI would go to the Spinal cord injury rehabilitation unit at Princess Marina Hospital for acute care and rehabilitation. Those with non-traumatic SCI who had surgical procedures in Botswana are discharged without having commenced a comprehensive rehabilitation program; often already with pressure ulcers.

Other than the Spinalis Botswana SCI rehabilitation unit, the Cheshire foundation in Mogoditshane, a non-governmental organisation, offers non-specific in and outpatient rehabilitation.

Since the establishment of Spinalis Botswana SCI rehabilitation in 2010 a database of clients with traumatic SCI has been kept. According to this data base 35 to 40 traumatic SCI occur yearly in Botswana. It is thought that around the same number of non-traumatic injuries also do occur. It is however unfortunate that a database for non-traumatic SCI does not exist.

### Study population, sampling and participants

The population studied comprised of persons with SCI residing in the greater Gaborone city area. This included persons with traumatic and non-traumatic SCI. No exact number on the size of the total population was available.

### **Inclusion criteria**

- People with traumatic and non-traumatic SCI
- People who have been discharged from inpatient care for at least a year
- People with complete and incomplete SCI
- Older than 21 years

### **Exclusion Criteria**

- People with incomplete SCI that do not use assistive devices. They are likely to experience less physical barriers and structural inaccessibility.
- People with SCI and other co-morbidities like mental disability, head injury or stroke. They may face challenges that are not only related to their impairments from SCI but rather from other impairments

### **Identification of possible participants**

At the time of the study the database at Princess Marina had 197 names of people with traumatic SCI from the entire country. This database was used to identify participants with traumatic SCI.

The orthopaedics department of Princess Marina hospital keep a database of their discharged patients, including patients with non-traumatic spinal cord lesions. Addresses and phone numbers are available from these records. The spine clinic also keeps a database of their clientele complete with a diagnosis but without contact details. The two sources were accessed to identify as many people with non-traumatic SCI in the study setting as possible.

In total 60 persons with traumatic SCI residing in the study area were identified in the Spinalis database and 6 persons with non-traumatic SCI persons were identified in the Orthopaedic database. The contact numbers of nine persons did not work. All 57 others agreed to take part in the study. No further sampling was done. In total 51 participants with traumatic SCI and 6 with non-traumatic SCI took part in the study.

All persons with SCI who could be identified in the study setting were asked to participate in the study. Even so some groups/individuals that differed in important ways from those identified might have been excluded. The final number of participants was not based on power analysis, but is almost twice the minimum number of 30 participants recommended by O`Leary (2017) for small quantitative studies. This number was also seen as reasonable considering the budget and time frame for masters by research assignment purposes and the fact that clients were visited at home to complete the questionnaires. As Carter, Lubinsky and Domholdt (2011) suggested, one has to balance aims for better precision with cost related with larger samples.

### Data collection instrument

A self-developed questionnaire (*appendix 1*) was used for data collection. This questionnaire addresses the following aspects:

- a. Basic demographic information (without a name – for confidentiality)
- b. The cause of SCI
- c. Level of SCI and the Asia classification
- d. Closed and open ended questions on
  - i. Primary health care services availability
  - ii. Primary health care services accessibility
  - iii. Primary health care service affordability
  - iv. Primary health care adequacy
  - v. Primary health care acceptability

The questionnaire was based on the ACCESS framework (Obrist *et al.* 2007). Care was taken to include factors identified to impact health care access by Van Rooy *et al.* (2007) and Peters *et al.* (2008) in the questionnaire.

The questionnaire was developed in English translated by the researcher, who is a Setswana first language speaker to Setswana, with subsequent back translation done by a Setswana language teacher who is also a Setswana first language speaker.

### Pilot study

A pilot study was done with five persons with traumatic SCI who met the studies inclusion criteria but did not reside in the greater Gaborone City area. The purpose of the pilot study was to assess whether the questions asked were understood by participants and illicit information to answer the study aim and objectives. The methodology and logistics of collecting data was also tested by this pilot study. No adjustments were made to the methodology or the questionnaire after the pilot study.

### Data collection

Potential participants was contacted by phone or in person and informed of the study. Appointments were made with those willing to participate either at their home, work place and University of Botswana disability department. On meeting with participants the study was explained to them and written informed consent was obtained. Participants were requested to complete the questionnaire by themselves, with or without assistance from a family member as needed. This was to allow for comfort as clients may feel intimidated by a health care provider asking them questions and completing the questionnaire on their behalf. The option for the researcher to fill in the questionnaire was availed for all participants should they want that.

## Data analysis

After the data was checked for errors it was manually transferred onto an Excel spreadsheet. Data was mainly categorical (nominal or ordinal) in nature and descriptive analysis was done.

## **Ethical considerations**

The study was approved by the Health Research Ethics Committee at Stellenbosch University (reference number: S14/10/241), permission was also obtained from the Botswana Ministry of health ethics committee (Reference number HPDME 13/18/1 IX (386) and the Princess Marina Ethics committee (reference Number PMH 5/79(215)).

Regarding beneficence the recommendations focus on issues that can improve primary care access for persons with SCI. If implemented the entire population of people with SCI in and around Gaborone stands to benefit. The researcher is a health care worker and where medical care needs were identified during data collection steps to provide appropriate services were taken. Non maleficence is acting in a manner that does not cause preventable harm to participants (Carter, Lubinsky & Domholdt 2011). In this research there were no therapeutic interventions, and no risk of physical harm. It is understood however that answering the questionnaire might bring unpleasant memories therefore psychological harm might have occurred. Clients would have been referred for counselling should such incidences occur.

To insure confidentiality of the information gathered and avoid social harms, the participants did not write their names on the questionnaires. A code was allocated to all the participants. A password protected electronic database of names and codes was kept by the researcher.

Carter, Lubinsky and Domholdt (2011) argue that in research autonomy issues pertain to informed consent. Participants were informed of the reason why the

