Do clients with spinal cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, beliefs and practices about pressure ulcers.

Adri Marica Visser

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UNIVERSITY OF STELLENBOSCH FACULTY OF MEDICINE AND HEALTH SCIENCES
CENTRE FOR REHABILITATION STUDIES

Supervisor: Dr Surona Visagie
Co-supervisor: Jenny Hendry

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Declaration

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Adri Marica Visser

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Abstract

Background: Pressure ulcers are a serious, but preventable, secondary complication of spinal cord injury (SCI). Pressure ulcers limit community integration, and are potentially life-threatening. They also put an increased financial and care burden on health systems. Pressure ulcers can be prevented by following the guidelines for good skin care and pressure-ulcer prevention programmes. Adherence to pressure-ulcer prevention practices is influenced by a person`s knowledge and beliefs.

Aim: To describe the knowledge, beliefs and practices about pressure ulcers of clients with SCI who received rehabilitation at a Cape Town rehabilitation centre.

Methods: A quantitative, descriptive study, that employed consecutive sampling, was done. Participants included in-patients (n=30), out-patients (n =33) and peer supporters (n = 8). Data was collected during April and March 2015 with a questionnaire developed through collating existing questionnaires and adapting them for the study context. Descriptive and inferential analyses of data was done. To determine if any relationship existed between the variables, the Fisher's exact test and Kruskal-Wallis test were applied. A P-value of <0.05 was considered statistically significant.

Results: The mean age of participants was 36.3 years with 86% being male. Only 31% of participants finished school and 77% were unemployed. Of all the participants, 43% had developed a pressure ulcer at some stage.

The mean combined knowledge score was 23.9 out of a possible 56 (42.7%). The in-patients and out-patients had similar scores (40.4% and 39.4% respectively). Areas of knowledge that were particularly challenged, included nutrition to prevent pressure ulcers, the staging of pressure ulcers, the time it takes for a pressure ulcer to develop and the risk factors for pressure ulcer development. While having a similar knowledge score as in-patients, personal experience of life with SCI and contact with others might have influenced the beliefs of out-patients over time as more of them saw themselves as likely to develop pressure ulcers, and a higher percentage believed PU would seriously impact their activities. Peer supporters had a higher mean knowledge score than the other two groups. Despite their higher mean knowledge score, their scores might be too low to effectively teach others PU prevention practices. The majority of participants (88.7%) believed pressure ulcers to be serious and 45% thought they were likely to develop a PU. They believed daily skin checks (80.3%), weight shifting (86%) and limiting sitting time (80.3%) could prevent PU development. Pressure relief was not practised correctly by 51% of participants, while 39% did not perform skin inspection correctly and 38% of participants smoked.

Inferential statistics showed that most of the variables did not have a statistically significant relationship. An increase in time since injury had a significant impact on the belief that PUs would interfere with ADL (p=0.024), and increased knowledge scores impacted significantly on correct pressure relief practices (p=0.001).

Conclusion: Participants showed a lack of knowledge which might have impacted their beliefs and pressure-ulcer prevention practices negatively. It seems as if participants were not equipped with sufficient knowledge to assist them in adhering to pressure-ulcer prevention practices, even though they realised pressure ulcers were serious and would impact their lives negatively. The study findings can be used to assist with the development of a contextually relevant training programme on pressure care.

Key Terms: Spinal Cord Injury, Pressure Ulcer, Knowledge, Beliefs and Practices

Abstrak

Agtergrond: Druksere is ’n ernstige, maar voorkombare, sekondêre komplikasie van spinaalkoord beserings (SKB). Druksere maak dit moeilik vir pasiënte om weer deel van hulle gemeenskappe te raak, en dit kan lewensgevaarlik wees. Dit plaas ook groter finansiele druk en ’n onnodige sorglas op ons gesondheidsorgsisteem. Druksere kan voorkom word deur ’n goeie velsorgroetine en drukseervoorkomingsprogramme. ’n Persoon se kennis en sienings het ’n invloed op hoe doeldreffend hulle drukseervoorkomingspraktyke navolg.

Doelwit: Die beskrywing van die kennis, sienings en praktyke rondom druksere van kliënte met spinaalkoord beserings by die Wes-Kaapse Rehabilitasiesentrum.

Metodes: ’n Kwantitatiewe, beskrywende studie is gedoen met opeenvolgende proefsteke. Deelnemers sluit in binne-pasiënte (n=30), buite-pasiënte (n =33) en portuurondersteuners (n = 8). Die data is bymekaar gemaak in Maart en April 2015 met ’n vraelys. Die vraelys is ontwikkel deur bestaande vraelyste saam te voeg en aan te pas binne die studiekonteks. Beskrywende en inferensiële analises is gedoen van die data. Fisher se toets en die Kruskal-Wallis-toets is toegepas om te bepaal of daar enige statisties beduidende verhouding bestaan tussen die veranderlikes. ’n P-waarde van <0.05 is beskou as statistiesbeduidend.

Resultate: Die gemiddelde ouderdom van die deelnemers was 36.3 en 86% was manlik. Slegs 31% van deelnemers het skool voltooi en 77% was werkloos, en 43% van die deelnemers het op een of ander stadium ’n drukseer gehad.

Die gemiddelde saamgestelde kennistelling was 23.9 uit ’n moontlike 56 (42.7%). Die binne- en buite-pasiënte het soortgelyke tellings gehad (40.4% and 39.4% onderskeidelik). Kennisgebiede wat veral uitdagend was, sluit in voeding om druksere te voorkom, die stadiums van druksere, hoe lank dit neem vir ’n drukseer om te ontwikkel en die risikofaktore vir drukseerontwikkeling. Buite-pasiënte het soortgelyke tellings gekry as binne-pasiënte, maar persoonlike ervaring van SKB en kontak met ander kon die sienings van buite-pasiënte oor tyd beinvloed. Meer buite-pasiënte het aangedui hulle gaan waarskynlik druksere ontwikkel, en ’n hoër persentasie het geglo dit gaan ’n ernstige impak op hulle aktiwiteite hê.

Portuurondersteuners het ’n hoër gemiddelde kennistelling gehad as die ander twee groepe. Steeds was hulle tellings te laag om ander doeltreffend te leer van drukseervoorkomingspraktyke. Die meerderheid van die deelnemers (88.7%) glo druksere is ernstig en 45% glo hulle kanse is goed om ’n drukseer te ontwikkel. Hulle glo daaglikse velkontrole (80.3%), gewigverskuiwing (86%) en beperkte sittyd (80.3%) kan die ontwikkeling van druksere verhoed. Drukverligting is nie reg toegepas deur 51% van die deelnemers nie terwyl 39% nie vel-inspeksies gedoen het nie en 38% rook.

Inferensie-statistiek dui aan dat die meeste van die veranderlikes nie ’n statistiesbeduidende verhouding het nie. Die tydsduur sedert die besering het ’n beduidende impak gehad op die siening dat druksere sal inmeng met daaglikse aktiwiteite (p=0.024), en hoër kennistellings oor drukverligingpraktyke het ’n beduidende impak gehad op die regte drukverligtingpraktyke (p=0.001).

Bevinding: Deelnemers toon ’n gebrek aan kennis, wat moontlik hulle sienings en drukseervoorkomingspraktyke negatief beinvloed het. Dit lyk asof die deelnemers nie toegerus is met genoegsame kennis om drukseervoorkomingspraktyke na te kom nie, selfs al besef hulle druksere is ernstig en het ’n negatiewe impak op hulle lewe. Die bevindings kan gebruik word vir die ontwikkeling van ’n kontekstueel relevante druksorg-opleidingsprogram oor.\

Sleutelterme: Spinaalkoord beserings, druksere, kennis, sienings en praktyke.

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Table of Contents

List of Figures

List of Tables

List of Appendices

Glossary of Terms

Dial-a-ride: “Dial-a-Ride (DAR) is a public transport service for people with disabilities who – due to the nature of their disability – are unable to board and/or alight from mainstream public transport such as trains, buses and minibus taxis for their daily commute between home and work.” (City of Cape Town, 2016)

Finger-pressure-test: A test to check if a foam wheelchair cushion is still giving sufficient pressure relief.

Healthnet: “Healthnet provides non-emergency transport to patients between health care facilities (inter-facility transport) as advised and booked by supervisors of provincial health care facilities.” (Western Cape Government, 2016)

Peer supporters: “Peer mentoring is described as a relationship between two individuals who share some common characteristic or experience and in which one provides needed assistance or support to the other.” (Hayes & Balcazar 2008 as cited in Ljunberg, Kroll, Libin & Gordon 2011:352).

Quality of life: “An individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to environmental factors that affect them.” (WHO 1997:1).

Rehabilitation: “Appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.” (WHO 2010:45).

Secondary complications: “Physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment.” (Jensen, Molton, Groah, Campbell, Charlifue, Chiodo, Forchheimer, Krause & Tate, 2012:374).

List of Acronyms

ASIA	America Spinal Cord Injury Association
CPG	Clinical Practice Guidelines
ICF	International Classification of Functioning, Disability and Health
NHS	National Health Service
NPUAP	National Pressure Ulcer Advisory Panel
OPD	Out-patient department
PGWC	Provincial Government of the Western Cape
PU	Pressure Ulcer
QoL	Quality of Life
SCI	Spinal Cord Injury
SU	Stellenbosch University
TB	Tuberculosis
UTI	Urinary tract infection
USA	United States of America
UK	United Kingdom
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation

Chapter 1: Introduction and overview

1.1. Background

A spinal cord injury (SCI) is any insult (traumatic or non-traumatic) to the spinal cord that results in changes in the normal motor and/or sensory functions of the body structures innervated by the spinal cord. Bladder and bowel function, sexual function, ambulatory function, regulation of body temperature and skin sensation are examples of functional areas that may be challenged. These changes may be either permanent or temporary (Chin, Dawodu, Mesfin & Kopell, 2015). If permanent, the changes to the neurological functions produce effects that continue throughout the person's lifetime and often result in severe disability (Van den Berg, Castellote, Mahillo-Fernandez & de Pedro-Cuesta, 2010). The nature of a SCI also puts a person with a SCI at risk for a number of secondary complications such as urinary tract infections (UTI), contractures and pressure ulcers (Adriaansen, Van Asbeck, Lindeman, Van der Woude, De Groot & Post, 2013; Kroll, Neri & Ho, 2007).

Pressure ulcers (PU) are one of the main secondary complications with which persons with a spinal cord injury (SCI) struggle (Chiodo, Scelza, Kirshblum, Wuermser, Ho & Priebe 2007; Adriaansen et al.. 2013). A PU manifests as the breakdown of the skin and sometimes underlying tissue, due to ischemia, usually caused by unalleviated pressure (Kruger, Pires, Ngann, Sterling & Rubayi 2013). These ulcers are potentially life-threatening (Burns & O'Connell, 2012) due to the high risk of sepsis leading to systemic shock and subsequent death (DeVivo and Stover in Dorsett & Geraghty, 2008). Pressure ulcers also limit the persons' social interaction and sometimes their work life due to the need to keep pressure of these ulcers for extended periods of time to allow them to heal. This practice often involves staying in bed for several months (Brem & Lyder, 2004). Pressure ulcers also put an extra burden of care not only on the person with the PU and their carers, but also on the health system as these ulcers are costly to treat. They are one of the most costly reasons for hospital re-admissions for persons with SCI (Middleton, Lim, Taylor, Soden & Rutkowski, 2004; Chan, Nanwa, Mittmann, Bryant, Coyte & Houghton, 2012). However, pressure ulcers can be prevented and training and education on the prevention of pressure ulcers should be incorporated in rehabilitation programmes for persons with SCI.

The prevention of pressure ulcers involves practices such as pressure relief, turning in bed, skin inspection, continence management, optimal positioning and a cushion in good working order, maintaining a healthy diet and good health, as well as no substance abuse (Hsieh, McIntyre, Wolfe, Lala, Titus, Campbell & Teasell, 2014; Garber, Bryce, Gregorio-Torres, Ho, & Rader, 2014; Stansby ,Avital, Jones, & Marsden, 2014). These practices should become part of the daily routine of people with SCI. Adherence to pressure-ulcer prevention practices is influenced by a person`s knowledge and beliefs. In order to engage in preventative practices and to ensure early detection of PUs, persons with spinal cord injuries need to have an adequate knowledge and understanding of the development and prevention of pressure ulcers (Burkell, Wolfe, Potter & Jutai, 2006). According to Michel, Willebois, Ribinik, Barrois, Colin and Passadori (2012) a lack of knowledge regarding preventative measures, constitutes an increased risk for pressure ulcer development. Health literacy and preventative practices are very important in learning to self-manage chronic conditions (Villaire & Mayer, 2007). In order to prevent pressure ulcers, people have to be able to evaluate and understand information given to them, know how to manage changes in their day-to-day lives, make decisions based on relevant information and know how to access medical care if and when needed.

Knowledge influences health beliefs (King, Porter & Vertiz, 2008). Health beliefs in turn, influence the actions (practices and behaviour) that one will take to prevent certain unwanted occurrences, such as developing a pressure ulcer (King et al., 2008). Health beliefs are influenced by internal and external cues. Internal cues come from within the person's body such as sensations that they may have, or the symptoms that they develop. External cues come from outside the person's body such as experiences that the person may have had, interactions with family or clinicians, or any knowledge that the person has gained or learned (King et al., 2008). Knowledge, attitudes, practices and beliefs are all interlinked. They influence each other and, in combination, they play a role in individual people's adherence to disease-prevention practices such as PU prevention.

1.2. Study Problem

The Western Cape Rehabilitation Centre (WCRC), a rehabilitation centre in Cape Town, for clients with physical disabilities, provides rehabilitation services to clients with SCI. The WCRC has no specific, standardised, pressure-ulcer prevention programmes in place. Pressure-ulcer prevention is taught to clients on an *ad hoc* basis. Team members providing rehabilitation to the client do training in the prevention of pressure ulcers according to how they see fit, based on their own knowledge and background. The only structured training material in use, is a 12-year-old video on pressure-ulcer prevention that is shown to clients during their in-patient stay.

Anecdotal information indicates that a high number of clients return to the rehabilitation centre with pressure ulcers, every year. Exact figures are not available since no incidence studies have been conducted. However, the anecdotal information does raise questions like:

- Whether clients with SCI, who received rehabilitation at this centre, have adequate knowledge about pressure ulcers to help them prevent the development of ulcers
- Whether they apply this knowledge
- What their beliefs are about pressure ulcers and their prevention

Thus, this study aimed to determine clients' knowledge, beliefs and practices with regard to the prevention of pressure ulcers.

1.3. Aims

To describe the knowledge, beliefs and practices about pressure ulcers and pressure-ulcer prevention of clients with spinal-cord injuries who attend the WCRC, a rehabilitation centre in Cape Town.

1.4. Objectives

- To describe the demographic information of the participants with regard to age, gender, race, employment status and marital status.
- To describe the relevant clinical information of the participants with regard to the level of injury, the nature of the injury and pressure ulcer history.
- To describe the knowledge, beliefs and practices of participants about pressure ulcers and pressure-ulcer prevention.
- To compare the knowledge, practices and beliefs of in-patients, out-patients and peer supporters.
- To make recommendations to inform the development of a structured programme for pressure-ulcer prevention at the rehabilitation facility.

1.5. Motivation for study

Every year, approximately 300 to 350 clients with SCI are discharged from the WCRC (manual counting of statistics from admission). These clients receive some information on how to prevent secondary complications like pressure ulcers. Yet, every year, clients return to the out-patient department (OPD) with pressure ulcers. Some of the clients only return to the WCRC when the ulcers have progressed so far that they require surgery.

As a physiotherapist working in the out-patient department of the WCRC, the researcher has personally observed first-hand the devastating effects that a pressure ulcer can have on persons with SCI. Having to keep pressure off the wounds in for them to heal, often means extended time spent in bed and limiting normal activities and social roles. For persons who work, this greatly interferes with their working life and, sometimes, by the time that sepsis sets in, these persons have either passed away, or died prematurely.

Thus, the researcher embarked on this study to gain an informed understanding of the gaps in not only the knowledge of clients about pressure ulcers and their prevention, but also, to obtain a clearer picture of the beliefs and practices of these clients. It is hoped that this information will be of use in enhancing training and education practices regarding pressure ulcers at the WCRC, and that it will, ultimately, assist in decreasing the prevalence of pressure ulcers in this particular institution.

1.6. Significance of the study

The first step in changing health knowledge, beliefs and practices, is information about the current knowledge, practices and beliefs of a certain target group. Studies on the knowledge of, attitudes to, practices and beliefs about pressure ulcers of people with spinal-cord injuries have been conducted in the United States of America (USA) and other developed countries. This has resulted in changes in training programmes (Guihan, Bombardier, Ehde, Rapacki, Rogers, Bates-Jensen, Thomas, Parachuri & Holmes, 2014) and new methods of teaching and training pressure-ulcer prevention practices to people with SCI. However, South Africa has unique challenges and problems that may impact on the health knowledge, beliefs, attitudes and practices of our population. Issues such as low educational levels, extreme poverty, violence and crime, diverse cultural practices and beliefs, high levels of alcohol- and drug abuse and lack of access to information could all have negative impacts on the knowledge, attitudes, practices and beliefs of South Africans. Thus, findings from studies done in developed countries, like the USA, may not be relevant to informing health education practices in rehabilitation in South Africa. This is especially true when looking at aspects such as attitudes and beliefs which are classified as external cues for health behaviour and are greatly influenced by cultural differences and beliefs (King et al., 2008). The literature search uncovered no South African study on the knowledge, attitudes, practices and beliefs of people with SCI regarding pressure care. Therefore this study can contribute to knowledge of this topic in a South African context with the country’s unique cultural, educational and social challenges.

Information about the knowledge, attitudes, practices and beliefs of clients with SCI, with particular reference to pressure ulcers and pressure-ulcer prevention, could assist the clinical teams at the WCRC in developing a structured training programme on pressure care. Findings from the study should provide the teams with a better understanding of what might be lacking in current education. Effective client education, during rehabilitation, could assist in more effective discharge from hospital care to the community, and help guide the ongoing process of living with a disability such as a SCI (May, Day & Warren, 2006). In their letter to the editor in Spinal Cord in 2013, Rathore and Mansoor (2013) state that the lack of statistical data and data capturing of figures on persons with SCI in developing countries, are hampering the development of effective preventative actions and strategies to prevent PUs.

1.7. Summary

People who have suffered a spinal-cord injury are at a high risk of developing pressure ulcers. Pressure ulcers limit the integration of people with spinal cord injuries and are potentially life-threatening. One of the important ways to combat pressure ulcers, is by having the correct information and training in the prevention of pressure ulcers. There is no structured training programme for pressure-ulcer prevention at the WCRC, a rehabilitation centre in Cape Town.

Before such a programme can be developed, it is necessary to explore the current knowledge, beliefs and practices of clients with spinal cord injuries at the centre. Thus, this study evolved to describe the knowledge, beliefs and practices about pressure ulcers of clients with spinal-cord injuries who received rehabilitation at the WCRC.

1.8. Outline

Chapter 1 provides background information on the study, presents the study problem, aim and objectives and explores the possible significance of the study. This is followed by an overview of findings from previous studies and currently available research on pressure-ulcer prevention and the knowledge, attitudes, practices and beliefs of clients with spinal-cord injuries about pressure ulcers in Chapter 2. In Chapter 3, the methodology that was used in the study is presented. Chapter 4 presents the results of the study, which are further discussed in Chapter 5. Chapter 6 ends the research assignment with a presentation of study limitations, conclusions and recommendations.

Chapter 2: Literature Review

2.1. Introduction

In this chapter an overview of the literature is presented. First of all, the epidemiology of spinal cord injuries is presented. This is followed by an overview of the causes, risk factors, incidence and prevalence of pressure ulcers in relation to people with spinal-cord injuries and the subsequent impact that pressure ulcers have on their lives. Finally, pressure-ulcer prevention is discussed, in general and then specifically, with regard to the impact of knowledge, beliefs and practices on the prevention of pressure ulcers.

2.2. Epidemiology of Spinal Cord injury

2.2.1. Incidence and prevalence

International incidence data shows that between 250 000 and 500 000 people are newly diagnosed with SCI worldwide every year (WHO 2013). Epidemiological studies report varied annual incidence rates for traumatic spinal cord injuries of between 2.3 to 83 per million (Hagen, Rekand, Gilhus & Grønning, 2012; Cripps, Lee, Wing, Weerts, Mackay & Brown, 2011). These variation are due to studies being conducted in different countries. Similarly, varying prevalence rates of 236 to 1800 per million are reported for traumatic SCI (Hagen et al. 2012; Cripps et al. 2011). Very little epidemiological research data is available for non-traumatic SCI in terms of incidence, outcomes and demographics (Van den Berg et al., 2010). New, Cripps and Bonne Lee (2014) conducted a systematic review and found that prevalence figures for non-traumatic SCI were available for two countries only (India and Canada) and that only one of the publications provided information on survival rates. Due to the wide variation in mortality rates over the world and the lack of data, it is difficult to estimate how many people are currently living with a SCI. It is however important to know SCI prevalence rates in order to estimate not only the need for health care and support, but also, to attempt to assess the success of preventing secondary complications (WHO, 2013).