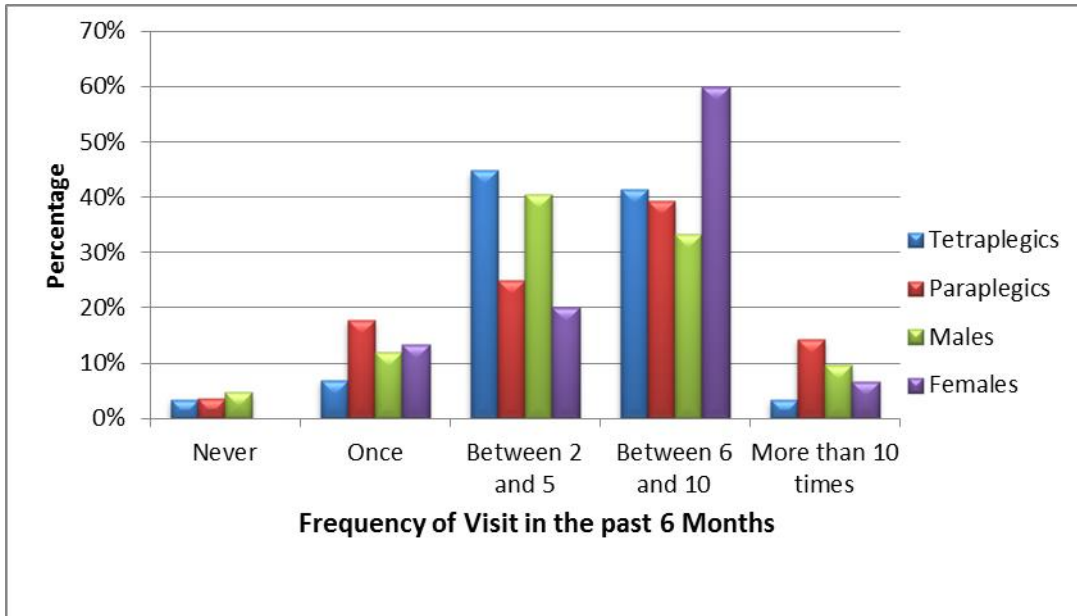
research was conducted; they were also assured that they should not feel obliged to take part. An information and consent form (see appendix 2) in Setswana or English depending on the patient's preference, was given to them and those who were not able to read had the information read to them by a person of their choice and signed by a witness of their choice.

Researchers need to be just and the principles equality and equity should be applied (Joubert *et al.* 2007). In the current research it would have been easier and more convenient to include only persons with traumatic SCI, but in the interest of justice those with non-traumatic injuries was included as well.

## Results

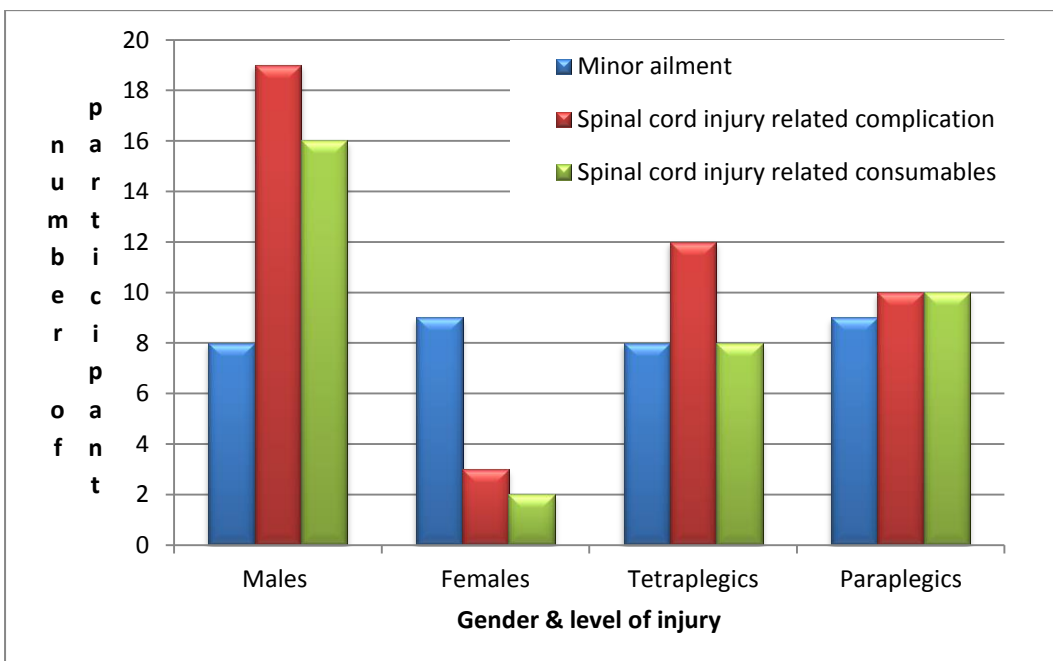
The male to female ratio amongst study participants were 2.8:1 with 73.7% (42) being men and 26.3% (15) women. The mean age of participants at the time of data collection was 40 (SD 9.59); ranging from 22 to 64. On average the years since the injury were 4 (SD 12); ranging from 2 to 5 years. The most common cause of SCI among the participants was road traffic accidents (48; 85%). Other causes such as violence (3; 5%), tuberculosis (3; 5%) and compressive myelopathy (3; 5%) were rare. Almost the same number of participants had paraplegia (28; 49.1%) and tetraplegia (29; 50.9%). Information on the completeness of injuries was not collected successfully as most participants could not tell whether their injuries were complete or incomplete.

Figure 1 demonstrates that most participants visited primary care facilities between 2 to 10 times in the six month period before the study. There was not much difference in this pattern between gender and those with paraplegia and tetraplegia.



**Figure 1 Frequency of primary care visits by participants in the 6 months before the study (n=57)**

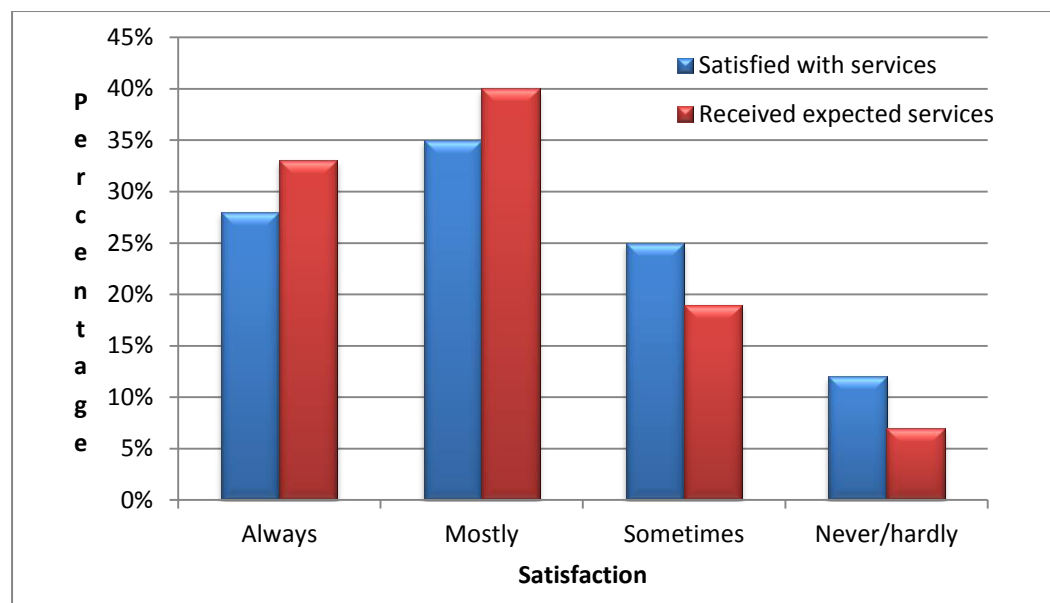
A higher percentage of women (9/15; 60%) visited a facility for minor ailments than men (8/42; 19%) (Figure 2). Men (35/42; 83.3%) more often visited facilities for SCI related care than women (5/15; 33.3%). The most common reason for visiting the health facilities was SCI related complications (22; 38.6%) followed by SCI related consumables (18; 31.6%).