There is a lack of recent epidemiological statistics on spinal cord injuries in South Africa. The most recent reported studies were conducted by Hart and Williams (1994) and Velmahos, Degiannis, Hart, Souter, & Saadia (1995). In 2007, Frielingsdorf and Dunn conducted an epidemiological study at one of the major tertiary hospitals in Cape Town, but this study was only looking at clients admitted to the spinal cord injury unit at this particular hospital and they only described clients with cervical injuries. The study did not provide any information on nationwide incidence or prevalence statistics (Frielingsdorf & Dunn, 2007). Another epidemiological study was conducted at the Acute Spinal Cord Injury Unit of the same hospital in 2015 (This unit admits only patients with acute traumatic SCI). The authors indicated an average of 185 patients per year, but provided no incidence or prevalence figures (Sothmann, Stander, Kruger & Dunn, 2015).

2.2.2. Etiology

In the past, up to 90% of SCI, internationally, was due to traumatic causes (WHO, 2013). However, more recent studies show a trend towards an increase in non-traumatic causes of SCI (WHO, 2013). This could be due to an aging global population as people who sustain non-traumatic spinal cord injuries generally tend to be older and have degenerative diseases (WHO, 2013). New et al. (2014) reviewed the literature and found that non-traumatic spinal-cord injuries were most commonly caused by tumours and degenerative diseases in developed countries and by infections, like TB and HIV, in developing countries. Draulans, Kiekens, Roels, and Peers (2011) further suggested that the number of traumatic spinal cord injuries in sub-Saharan Africa is still much higher than that of non-traumatic spinal-cord injuries. A lack of current epidemiological information on SCI in South Africa. makes it difficult to ascertain the national rate of traumatic versus non-traumatic SCI.

The main causes of traumatic SCI worldwide are motor vehicle accidents and falls (Hagen et al., 2012; Cripps et al., 2011). Based on what little evidence is available, motor vehicle accidents appear to be the main cause of SCI in the Western Cape Province of South Africa. Other common causes of SCI in this context are interpersonal violence and falls (Frielingsdorf and Dunn, 2007; Sothmann et al. 2015) Violence has been reported by other researchers as the main cause of traumatic SCI in South Africa (Draulans et al., 2011; Hart & Williams, 1994).

2.2.3. Age

The age distribution differs between persons with traumatic and non-traumatic SCI. In people who have suffered a traumatic SCI it seems as though the trend is for the injury to either occur in young adults (15 to 29) or the elderly (65 and up). In non-traumatic SCI, a steady increase in incidence is found with advancing age (Van den Berg et al., 2010; WHO, 2013). Sothmann et al. (2015) found in their study performed in the Western Cape that SCI occurred most commonly between the ages of 20 and 40 years.

2.2.4. Gender

Globally, males are more at risk of sustaining a spinal-cord injury than females with the average ratio being 2:1 (WHO, 2013). Vasiliadis (2012) confirmed this, but also added that, in some regions this ratio is even higher. In Africa it appears that the male-to-female gender distribution of SCI is closer to 10:1 (Vasiliadis, 2012; Obalum, Giwa, Adekoya-Cole & Enweluzo, 2009 ; Gosselin and Coppotelli, 2005). Sothmann et al. (2015) reported a gender ratio of 5.25:1 between males and females.

2.2.5. Participation and quality of life (QoL) after SCI

In a study by Geyh, Ballert, Sinnott, Charlifue, Catz, D'Andrea Greve and Post (2013) the quality of life of persons living with SCI was compared in six different countries (Australia, Brazil, Canada, Israel, South Africa and the USA). For the purpose of this study, the researchers used five components of the World Health Organization Quality of Life Assessment related to satisfaction. It was found that, irrespective of the country of origin, higher QoL was reported by participants who were gainfully employed and those who had been diagnosed with a SCI for a longer time period. This study found no relation between the participants' lesion-related limitations (level of injury, medical complications, ASIA classification) and QoL. It is however suggested that although QoL is not impacted directly by the impairments or lesion-related limitations, the effects of the impairments on participation and activities have an indirect impact on QoL. Chang, Wang, Jang and Wang (2012) measured QoL based on the International Classification of Function (ICF). They found that participation, marital status and independence in activities were significant predictors for QoL and that participation was the most significant predictor. Confirming the findings of Geyh et al. (2013), Chang et al. (2012) stated that although impairments were not significant predictors of QoL, it did have an impact on participation and subsequently an indirect influence on QoL.

2.2.6. Mortality

According to Cripps et al. (2011) and Burns and O'Connell (2012), the mortality rates for people living with SCI are very high in developing countries. In certain sub-Saharan African countries the average length of time of survival after a spinal-cord injury, is likely to be less than one year (Burns & O'Connell, 2012). Øderud (2014) conducted a systematic review to explore life expectancy and living conditions of people living with SCI. This review showed that up until the 1990's, urinary tract infections and pressure ulcers were the most common causes of premature death among people living with SCI in high-income countries. Over the years, advances were made in pressure care and urological management in these countries over the years and the main causes for mortality are now pneumonia and respiratory complications followed by septicaemia, heart diseases and suicide. From the available literature, it was found that in low-income countries septicaemia and infection due to pressure ulcers and urinary tract infections remained the most common cause of mortality after SCI (Øderud, 2014).

In a retrospective study published by Rabadi, Mayanna and Vincent in 2013, the researchers examined the mortality rates and reasons for mortality of 147 participants with a traumatic spinal cord injury over a 12-year period at one centre in the USA. It was found that the survival rate over the 12 year period was 60%. They found three main causes for death; infections (e.g. pneumonia (21%), UTIs(14%) and PUs(11%), cardiovascular problems (e.g. heart failure, coronary artery disease) and cancer-associated problems. In the population with complete injuries, mortality was mostly due to infection-related problems and these mainly happened in hospitals, while in the population with incomplete injuries, mortality was mainly due to cardiovascular and cancer problems, occurring mainly in the community (Rabadi et al., 2013). Strauss, DeVivo, Paculdo and Shavelle (2006) found that the main causes for mortality were pneumonia and septicaemia due to pressure ulcers. This was a study conducted over a 29-year period where data was obtained for 30 822 clients with SCI from various centres across the USA. Cao, Krause and DiPiro (2013) confirmed these findings and also found that hospitalisation in the previous year and stage 3 or 4 pressure ulcers (see staging of pressure ulcers in 2.3.1) were both positive predictors for mortality in clients with SCI. (This study was also conducted in the USA.) These studies confirm that pneumonia is, indeed the most common cause of premature death in people living with SCI in high-income countries, but also highlights the fact that even in high income countries, death due to pressure ulcers is still quite prevalent.

Krause, Carter, Pickelsimer and Wilson (2008) reported that with every surgery intervention required for a pressure ulcer, there is a 10% higher risk of mortality. It has been reported that clients living with SCI have a 64-times increased risk of mortality due to septicaemia than the general population. The septicaemia is mostly due to PUs (DeVivo and Stover in Dorsett & Geraghty 2008).

2.3. Pressure Ulcers

2.3.1. Mechanisms and causes

The National Pressure Ulcer Advisory Panel (NPUAP) in the USA defined a pressure ulcer as "a soft-tissue injury resulting from unrelieved pressure over a bony prominence, resulting in ischemia, cell death, and tissue necrosis" (Kruger, Pires, Ngann, Sterling & Rubayi 2013:573). Thus, on a cellular level a pressure ulcer is caused by pressure, shear or friction forces applied to the skin leading to decreased blood flow to a particular area (Manorama, Meyer, Wiseman & Bush, 2013). This decreased blood flow can cause body-tissue necrosis, which in turn leads to the development of deep, skin-penetrating wounds. These wounds are the pressure ulcers. This continuous sequence of pressure (resulting in anoxia), ischemia and then necrosis can be halted and turned around if the cause of the pressure is identified timeously and removed as soon as possible (Kruger et al., 2013).

Pressure ulcers can be classified into four stages based on the severity of the ulcer:

- Stage 1: Non-blanchable erythema.
  In stage one the skin is still intact and the pressure ulcer shows as a localised area of non-blanchable redness. In darker skin the colour of the affected area may differ from to the surrounding area. The area may be warmer, cooler, more painful, firmer or softer than surrounding tissue. It is usually found over a bony prominence.

- Stage 2: Partial thickness.
  This stage manifests as a shiny or dry ulcer that is shallow without bruising or slough. Dermis and epidermis are involved, thus presenting as a partial-thickness open ulcer with a pink wound bed.
- Stage 3: Full-thickness skin loss.
  Stage 3 typically shows a break in the skin through the dermis, epidermis and subcutaneous tissue below. Slough (necrosis or dead tissue) may be present. Bone, muscle or tendons are not exposed, but subcutaneous fat may be visible. Drainage or fluid seepage may occur.
- Stage 4: Full-thickness tissue loss.
  Exposed bone, muscle or tendons are visible. Can extend into supporting structures such as joint capsules and often includes undermining and/or tunnelling. Area may be infected and drainage or fluid seepage usually occurs.

(National Pressure Ulcer Advisory Panel, 2014).

The risk factors contributing to the formation of pressure ulcers are numerous. Pressure ulcers are usually due to an interplay between various risk factors and not one single factor alone (Coleman, Gorecki, Nelson, Closs, Defloor, Halfens, Farrin, Brown, Schoonhoven & Nixon, 2012). The injury to the tissues can be related to intrinsic and extrinsic risk factors. The intrinsic factors are associated with the condition of the person, e.g. the presence of any sepsis or localised infections, anaemia, malnutrition, decrease in sensation, the presence of contractures or spasticity. Extrinsic factors are shear, friction, pressure, being immobile and the presence of moisture (Kruger et al., 2013).

2.3.2. Risk factors

Coleman et al. (2012) presented a systematic review of 54 studies to investigate the risk factors for pressure ulcer development in adult patients. From the data found in these studies, it was suggested that the three main domains of risk factors were decreased mobility, poor skin perfusion and previous pressure ulcers. With regard to perfusion, the variables that were considered were diabetes, circulation, vascular disease, smoking and blood pressure. In 19 of the studies, strong evidence was found that diabetes increases the risk of developing a pressure ulcer. The other perfusion variables seemed to also pose increased risk of PU development, but the evidence was not conclusive.

Of the studies stating previous PU as a variable, all reported odds ratios and confidence intervals and, at least three were considered to be of very high quality. Their findings suggested previous PU could be predictive of future PU development and that even just having a grade 1 pressure ulcer increased the odds 2 to 3 times higher of developing a future grade 2 pressure ulcer (Coleman et al., 2012).

Coleman et al. (2012) also suggested that moisture, nutrition, general health, body temperature and immunity might be important risk factors, but that further research into these areas was necessary. A somewhat surprising finding was that of the nine studies that included sensation, only two reported a lack of sensory perception as a statistically significant risk factor for PUs.

Eslami, Saadat, Habibi Arejan, Vaccaro, Ghodsi and Rahimi-Movaghar (2012) studied the impact of demographic factors on pressure ulcer risk in a group of 7489 Iranians with SCI. They found that male gender, increased age, not having an intimate partner and lower levels of education increased the risk of developing a pressure ulcer. When the researchers studied the time since the injury has occurred, it emerged that being a male, having a quadriplegic injury and being older were associated with pressure ulcer risk in both participants who had suffered the injury less than a year before and more than a year before. For participants where more than one year have passed since their injury, not having an intimate partner and having lower levels of education were also strongly associated with the development of a pressure ulcer.

In response to the above article, Rathore and Mansoor wrote a letter to the editor of ‘Spinal Cord’ in 2013 (2013) and proposed that the four major contributors to pressure-ulcer development in Pakistan were a lack of knowledge demonstrated by medical personnel, clients not having access to pressure-relieving mattresses, inadequate changes in posture and clients’ not being able to detect the early signs of pressure ulcers. They also suggested that clients living with SCI in developing countries are more at risk and has a very high incidence of PU. Zakrasek, Creasey & Crew (2015) who completed a systematic review of the literature on PUs in people with SCI living in low-income countries agree that PU in SCI are more common in developing countries. They found that while PU risk factors are similar throughout the world, the risk factors are more prevalent in developing countries. Risk factors specifically mentioned by Zakrasek et al. (2015) included low income levels, low levels of education, immobility (due to the injury, but also, due to a lack of assistive devices and environmental barriers), lack of basic pressure care equipment, malnutrition and challenges with regard to health care service delivery.

Saunders, Krause and Acuna (2012) explored the relationship between the development of pressure ulcers and race and socio-economic status through a cross-sectional study where surveys were completed by 2549 clients who were at least one year post injury. They found that there was no significant association between race and PU risk, but that low household income was a significant risk factor associated with PU in clients with SCI. Even though this study was done in the United States, a developed country, this finding is significant for a country like South Africa where poverty levels are high.

Gould, Olney, Nichols, Block, Simon and Guihan (2014) reported that more than 200 factors can be associated with an increased risk of developing a PU. However the papers reported on focused more on the elderly living in nursing homes than on persons living with SCI. What Gould et al. (2014) did find that is relevant to persons with SCI, is that, unlike the elderly who develop their PUs in a nursing home, most clients living with a SCI develop PUs in the community. Gould et al. (2014) investigated modifiable risk factors and postulated that for clients living in the community and having a cumulative smoking history significantly increased the risk of developing a PU. They also found that persons being moderately overweight might have a protective effect against developing a pressure ulcer and that using a care giver more regularly did not reduce the risk of developing a PU.

From the above findings it seems as if one can conclude in accordance with the ‘Consortium for Spinal Cord Medicine Clinical Practice Guidelines and Spinal Cord Injury Rehabilitation Evidence’ (SCIRE) that the most common risk factors for the development of PUs post SCI are increased age, being male, having lower education levels, higher, complete lesions, having various co-morbidities associated with having a SCI, being underweight, depression, smoking and lacking the knowledge and understanding of how to prevent PUs (Houghton, Campbell. & CPG Panel, 2013).

2.3.3. Incidence and Prevalence

Incidence rates of pressure ulcers vary significantly. Pyatak, Blanche, Garber, Diaz, Blanchard, Florindez and Clark (2013) reported an average incidence rate in the USA of 15,2% during the first year after the spinal cord injury was suffered. They also stated that incidence rates increased over time ranging from 5,6% (incomplete paraplegia during their first year post injury) to 40,6% (complete tetraplegia at 20 years after injury) (Pyatak et al. 2013). Prevalence rates of pressure ulcers range between 20% and 33% in persons with spinal cord injuries, living in the community in developed countries (Gelis, Daures, Benaim, Kennedy, Albert, Colin, Joseph, Pelissier & Fattal, 2011; Guihan & Bombardiem, 2012). Lala, Dumont, Leblond, Houghton and Noreau (2014) found that out of 1137 Canadians with SCI, 381 (33,5%) reported having developed a minimum of one pressure ulcer in the previous 12 months. About 27% of the respondents had developed one or two pressure ulcers and 6,4% had developed three or more. Niazi, Salzberg, Byrne and Viehbeck (in Lala et al. 2014) further found that the life-time prevalence rate of pressure ulcers in clients with SCI, could be as high as 85%. Bates-Jensen, Guihan, Garber, Chin and Burns (2009) found that the recurrence rate for pressure ulcers in persons with SCI could be as high as 79%. These are all studies published in developed, high-income countries leading to the question of what the situation looks like in a country like South Africa.

No pressure-ulcer prevalence figures are known for people living with SCI in the community in South Africa. Zakrasek et al. (2015) published a literature review on pressure ulcers in developing nations. According to this review the reported incidence and prevalence rates vary considerably with reported prevalence figurers varying between 26.7 and 46.2% (Zakrasek et al., 2015). Zakrasek et al. (2015) argue that these figures, while high are probably an understated representation of the situation.

2.3.4. Impact of pressure ulcers on persons with SCI

Having a pressure ulcer has very significant participation, activity, care and cost implications for persons living with an SCI (De Jong, Hsieh, Brown, Smout, Horn, Ballard & Bouchard, 2014). Of the 381 Canadian participants in the study by Lala et al. (2014) who reported the development of at least one pressure ulcer, 65.3% stated that their activities had been reduced somewhat due to having the pressure ulcer. Of the participants who developed three or more pressure ulcers, 53% stated that they were severely or completely limited in their activity level. The reported time in hours spent on participating in the client's preferred main activity (employment, self-employment, being a homemaker, studying etc.) did not greatly differ between the clients with pressure ulcers and those without pressure ulcers. The participants with pressure ulcers did however report being less satisfied with their perceived ability to participate in their chosen main activity.

Lala et al. (2014) also examined the impact of PUs on quality of life (QoL). The QoL of participants who had three or more pressure ulcers in the previous 12 months were significantly lower than the QoL of those who did not have pressure ulcers. These findings were confirmed in a cross-sectional study by Lourenco, Blanes, Salomé and Ferreira (2014) who compared health-related QoL and self-esteem of 60 participants with PUs to 60 without pressure ulcers. The participants with pressure ulcers scored significantly lower on both the health-related QoL and self-esteem.

To fully understand the effect of a pressure ulcer on a person, their quality of life and self-esteem, it is important to describe their lived experiences. Thus, Langemo, Melland, Hanson, Olson and Hunter (2000) conducted a descriptive, phenomenological study involving eight participants. Of these participants, four had pressure ulcers at least six months prior to the study and four had pressure ulcers at the time of the study (Langemo et al., 2000). Themes from this study included the impact the pressure ulcer had on participants' lives and the "psychospiritual impact" of having a pressure ulcer. The life impact theme was divided into three areas, namely physical, social and financial. Under this theme most of the respondents reported having difficulty dealing with the compulsory bed rest associated with treatment of the pressure ulcers and issues of social isolation due to having the pressure ulcers. Under the theme "psychospiritual impact", respondents reported problems with their body image, their need for independence and the continued struggle with stereotyping. One of the strongest issues that arose, was a need to be in control of the decisions made regarding care and time management (Langemo et al., 2000).

Krueger, Noonan, Williams, Trenaman and Rivers (2013) set out to develop a conceptual framework to study the relationship between the secondary complications of SCI such as pressure ulcers and the prevalence of depression. From their literature review it seems that PUs are the secondary complications most identified as having a possible link with depression (Krueger et al., 2013). The authors did state that it was unclear if the PUs had caused the depression or whether depression resulted from developing the PUs (Krueger et al., 2013).

Another major concern with regard to the psychological well-being of clients living with SCI, is the issue of employment. Being employed is linked to a higher quality of life and improved life satisfaction (Meade, Forchheimer, Krause & Charlifue, 2011). In 2011 Meade et al. published a research paper on the effects that secondary complications have on employment status among people with SCI living in the USA (Meade et al., 2011). The researchers performed a retrospective analysis of longitudinal information that was obtained from multiple centres as the result of studying 9501 participants who were unemployed and 5150 participants that reported having gainful employment. The results from this study showed that being hospitalised somewhere in the last 12-month period led to a diminished chance of obtaining gainful employment. With regard to the retention of gainful employment, being hospitalised and having a pressure ulcer, lowered the chances of remaining employed. Since having meaningful or gainful employment is associated with a sense of self-worth, self-esteem and reported QoL (Ottomanelli, Barnett & Goetz, 2013) these findings echo the findings in the studies mentioned previously.

2.3.5. Management and Cost of Pressure Ulcers

Due to the potential high prevalence rates of PU in clients with SCI, it is important to not only be able to identify the possible formation of a PU as soon as possible, but also to start treatment of the PU without any delay. The first line of defence for the proper management of PUs is being able to identify the presence of a pressure ulcer and to correctly determine the staging/grading of the ulcer for optimal treatment (Kruger, Pires, Ngann, Sterling & Rubayi 2013). This will not only save costs, but also decrease the time it takes for the PU to heal as a grade one(1) ulcer, for example, will heal significantly faster than a grade three(3) or a grade four(4) ulcer. Generally, grade one and two PUs only require conservative wound care, whereas grade three and four PUs need surgical intervention. At all stages it is important to incorporate the basic treatment protocols of pressure-relieving strategies and optimize nutrition and education of the client and their care givers, to prevent further ulcer formation (Kruger et al. 2013).

In 2006 it was estimated that the total annual cost of hospital re-admissions due to PUs was about $11 billion in the USA (Kruger et al., 2013). Scheel-Sailer, Wyss, Boldt, Post and Lay (2013) also reported that the rehospitalisation of persons with SCI, is frequently due to PUs and are associated with high costs annually. As no pressure ulcer incidence or prevalence numbers are known for persons with SCI in South Africa, it is difficult to estimate the cost of treating this complication. Dunn and Stander (2008) explored possible cost savings with better PU prevention at one acute care hospital in Cape Town. They found that with proper prevention strategies in place, an estimated R738 239 (more or less $49 215) could be saved by that unit annually. These savings were due to a reduction in treatment and interventions, as well as a decrease in hospital stay (Dunn & Stander, 2008). As shown by the above figures and stated by Kruger et al. (2013) the prevention of PUs is much less costly than their management.

2.4. Pressure-ulcer prevention

The old adage goes that prevention is better than cure is true and in the case of Pus, prevention would also be more cost effective. In the Healthcare 2030 plan (Western Cape Government, 2013) the discrepancy between the limited resources that exist in South Africa and the growing need for more effective health care is noted and there is a call for more cost-effective ways of delivering health care and promoting prevention strategies. It is thus important to assist clients and their carers to prevent pressure ulcers from occurring. To do this, clients with spinal cord injuries need to have adequate knowledge and understanding about pressure ulcers (Burkell et al., 2006).

To effectively manage and prevent pressure ulcers it is important that they are addressed on all levels of health care. Health-care provision in South Africa is based on the primary health-care model or philosophy. Primary Health Care (PHC) was formulated by the WHO in the Alma Ata Declaration as a way to manage principles and strategies to help with the organisation of health systems (WHO, 1978). PHC has five pillars, or aspects, namely health promotion, prevention of diseases, treatment of disease, rehabilitation and palliative care (Western Cape Government, 2013). With regard to pressure ulcers, clients and their care-givers have an important role to play especially in the first two facets, but also in being able to identify when there is a need to seek further assistance from curative and rehabilitative services. As part of a rehabilitation programme post-spinal-cord injury, clients should receive education on, not only regarding their disability, but also, with regard to secondary complications (e.g. pressure ulcers), how to prevent them, how to detect when they develop and what to do when they are detected.

In recent years, a number of clinical best practice guidelines on the prevention and management of PU in people with spinal-cord injuries have been published. Examples include the Pressure Ulcers following Spinal Cord Injury booklet published by the Spinal Cord Injury Rehabilitation Evidence Project in 2013 (Hsieh et al., 2014), ‘The Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury’ published in 2013 (Houghton, 2013), ‘Prevention and management of pressure ulcers in primary and secondary care: summary of NICE guidance’ published by The British Medical Journal in 2014 (Stansby et al., 2014) and, most recently, ‘Pressure-ulcer prevention and Treatment Following Injury: A Clinical Practice Guideline for Health-Care Providers published by the Consortium for Spinal Cord Medicine in the United States’ in 2014 (Garber et al., 2014). In formulating Clinical Practice Guidelines, expert opinion is often combined with Evidence Based Treatment guidelines (Henzel, Bogie, Guihan & Ho, 2011). Most of these practice guidelines aim to reduce the number of pressure ulcers among clients living with SCI by providing recommended protocols and methods to prevent and treat pressure ulcers. These guidelines include the elements that should form part of a training-and-education programme to help prevent pressure ulcers. According to the guidelines, the following information should be included in PU prevention programmes:

- The etiology or causes of a pressure ulcer
- How to reduce pressure-ulcer risk including lifestyle changes and precautions regarding burn wounds and activities of daily living
- How to care for the skin and the importance of cleaning the skin
- Incontinence management (bladder and bowel)
- Skin inspection techniques and frequency
- The recommended position-change techniques, duration and frequency
- The recommended pressure-redistribution techniques, duration and frequency
- The importance of the correct nutritional intake relating to skin integrity
- Wheelchair, pressure redistribution cushion and mattress: correct use and maintenance
- How and when to report skin changes to the health-care team
- Limiting or stopping substance use like smoking and alcohol intake

(Hsieh et al., 2014; Garber et al., 2014; Stansby et al., 2014)

In their study on the perceptions of service providers of the use of the first edition of the ‘Clinical Practice Guideline for Health-Care Providers’ published by the Consortium for Spinal Cord Medicine in the United States for the first time in 2000 for clinical practice, Thomason, Evitt, Harrow, Love, Moore, Mullins, Powell-Cope and Nelson (2007) showed that even though doctors and nurses who work with clients with SCI agreed on the content of the guidelines as set out in the publication, they thought that the guidelines were not being implemented as recommended. The two main reasons for this were not having enough knowledge on the management of pressure ulcers and other factors relating to organisational structures, e.g. difficulties with communication across teams and shifts (Thomason et al., 2006).

2.4.1. Prevention during the acute and rehabilitation phase

De Jong et al. (2014) reported that about a third of clients with newly acquired SCI developed PUs during their stay in rehabilitation, of which 45% were stage 1 PUs. These numbers were from statistics gathered from 2004 to 2006 in the USA. According to De Jong et al., it is difficult to compare these numbers to any earlier periods, because length of stay in rehabilitation centres had decreased. De Jong et al. postulate that having shorter length of stay in rehabilitation can either increase the risk of PU due to less time to be educated on PU prevention, or decrease the risk of a PU developing in the centre due to fewer hospital days in which to potentially acquire a PU in. According to Zagrasek et al., (2015) up to 47.7% of persons with SCI, in developing countries developed PU during the acute hospitalisation period, while up to 20% were admitted with PUs and up to 57.1% developed PUs during rehabilitation. Frielingsdorf & Dunn (2007) found in their South

African study, that 11% of participants developed PUs during the acute hospital stay and 11% were admitted with Pus already present.

In the USA new and/or worsening PUs are being used as quality-of-care indicators in the rehabilitation setting (De Jong et al., 2014). In 2008, one of the major medical insurance companies in the USA have stated that they will no longer be reimbursing hospitals for a number of preventable conditions, amongst other things, the development of pressure ulcers (Kruger, 2013). In South Africa, new national core standards are in the initiating phase where complications such as hospital-acquired pressure ulcers are being used to measure quality of care (Department of Health, 2011; WCRC Annual Operational Plan, 2016). These shifts in policy increase the urgency to not only identify clients with the highest risk of developing PUs, but also to be more effective in preventing the onset of PUs (De Jong et al., 2014).

There is evidence to suggest that prompt admission to a specialised spinal cord injury unit, significantly decreases the risk of pressure ulcer development. In the best practice guidelines published by the Consortium of Spinal Cord Medicine in 2014 (Garber et al., 2014) three studies are quoted, showing that persons with SCI admitted to a specialised unit within 72 hours have lower pressure-ulcer-incidence rates. The authors suggested that this was due to the knowledge and skills of staff in the specialised units regarding the potential risk for pressure ulcers and their subsequently implementation of the correct preventative strategies. These strategies include turning and repositioning the clients regularly, doing daily skin checks, correct handling techniques with transfers and repositioning and the correct nutritional support for the client (Garber et al., 2014). As clients who are newly diagnosed would not know how to perform all the preventative measures, it is crucially important for the medical staff to know how to perform them and actually performing them correctly. By doing these techniques correctly and timeously, the client is also slowly introduced to the preventative measures and taught how to apply them.

2.4.2. Prevention during the community phase

In 2013, the NHS (National Health Service) in the UK, published an article on the prevention of pressure ulcer in the community setting (Jones, 2013). They also recognised the great need for prevention strategies. According to the article, the NHS spends 4% of its annual budget on the management of pressure ulcers. This article focuses on equipping community-based nursing staff on how to not only prevent pressure ulcers, but also how to detect them early and what to do if they are detected. The prevention programmes used are much the same as that which are used for in-patient settings. In the community setting however, more emphasis is put on involving the clients and their family/carers in these programmes. This is done because of the limited contact that some clients may have with nursing staff and, also, to help empower the clients in their own health management (Jones, 2013).

In the best practice guidelines set out by the Consortium on Spinal Cord Medicine, in 2014, regarding pressure-ulcer prevention it is stated that the practice of only using education programmes that are hospital-based and implemented during the acute rehabilitation phase is not adequate (Garber et al., 2014). Hospital admission periods have decreased. This means that clients are leaving the acute rehabilitation setting with less information and there is less time and opportunity to reinforce the information on pressure-ulcer prevention (Garber et al., 2014). This again, highlights the importance of follow-up in the community and on-going education programmes. As stated before, Gould et al. (2014) found that people with SCI develop pressure ulcers more often when they are out in the community than as in-patients during rehabilitation.

2.5. Knowledge/Education and behaviour change

Patient education is an important component in the prevention of pressure ulcers. An appropriate educational programme is important to help facilitate prevention strategies (Henzel et al., 2011). According to Michel et al. (2012) a lack of knowledge about preventative measures, implies an increased risk for pressure-ulcer development. Most of the previously-mentioned clinical practice guidelines outline education or knowledge that should be given to clients or learned by them in order for them to effectively contribute to the prevention and efficient management of pressure ulcers. The ‘Best Practice Guidelines’ that were developed in Canada (Houghton et al., 2013) propose that the information that needs to be covered in such an education programme needs to be individualised for the specific client, but should include the following elements:

- The potential risks and causes of developing a pressure ulcer
- How to detect pressure ulcers and monitor the skin
- The preventative actions that can be taken to reduce the risks of pressure-ulcer development (Houghton 2013 et al.).

Rintala, Garber, Friedman and Holmes (2008) found that a structured, individualized education programme had a positive impact on clients’ knowledge of pressure-ulcer prevention and decreased the occurrence of pressure ulcers. Garber, Rintala, Rossi, Hart and Fuhrer (1996) found the knowledge that clients, living with SCI, have about pressure ulcers was significantly more in clients who had had previous pressure ulcers. This would make sense, as a person would be expected to know more about a condition that they themselves had suffered. In the same study, it was also shown that clients who reported that they were performing more of the actions to prevent pressure ulcers also knew more timeously what to do once the first signs of a pressure ulcer were encountered (Garber et al., 1996). The authors emphasised that knowing how to detect a pressure ulcer and knowing what your immediate action should be would be more effective in preventing pressure ulcers from progressing to stages three or four.

Thietje, Giese, Pouw, Kaphengst, Hosman, Kienast, Van de Meent and Hirschfeld (2011) explored the gaining of knowledge about SCI and the associated secondary complications. The researchers included 214 participants with traumatic and non-traumatic SCI who had been admitted to a trauma centre in Germany over a three-year period. Knowledge of SCI and its associated secondary complications was tested on admission, twice during the rehabilitation programme and at 6, 18 and 30 months, post-discharge. It was found that less than 50% of participants had good knowledge regarding SCI and its associated secondary complications on discharge. They also found that knowledge decreased over time, post-discharge. The knowledge scores decreased the most significantly in the group of participants 65 years and older and in those participants who were uneducated. Another finding in this study, was that the three most important sources of information were the rehabilitation specialist physician, the general practitioner and the physiotherapist (Thietje et al., 2011).

In a study conducted by Burkell et al. in 2006, on the information needs of persons with SCI, 206 participants were questioned on their educational needs and how they sourced their information (Burkell et al., 2006). The results showed that participants had a need for more information, that this need was not adequately met and 78.7% of the respondents stated that they received most of their information from SCI specialists. In the study conducted by Njoki, Frantz and Mpofu (2007) where the authors explored the health needs of youth with SCI, in the Western Cape it was found that health professionals, friends, family and peers were important sources of information, guiding these participants to health behaviours that were positive. These findings emphasise the importance of giving clients sufficient information during rehabilitation not only on how to prevent pressure ulcers, but also on how to detect them and what to do once they have been detected.

2.6. Beliefs and Behaviours

The Health Beliefs Model describes the relationship between beliefs about health and ‘health behaviour’ with regard to prevention (Guihan & Bombardier, 2012). This is a conceptual model that suggests whether a person will follow certain guidelines or recommendations in relation to their health is motivated by certain beliefs. These beliefs are related to:

- Whether you think you are at risk of contracting the condition
- How severe you believe this condition to be
- Whether you believe that the guidelines or recommendation will decrease your susceptibility to the condition
- Whether you believe that the benefits from following the guidelines are more than the costs or barriers presented when following the guidelines
- Whether you believe that the guidelines or recommendations can be performed and implemented by you or your caregivers.

In other words, “People who believe they are susceptible to a serious condition and feel threatened are more likely to consider taking action to improve their health” (King, Porter & Belfanz 2008:155).

The Health Beliefs model was first applied to skin care and PU prevention by Dai and Catanzaro (in King et al. 2008). Later King et al. (2008) used the Health Beliefs Model as study framework in a qualitative, descriptive study on PU prevention. They used purposive sampling to recruit 22 participants with spinal-cord injuries. Their findings showed that most participants believed that they were at risk of developing a pressure ulcer and that preventative care was regarded as being important. Their reported practices, however did not reflect this belief. Four main themes were identified from the data. These were: 1) diligent/vigilant care-taking, 2) taking charge of skin care, 3) health maintenance and 4) passing the responsibility of care to another. The first three themes showed positive beliefs that resulted in positive decisions regarding skin care. The last theme was associated with negative beliefs e.g. barriers and the impact of the skin care one's life. The study found that participants with positive skin-care beliefs more often prioritised preventative strategies and were more likely to take responsibility for their skin care.

Garber, Rintala, Holmes, Rodriguez and Friedman (2002) conducted a randomised, controlled trial with 41 participants with SCI, who had been admitted for pressure ulcer surgery. The experimental group received in-depth education on pressure-ulcer prevention in an individualised, structured programme while the control group received standard pressure-ulcer prevention education. The knowledge and health beliefs of both these groups were then tested. The results showed that most of the participants in both groups believed that they were somewhat likely to develop a pressure ulcer, that pressure ulcers are difficult to treat and that getting a pressure ulcer were very serious (Garber et al., 2002). In both groups, they found that the participants who had had lower knowledge scores on admission, also did not believe that a pressure ulcer would interfere "a lot" with their lives or that doing skin checks daily made "a lot" of difference in one's chances of developing a pressure ulcer. In both groups, participants with lower knowledge scores on discharge, were more likely to believe that doing skin checks every day did not make "a lot" of difference in their chances of developing a pressure ulcer (Garber et al., 2002).

The health beliefs of 148 persons with SCI who were admitted for pressure ulcer surgery at six spinal rehabilitation hospitals in the USA, were studied by Guihan and Bombardiem (2012). They found that most of the participants believed that pressure ulcers are serious and that they are at a high risk of developing them. A large number of participants reported difficulties associated with practising good skin-care techniques. These difficulties included forgetting to do the techniques, the belief that they take too much time or are too much trouble to perform, not having help and the belief that they are unpleasant to do (Guihan & Bombardiem, 2012).

2.7. Self-management and Practices

One of the most important parts of any pressure-ulcer prevention programme is the activities or practices that are taught to clients. These activities do not only include skin-care activities, but also health-maintenance activities. King, Champion, Chen, Gittler, Heinemann, Bode and Semik (2012) studied the skin-care behaviour of 406 clients living with SCI (King et al., 2012). The researchers used an activity log that recorded four skin care activities for two consecutive weeks. These activities included skin checks, pressure relief in the wheelchair, the longest time sitting in the wheelchair without getting out of the chair and the longest time between turning in bed. They found that daily skin checks were only performed by 75% of the clients. They also found that 59% of clients did not perform pressure relief in the wheelchair, as recommended, and that 33% to 43% of the clients, routinely, went 1.5 hours or longer without doing pressure relief in their chairs.

Bloemen-Vrecken, De Witte, Post and Van den Heuvel (2007) sent out a 22-item self-report questionnaire to 410 persons with SCI, living in the Netherlands. They found considerable variance in the frequency of health behaviour adherence and particularly found that participants frequently did not engage in pressure-relief techniques while using a wheelchair. Guihan and Bombardiem (2012) presented similar results and found that most of the participants in their study reported not following skin-care-behaviour guidelines that are commonly recommended. Only 55% of the participants in their study reported doing pressure relief as recommended.

Guihan and Bombardiem (2012) also investigated health behaviours, like smoking and drinking. Ten to 12% of the participants reported putting themselves at risk with these practices (Guihan & Bombardiem 2012). Of the participants that reported not following the recommended guidelines, only about 50% reported that they were trying to change their adherence to the recommended health maintenance guidelines with regard to alcohol-and-drug use and smoking. A large number of participants also reported never following some of the general dietary advice given. In this study alcohol, drug and tobacco use were not reported to be very high (11%, 13% and 35%, respectively). These percentages will most probably be much higher in the South African context as it has been suggested by Njoki et al.(2007) that substance abuse might be much higher in the South African population of clients with SCI than in the reported studies from developed countries.

Another very important practice that was emphasised by Garber, Rintala, Rossi, Hart and Fuhrer (1996) is how soon appropriate action is taken on detection of a pressure ulcer. It was found that participants who immediately took appropriate action after detecting a PU, also reported more frequent, preventative health behaviours. Guihan and Bombardiem (2012) recommended that the adherence to and barriers in the adherence to protective skin-care behaviours should be discussed with clients to determine the client's readiness to change and to provide them with resources that would assist them.

2.8. The role of peer support counselling in pressure-ulcer prevention.

A peer supporter or peer mentor is someone who enters into a relationship with someone else who has some of the same characteristics or experiences and gives the second person support or assistance as needed (Hayes & Balcazar 2008 as cited in Ljunberg et al., 2011). Peer-mentoring programmes have been used successfully in various settings, not only in education and business, but also in health programmes (Rhodes & DuBois 2008 as cited in Ljungberg et al., 2011).

A study was conducted at a rehabilitation centre in Washington DC, in the USA, where the effect of a peer-mentoring programme for clients with SCI was studied, especially its effect on the development of secondary complications. It was a small study using non-random sampling and relying on self-reported data. During the study, 24 clients who had successfully completed the programme, were interviewed. The findings were that 67% of the clients had shown an increase in their self-efficacy scores and that doctors' visits and secondary complications showed a significant decrease after 12 months (Ljungberg et al., 2011). Although this was a small study, this could indicate the potential benefits that could be gained from using peer supporters more often in training on pressure-ulcer prevention. A qualitative study with 14 participants from the United Kingdom, showed that persons with SCI valued the psychological and emotional support that peer supporters offered. Participants also benefited from practical advice and information, which included information on skin care, provided by the peer supporters (Haas, Price & Freeman, 2013).

Due to the decreases in length of hospital stay, using a peer-support programme could greatly assist the rehabilitation team in providing ongoing support especially after discharge (Ljungberg et al., 2011).

2.9. Summary

The review of the literature has shown that pressure ulcers are a serious and costly complication of SCI that impacts negatively on participation and quality of life and can eventually lead to death. Lifetime risk for PU of persons with SCI is reported to be as high as 85%. PUs are caused by pressure, shear or friction and the risk for PU is aggravated by a number of risk factors including poor health, decreased skin perfusion, malnutrition, decreased sensation, being immobile and moisture. Previous PU increases the risk for further ulcers. Socio-economic status, age, gender, educational level, health-care-service delivery and access to equipment also play a role.

Pressure-ulcer prevention guidelines emphasise the need for adequate training of any person with SCI in the prevention of PU. A lack of knowledge can lead to a higher risk of PU. However, knowledge on its own is not enough to influence practice and ensure that preventative practices are introduced and applied. Beliefs also play a role and persons who think PU is serious, that they are at risk of contracting a PU, and that they can decrease the risk by implementing prevention practices, are more likely to implement preventative practices.

Chapter 3: Methodology

3.1. Introduction

Chapter 3 introduces the reader to the study methodology. The choice of a quantitative descriptive study design is explained, followed by the reader being introduced to the study setting. The study population is demarcated, in- and exclusion criteria as well as participant selection are explained. The development of the data-collection instruments, the pilot study and the data-collection process as well as the recruitment and role of research assistant is clarified. Finally, the data-analysis process will be discussed as well as the ways in which rigour was applied in this study.

3.2. Study Design

A quantitative, non-experimental survey design was used. Non-experimental study designs are particularly useful when little is known about a subject, when an experimental study would prove to be unethical or when the research does not aim to determine the effects of particular treatments (Carter, Lubinsky & Domholdt, 2011). Very little is known about South Africans with SCI's knowledge, practices and beliefs on pressure care. It would be unethical to do an experimental study where information on pressure care is withheld from clients. According to Carter et al. (2011) surveys gather information by asking participants what they know, how they act and what they believe. Surveys may thus be used to analyse relationships and differences as well as for descriptive purposes. Survey research is mostly non-experimental in nature and collects self-reported information. Information on knowledge, practices and beliefs may be gathered through self-report surveys (Carter et al., 2011).

3.3. Study Setting

The study was performed at the Western Cape Rehabilitation Centre (WCRC). The WCRC provides rehabilitation for clients with physical disabilities. It is based in Cape Town, South Africa. It is the only state-funded rehabilitation centre of its kind in the Western Cape. Clients are referred to the WCRC from all levels of health care in the public, as well as the private sector. Clients may also be self-referred or referred by a family member or care giver (WCRC, 2007). Clients are admitted to the centre once they are medically stable and able to participate actively in a comprehensive rehabilitation programme. Rehabilitation is provided by a team consisting of a doctor, nursing staff, a physiotherapist, an occupational therapist, a social worker, clinical psychologist and speech therapist when appropriate. Annually, approximately 750 clients are admitted to the WCRC. About half of the clients admitted, have sustained a spinal-cord injury (SCI) or have been diagnosed with pathology affecting their spinal cord. Clients who have sustained a SCI receive in-patient rehabilitation for periods varying from two to three months. Their rehabilitation programme focuses on the retraining of activities of daily living, mobility strategies and reintegration into their communities. It also includes teaching clients the medical management of their newly-sustained spinal cord injury and the prevention of secondary complications that may result from a SCI. After discharge from in-patient rehabilitation, most of the clients are followed up as out-patients for specialist rehabilitation needs, e.g. bladder and bowel tests, seating assessments and the following up of clients who are at high risk for pressure ulcers.

3.4. Study population, sampling and participants

3.4.1. Study Population

The study population consisted of persons (N=93) who suffered a SCI (traumatic or non-traumatic) and received rehabilitation at WCRC, or visited WCRC out-patient clinics between 31 March 2015 and 19 May 2015.

Inclusion criteria:

- Clients with complete and incomplete spinal-cord lesions who use manual wheelchairs as their primary means of mobility. Clients with incomplete spinal-cord lesions may have decreased sensation, mobility or continence that may put them at risk of developing a pressure ulcer.
- Clients with a SCI due to traumatic and non-traumatic causes
- Clients older than 18
- Clients of all races
- Clients of both genders

Exclusion criteria:

- Clients who were not primarily manual wheelchair users. The study was looking specifically at clients who used wheelchairs and some of the questions spesifically deal with behaviour in the wheelchair.
- Clients with cognitive impairments who could limit the ability of the client to consent, participate or remember information provided on pressure ulcers during rehabilitation. While acknowledging that this is an important sub-group of the population who are even more at risk of developing pressure ulcers (Raetz & Wick, 2015), preventative practices for this group may not be self-driven and the aim of this study was to, specifically describe the knowledge, practices and beliefs of clients with SCI.