**Figure 2: Reasons for visiting a primary care facility (n=57)****Satisfaction with primary care**

Figure 3 shows that the general level of satisfaction with primary care services was good with 39 (63.0%) participants being always or mostly satisfied. Similarly 42 (73.7%) participants received the service that they expected.

**Figure 3 Satisfaction with and receiving of expected services (n=57)****Availability of primary care**

The majority of participants (41; 71.9%) accessed a clinic for primary care, while 11 (19.3%) accessed a primary hospital and five (8.8%) accessed a health post.

According to table 1 the prescribed medication was always available for 45.6% (26) of participants and sometimes for a further 36.8% (21). This trend was observed for all three types of primary care delivery points with somewhat lower availability at hospitals (40%) than clinics (45%) and the highest availability at health posts (55%).

**Table 1: Availability of services (n=57)**

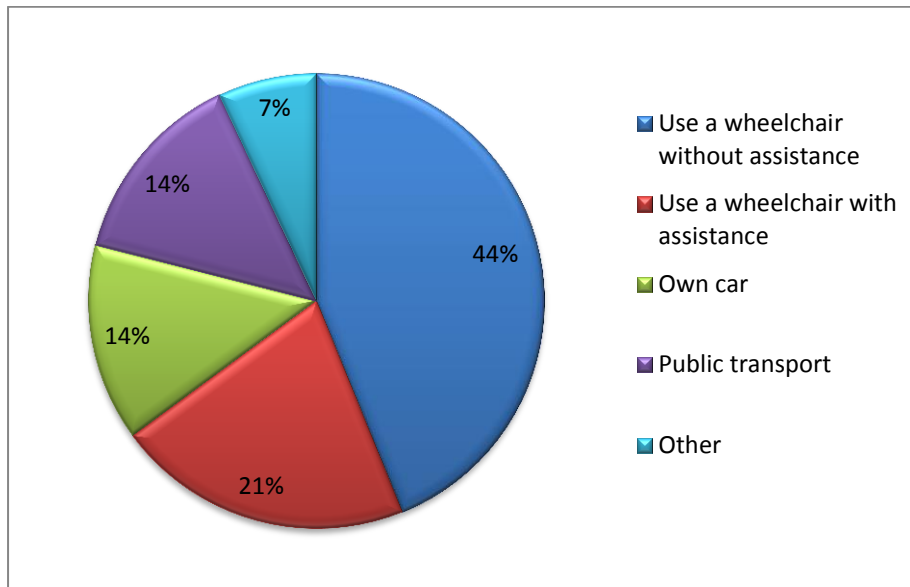
		Never/ hardly ever	Sometimes	Always
Availability of prescribed medication	Clinic	(12%)	(43%)	(45%)
	Health post	(27%)	(18%)	(55%)
	Hospital	(40%)	(20%)	(40%)
	Overall	10 (17.6%)	21 (36.8%)	26 (45.6%)
Availability of consumables	Clinic	60%	27%	23%
	Health post	60%	20%	20%
	Hospital	45%	46%	9%
	Overall	33 (57.9%)	13 (22.8%)	11 (19.3%)
Availability of staff	Very poor/poor	Good	Excellent	
	16 (28%)	17 (29.8%)	24 (42.1%)	
Staff knowledge on SCI	41 (71.9%)	16 (28.1%)	0%	

Table 1 further show that consumables were less often available, and that this problem was experienced at all three points of primary care delivery. While 71.9% (41) of participants thought that the number of staff was excellent or good they perceived challenges with regard to the knowledge of staff members on SCI related problems with 71.9% (41) scored this aspect as poor or very poor and none scored it as excellent.

### Accessibility of primary care

Just over half of the participants (52.6%; 30) could not reach the health care facility with ease. 84.2% (48) of participants stayed less than 5km from their primary care

facility, and 15.8% (9) stayed more than 5 km from the facility. Figure 4 shows that most participants (37; 65%) used their wheelchairs with (12; 21%) or without assistance (25; 44%) to get to the health care facilities.



**Figure 4: Mode of travel to the health care facility (n=57)**

In most instances (46; 82.2%) the buildings were single story; six (10.7%) of the ten double story buildings had a lift (one participant did not answer this question).

Twenty-four (42.1%) participants could not enter the facility by themselves. The reasons for this included the absence of a ramp (1), too steep a ramp (7), sandy or rough terrain outside (5), the door being too narrow (4), inability to open the door (4), a door mat (1) and other not specified(2)

Thirty-three point three percent (19) of participants indicated that they need wide parking bays while 57.9% (33) answered that they do not. Five participants did not respond to this question. The majority of participants do not use cars to get to the point of service. Participants also utilised the wide yards at clinic grounds and therefore do not necessarily need wide parking bays.

Questions relating to use of the toilet, hand washing facilities and emergency call buttons were also not answered by all as eleven (19.3%) participants have never attempted to use the bathroom at the health care facility. Of the 46 (80.7%) who did answer these questions the majority (26/46; 56.2 %) were unable to access the toilet, and use hand washing and (22/46; 47.8 %) drying facilities (26/46; 56.2 %). None of the participants had access to an emergency call button in the toilets.

### **Affordability of primary care**

Issues of affordability is summarised in table 2. Most participants (48; 84.2%) were not required to pay. Six of the participants who paid for health care paid more than 100 BWP (120 Rands), two payed between 10 to 100 BWP (12-120 Rands) while one participant paid 5 BWP (6 Rands) (the amount charged by government for consultations at the time of the study). On the other hand 64.9% (37) of participants incurred costs through having to access private services such as a doctor, medication or consumables when these were not available through the public service.

**Table 2: A summary of various affordability, acceptability and adequacy aspects (n=57)**

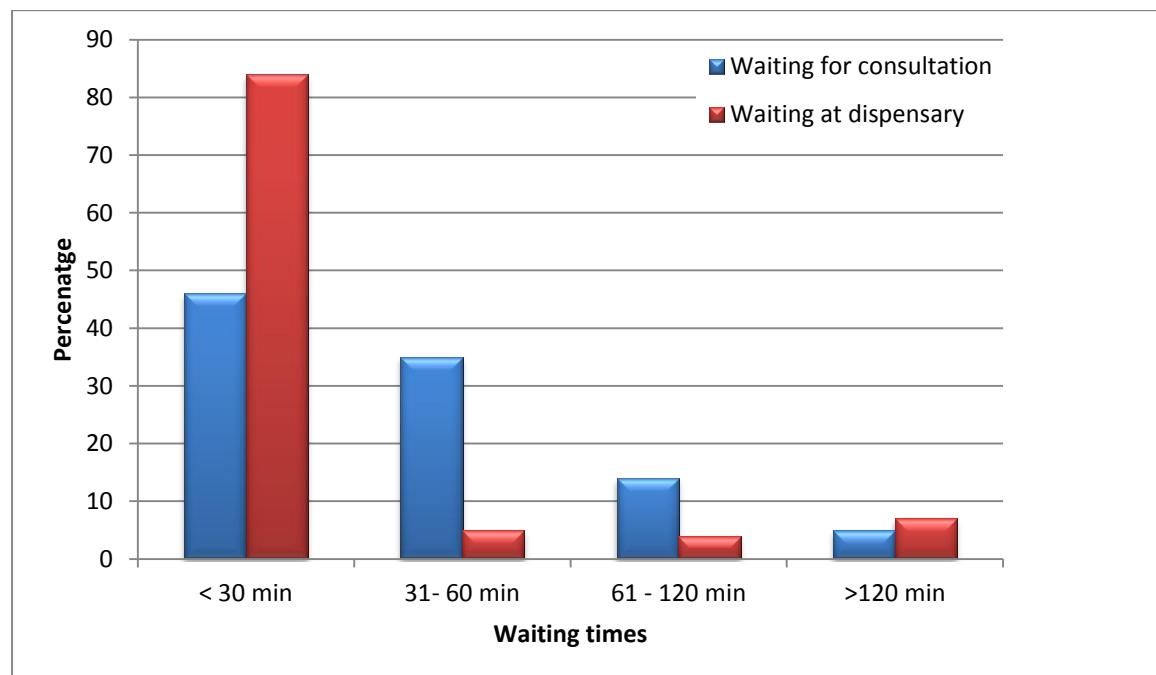
		Yes
Affordability	Payment required for primary care	9 (15.8%)
	Asked for bribe	0
	Incurred cost through accessing private care	37 (64.9%)
	Used money to get to service	17 (29.8%)
	Found primary care expensive	16 (28.1%)
	Appointment system	34 (59.6%)
Acceptability	Date and time	11 (19.3%)
	Only date	23 (40.4%)
	Assessed in wheelchair	37 (64.9%)
	Height adjustable bed	19 (33.3%)
	Refused care a primary care facility	4 (7%)
	Referred to another facility	42 (73.7%)
Adequacy	Transport offered with referral	8 (14.0%)
	Preferential treatment	42 (73.7%)
	Treated with dignity	51 (89.5%)
	Facility hours convenient	51 (89.5%)

Most (40; 70.2%) of the participants did not spend money to reach the primary care facilities. Four (7%) participants however spend more than 300BWP (360 Rands) to get to the primary care facilities; this may be due to use of special taxis. Eight (14%) participants spend between 100BWP to 300BWP (120-360 Rands) while 4 (7%) spend

between 50.01BWP to 100.00BWP(60.12-120 Rands). The majority (41; 71.9%) of the participants held the view that accessing primary care services was not expensive.

### Acceptability of primary care

Table 2 show that 59.6% (34) of the participants used facilities that had an appointment system of which 11 (19.3%) were given appointments for a specific time. The majority of participants waited less than 30 minutes for consultations (26; 46%) and at the dispensary (48; 84%) (Figure 6). The length of consultation times varied from shorter than 10 minutes (21; 36.8%) through 11 to 30 minutes (29; 50.9%) to longer than 30 minutes (7; 12.3%).

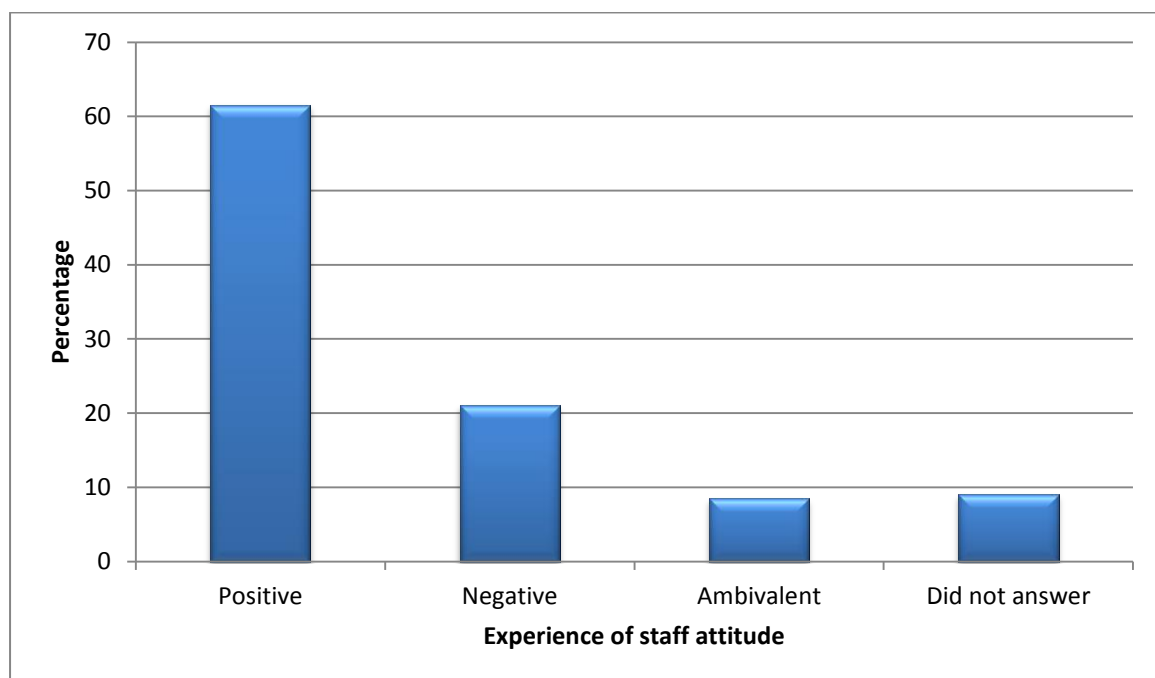


**Figure 6: Waiting times at the primary care facilities (n=57)**

The majority of participants (37; 64.9%) were assessed in their wheelchairs. Most facilities (38; 66.7%) used by participants did not have height adjustable beds. Four (7%) of the participants said that they have been refused primary care at some stage. All of them indicated that the reason for the refusal was either unavailability of an appropriate health worker or need for equipment that was not available at the health

facility. Forty-two (73.7%) participants have at one point been referred to another facility, among those referred 34 (59.6%) had no transport offered to them.