- Clients who could not self-propel their wheelchairs and/or used motorised wheelchairs. The reasoning behind excluding clients who were not able to self-propel their wheelchairs was two-fold. In the study done by Taule, Bergfjord, Holsvik, Lunde, Stokke, Storlid, Sørheim and Rekand (2013), it was found that one of the factors that significantly increased seating pressure in clients with SCI, thus putting them at greater risk of developing pressure ulcers, was if the participant was using a manual wheelchair. It has also been found in a study conducted by Chiodo et al. (2007) that clients with paraplegia and who are able to self-propel their wheelchairs, are at greater risk of developing pressure ulcers.

In addition, persons who provided peer counselling to persons with SCI at WCRC in 2015 (N=8) were included in the study. Peer supporters were included as study participants, as it is important to determine whether their knowledge of pressure-ulcer prevention is sufficient and correct. The peer supporters often assist with the training of clients and are also often asked questions regarding pressure care, by clients. The peer supporters that volunteer at the WCRC are former clients of the WCRC and are themselves wheelchair users.

3.4.2. Sampling

Consecutive sampling was used. According to Carter et al. (2011) this is when all the clients that meet the inclusion criteria over a certain period of time are invited to participate in a study. All clients who had been receiving rehabilitation as in-patients at WCRC, who were to be discharged during the study period and met the inclusion criteria, were invited to participate in the study. In addition, all clients with SCI who visited the out-patient clinic at WCRC during the study period, met the inclusion criteria and had been discharged for at least three months, were invited to participate in the study. This ensured results from clients who had just completed their rehabilitation as well as from clients who had been discharged for more than three months.

The Biostatistics Department of Stellenbosch University (SU) was contacted to ascertain the sample size needed for meaningful statistical analysis. Due to the study being descriptive in nature, the researcher was advised that a minimum of 30 participants were required, but that more participants would be preferable. In the studies on knowledge, attitudes, beliefs and practices referred to in the literature review, the number of participants ranged from 21 (King et al., 2008) to 148 (Guihan & Bombardiem, 2012). The researcher decided to try and recruit a minimum of 30 participants from the two client groups and all of the peer supporters (who numbered less than 30 in total).

With regard to the number of out-patients, the researcher studied the booking records of the out-patient department (OPD) at the WCRC and discussed it with doctors and nursing staff working in OPD. From this exercise she gathered that an average of twenty (20) clients with spinal-cord injuries had an OPD appointment every Tuesday, with another fifteen (15) to twenty (20) having appointments throughout the rest of the week. It was estimated that about half of these clients would adhere to the inclusion criteria as about half of the clients visiting the OPD are either not wheelchair users or used motorised wheelchairs. Clients are booked for follow-up appointments every six weeks if needed. Thus, after six weeks excessive duplication might occur and fewer participants eligible for the study might visit OPD. The researcher concluded that within a six-week period, on average, 90 out-patients might meet the inclusion criteria.

From the in-patient data it was found that on average three to four clients adhering to the inclusion criteria were being discharged from the centre weekly. It was thus estimated that in a six-week period 18 – 24 clients might possibly adhere to the study-inclusion criteria.

3.4.3. Study Participants

The number of clients included in the study was as follows:

- Out-patients: 33
- In-patients: 30
- Peer supporters: 8

Table 3.1 provides additional information on the numbers of study participants.

Table 3.1 Study Participants

	Number of participants identified	Number of participants refusing/unable to take part	Number of inappropriate participants *	Number of participants included in study
In-patients	42	5	7	30
Out-patients	43	10	0	33
Peer supporters	8	0	0	8
Total	93	15	7	71

* During the time of data collection, there were seven clients admitted to the WCRC who were awaiting surgery. These clients had all undergone rehabilitation on a previous occasion and were thus being re-admitted for the sole purpose of the surgeries. It was decided not to include these clients in the study as they had not recently finished their rehabilitation process as in the case of the other in-patients and this might subsequently influence their knowledge and beliefs.

3.5. Data Collection Instruments

A questionnaire was developed from assessment tools that had been used in a series of studies on pressure ulcers by a group of researchers, led by Dr Marylou Guihan from the Spinal Cord Injury Quality Enhancement Research Initiative at the Edward Hines Jr VA Hospital in Hines, Illinois, USA (Guihan et al., 2014). Among other things, the knowledge, practices and beliefs of clients with SCI regarding pressure ulcers and pressure care were studied by this group (Guihan & Bombardierm, 2012). To enable the researchers to conduct this study, they developed three assessment tools namely the Pressure Ulcer Knowledge Test, the Health Beliefs and Practices Form and the Skin Behaviour Checklist. Furthermore they developed a shortened version of the Pressure Ulcer Knowledge Test. These assessments were developed as follows:

- **The Pressure Ulcer Knowledge Test** was adapted from a test developed by Barbara Pieper (Pieper and Zulkowski, 2014) that was also used in the study by Garber et al. (2002) to assess participants with SCI's knowledge about pressure care.
- **The Health Beliefs and Practices Form** is based on the health beliefs model (King et al. 2008).
- **The Skin Behaviour Checklist** is based on a list of recommended skin-care behaviours. This checklist was also used in the study by Guihan and Bombardiem (2012) as a way of measuring adherence through self-report.

The primary author of the study by Guihan and Bombardierm (2012) was contacted to obtain permission to use the Pressure Ulcer Knowledge Test, the Health Beliefs and Practices Form and the Skin Behaviour Checklist in the current study. In addition, permission was obtained to modify the tools to be more relevant for the South African setting and to combine them into one questionnaire. Permission was granted via e-mail, provided that the original author would be acknowledged in the study. The researcher proceeded to combine and adapt the original assessment tools into one questionnaire. The reason for the tools being combined was to make the questionnaire-led interviews less time-consuming and to prevent duplication of questions. The assessment tools also had to be adapted for the local setting as the original tools had been used in a developed country making some of the questions irrelevant/ difficult to understand. An example of such changes is changing the words ‘pressure ulcer’ to ‘pressure sore’ which is the word commonly used in South Africa and not including combination cushions as an option as they are not available for issue at the WCRC.

The revised questionnaire used in the current study has five sections (See appendix B):

Section 1: Demographic information

Demographic data (age, race, gender, educational level and marital status) and basic clinical data (level and type of injury, time since onset of injury, pressure-ulcer history) were collected at the beginning of the questionnaire.

Section 2: Knowledge

This section explored the participant's knowledge of pressure ulcers and pressure-ulcer prevention. It consisted of structured questions where participants had to list information or provide answers. The original, shortened Pressure Ulcer Knowledge Test is a 14-item questionnaire. For the purposes of this study the researcher adapted the above tool by including some questions from the longer version, because it was felt that more emphasis needed to be placed on certain aspects of pressure care regarded as relevant for the study population and as recommended by the experts who reviewed the questionnaire.

Section 3: Beliefs

This section explored the participant's beliefs about pressure ulcers and pressure-ulcer prevention. It was based on the Health Beliefs and Practices Form. In the study by Guihan and Bombardierm (2012), they changed the standard content of the questionnaire to look at skin care issues. King et al. (2008) also used this model to look at skin care beliefs and attitudes. For this section of the questionnaire, it was decided to use the original tool almost exactly as it was originally developed. Forced choice, Lickert type answer scales were used (Joubert & Ehrilch, 2007).

Section 4: Practices

This section explored the participants' practices and wass based on the Skin Behaviour Checklist. It was decided, in conjunction with the study supervisors and the expert reviewers (see below), to change the checklist into Lickert-Type answer scales so as to be less leading to the client and to elicit truer responses.

Section 5: Skills Test

One of the expert reviewers suggested that a skills test be incorporated to test actual skills and practices. Thus, section five comprises of three tests (transfer, pressure relief and use of cushion) and a score sheet for each.

3.5.1. Instrument review

The questionnaire was sent to five experts in the field of pressure ulcers and seating for comments and feedback on possible amendments. The experts were provided with the background of the study and the original tools from which the questionnaire had been developed to assist with suggestions for amendments. The experts provided feedback and the suggested amendments were made where appropriate. The experts were Dr Elsje Scheffler (physiotherapist, disability consultant and master trainer for seating courses), Dr Janine Botha (general practitioner with a special interest in rehabilitation and seating), Dr Helen Sammons (the head of the medical services at WCRC and head of the pressure-ulcer-prevention committee at the hospital), Dr Juliette Stander, (general practitioner, working at the acute-spinal-injury unit at Grootte Schuur Hospital in Cape Town) and a colleague's husband who had personally suffered a spinal-cord injury and is a wheelchair user. Feedback was received from four of the expert reviewers.

The amended questionnaire was then sent to the Biostatistics Department of the University of Stellenbosch to assist with the development of a scoring system. Feedback was received and the scoring system was amended. This questionnaire was then ready to be used in the pilot study. After the first part of the pilot study had been completed, the questionnaire was amended as needed. The amended questionnaire was translated and reverse-translated to ensure accuracy of Afrikaans and Xhosa versions. As the questionnaire used words specific to the field of spinal-cord injuries and pressure ulcers, the translated questionnaire was sent to both an Afrikaans and a Xhosa-speaking person working in the field of rehabilitation, to ensure clarity and correct word usage.

3.6. Pilot Study

The questionnaire and the data-collection procedure were tested in two pilot studies. The first round was to check for utility and feasibility of the instrument and to see if the data collected would address the study aims and objectives. It also gave an indication of how long it would take to complete the questionnaire with a participant. The two clients who participated in the pilot study were not part of the study population for the main study. They complied with all the inclusion criteria, but their discharge/OPD visit fell outside the study period. They were asked to give feedback as to the suitability and clarity of the questions. The questionnaire was then amended. Any amendments or changes that needed to be made to the data-collection procedure were noted. (See attached Appendix C for a list of changes.)

The second pilot study was conducted by both the research assistant (see below) and the researcher and served to further amend the questionnaire as needed and to finalise the training of the research assistant. Four different participants participated in this pilot study.

Participant one was interviewed by the researcher while both the researcher and assistant completed the questionnaire. Participant two was interviewed by the assistant while both the researcher and the assistant completed the questionnaire.

This enabled the researcher to train and guide the research assistant in conducting the interview and to identify discrepancies in the completion of the questionnaire. This process was repeated twice with different participants until the researcher and assistant had at least an 80% similarity in scoring.

3.7. Research Assistant

One of the therapy assistants employed at the WCRC acted as research assistant to assist with data collection. As the questionnaire's skill test required certain background knowledge of wheelchairs and seating devices, it was important to use a therapeutic assistant and not a lay person. The relevant managers allowed the therapy assistant to act as a research assistant during official office hours as they felt that the exposure of the therapy assistant to research would contribute to her professional development. After permission was obtained, an e-mail was sent out to all therapy assistants to invite them to participate in the study as research assistants. The study, its aims, objectives and methodology were explained in the e-mail. The researcher asked for volunteers to come forward from this group of assistants. (As another study was being conducted at the same time in 2015, the researcher wanted to give the assistants the chance to express in which field they were more interested in which to assist.)

One therapy assistant volunteered to assist in the study. Once this assistant had been identified, she was trained in the method of administering the questionnaire and in obtaining informed consent through role playing and corrections. The second pilot study was then launched as part of the training. The researcher observed the research assistant to ensure that the measuring tool was applied accurately and consistently and additional training was given as needed. There was no remunerative compensation for the assistant as the understanding with the therapeutic supervisor was that the assistance would occur within normal work hours.

3.8. Data Collection

Following Health Research Ethics Committee approval and permission to conduct the study from the Department of Health of the Western Cape and the CEO of the WCRC, data collection commenced. This started on 31 March 2015 and continued until 19 May 2015. The time period for collection of the data from the in-patients had to be extended by one week as there was a week of public holidays in the middle of the data collection period where most of the clients went home for the week, thus delaying their discharge by one week.

In cases where a client was not able to speak or understand English or Afrikaans (the languages spoken by the researcher and research assistant), a translator was used to conduct the structured interview. The translator was not trained as a research assistant. She was, however briefed in terms of confidentiality issues. Her role was only to read the questions to the participants and translate the participants' answers.

Participants were identified as follows:

Out-patients:

Clients that visit the out-patient department (OPD) come early in the morning as there are no specific time slots for clients and they are seen on a first-come-first-served basis. By 8am about 80% of clients with appointments for that specific day, are already present in the waiting area. All the nursing and therapeutic staff, as well as the clerk working at the reception desk in the OPD, were briefed about the study and the inclusion and exclusion criteria for the study participants. A list of the inclusion and exclusion criteria was also left at the reception desk. A list of clients complying with the inclusion criteria was collated by the reception clerk and handed to the researcher. (The staff at OPD did not obtain informed consent.)

The researcher or research assistant introduced themselves to the prospective participant, explained the study to them and obtained informed consent. Once informed consent had been obtained the questionnaire was completed through a structured interview. All interviews were conducted in a pre-identified, private room in OPD. Interviews were timed to ensure that they did not interfere with the participants' OPD appointment.

In-patients:

In-patient participants were identified two to three weeks prior to being discharged, as training with regard to pressure care would have been completed by then. Team discussions are held every Monday afternoon at the WCRC. Among other things, it is confirmed during these meetings which clients will be discharged in the next two or three weeks. The researcher asked one of the senior therapists, working in each of the three teams, to identify possible study participants. These names were sent to the researcher. An appointment for the interview that suited the client and his/her therapeutic team was arranged. The researcher and/or the research assistant went to the ward at the appointed time. Informed consent was obtained and then the questionnaire was completed with the participants in a pre-identified quiet, private room in the ward or therapeutic area.

Peer supporters:

A list of the peer supporters was obtained from their co-ordinator at the rehabilitation centre. They were all contacted telephonically or by-word-of-mouth where the researcher could not contact them personally, and the study was explained to them. Appointment times were arranged with them on the days when they could visit the centre that suited their schedule and the researcher's clinical commitments. Obtaining informed consent and administering the questionnaire were performed in exactly the same manner as for the in- and out-patients.

3.9. Data Analysis

The researcher consulted a statistician for assistance with the data analysis and made use of Microsoft Excel to analyse the data. The statistician at the Biostatistics Department used STATA 14 for analysis.

Data entry:

Data was transferred onto a Microsoft Excel spreadsheet to prepare it for data analysis. Response options of all variables were coded numerically.

The demographic information from the questionnaire rendered categorical (e.g. gender and type of injury) and numerical (e.g. age) data. The knowledge section provided categorical data that could be collated into an overall score out of 56. The beliefs-and-practices sections rendered mostly ordinal categorical data while the skills tests provided nominal categorical data.

Missing data:

All efforts were made to ensure that there was no missing data. However, onto entering data in the spreadsheet, it was found that the question number 12, on the age of the cushion was not asked of 14 participants. Since participation in the study could not have influenced the age of the cushion, these participants were contacted telephonically to obtain the information. The researcher was unable to reach three of these participants. In this instance, where there is missing data, the number of participants who completed the specific question is indicated.

Descriptive statistics:

Numerical data was described through central tendency (means and medians) and distribution (range and quartile ranges). Categorical data was presented in percentages (or proportions). Tables and graphs were used to present the data.

Inferential statistics:

Some inferential analysis was done to determine whether there were statistically significant relationships between certain variables. A significance level of alpha at 0.05 was considered statistically significant. Due to small expected values in some cells, the Fischer’s exact test was used. (See Appendix D for outline of collapsing of categories for inferential analysis.)

3.10. Rigour

Bias:

Sampling bias:

The out-patient clients, who were studied, were all clients who were able to come to the OPD, thus, possibly excluding clients with transport problems. There are, however clients who do access the OPD with special transport services such as Healthnet or Dial-a-ride. The clients visiting the OPD could have been clients with more knowledge and persons had already known that they needed to see a spinal-cord injury specialist and that could have introduced bias. Due to the limited scope and time frame of this study, for degree purposes neither random sampling, nor visiting clients at their homes, was feasible. Random sampling of clients who had been discharged from the rehabilitation centre would have introduced major logistical problems as clients who generally receive treatment at the Centre, come from as far away as the Eastern Cape. As a skills test was done as part of the questionnaire, it was not possible to send out questionnaires and/or to do telephonic interviews.

Information bias:

Due to the fact that the researcher had been working at WCRC for six years, at the time of the study it is possible that some of the participants could have been clients who had been treated by the researcher in the past. The research assistant had also worked at the centre for a long time. This could possibly have introduced bias in two ways. The researcher or research assistant could have felt that the client had indeed been given the correct information and may have prompted them more or given clues to the answers. The other risk was that the clients could have felt that they needed to please the researcher or research assistant and may not have given a true reflection of their practices, but had rather volunteered the answers that they had felt was expected from them. To try and eliminate the first aspect as far as possible, the questionnaire was very structured with specific prompts that were used in the same way, for all clients. This was also practised with the research assistant during training in the use of the questionnaire. For the second aspect, a thorough explanation of the purpose of the study was given at the beginning of the interview, to ensure that participants understood the importance of answering the questions truthfully.

Reliability:

Reliability describes whether results would be similar if the measurement were repeated (Joubert & Ehrlich, 2007). According to Carter et al. (2011) there are several components of reliability and the ones that could have influenced this study are instrument reliability, intra-rater reliability, inter-rater reliability and intra-subject reliability. The instrument that was used was developed from instruments used in previous studies. It had also been reviewed by four experts in the field of pressure care. Internal consistency was checked after the pilot study had been completed where the responses to individual items was evaluated (Carter et al., 2011). Data collection errors were minimised by the researcher double-checking the data.

Inter-rater reliability was addressed to some extent, during the pilot study by having the researcher and research assistant score the clients separately and then comparing answers as discussed before. The researcher carefully observed the training sessions with the research assistant to ensure consistent and accurate use of the questionnaire. The reliability of the programme was controlled by the training of the research assistant in the use of the questionnaire. The researcher and the research assistant conducted four pilot interviews together. The similarity scores for the pilot studies was 91%, 92.9%, 92.9% and 92.9% respectively. Reflection sessions were held with the research assistant after every pilot interview, to discuss the questions and any problems that may have arisen. Even with all these measurements in place, the instrument has not been tested for reliability.

Validity:

Validity of a measurement is whether the results are appropriate, meaningful and useful (Carter et al., 2011). One way to ensure face and content validity is to have measurement instruments reviewed by experts in the field (Carter et al., 2011) as was done in the current study. Criterion validity was not evaluated.

Generalisability:

As the study was conducted at a state-funded, government hospital, the results could be transferable to other clients at the WCRC. It could also be transferable to other tertiary institutions in South Africa, depending on the context.

3.11. Ethical considerations

3.11.1. Collaborative partnerships and permission (SUN, 2011)

The study was approved and registered with the University of Stellenbosch Faculty of Medicine and Health Sciences, Human Research Ethics Committee (S14/10/213). Permission to perform the study was applied for and received from:

- The Department of Health's Provincial Health Research Committee (PHRC).
- The research co-ordinators for Cape Town City Health and the Department of Health of the Provincial Government Western Cape (PGWC).
- The CEO of the WCRC.

3.11.2. Autonomy

According to Joubert and Ehrlich (2007), autonomy takes into account the fact that participants or individuals should be seen as having their own free will and the fact that participants with decreased autonomy, need to be protected. Vulnerable clients such as minors and clients with severe cognitive/intellectual deficits, were excluded from the study. Autonomy was further addressed through informed consent and confidentiality (Carter et al., 2011; Joubert & Ehrlich, 2007).

Informed Consent:

According to Carter et al. (2011), informed consent depends on disclosure, comprehension, voluntariness and competence. The purpose of the study, the participants' role in it and how the information could be used in the future, were fully explained to participants. Time commitments were also disclosed by explaining to the client how long the questionnaire would take to complete. Comprehension was ensured by making sure all the information was presented in lay language. The informed consent and information leaflet was available in English, Xhosa and Afrikaans. The clients all signed the English version of the informed consent form to enable the researcher and research assistant to complete the forms with the clients, but the translated versions were always available and offered to participants when requested. Participants were allowed ample time to ask questions. Voluntariness was guaranteed by ensuring no participant was coerced into taking part in the study. It was also explained that refusal to take part in the study would in no manner negatively affect any future treatment of the client at the Rehabilitation Centre.

Confidentiality:

No information that could be used to identify individual participants was used on the questionnaires, spreadsheet or during dissemination of findings. The researcher assigned numbers to the participants and only those particular numbers were used. A list of participants' names and assigned numbers is kept in a password protected electronic file. Only the researcher has access to this file.

3.11.3. Beneficence

The study may benefit the participants and the institution in the following ways:

- **The study participants:**
  The participants will be given the correct information on pressure care and pressure-ulcer prevention after the study is completed. This could directly benefit them as it may assist them in preventing the development of pressure ulcers. After a more structured programme on PU prevention has been developed at the WCRC, the participants will also be invited to attend

training sessions. Completing the questionnaire may have raised the participants' awareness of pressure care that could lead to a higher alertness regarding this issue.

- **The institution:**
  The WCRC will get information on clients' knowledge, practices and beliefs regarding pressure care that in turn could assist with the development of a more structured, targeted training programme in pressure-ulcer prevention.

3.11.4. Non-maleficence

Non-maleficence refers to doing no harm (Carter et al., 2011). One of the risks for participants in this study is social risk where participant's information could become public knowledge. This risk is combatted by ensuring confidentiality. The other possible risk for participants was psychological risk. Participants could become agitated because they may feel that they do not possess the knowledge that they need for effective pressure care. The researcher attempted to combat this problem by assuring the participants that they would receive information regarding pressure care once the study is complete. Every effort was also made to ensure that participants understood the purpose of the study. This would determine that the participants understood that the questionnaire's purpose was not to test them specifically, but to gather information on the possible (if any) gaps in knowledge and understanding.