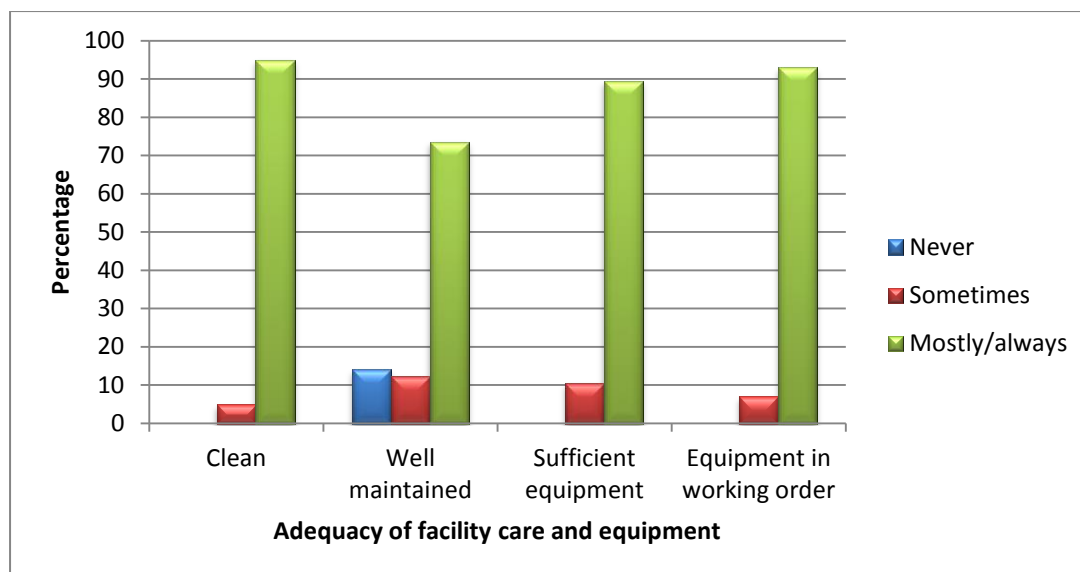
Most participants (42; 73.7%) stated that they received preferential treatment and that they were treated with dignity (51; 89.5%). With regard to staff attitude towards them 35 (61.4%) of the participants felt it was positive; while 12 (21.1%) felt it was negative as shown in figure 7.



**Figure 7: Participants' opinions about the attitudes of staff (n=57)**

### **Adequacy of primary care services**

The majority of participants (51; 89.5%) were of the opinion that the facilities were open at hours convenient for them. They also indicated high levels of satisfaction with both cleanliness and facility maintenance as shown in figure 7.



**Figure 8: Participants opinions on aspects related to the adequacy of primary care (n=57)**

Figure 8 further shows satisfaction with both the sufficiency and working order of equipment.

## Discussion

### Demographic information

The higher ratio of men to women is consistent with worldwide trends as males are more susceptible to SCI when compared to women. The percentage of men is also similar to that find by Lofvenmark *et al.* (2015) in a previous study done in Botswana. The finding that participants were on average younger than 40 years old is also consistent with international and national data on SCI, as presented in the literature review. The low average time since the injury could indicate poor long term survival of people with SCI in Botswana. The short duration of the presence of a SCI rehabilitation unit in the country is also a likely cause. However, further study is necessary to come to any definite conclusion on this.



## **Medical Information**

In accordance with previous findings (Lofvenmark *et al* 2015; Rahimi-Movaghar *et al* 2013; Singh *et al* 2014) participants had mostly been injured through road traffic accidents. Other traumatic causes as well as medical causes were rare. While this indicate that road traffic accidents were the most common cause of traumatic SCI, one cannot conclude that traumatic SCI occurred at higher frequency than non-traumatic SCI in the study setting. A database for persons with traumatic SCI was readily available, while there was one dedicated to persons with non-traumatic injuries. Very few persons with non-traumatic SCI could be identified, but it is assumed that not all were identified and that results cannot be generalised to this group.

The finding that similar numbers of participants had paraplegia (28; 49.1%) and tetraplegia (29; 50.9%) is inconsistent with findings from Löfvenmark *et al* (2015), where tetraplegia was said to be more common than paraplegia. This difference could be due to a higher mortality rate of people with tetraplegia when compared to those with paraplegia as also noted by Löfvenmark *et al* (2015) and Oderud (2014), since Löfvenmark *et al* (2015) collected data on admission to rehabilitation.

## **Primary Care Visits**

The results demonstrated an increased need of health care services among people with SCI, due to SCI related complications and the need for consumables that is consistent with literature findings (Hitzig *et al* 2009, Chamberlain *et al* 2015, Amatachaya, *et al* 2011 and Oderud 2014). The finding that women visited the facilities more often than men was interesting and might point to increased health care needs among women or a reluctance of men to visit health care facilities. However, further investigation is needed. The majority of participants (40; 70.2%)

accessed a clinic for primary care. This is consistent with the number of such facilities in the area.

The finding that the majority of participants were satisfied with the services they received at primary care facilities was consistent with international findings (Stillman et al 2017; Stillman et al 2014) It is possible that patient satisfaction could be influenced by what users perceive to be appropriate or ideal. These answers may not mean that the patients receive appropriate services of high quality. A bigger percentage of participants (20% or more) were not satisfied with service than what was found in the international studies. This might be an indication that persons with SCI in Botswana do discern between any care and care of higher quality. It might also be due to the real challenge of providing primary care of continuous high quality in developing countries (O' Donnelle & Owen 2007).

### **Access to primary care**

The findings on the five components of access are discussed in an integrated fashion. Primary care was available to all participants. Most participants were happy with the number of staff at their health care facilities; an opinion that was confirmed by relatively short waiting times for both consultations and drugs. The few participants who were denied care said it was because of unavailability of an appropriate health care provider or equipment.

However, the knowledge of care providers created some access barriers. In general participants thought that the staffs' knowledge on issues related to SCI was insufficient. Participants therefore are of the view that services to them were often rendered with limited skill. The cause for such an observation could be that services were mostly received from clinics and offered by general care providers who are not particularly trained on care for people with SCI. SCI are not that common and most primary care providers might not be familiar with its management. Thus persons

with SCI might have to 'educate' their primary care providers in SCI related issues as also suggested by Goodridge et al (2015). This implies a need for them to have a good understanding of their own condition, something that might be lacking if one considers their inability to answer the question on whether they had a complete or incomplete SCI.

A worrying finding was that availability of prescribed medication was generally poor. This trend was observed in all three types of facilities. This overall trend of unavailability of medication could be due to the fact that none of the facilities actually does independent procurement of drugs. In Botswana all drugs are sourced from the central medical stores (CMS), therefore if the CMS has items unavailable they would not be available to any facilities in the country.

It appears that availability of prescribed medications was slightly better for Health posts followed by Clinics and worst in Hospitals. This could possibly be attributed to prescribing patterns; hospitals being staffed with highly trained personnel as opposed to clinics and then health posts where the training of staff might be of a more basic nature, may be prescribing items that are unlikely to be prescribed at the other facilities hence unavailability increases as one goes up the ladder. Also in most health posts the same person is prescribing and dispensing; it is likely that they might selectively prescribe available medications.

Availability of SCI related consumables was also very poor. Again this trend is general with hospitals faring better on this regard. The reason for better availability of SCI related consumables in hospitals might be attributable to the presence of more skilled personnel at the hospitals as opposed to other facilities. In hospitals ordering of non-consumables are done by pharmacists and guided by the in-hospital requests from doctors in the facility. Doctors are authorised to order all items in the non-drug CMS catalogue and those not in the catalogue through special request procedures. In clinics, orders to CMS are done by nurses and sometimes Health care auxiliaries who

are not authorised to order many of the items in the drug and non-drug catalogues. Special order procedures require a medical officer and a specialist to fill in a special order form and clinics seldom have resident doctors.

In addition to challenges with availability accessibility challenges might have negatively impacted quality of care. While the majority of the participants stayed less than 5 km away from the nearest health care facility most were not able to reach the facilities with ease. It seems the physical access objective of the majority of the country's population living within 5km radius Seiteo-Kgokgwe *et al* (2014) proves to be too far for most people with SCI. This might be due to challenges or cost of transportation; it might also be due to wheelchair inaccessible terrain as roads in Gaborone and surrounds are often not tarred and even the tarred ones do not have wheelchair accessible walkways.

The finding that most participants (44%) used their wheelchairs to access primary care facilities is probably facilitated by the proximity of health care facilities to participants' homes or it may reflect the difficulty of using other means of transportation. A high proportion of clients used wheelchairs with assistance. This demonstrated a lack of independence in community mobility and may be due to the physical environment, inappropriate technical assistive devices (e.g. a lack of motorised wheelchairs) and/or a lack of alternative more convenient modes of transportation.

Public transport was used by only 14% percent of the participants. This might be due to inaccessibility of public transport as in Gaborone and the surrounding villages studied, public transport is mostly by minibus combis and taxis which are difficult to transfer into and not adapted for wheelchair users. Where public transport was used to access primary care affordability of care was impacted negatively. Four participants spend more than three hundred Pula to get to the health facilities. This high transport costs compared to the standard combi fare of

3.50 Pula and 3.75 Pula standard Taxi fare, is probably due to the use of special taxis service.

Access to toilet facilities was poor. The lack of a call button is a serious safety oversight. Failure to attempt to use toilet facilities by people with SCI may reflect poor expectations in access to such facilities. It is also possible however that primary care visits were so short that participants did not have a need to use the bathroom, as consultations and waiting times together were seldom longer than one and a half hour.

Another aspect that negatively impacted accessibility and caused challenges with acceptability was the lack of height adjustable examination beds. It is possible that a lack of height adjustable beds was one of the reasons why many participants were being examined while sitting in their wheelchairs. Examining persons with SCI in their wheelchairs is unacceptable since important symptoms such as erythema or even pressure ulcers might be missed.

Most participants went to public facilities and were in accordance with policy not required to pay. The few that were required to pay the government standard fee of 5.00 BWP for consultation were likely charged erroneously as PWD are not expected to pay that fee in Botswana. Participants (37; 64.9 %) however incurred cost through having to access private services such as a doctor, medication or consumables due to the lack of availability of drugs and other consumables at government primary care facilities. This increased the overall cost of care. It is therefore possible that those who reported not having incurred such costs, are simply forfeiting these essential services due to unaffordability. Few participants had to pay for transportation to visit the health facilities, however these few paid a highly inflated fare as noted above.

In general the majority of participants were of the view that accessing health care was cost effective. The perception of cost effectiveness could have been due to the fact that most of the participants were victims of road traffic accidents and the motor vehicle accident (MVA) fund pays for most of the technical assistive devices, consumables, transportation and even medicines. The participants themselves may therefore not report high costs.

While 40% of participants attended facilities that had no appointment system at all and only 20% could make an appointment for a specific time, waiting times were relatively short and can overall be seen as acceptable. The length of consultation times varied and a consultation of less than 10 minutes is bothersome as it might be difficult to do a thorough physical assessment in such a short time in the light of the mobility challenges persons with SCI experience (Iezzoni et al., 2006).

Another aspect that was challenging is that very few (19.04%) of those that were referred to another facility were offered transportation. It is not acceptable that clients who may have reached a health facility with difficulty and possibly at high costs are expected to arrange transportation to another facility. The cost and effort involved might lead to them not attending the appointment with detrimental consequences to their health.

The findings that most participants were treated with dignity (50; 89%) and were given preferential treatment (42; 73.74%) reflect a good attempt by health care providers to offer a service that is acceptable. Attempts are however not consistent as the number of clients answering no to these questions is significant. Staff attitude towards participants was also mostly reported to be positive; these may be facilitators of access to the primary health services. It appears as if health care services adequacy was also a facilitator of access to primary care for participants as the majority found the hours convenient and facilities clean and well maintained.

## Limitations

Not being able to identify many participants with SCI due to non-traumatic causes was unfortunate as this subgroup might differ considerably from the larger population of persons with SCI and comparison between the two groups would have enhanced findings and recommendations from the study. While adequate for basic descriptive analysis (O`Leary 2017) the number of participants was low and no inferential analysis could be done. Subgroups of the population that differ from those participating in the study might have been excluded. The questionnaire was self-developed and not tested for reliability and validity. The researcher has treated most of the participants as patients in the past, although not at primary care facilities. Still this previous relationship might have influenced responses since participants might view him as part of the health care system and hesitated to share negative experiences.

Results of the study cannot be generalised to other regions of the country as basic health care services might be different from those in the greater Gaborone city area. Since the sample was not randomly selected one also has to be careful when generalising findings to all persons with SCI in the study setting.

## Conclusions

Demographically and medically the study participants followed international and local trends regarding traumatic SCI. Unfortunately too few participants with non-traumatic SCI could be identified to determine any trends in this regard specifically.

Primary care services were for the most part affordable, acceptable and adequate. In general most of the participants did not feel care was too expensive. Free public health care, and close proximity to a health care facility facilitated low cost of care. Cost were however incurred through having to access private health care services for consultations, medications and consumables that could not be acquired from

public facilities. High public transport fees for wheelchair users and a lack of universally accessible public transport further decreased affordability of services. Culturally acceptable and a dignified way of offering services to participants as well as short waiting times and convenient hours was found to be facilitators to provision of an acceptable and adequate service.

Service accessibility and availability were challenged in various ways. Participants visited primary care facilities frequently and visits were often connected to health care needs related to the SCI. Unfortunately primary care services could not always provide in these needs as availability of providers with sufficient knowledge on SCI was limited and consumables related to management of SCI more often than not unavailable.

While most of the clients stayed less than 5 km from the health care facilities, accessing the facilities was found to be difficult. This was probably due to poor community mobility that might be related to environmental barriers and inaccessible public transport. In the light of participants already struggling to access primary care it is a challenge that referrals to other services were not supported by transport services as increased distances to these services will undoubtedly increase transport challenges and cost.

Access was also negatively impacted by structural challenges such as steep ramps, inaccessible toilets and lack of appropriate equipment such as height adjustable examining couches. The toilets were also found to be dangerous as none of them had an emergency call button within reach of a person using a wheelchair.