3.11.5. Justice

According to Joubert and Ehrlich (2007), justice refers to equality, equity and making sure that the benefits and burdens of research are distributed fairly. No person was excluded based on race, gender, educational level or language spoken. According to Joubert and Ehrlich (2007), equity is giving according to need. By doing this study at a state-run hospital where many clients may have fewer resources than at a private rehabilitation hospital, the issue of equity may be more effectively addressed as the need for the information may be greater at such a facility. However, this particular hospital is quite well resourced and is in an urban area where resources are more accessible than in rural areas.

3.11.6. Publication integrity (Ezekiel, Wendler, Killen & Grady, 2004)

Every endeavour has been made to ensure that results are reported correctly. This was also achieved with the assistance of the Biostatistics Department. All contributions towards, and assistance with the study was acknowledged. The researcher has signed the plagiarism declaration and will adhere to it.

3.12. Summary

A quantitative descriptive survey design was used. Seventy-one consecutively sampled persons with SCI participated in the study. Data was collected by the researcher and a research assistant through a questionnaire based on existing tools that was developed by the researcher. Descriptive and inferential analysis of data was done. Ethical clearance and permission were obtained before commencement with the study. Informed consent was obtained and participants were ensured that all information would be treated as confidential.

Chapter 4: Results

4.1. Introduction

The chapter starts by introducing the participants to the reader by describing demographic and medical information. Thereafter, the participants' knowledge, beliefs, practices and skills regarding the prevention of PUs are described. In some instances, the relationship between variables was analysed. The findings from that inferential analysis are presented in the final section of the chapter.

4.2. Demographic information

The majority of the participants were 40 years old or younger (Figure 4.1).

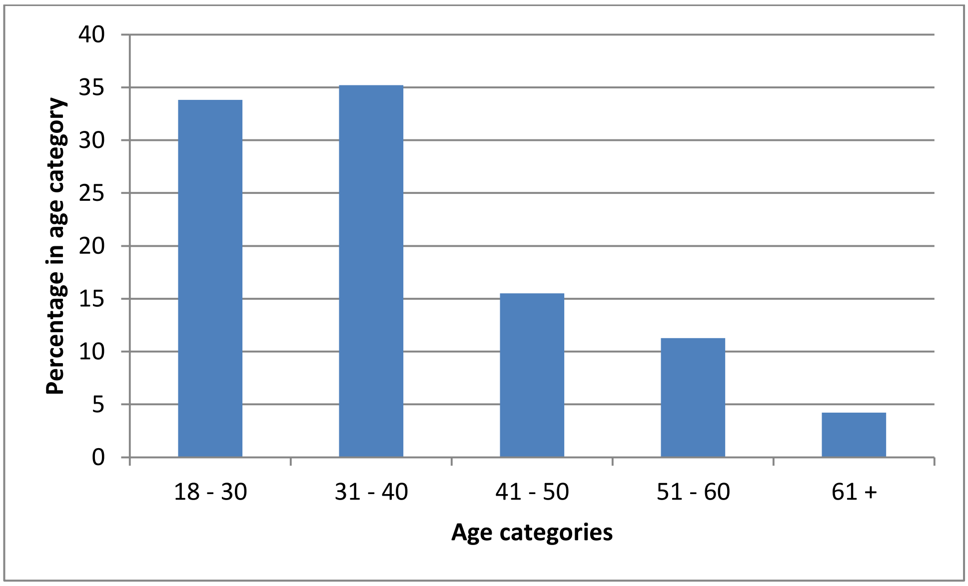

Figure 4.1 Age distribution of participants

The descriptive statistics on age in table 4.1 shows that the mean age was 36.3 (SD=12.3) and the median 35. In-patients and peer supporters were on average, slightly younger than out-patients.

Table 4.1 Descriptive statistics for participants' age

	Mean	SD	Min	Max	Median	1st quart	3rd quart
Overall	36.3	12.3	18	70	35	28	45
In patient	32	11	18	56	31.5	21	37.5
Out patient	40.5	13	21	70	37	29	51
Peer supporters	34.8	8.4	24	49	31.5	28	42

According to Table 4.2, the majority of participants, overall and in all three subgroups, were males. None of the peer supporters was female.

Table 4.2 Demographic information of participants in percentages (numbers in brackets are actual number of participants)

	Total (71)	In-patients (30)	Out-patients (33)	Peer supporters (8)
Mean age	36.3	32	40.5	34.8
Males	86 (61)	76.7 (23)	90.9 (30)	100 (8)
Females	14 (10)	23.3 (7)	9.1 (3)	0 (0)
Race				
Coloured	53 (38)	40 (12)	67 (22)	50 (4)
Black	44 (31)	60 (18)	30.3 (10)	37.5 (3)
White	3 (2)	0 (0)	3 (1)	13 (1)
Formal education				
No or primary school education	14 (10)	17 (5)	15 (5)	0 (0)
Some high school education	55 (39)	57 (17)	55 (18)	50 (4)
Completed high school	23 (16)	13 (4)	30 (10)	25 (2)
Tertiary education	8 (6)	13 (4)	0 (0)	25 (2)
Marriage				
Never married	59 (42)	73 (22)	43 (14)	75 (6)
Married or lives with a partner	27 (19)	20 (6)	33 (11)	25 (2)
Divorced or widowed	14 (10)	7 (2)	24 (8)	0 (0)
Employment				
Unemployed	77 (55)	80 (24)	78.8 (26)	62.5 (5)

Table 4.2 also shows that more than 90% of participants were either from coloured (53%) or black descent (44%). There were no participants of Asian descent. The majority of participants had some high school education (55%) and were unemployed (77%). The percentages of participants who were unemployed were very similar for in-patients (80%) and out-patients (78.8%) patients and slightly lower for peer supporters (62.5%) as shown in Table 4.2. If being self-employed, being part-time employed or being a pensioner, is considered as being employed, then 77% (55) of the total participant sample was unemployed.

4.3. Medical information

Time since injury varied significantly between participants with a range of less than six months to more than 10 years. Figure 4.2 shows that the majority of in-patients had been injured less than six months before, at the time of data collection, while most of the peer supporters had been injured five years or longer prior to the research.

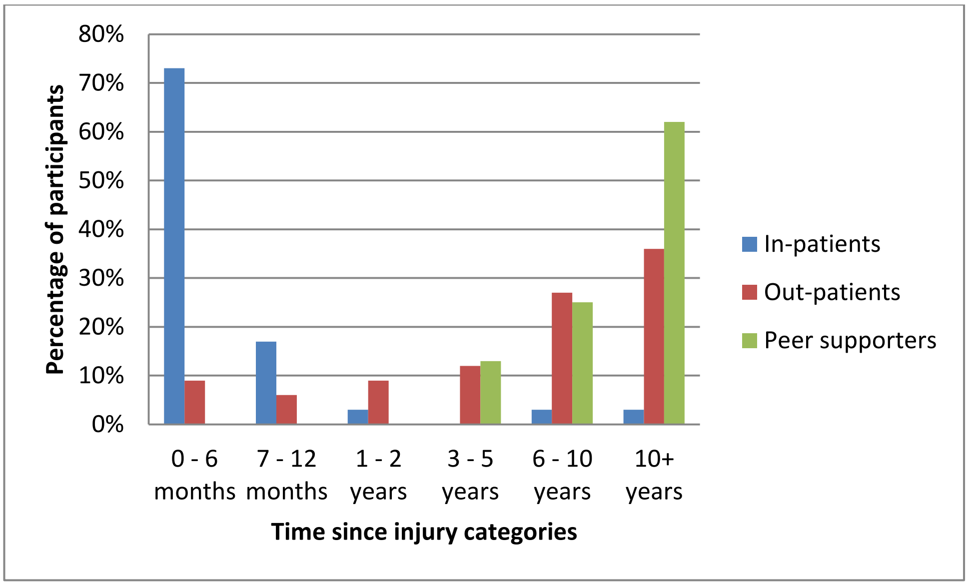

Figure 4.2 Time since injury

The majority of participants (89%) suffered traumatic injuries below the level of T1 (paraplegia) (76%). These trends were also clear in all three sub-groups as shown in table 4.3.

Table 4.3 Participant's medical information in percentages (numbers in brackets are actual number of participants)

	Total (71)	In-patients (30)	Out-patients (33)	Peer supporters (8)
Traumatic injuries	89 (63)	87 (26)	88 (29)	100 (8)
Non-traumatic injuries	11 (8)	13 (4)	12 (4)	0 (0)
Paraplegic level	76 (54)	70 (21)	85 (28)	62 (5)
Quadriplegic level	24 (17)	30 (9)	15 (5)	38 (3)
No history of pressure ulcer	57 (40)	70 (21)	45 (15)	50 (4)

According to Figure 4.3, 57% of participants never had a pressure ulcer, while 4% had continuous problems with pressure ulcers. Table 4.3 shows that more out-patients (55%) than in-patients (30%) or peer supporters (50%) had pressure ulcers.

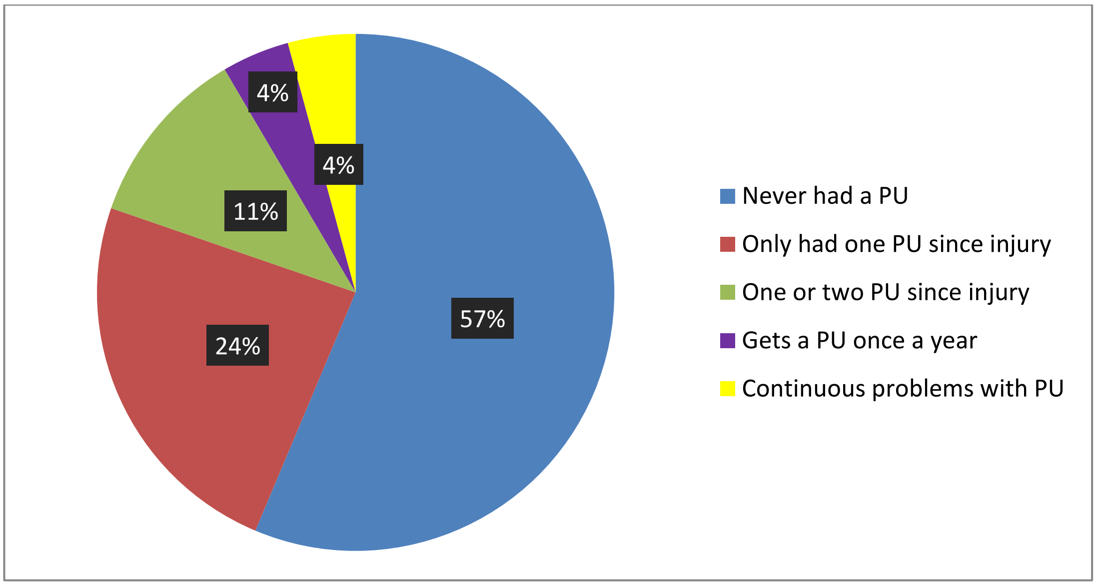

Figure 4.3 Pressure-ulcer history of participants

4.4. Knowledge

The mean knowledge score for all three sub-groups together was 23,9 out of a possible 56 (42,7%) with a standard deviation of 7,8 and a 95% confidence interval of 1,8. With regard to the three sub-groups in-patients had a mean score of 40.4%, out-patients 39.4% and peer supporters 65.2% (Table 4.4).

Table 4.4 Descriptive statistics of participants' knowledge scores

	N	**Mean**	**SD**	**Min**	**Max**	**Median**	**1st Quant**	**3rd Quant**
Overall	71	42.7	7.8	17.9	80.4	41.1	34.8	51.8
In-patients	30	40.4	10.6	17.9	57.1	41	37.5	44.6
Out-patients	33	39.4	12	19.6	64.3	39.3	31.3	50
Peer supporters	8	65.2	12.9	44.6	80.4	67.9	54.5	75.9

The aspects that created the greatest challenges according to average scores (Table 4.5), were knowledge about the risk factors of PU, the stages of a PU, knowledge about weight shift, nutrition, prevention of burn injuries and the time it takes for a PU to develop. Table 4.5 also shows that fewer than 20% of participants scored 100% for causes, risk factors, nutritional support, cushion care and prevention practices. Similarly, less than 20% of participants had 100% knowledge about the stages of a PU. Knowledge about the type of cushion and when to replace it, showed high average scores with a high percentage of participants achieving 100%, but scores for cushion care were much lower. Table 4.5 shows that peer supporters achieved the highest scores in all the knowledge categories.

Table 4.5 A summary of overall and sub-group knowledge scores

	No of participants achieving 100% per category	Average overall scores	In-patients	Out-patients	Peer Supporters
Causes of PU	14.1	59.2	52	59	88
Risk factors for PU	1.4	23.4	19	20	55
Risk areas for PU	21.1	60.8	61	56	83
Time to PU development	5.6	5.6	7	0	25
First sign of a PU	62	62	67	52	88
Action on noticing first sign	71.8	71.8	60	79	88
Number of stages of PU	10	10	0	9	50
Description of stages of PU	11.3	23.9	23	16	63
Prevention practices	10	51.3	44	52	75
Number of skin checks daily	66.2	66.2	70	58	88
Frequency and duration of weight shift	28.2	28.2	37	18	38
Nutrition to prevent PU	0	19.9	9	10	22
Type and age of wheelchair cushion	77.5	87.3	83 (n=27)	88	100
Cushion care	14.1	35.9	37	32	50
When to replace cushion	60.6	60	57	53	100
Weight shifts on a speciality cushion	69	69	67	67	88
Burn wound prevention	1.4	27.5	24	27	44
Management of incontinence	32.4	57.7	55	53	88
Can PU recur	85.9	85.9	80	88	100
Prevention of PU recurrence	42.3	60	62	50	94
Total		23.9			

4.4.1. Causes of PUs

As shown in Figure 4.4, 80% of participants knew that not turning at night could cause pressure ulcers, while 65% knew that sitting too long could cause pressure ulcers. The two causes most participants did not mention were shear and/or friction forces and trauma. Figure 4.4 further shows that 53% of in-patients were not aware that sitting too long causes PU, while all peer supporters were aware of that fact.

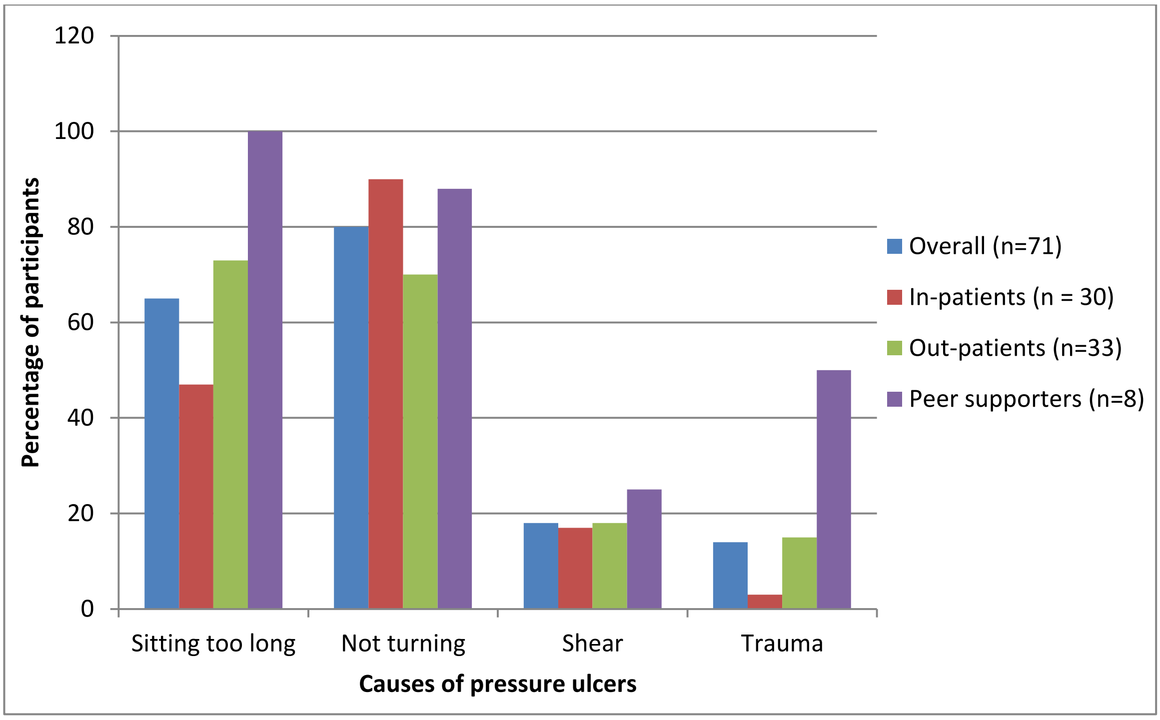

Figure 4.4 Knowledge about the causes of pressure ulcers

4.4.2. PU risk factors

Average scores for PU risk factors were low and 36.6% of participants scored 0 for this question, meaning that 63.4% had named at least one correct risk factor. Figure 4.5 shows that peer supporters, in general, had more knowledge about the various risk factors. Less than 10% of participants said that tight clothes, not using a wheelchair cushion, burning themselves, having had previous pressure ulcers, being over or underweight and having poor health could increase their risk of developing a pressure ulcer (Figure 4.5). The other factors mentioned included alcohol abuse, poor transfers and dehydration. Half of the peer supporters mentioned alcohol abuse and two others mentioned not checking for danger when transferring.

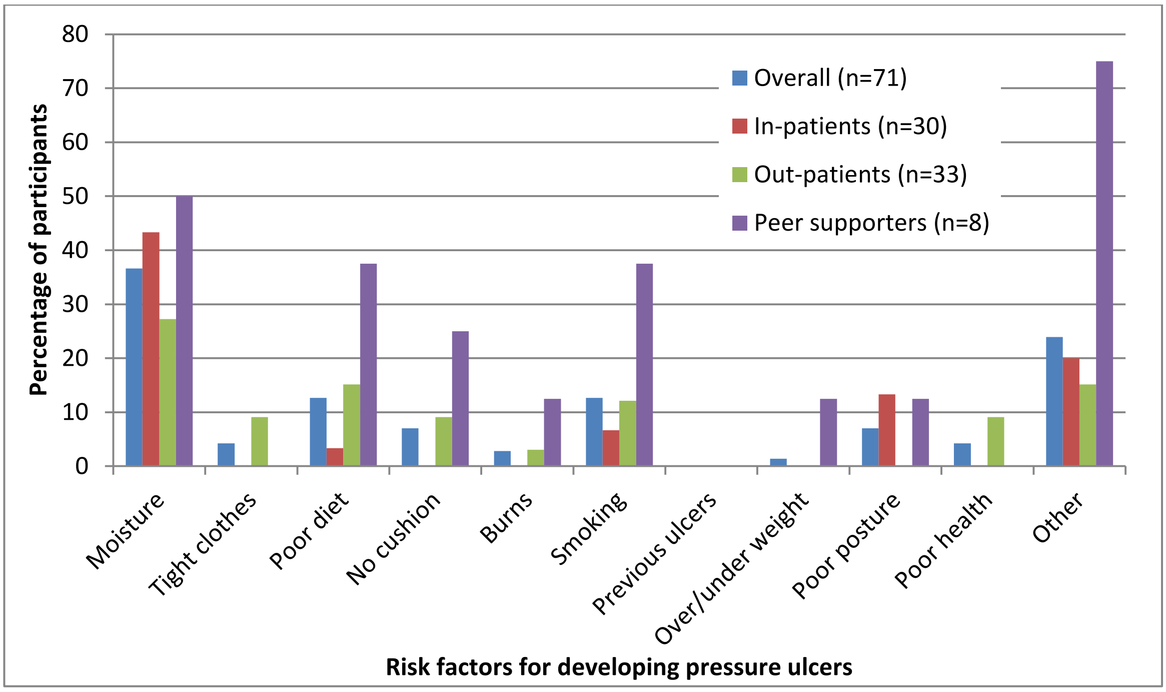

Figure 4.5 Knowledge about the risk factors of pressure ulcers

4.4.3. Areas at risk for PU development

One participant could not name any of the areas that were at risk for PUs. Figure 4.7 shows the option most often named by participants was the ischia (85%). Less than 10% of the participants said that the feet were areas at risk of developing a pressure ulcer and 31% mentioned the sacrum. Other areas mentioned included the scapulae and the back of the head.