One-fifth of participants indicated dissatisfaction with services. This in conjunction with the availability challenges re knowledge, consumables and drugs that were identified lead to the conclusion that there is room for improvement in the services.



## Recommendations

General awareness and knowledge on the management of SCI and the consumables and drugs persons with SCI need from primary care services must be raised. It is recommended that Princes Marina hospital, as the specialist SCI unit in the setting, develops and provides outreach training opportunities and ongoing support in this regard. Consumables and drugs for persons with SCI should be made more available at primary level and managers from primary level services must petition central medical stores on this need.

Primary care facilities should acquire at least one height adjustable examining couch per facility. These must be primarily used for people using wheelchairs, those with other impairments that make climbing onto a high examining couch difficult and older people. Similarly it is recommended that one toilet in each facility adheres to international standards for wheelchair users.

Transport should be offered to people with mobility impairments who are referred to other services.

Local government representatives must be educated on the barrier that inaccessible road surfaces create in community mobility for persons using wheelchairs. And lobbies must promote the need for universally accessible public transport. Botswana Federation of the Disabled (BOFOD) is ideally suited to take on this responsibility.

Botswana Ministry of Health (MOH) should start a national data list on persons with SCI, both due to traumatic and non-traumatic causes.

It is recommended that the knowledge and understanding of people with SCI on their condition is studied. It is also recommended that the knowledge and understanding of primary level health care service providers on SCI is studied

## Acknowledgements

We wish to thank participants who took part in this study as well as their families.

We also thank staff at Princess Marina Orthopaedic department and Botswana Spinalis rehabilitation unit for their assistance in identifying participants.

## Competing interest

The principal Investigator had worked as a medical officer in the Orthopaedic department of Princess Marina Hospital from 2010, he has served in the spinal cord injury rehabilitation unit from 2012 to 2014. He served in as a Family medicine registrar and therefore involved in provision of primary care from 2015. He therefore has seen most of the participants as patients during rehabilitation and acute care. It is acknowledged that; some participants view him as their primary care physician and may have a halo effect.

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## Appendix 1: Questionnaire, English version

### Demographic Information and Medical Information

Participant identification number: \_\_\_\_\_

1. Gender: Male  Female

2. Age:.....

3. Years since Injury:

< 1 year  Between 1 and 2 years  Between 2 and 5 years  More than 5 years

4. Level of SCI

Paraplegic

Tetraplegic

5. ASIA classification

A

B

C

D

E

Unknown

6. Cause of SCI

Road traffic accident

TB

Fall

Compressive myelopathy

Violence

Spinal cord tumour

Diving accident

Spinal cord Ischaemia

Other\*

\*(Please specify).....

**NEED ASSESMENT**

**7. How often have you visited a primary health care facility in the past six months?**

- Never    Once    Between 2 and 5 times    between 6 and 10 times  
 More than 10 times

**8. What has been the most common cause of your need to visit the local primary health care facility**

- |   |   |
|---|---|
| <input type="checkbox"/> Minor ailment        | <input type="checkbox"/> Spinal cord injury related complication* |
| <input type="checkbox"/> Trauma               | <input type="checkbox"/> Need for technical assistive devices     |
| <input type="checkbox"/> Routine booked visit | <input type="checkbox"/> Spinal cord injury related consumables   |
| <input type="checkbox"/> Chronic medications  | <input type="checkbox"/> *Other                                   |

\*(Please specify).....

**9. On a scale of 1 to 4, 4 being the highest level of satisfaction, how satisfied are you with services you get from your local clinic**

- 1    2    3    4

**10. How often do you receive the expected service at the local clinic during your visits?**

- Never    Hardly    Most times    Always

**11. In General how much do you think your needs for primary healthcare are**

- Do not need it    Need it a little    Need it moderately    Need it a lot

**HEALTH CARE SERVICE AVAILABILITY**

**12. What Primary health care facility do you mostly utilise**

- Mobile Stop    Health post    Clinic    Primary Hospital

**13. On a scale of 1 to 4, 4 being the ultimate availability, How available are SCI related consumables (catheters, gloves) at your primary health facility**

1. Never     2. Hardly     3. Sometimes     4. Always

**14. on a scale of 1 to 4 ,1 being the least availability and 4 being the most availability, what is the availability of prescribed medication at your local clinic?**

1     2.     3.     4.

**15. Do you think there is enough staff members at your local primary health care facility**

1. very poor     2. poor     3. Good     4. Excelent

**16. In your opinion how knowledgeable are your local care providers on SCI related problems  
Please rate them from 1 to 4 with 1 being very poor knowledge and 4 being excellent**

1: Very poor     2: poor     3: Good     4: Excellent

**17. On a scale of 1 to 4 how available do you think of primary health care are to you?**

1     2     3     4

**HEALTH CARE SERVICE ACCESSIBILITY**

**18. Do you generally find it easy to reach your local clinic**     Yes     No

**19. If no what explain why you think it is difficult**

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**20. How far is your local clinic from your home**

Less than 1 Km     Between 1.1 and 2 Km     Between 2.1 and 5 Km     More than 5 Km

**21. How do you travel from your home to the local clinic**

Walk without assistive device

Walk with a walking aid

Use a wheelchair without assistance

Use a wheelchair with assistance

Own car

Public transport

\* Other

\*(Please specify).....

**22. How long do you normally take to reach the local clinic?**

Less than 30 mins

31mins-1hr

1hr1min-2 hrs

2hr1min-4hrs

more than 4hrs

**23. Are you able to get into the clinic without assistance**

Yes

No

**24. If No what are the restrictions (more than one option may apply)**

No Ramp

Steep ramp

Too much sand around the clinic

Narrow door

Other\*

\*(Please specify).....

**25. Do you need wide disabled parking bays at your local clinic?**

Yes

No

**26. If answered yes to the question above. Are you able to use wide disabled parking bays at the local clinic**

Always     most times     hardly     Never

**27. If there are staircases at the Facility do they have hand rails**

No Staircases     Staircases without hand rails

Staircases with hand rails

**28. Is the clinic door automatic?**

Yes     No

**29. If not does the door have pull lever type handles?**

Yes     No

**30. Is there a flat landing at the door allowing you to stop and open the door from outside?**

Yes     No

**31. Are you able to go through the door way in a wheelchair**

Yes     No     Non applicable

**32. Are you able to reach the reception counter from a wheelchair if you use one**

Yes     No

**33. If not what is the reason**

Counter is too high     No clear space underneath

\*other

\*(Please specify).....

**34. Are you able to easily access the toilet at the clinic**

Yes  No

**35. If no to question above. What is the restriction**

No ramp  Ramp too steep  Narrow doorway  Narrow toilet

Lack of usable rails in the Toilet  High Toilet seat  \*Other

\*(Please specify).....

**36. Are you able to use the wash basin in the toilet**

Yes  No

**37. If no to the question above, what is the restriction**

No wash basin  Wash basin too high  No clear space under the wash basin

\*Other

\*(Please specify).....

**38. Are you able to use the hands drying facility in the toilet**

Yes  No

**39. If no to the question above, what is the restriction**

No Hand drying Facilities  Hand drying facilities too high for a wheel chair user

\*Other

\*(Please specify).....

**40. Is there an emergency call button within your reach in the toilet**

Yes

No

**41. On a scale of 1 to 4 are you satisfied with your ability to access the health care service at the local facility**

4. Well Satisfied  3. Moderately satisfied  2. Poorly satisfied  1. Not satisfied

**HEALTH CARE SERVICE AFFORDABILITY**

**42. Are you required to pay a fee for service at the Primary health care facility?**

Yes

No

**43. If yes how much are usually expected to pay**

5 BWP

5.01-10BWP

10.01-100BWP

more than 100BWP

**44. How much money do you generally use to reach the clinic from your home**

Nothing

less than P3.50

P3.51-P10.00

P10.01-P50.00

P50.01-P100.00

P100.01-P300

More than P300.

**45. Were you ever ask for bribes in order to receive a service**

Yes

No



Do you incur costs through having to access private services such as a doctor, medication or consumables?

Yes

No

46. In general what do you think of the cost of primary health care in your area

Very expensive  somewhat expensive  Not expensive  Cost effective

### HEALTH CARE SERVICE ADEQUACY

47. Is the facility open at hours convenient for you?

Yes

No

48. On a scale of 1 to 4 do you think the facility is maintained? 1 being poor maintenance and 4 being excellent

1

2

3

4

49. On a scale of 1 to 4 how would you rate the cleanliness of the facility 1 being the lowest and 4 being the ultimate level of cleanliness Is the facility

1

2

3

4

50. On a scale of 1 to 4 how would you rate equipment sufficiency. 1 being least sufficient and 4 being most sufficient

1

2

3

4

51. Is the equipment in working order

Never

Sometimes

Most times

Always

52. On a scale of 1 to 4 how satisfied are you with the primary health care service adequacy in your area

Well Satisfied  Moderately satisfied  poorly satisfied  Not satisfied

**HEALTH CARE SERVICE ACCEPTABILITY**

**53. Is there an appointment system at your local health care facility**

- None     Appointments per dates     Appointments per dates and times

**54. How long do you usually wait before being seen by a health professional**

- Immediately     Before 30 mins     30mins-1hr     1-2hrs     2-4hr
- More than 4hrs

**55. In your opinion what usually causes the delay**

- Too many patients     Few health care workers     Inefficiency of health care workers
- Other\*
- \*(Please specify).....

**56. What is the approximate time that you spends with a health care professional**

- 0-10 mins     11-15 mins     16-30mins     31-45mins
- 46-60mins    more than 1hr

**57. Approximately how much time do you spend waiting at the dispensary?**

- 0-15 mins     16-30mins     31-60mins     1-2hrs     2-3hrs
- More than 3 hrs

**58. Are you assessed on a wheelchair or on an bed**

- Bed     Chair

**59. Should you need to transfer to a bed who usually assists you?**

- No need for assistance     Relative     Health care providers
- Other clients     other\*

Other\* Please state.....

**60. Is the examination bed height adjustable?**

- Yes     No

**61. Have you ever been refused treatment at the local clinic?**

- Yes     No

**62. If yes to the question above, Please state the reason**

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**63. Were you then referred to another facility?**

- Yes     No

**64. If you were referred was transport offered?**

- Yes     No

**65. Are you given any preferential treatment at the clinic**

- Yes     No

**66. If yes Please explain**

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**67. in your opinion are services rendered at the clinic done in a way that respect your dignity**

- Yes     No

**68. please explain**

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**69. Describe the attitude that the clinic staff has towards you as a person**

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**70. Is your privacy respected when you are being assisted at the Health care facility please explain**

Yes

No

**71. on a scale of 1 to 4 how do you feel about the acceptability of health care service that you receive at your local clinic**

1

2

3

4

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**72. What improvements would make your visit to the clinic more rewarding**

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**Thank you for answering these questions**

## Appendix 2:

# PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE RESEARCH PROJECT:** Access to Primary health care services for people with spinal cord injuries; A descriptive study from the greater Gaborone city area, Botswana

**REFERENCE NUMBER:** S14/10/241

**PRINCIPAL INVESTIGATOR:** Thato Michael Moutie Paulus-Mokgachane

**PHYSICAL ADDRESS:** Plot number 38957, Bock 6, Gaborone, Botswana

**POSTAL ADDRESS:** PO BOX 221 Gabane, Botswana

**CONTACT NUMBER:** 00276 74716150

Dear Participants

My name is Thato Michael Moutie Paulus-Mokgachane and I am a medical officer at Princess Marina Hospital as well as a student at Stellenbosch University. I would like to invite you to participate in a research project that aims to investigate Challenges and Facilitators of Accessing Primary health care services among Spinal cord injured clients in the greater Gaborone City area

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

### **What is the study about?**

This is a study to determine access of primary health care services by spinal cord injured clients in your area of residence. Information will be collected by a questionnaire. If you cannot write you may ask any person who you trust to help you fill in the questionnaire. You are not required to state your name on the questionnaire. The questionnaire however has a code. A separate database connecting the code to you is kept by the principal researcher electronically and protected by a password. This database is kept to enable follow up if there is need for it, it shall not be disclosed except for that purpose. Personal information that you may give will be kept confidential and will not be accessible to your primary health care provider or any other person other than the researcher without your permission

Results of this research will be presented without names and will not link any participants to the institution that provides them health care. Publication of such results therefore should not predispose you to prejudice. Commentary on information gathered will not disclose your identity. Fifty people with spinal cord injuries will be asked to take part in the study.

**Why have you been invited to participate?**

You are asked to participate in the study since you have a spinal cord injury and you might need to use health care services.

**What will your responsibilities be?**

You will be asked to complete the questionnaire

**Will you benefit from taking part in this research?**

The information gained from the study might in time lead to changes at the clinics that might improve health care access for you and other persons with disabilities.

**Are there risks involved in your taking part in this research?**

You will not be exposed to any harm by taking part in the study.

**Who will have access to your records?**

No one will look at your medical records during the study

**Will you have access to information/answers?**

A summary of the results of the study will be made available to all participants

**Will you be paid to take part in the study?**

You will not be paid to take part in the study. It will cost you no money to take part in the study.

**Is there anything else that you should know or do?**

- You can contact Thato M.M Paulus-Mokgachane at 74516150 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

**If you are willing to participate in this study please sign the attached Declaration of Consent and hand it to the researcher**

Yours sincerely

TMM Paulus-Mokgachane

Principal Investigator

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled: Access to Primary health care services for people with spinal cord injuries; A descriptive study from the greater Gaborone city area, Botswana  
I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... On (*date*) ..... 2015.

.....

**Signature of participant**

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) ..... On (*date*) ..... 2015.

.....

**Signature of investigator**

.....

**Signature of witness**