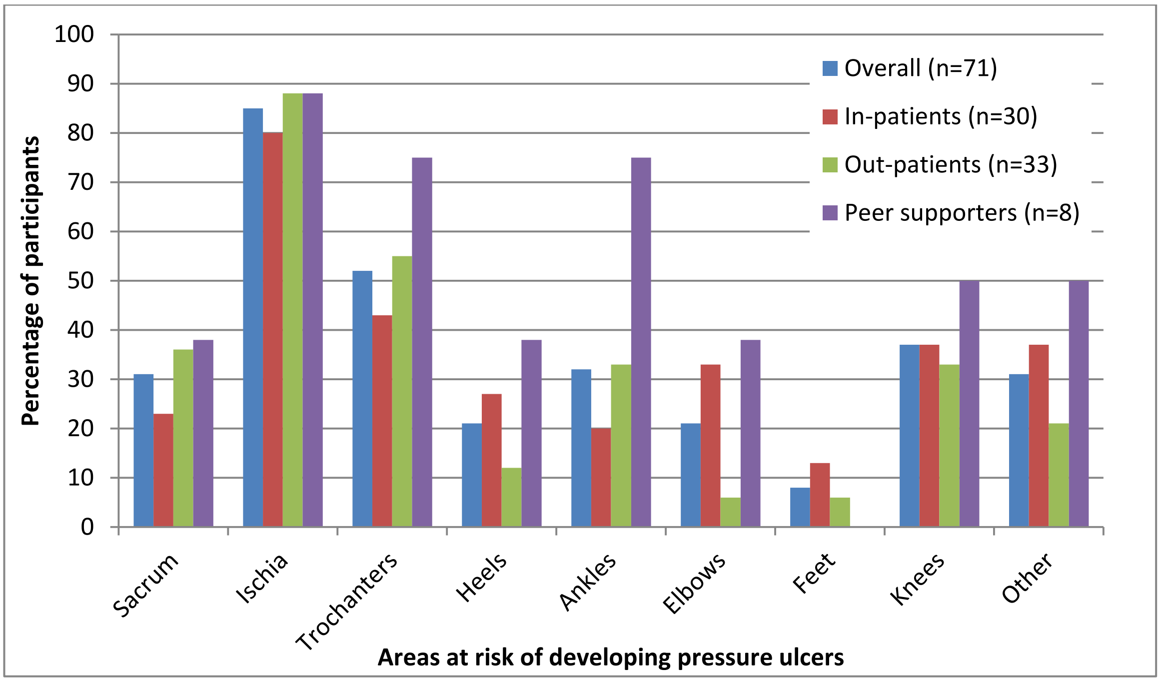

Figure 4.6 Areas at highest risk of developing pressure ulcers according to participants

4.4.4. Time to PU development

Four (5.6%) of the 71 participants knew that it takes between half an hour to an hour of unrelieved pressure for a pressure ulcer to start. Twenty-six (36.6%) of participants said that they did not know, while 41 (57.7%) answered the question incorrectly. Wrong answers ranged from 3 hours to 6 months with 24 to 48 hours the most frequently given time frame with 17 (23.9%) participants saying 24 to 48 hours.

4.4.5. Stages of PUs

Of the 71 participants, eight knew that a PU has four stages, while seven said there were two and three stages and one participant said there was only one stage. Forty-eight participants could not answer the question. Thirty percent could describe stage one signs correctly, while 27%, 25% and 15% could respectively describe stage 2, 3 and 4 signs correctly.

4.4.6. Prevention practices

Two-point-eight percent of participants (2.8%) could not identify any preventative measures, while 51% scored 100% in this question (i.e. they could identify five preventative measures correctly).Figure 4.6 shows that weight shift (pressure relief while sitting) and turning in bed were the preventative measures named most frequently, while preventing burn injuries and using a special mattress were mentioned least often. Overall, peer supporters showed a better knowledge of preventive practices than the other two groups. Other preventive practices mentioned by participants, included being careful to not injure the legs when transferring, staying fit and active, to always wear shoes and to use cushions for positioning in bed.

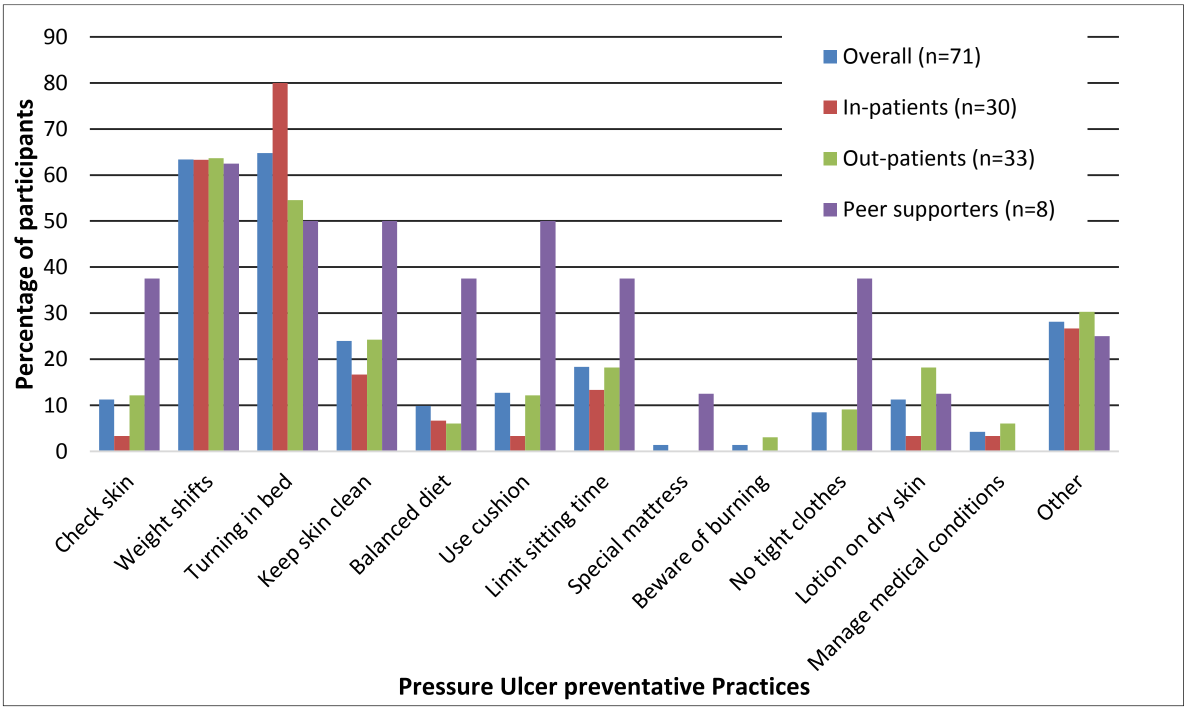

Figure 4.7 Knowledge on pressure-ulcer prevention practices

4.4.7. Nutrition

None of the participants achieved a score of 100% for the question on nutrition and the types of food that are needed to build muscles and protect the skin. This question scored an average of 10,9%. Figure 4.8 shows that fish/meat and dairy products were named most often. During data analysis it was found that 77% (55) of the participants named fruit and vegetables. This answer would have been correct if the focus was on general nutrition, but the question specifically asked information regarding nutrition for building muscle and strengthening skin.

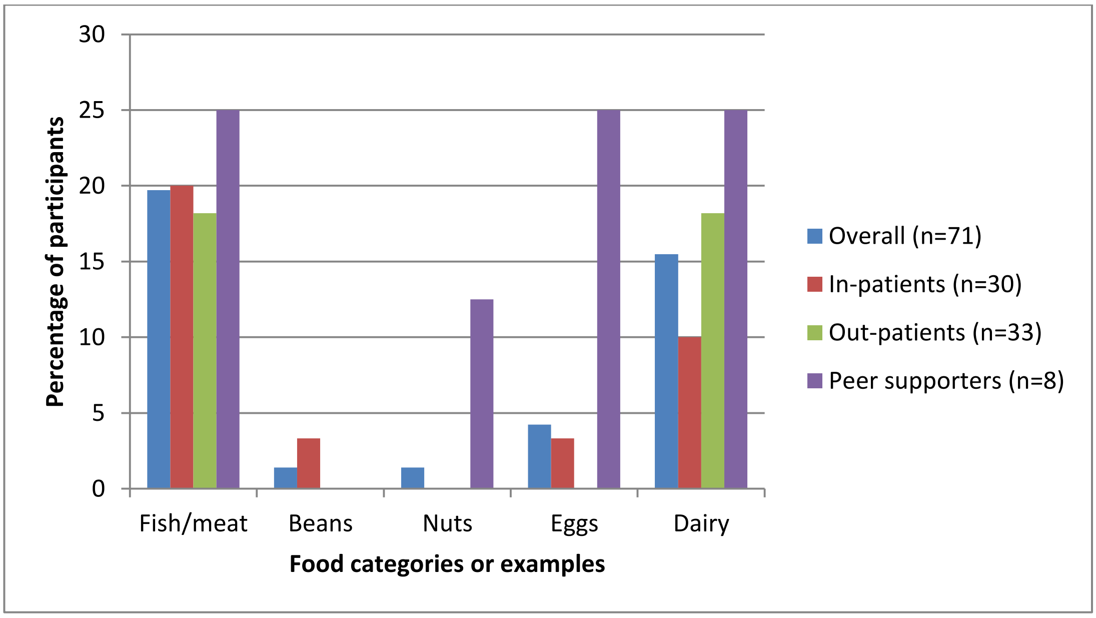

Figure 4.8 Participants' knowledge on food categories that build muscles and protect skin

4.4.8. Cushion use and care

Figure 4.9 shows that foam cushions (75%) were most commonly used. Of the participants using foam cushions, 30% were using a cushion that was older than one year. Two (2.8%) of the clients did not know what type of cushion they were using and 6 (8.5%) did not know how old their cushion was.

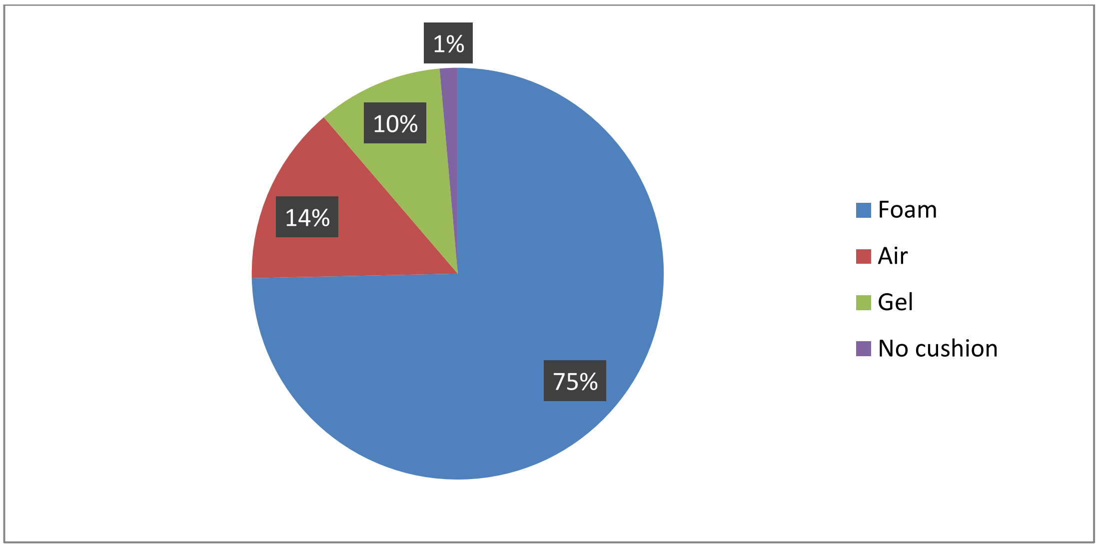

Figure 4.9 Type of cushion used by participants (N=69)

Participants showed little knowledge regarding the care of the various cushions. With regard to foam cushions, washing the cover was the care action most frequently mentioned (26%) and no participants mentioned not leaving the cushion in the sun (Figure 4.10). Of the 53 participants using foam cushions, only 31 (58%) knew that if the cushion bottomed out, it needed to be replaced. None of the participants knew about the finger-pressure test.

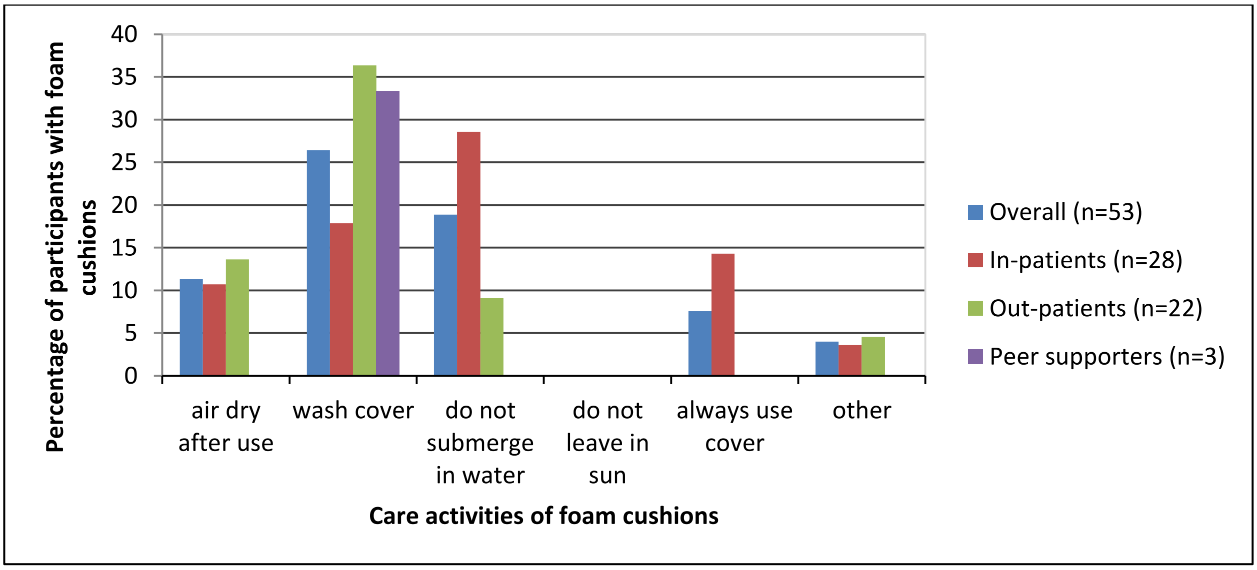

Figure 4.10 Knowledge about foam cushion care (N=53)

Of the ten participants using air-filled cushions, seven knew that if the cushion could not be inflated properly, it needs replacing and only one reported that the loss of air was a problem (Figure 4.11). One of the two in-patients using these cushions knew not to leave the cushion in the sun.

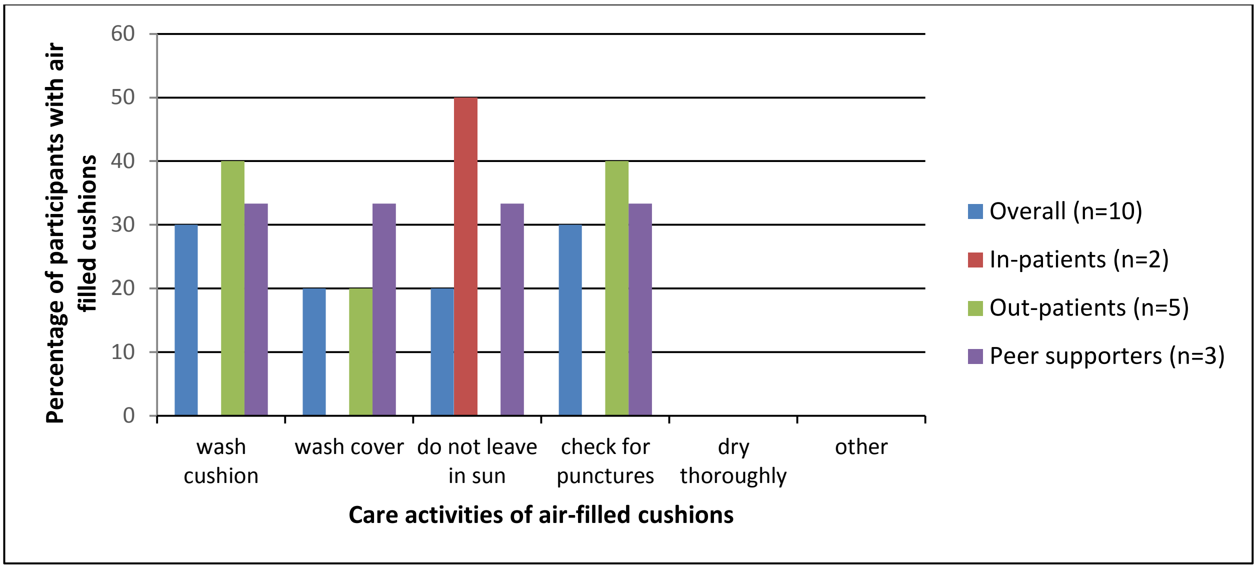

Figure 4.11 Knowledge on air-filled cushion care (N=10)

Two of the seven participants using gel-filled cushions reported that if gel leaked out, the cushion needed to be replaced and only one knew that if the gel could not be repositioned anymore, the cushion also needed to be replaced (figure 4.12). Of the five out-patients using gel-filled cushions, none could mention any of the recommended care activities, but two mentioned the importance of repositioning the gel at the end of each day under “other”. One of the peer supporters using a gel-filled cushion could name two of the recommended care activities. No-one reported that it was important to wash the cover or to dry the cushion thoroughly after washing it.

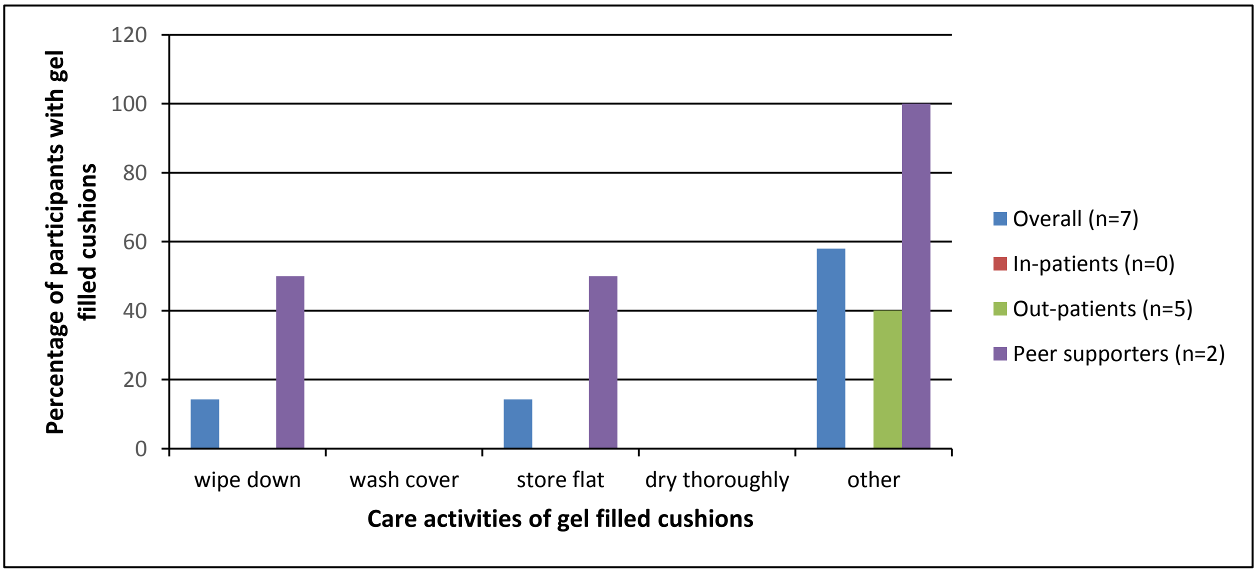

Figure 4.12 Knowledge on gel-filled cushion care (N=7)

4.4.9. Prevention of burns

As shown in table 4.5, many participants were not aware that burns could cause pressure ulcers. This might be because they saw a burn as something different from a pressure wound. The result and management of a burn on skin with no sensation are, however similar to that of a pressure ulcer. The low scores in figure 4.13 indicate that participants did not have enough knowledge of the danger of heaters, hot bathwater, hot surfaces and sun-tanning.

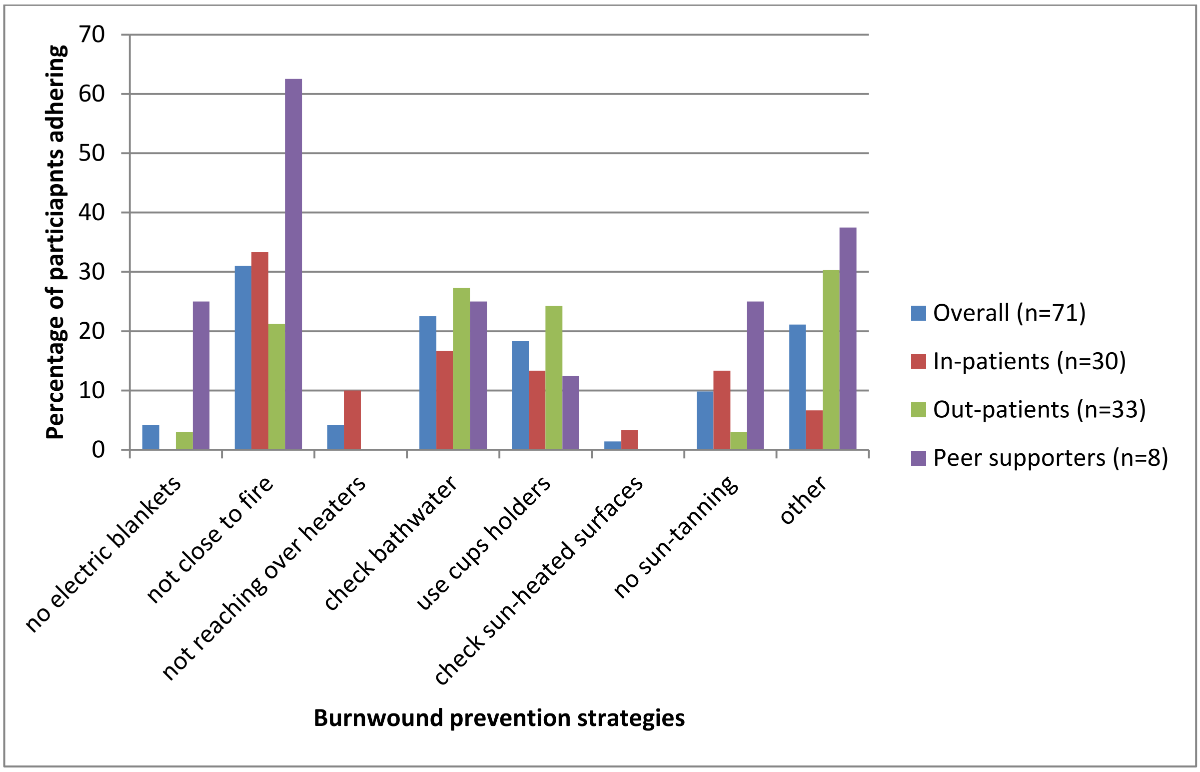

Figure 4.13 Participants knowledge of strategies to prevent burns

4.4.10. Incontinence

Even though 32% of the 71 participants scored 100% with regard to incontinence-related PU prevention strategies, 36 (50%) of the participants could name only one of these strategies (see Figure 4.14). Peer supporters had the highest average score (88%), with in-patients and out-patients scoring 55% and 53%, respectively.

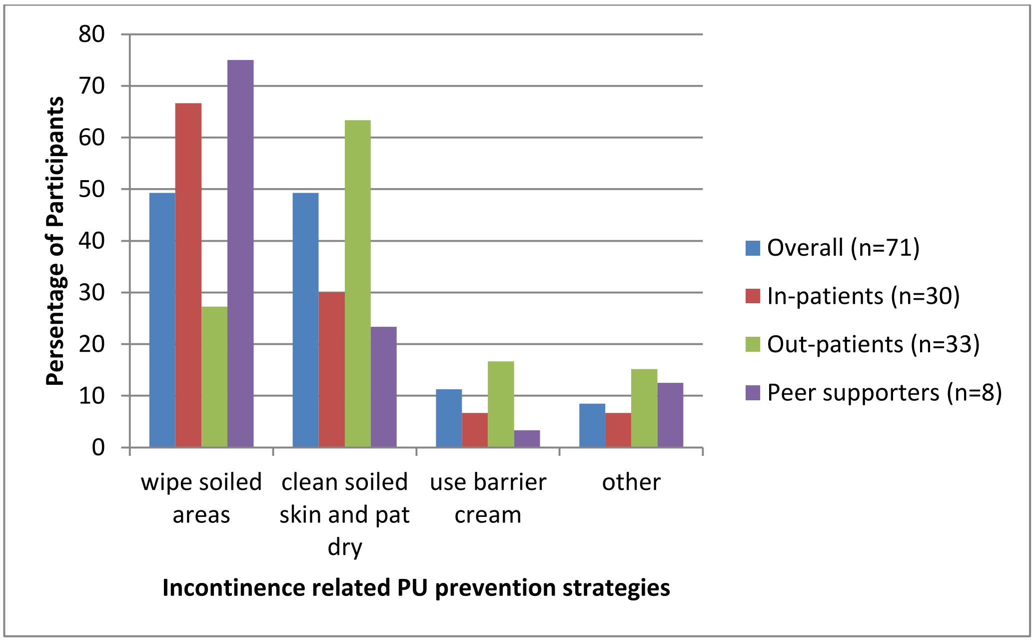

Figure 4.14 Participants' knowledge of incontinence-related strategies to prevent PU

4.4.11. Strategies to prevent recurrence of PUs

The majority of participants (85.9%) knew that pressure ulcers could recur and the overall average score for knowledge about the prevention of recurrence was 60%. However, Figure 4.15 shows that few, if any, participants knew that the correct diet, maintaining overall health and regular exercise could assist in preventing the recurrence of pressure ulcers. Of the participants, 85.9% knew that pressure ulcers could recur.

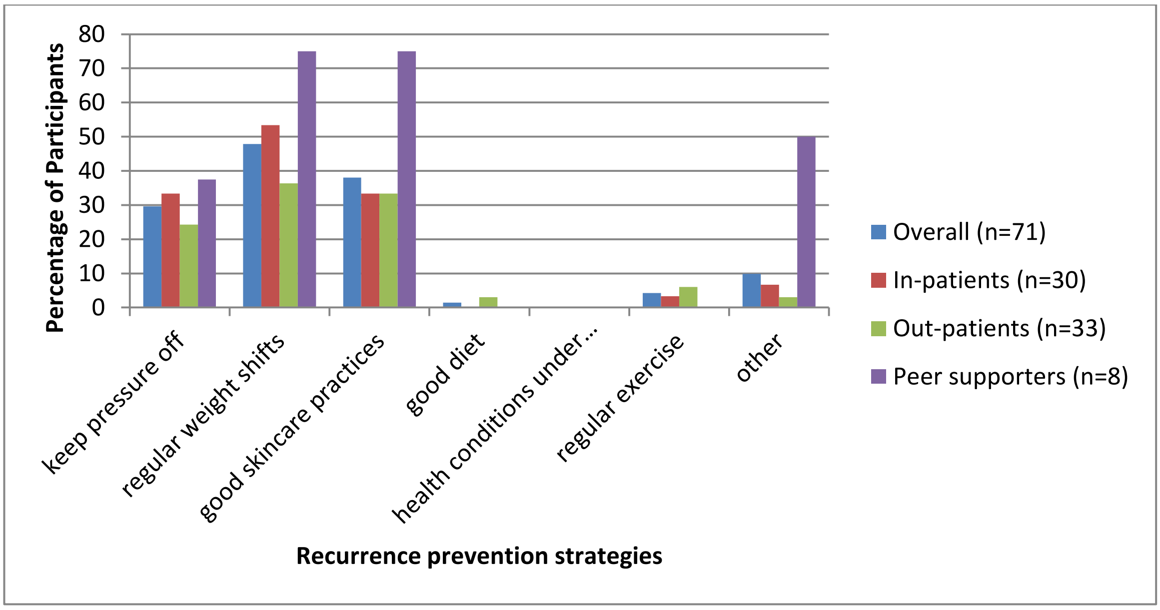

Figure 4.15 Participants' knowledge of strategies to prevent recurrence of pressure ulcers

4.5. Beliefs

The beliefs section of the questionnaire can be divided into four main categories of beliefs. These are beliefs on the seriousness of PUs, the prevention of PUs, the benefits of prevention and the barriers to preventative skin-care practices.

4.5.1. Seriousness of PUs

Participants believed that pressure ulcers are a serious condition with 88.7% saying that it is serious or life-threatening. This was true across all three groups with 100% of peer supporters, 90% of in-patients and 84% of out-patients expressing the same belief. Similarly, the majority (73.2%) felt a PU would have a great impact on their daily activities. While 53% of in-patients believed a PU will interfere a lot with their daily activities, over 85% of out-patients and peer supporters held that belief. There was more dissention in the findings on whether participants believed they were likely to develop a PU, with 45% regarding it as a fairly, or very likely occurrence and 39.4% believing that it was unlikely to occur. With regard to out-patients and peer supporters, 30.3% of out-patients, 37.5% of peer supporters saw themselves as very likely and not likely, to develop a PU. A higher percentage of in-patients (40%) saw themselves as not likely to develop a pressure ulcer than the 23.3% who saw it as very likely.

Participants across all three groups agreed that PUs in stages three and four were more difficult to treat than in stages one and two, with 55% believing PUs are easy to treat in the beginning stages and 8.5% believing it is easy to treat PUs in the later stages. A similar number (8.5%) believed PUs could not be treated in the later stages.

4.5.2. Prevention of PUs

With regard to the prevention of PUs 60.6% of participants believed they were able to completely prevent pressure ulcers. On the other hand, 4.2% believed they could not prevent PUs and 35.2% believed they had some control over the prevention of PUs (figure 4.16). The majority of participants believed that daily skin checks (80.3%), weight shifting (86%) and limiting sitting time (80.3%) could make a difference to whether or not one developed a PU. Most of the in-patients (80%) and the out-patients (76%) and all of the peer supporters believed daily skin checks could make a difference. Of the in-patients 80% said weight shifts made a difference, 88% of the out-patients and all of the peer supporters agreed. In addition, 78.8% of participants believed that using a wheelchair cushion made a lot of difference to whether or not one developed a PU.

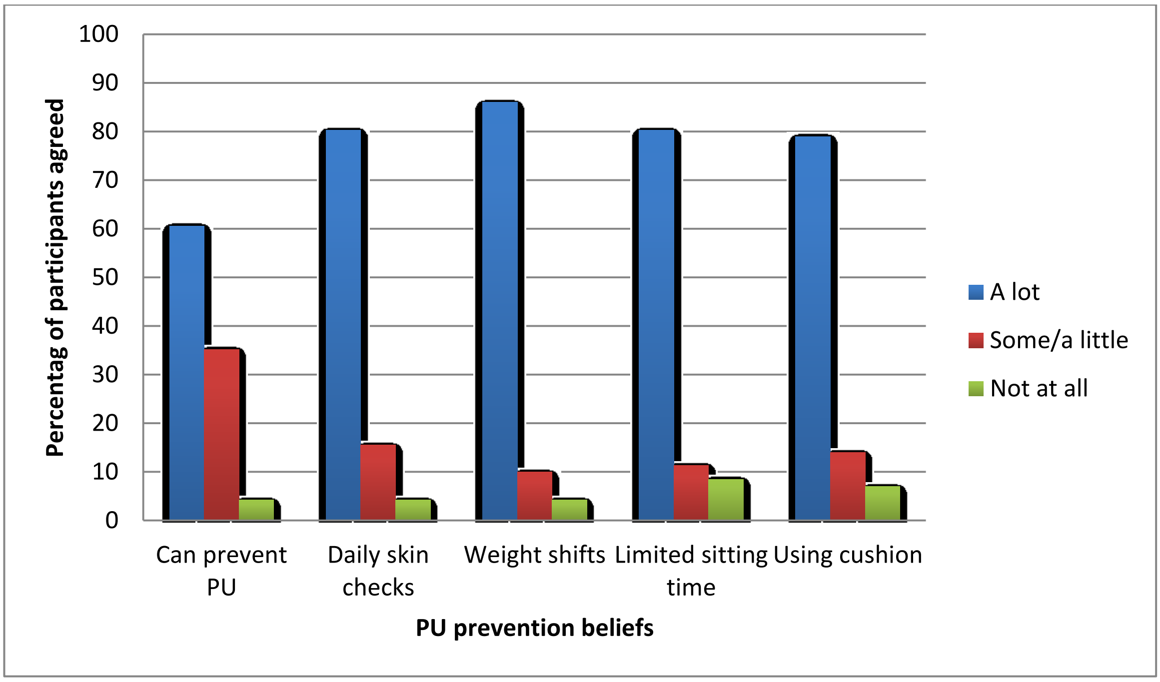

Figure 4.16 Beliefs on prevention of pressure ulcers

4.5.3. Benefits of prevention

Figure 4.17 shows that participants believed skin care have many benefits of which the prevention of PUs, feeling better physically and the satisfaction of caring well for oneself, scored the highest.

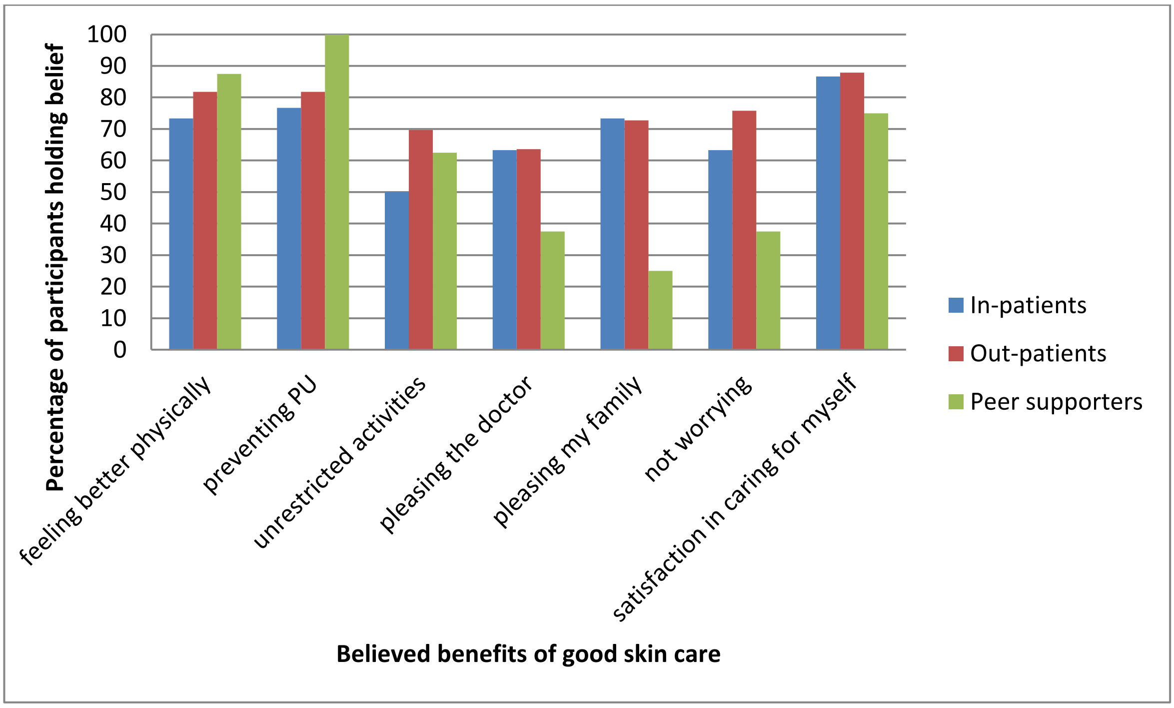

Figure 4.17 Believed benefits of good skin care

4.5.4. Barriers to prevention

Of the participants, 65% (46) reported that it was not difficult to follow good skin-care practices, meaning that 35% (25) believed it was difficult to some degree. Of the in-patients 60% (18) reported that skin-care was not difficult, 73% (24) of out-patients reported that skin-care was not difficult and 50% (4) of the peer supporters reported that it was not difficult. Those who believed that it was difficult to follow good skin care practices list the reasons shown in figure 4.18. No participants felt that skin-care was unpleasant or unsafe.

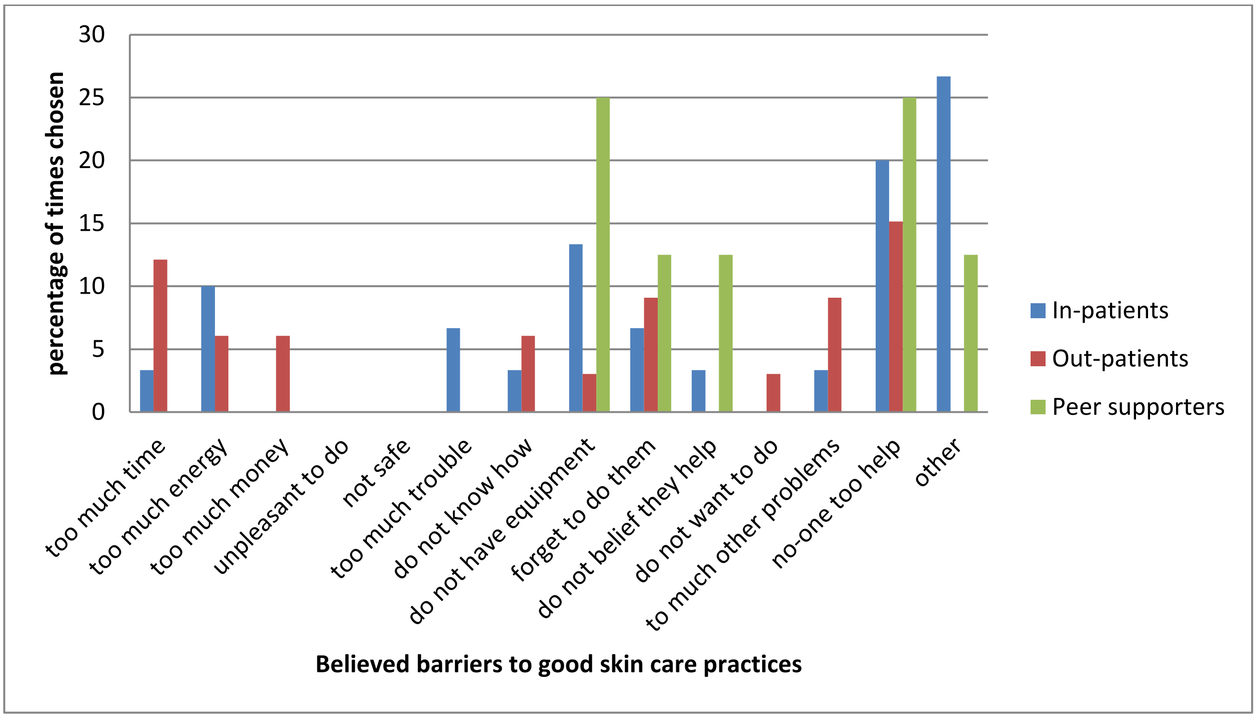

Figure 4.18 Believed barriers to good skin-care practices

4.6. Practices

Figure 4.19 shows the percentage of reported compliance with recommended practices. Reported compliance was determined by collating the number of participants who had chosen the correct answer for each question in the practice section of the questionnaire. The recommended practice that showed the lowest percentage of reported compliance overall, was performing pressure relief (49%). From Figure 4.19 it was clear that the pressure-relief practice only indicated low compliance amongst in-patients and out-patients as the peer supporters reported an 88% compliance. The peer supporters did, however, score lower in three categories than the in-patients and out-patients namely the reported alcohol use, drug use and the last skin inspection.

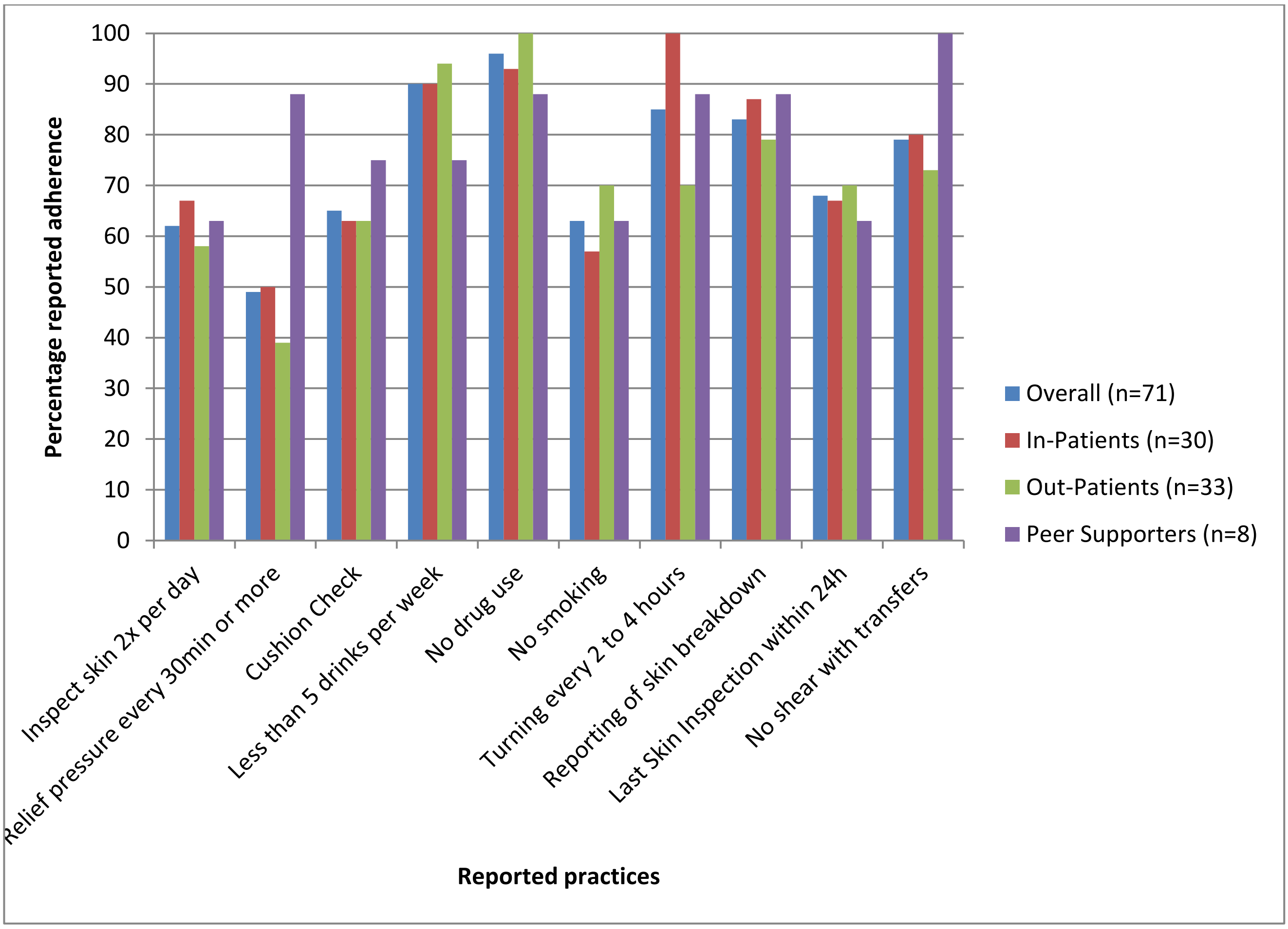

Figure 4.19 Reported compliance with recommended skin-care guidelines

4.7. Skills

Figure 4.20 shows the scores for the skills tests. The pressure relief (weight shifts) technique scored the lowest for all three sub-groups with peer supporters scoring the lowest. Five of the peer supporters did not maintain pressure relief long enough. Of the in-patients, nine did not maintain pressure relief long enough, while 15 of the out-patients did not maintain pressure relief long enough.

Table 4.6 Skills Test scores

	In-patients	Out-patients	Peer supporters
Correct use of cushion	93 (28)	85 (28)	100 (8)
Right side up	97 (29)	89 (29)	100 (8)
Right way around	97 (29)	91 (30)	100 (8)
Transfers	77 (23)	45 (15)	75 (6)
Safe	87 (26)	94 (31)	88 (7)
No shear or drag	77(23)	45 (15)	75 (6)
Pressure relief	70 (21)	52 (17)	63 (5)

Adequate relief	90 (27)	89 (29)	100 (8)
Adequate length	70 (21)	55 (18)	63 (5)

Shear often occurred when participants performed the transfer during the skills test. For the out-patients, who scored the lowest in the safe transfer test, 18 of the 33 out-patients did not transfer without experiencing shearing.

4.8. Inferential analysis

Inferential statistics showed that most of the variables did not have a statistically significant relationship. An increase in time since injury did have a significant impact on the belief that PUs would interfere with ADL, and increased knowledge scores impacted significantly on correct pressure-relief practices.

Table 4.7 Inferential statistics (Statistically significant P-values highlighted)

	P-value
Time since injury vs how serious a PU is believed to be	0.722
Time since injury vs how likely to get a PU	1.000
Time since injury vs how much a PU would interfere with ADLs	0.024
Time since injury vs percentage total skills test score	
PU history vs degree to which a PU can be prevented	0.577
PU history vs age	0.606
PU history vs gender	0.068
PU history vs race	0.605
PU history vs education level	0.205
PU history vs marital state	1.000
PU history vs employment status	0.775
PU history vs time since injury	0.229
Frequency of skin inspection vs PU history	0.807
Reported correctly-performed pressure relief vs PU history	0.813
Reported smoking vs PU history	0.322
Safe transfer skill vs PU history	0.329
Correct pressure-relief skill vs PU history	0.468
Knowledge on pressure relief vs reported pressure relief	0.001
Knowledge on pressure relief vs pressure-relief skill time component	0.292

Education level vs percentage knowledge score	0.272
Time since injury vs percentage knowledge score	0.197

4.9. Summary

The results show that most of the participants in this study fell within the 18-to-40-year age group with a mean age of 36. Of the participants, 86% were male, 77% were unemployed, only 31% had finished school and 73% did not have an intimate partner. With regard to their medical information, 89% had suffered traumatic injuries, 76% had a paraplegic level of injury and 57% had never had a pressure ulcer.

The average knowledge score for the whole group of participants, was 42.7% with out-patients scoring the lowest (39.4%), in-patients scoring only slightly better (40.4%) and peer supporters scoring the highest (65.2%). Of the participants, 88.7% believed PUs to be very serious or life-threatening and 60.6% of participants believed that they would be able to prevent a PU from developing. Preventing PUs and feeling better physically were the benefits of good skin-care practices most often chosen, while the barriers most often chosen were not having the correct equipment, not having someone to help and forgetting to do the practices.

Pressure relief was the recommended skin-care practice with the lowest reported compliance. The practice in which the in-patients scored the lowest was not smoking and the out-patients scored the lowest in reporting the PU to a medical professional. The skills test that had the lowest overall score was the pressure-relief technique with the peer supporters scoring the lowest for this skills test. The timing component of this test scored the lowest, with 59% of participants not doing the pressure relief for long enough.

Chapter 5: Discussion

5.1. Introduction

In this chapter, the findings of the study will be discussed. Reference will be made to literature, where applicable. Firstly, the demographic and medical information of the participants are discussed. In the second section the knowledge, beliefs, practices and skills of the participants, regarding the prevention of PUs as well as the correlations between the different aspects of the study, are discussed.

5.2. Demographic information

The mean age of current study participants (36,3 years) is slightly higher than the mean ages found in previous studies conducted in South Africa and internationally. In recent international studies two peak age categories were found with one peak being around the 15-to-29-years age group and another being after the age of 65 (Van den Berg et al., 2010). Maclachlan (2012) recorded the peak age of participants in a study that explored participation and activity profiles of persons with spinal-cord injuries living in the Cape Town metropole area, to be 20 to 29 years (median = 29). Similarly, Sothmann et al. (2015) found that SCI occurred most commonly between the ages of 20 and 40 years (mean = 34) in the same setting. It is important to note, though, that the age of onset was not measured in the current study, but only the age at the time of the study, a difference that may account for the differences between findings in the current study and other studies. Excluding participants younger than 18 years may also have had an impact on the overall mean age.

The mean age (32 years) of the in-patient participants was lower than the other two population groups. This might be due to the in-patient participant group, on average had a shorter time since injury than the other two groups. Their mean age was, thus, also closest to the age at onset of spinal-cord injury of the three participation groups. When comparing the mean age of the participants with traumatic injuries (35 years) to the mean age of the participants with non-traumatic injuries (39 years) the same trend is not evident as in international studies where there is a definite increase in age in people suffering from non-traumatic injuries (Van den Berg et al., 2010). This could be due to the fact that in African countries, non-traumatic causes are mostly as a result of TB or other infectious diseases whereas, in developed countries these causes are mainly due to tumours and degenerative illnesses (New et al., 2014).

The male to female ratio of 6.1:1 supports the trend for Africa to have a higher SCI rate amongst men (Vasiliadis, 2012) than the global trend (WHO, 2013). The much higher number of traumatic spinal-cord injuries than non-traumatic injuries could partly explain the difference in ratio between male and female. Traumatic spinal-cord injuries are often connected to risk-taking behaviour more generally associated with males (Reniers, Murphy, Lin, Para Bartolomé & Wood, 2016). Ninetytwo percent (58 of 63) of the participants with traumatic spinal-cord injuries, in the current study were male compared to 37.5% (3 of 8) of the participants with non-traumatic spinal-cord injuries.

Maclachlan (2012) reported a similar racial distribution as in the current study. Figures also correspond with overall population figures for the Western Cape which indicate that 32% of the population in this province are Black and 48,8% are Coloured (Census 2011). Census (2011) further showed that persons of Caucasian descent made up 15% of the population in the province, while only 2% of current study participants were of Caucasian descent. This difference may be due to the study being performed in a government institution that mainly provides services to persons with lower incomes.

Education levels were found to be quite low for the study population. This is not surprising, as the Department of Basic Education stated in their 2014 annual report that although 86% of children in South Africa between the ages of 16 and 18 were attending school, only 5% of them would successfully complete high school at age 18 (the expected age to do so) (Department of Basic Education, 2014). Census 2011 reported that 28.4% of South Africans had completed high school and 12.1% had successfully completed a tertiary qualification (Census 2011).

Unemployment rates are high in South Africa. In the last quarter of 2015, it was reported that 25% of all South Africans were not economically active (Quarterly Labour Force Survey, 2016). Universally, unemployment rates are high amongst people with spinal-cord injuries and even higher in developing countries, like South Africa (Maclachlan, 2012; Ganesh & Mishra, 2016). However, an unemployment rate of 77%, as found in the current study is very high. This can, potentially, be linked to the low educational levels. Dropping out of high school is linked to a much lower employment rate (Department of Basic Education, 2014). In addition, people without secondary school or tertiary education tend to be employed in manual labour which is a very difficult form of employment to return to after a spinal-cord injury due to the physical requirements of the occupation.

5.2.1. Pressure-ulcer risk and demographic variables

Although no statistically significant association was found between the participants' gender and their PU history ($p = 0.068$), there does seem to be some clinical association. Two of the ten female participants (20%) had a history of a PU. Both of them reported only having had one PU since injury. In contrast, 29 (48%) of the male participants had a history of PU. In addition, a p value of 0.068 is only marginally above the cut-off point of 0.05 and other studies have found a significant association between male gender and pressure-ulcer risk (Eslami et al., 2012; Houghton et al., 2013). Thus, it seems that male gender is a demographic variable that must be kept in mind when considering pressure-ulcer risks in the study setting.

Living with an intimate partner did not show a statistical or clinical significant association with PU history (fisher's exact test p= 1.0) in the current study. Level of education had no statistical (p=0.205), and limited clinical impact with 32% of participants who had completed high school or had tertiary education having a PU history versus 49% of those who did not finish high school. Level of education is, however, again a variable identified by previous research as giving rise to an increase in the risk of developing pressure ulcers (Eslami et al., 2012; Houghton et al., 2013; Zakrasek et al., 2015). Similarly, previous research has identified unemployment and low-income levels as a risk for PUs (Houghton et al. 2013; Zakrasek et al., 2015; Saunders et al. 2012). Even though socio-economic status, per se was not measured in the current study, employment status measured and unemployment could, generally, be strongly linked to lower household income. In the current study, no statistically significant association was found between employment status and PU history (Fisher's exact test p=0.775). This could point to another limitation of the study, as having a current PU, was not recorded. Having a current PU would probably impact more on employment status as Marti, Boes, Lay, Reuben Escorpizo & Trezzini (2015) reported that a person with SCI who currently had a PU was more likely to be unemployed. This might be due to the necessity to stay in bed to keep pressure off the ulcer which would allow it to heal properly. In accordance with findings from Saunders et al. (2012) no statistically significant association between race and PU history was found in the current study (Fisher's exact test p=0.605).

5.3. Medical information

The high percentage of participants whose SCI had been caused by trauma, was in agreement with international (WHO, 2013) and South African data (Hart & Williams, 1994; Vellhamos et al., 1995).

There is a clear distinction between the in-patients and the out-patients when considering time since injury. This is an expected outcome as in-patients tend to be admitted to a rehabilitation centre from an acute-care hospital as soon as they are medically stable. The peer supporters all suffered their injuries more than two years before. This matches the role of peer supporters as they tend to rely significantly on personal experience to give support and assistance (Hayes & Balcazar 2008 as cited in Ljunberg 2011). The high number of persons with paraplegia versus quadriplegia might be due to the inclusion criteria that state participants had to use manual wheelchairs. Persons with higher-level injuries resulting in quadriplegia would more often use motorised wheelchairs than those with paraplegia.

5.3.1. Pressure-ulcer history

Findings indicate that 43% of participants had developed a PU at some stage since injury. This percentage could possibly be higher as knowledge scores showed that participants were generally not knowledgeable about the stages of pressure ulcers. In particular, 38% of the participants did not know that a red area or skin discolouration is a grade 1 pressure ulcer or the first sign of a pressure ulcer. It is, therefore possible that some participants might have had grade 1 pressure-ulcers without knowing it. It is a limitation of the study that one of the options under pressure ulcer history was not a red area/darker colouration. In the researcher's experience, clients at the WCRC often refer to having had a red area, but do not equate this to having had a pressure ulcer. The danger of this lack of knowledge is that studies have shown that having a previous PU constitutes an increased risk for developing a PU in the future (Coleman et al., 2012). Not knowing that one has previously contracted a pressure ulcer may decrease one's vigilance with regard to skin-care. Guihan et al. (2012) also found a lack of knowledge in this regard. In that particular study, 57.9% of the participants could describe the stages of a pressure ulcer, while only 11.3% could describe it in the current study.

The 43% of participants who did have a pressure ulcer was a much lower percentage than the life-time risk figures of 85% (Niazi, Salzberg, Byrne & Viehbeck as reported in Lala et al., 2014) or higher (Zakrasek et al., 2015) mentioned in the literature. However, the current study figure does not refer to life-time risk, but only to the time since injury which is relatively brief, especially, in the case of in-patients. The figure might also be lower due to under-reporting as discussed in the previous paragraph. Out-patients with current or previous PUs may also be under-represented in this study. Transport for people with disabilities in South Africa is difficult to find (Njoki et al., 2007; McClagnlan, 2012) and could impact on the number of people accessing facilities like the WCRC as out-patients (Cawood & Visagie, 2012). The WCRC is also in an urban area, making it more difficult for people living in rural areas to access, implying that the people living with SCI in rural areas may prefer to rather access their local clinics or hospitals. The mortality rate for people living with SCI in South Africa is also not known. Burns et al. reported that the average length of time of survival after a SCI in sub-Saharan Africa is most likely less than one year (Burns et al., 2012). Mortality is often due to septicaemia, post pressure ulcer.

More out-patients (55%) than in-patients (30%) had a history of developing a pressure ulcer. One may argue that out-patients in this study were shown to be more at risk of developing a PU than inpatients, but one needs to take into consideration the time since injury and that in-patients were still under the care of a skilled SCI rehabilitation team.

The reasons for the relatively high number of in-patients developing Pus, may be complex. The PU did not necessarily develop at the rehabilitation centre as clients are not admitted directly to the Rehabilitation Centre post-injury. Clients who suffer a spinal-cord injury are first admitted to a district or regional hospital close to where the injury has occurred. From there they are transferred to one of the two major tertiary hospitals in Cape Town and are only referred to the WCRC once they are medically stable and able to start participating in a rehabilitation programme. Frielingsdorf and Dunn (2007) found pressure-ulcer development to be a major problem at the acute SCI unit where they conducted their study and a cause for concern as it escalated the cost of care and delays transfer to a rehabilitation centre. In the article, it is stated that 11% of the participants in their study had arrived at the unit with pressure ulcers and 11% developed the pressure ulcers at the unit. The reasons for the clients arriving with pressure ulcers, included delayed transfers from secondary and primary health-care services and the use of hard fracture-boards by paramedical transport services (Frielingsdorf & Dunn, 2007). In the current study, 24% of the participants reported having had only one pressure ulcer. It is possible that these PUs had developed directly after the injury and that they were in some instances due to the causes mentioned by Frielingsdorf and Dunn (2007).

Even though participants scored very low on the questions regarding the stages of a PU, most of them believed that treating a stage one or two PU was much easier than treating a stage three or four PU. This would imply that participants understood that with stage three and four PUs the level of care needed and the seriousness of the situation increased.

One of the guidelines of practices that need to be followed, is reporting the first sign of a PU. The overall score for this practice was quite high (83%) with all three sub-groups presenting with similar scores. Reporting the first sign of a PU is an important way to prevent grade one or two PUs from developing into grade three or four PUs. This is especially important for the out-patient group, because they do not have ready access to medical services as in-patients. It is worrying that out-patients scored the lowest in the knowledge section on the question about what the first signs of a PU are. If one did not know that one had the first signs of a PU developing, one would not seek assistance.

5.4. Knowledge, beliefs, practices and skills

In accordance with findings by King et al. (2008) and Guihan and Bombardier (2012), the majority of participants in the current study believed pressure ulcers to be either very serious or life-threatening. When investigating this further, it is clear that only 32% (23) regarded PUs as being life-threatening while 57% (41) thought of them as very serious, while they are, in fact, life-threatening (Øderud, 2014). It is also interesting to note that the proportion of in-patients believing pressure ulcers to be life-threatening compared to very serious, was much lower than the same proportion of out-patients and peer supporters. Even though there was no statistically significant association between time since injury and the perceived seriousness of a PU (Fisher's exact test $p = 0.71$), it would seem that people who had lived longer with a SCI and might have witnessed the possible devastating effects of PUs, may view PUs in a more serious light.

The degree to which participants believed that PUs would interfere with their daily lives, was also much higher amongst out-patients and peer supporters than in-patients. Longer time since injury had a statistically significant impact on the belief that a PU would interfere somewhat or significantly with ADL (Fisher's exact test p = 0.029). This could be because with increased time since injury, people with SCI have possibly experienced more of the effects of PU and how they could interfere with ADLs. Out-patients and peer supporters might have met more people with similar injuries or a similar disability and thus gained more insight into the effects of contracting a PU. Furthermore, being in hospital means that ADL routines of in-patients had already been disrupted and it might have been difficult for them to envision the effect of a pressure ulcer on their out-of-hospital routine.

The reported practices indicated that the participants had followed some, if not all, of the recommended preventative practices, but these were self-reported and not measured objectively. However, it seems from the knowledge section of the questionnaire, that many participants might have lacked the knowledge to prevent pressure ulcers from occurring even though they wanted to prevent them and regarded them as serious. There is no recommended percentage that should be scored for the knowledge component of the questionnaire. However, Guihan et al. (2012), who assessed knowledge with a similar tool, considered the 73.4% mean knowledge score which they had measured, too low to effectively prevent PU. Only four of the participants in the current study scored above 73% and the average score of around 40% for in-patients and out-patients is particularly worrying.

There were differences between the current study and that of Guihan et al. (2012), which might have impacted the findings on knowledge. The education levels of the participants in the study by Guihan et al. (2012) were much higher (87.8% completed high school or had tertiary education) than compared to participants in the current study (22% completed high school or had tertiary education). Eslami et al. (2012) found that lower levels of education significantly increased pressure ulcer risk and clinical findings from the current study support that observation. In addition, the study by Guihan et al. (2012) was conducted in a developed country (USA) where access to information and, especially, the internet is much more readily available. According to Thietje et al. (2011), the internet is becoming an increasingly important source of information regarding the prevention of secondary complications for people living with spinal-cord injuries. The different economic situation in South Africa could also have influenced the choices made and the answers given in the knowledge section of the questionnaire. One of the options for prevention, for example, is the use of a special mattress, but since most of the clients would most probably not be able to afford such a device, they might not even have thought to mention it.

One would expect a higher mean knowledge score amongst in-patients than out-patients since the in-patients had just completed their rehabilitation programme which should have included education about pressure ulcers and their prevention, and Thietje et al. (2011) found that PU knowledge decreased over time, post discharge. This was however, not the case in this study. A possible explanation could be the trend to have shorter lengths of stay due to budgetary constraints. In an environment where time is limited, clients may not have the time to fully absorb and understand all the information given to them, decreasing their knowledge retention. Another possible explanation for poor knowledge scores amongst in-patients was that little time had passed since their injury and that in-patients were overloaded with information and struggled to absorb vast amounts of new information in the face of the life-changing event with which they are dealing (Hsieh et al., 2014). It is however, still alarming that the mean knowledge score of a group of people who were about to be discharged and would have to take care of their own PU prevention was 40.4%.

The peer supporters had a much higher average knowledge score (65.2%). They underwent a specific training programme that included, amongst other things, skin-care and the prevention of pressure ulcers in 2010 which might have facilitated their higher score. However, their role included discussing prevention of PUs with clients. Thus, one would have expected them to have knowledge scores close to 100% or, at least, above 80%. There has not been any formal follow-up training to update the knowledge of the peer supporters since 2010.

According to the scores, certain aspects of the knowledge about PUs and the prevention of PUs were particularly lacking. The areas where less than 20% of the participants scored 100% (i.e. could provide all the correct options) were the causes of PUs, the risk factors for developing PUs, the stages of PUs, nutritional support needed for good skin health, cushion care practices, prevention of PU recurrence and the time it takes for a PU to develop. In some of these areas, participants could give some of the correct options e.g. although only 14.1% of participants knew all the causes of PU, the average score for that area was 59.2%, indicating that participants could name some of the causes.

5.4.1. Causes of PUs

According to Best Practice Guidelines on PU prevention, education on PU prevention should include the causes and risks of PUs (Houghton et al., 2013). If a person does not know what may cause or increase the risk for a PU, it will be very difficult to prevent PU development. Less than 20% of the current study participants mentioned shear and trauma as possible causes of PUs. Shear and trauma are especially important when considering transfers between different surfaces. The “typical” person with a SCI who uses a manual wheelchair, transfers on average 14 to 18 times a day (Rice, Smith, Kelleher, Greenwald, Hoelmer & Boninger, 2013). Thus, if they were unaware that shear and trauma which could occur during transfers, could cause pressure ulcers they had been exposed to possible PU-causing actions often, during the course of a day.

Best Practice Guidelines highlights the importance of doing transfers correctly (Houghton et al., 2013). Houghton et al. (2013:139) state: “any poorly performed transfer increases the risk of injury”. They reiterate the importance of teaching transfers without shear or drag (Houghton et al., 2013). Current study skills test findings showed that 90% of the participants could perform transfers, but only 62% could do the transfer without any shear occurring. In-patients scored the highest in the transfer skills test. This could be a reflection of the skills that had just been accomplished by the in-patients who were about to be discharged. According to Rice et al. (2013), the quality of transfers could be significantly improved by using a structured education and training program during in-patient rehabilitation.

More participants knew that sitting too long could cause pressure ulcers (62%) and the majority of participants believed that shifting weight during sitting (86%) could assist with pressure-ulcer prevention. However, practice in this regard was worrying, as practice scores indicated that less than 50% of in and out-patients performed weight shift (pressure relief) often and long enough. Peer supporters scored better in this section. Knowledge about the frequency and duration of weight shift was lacking. There was a statistically significant correlation between the knowledge about the correct way of doing the weight shift and the reported practice of doing weight shifts (Fisher's exact test p=0.001).

In the skills test, 58% of participants performed weight shift effectively. Although 88% of the peer supporters reported doing weight shifts according to recommended guidelines, only 38% of them executed them correctly in the skills test. Participants, generally, struggled to maintain pressure relief or weight shift for long enough.

It is recommended that weight shifts are performed every 30 minutes (Garber et al., 2014) for at least 1 to 2 minutes (Houghton et al., 2013). This is to allow oxygenation levels in the tissue to return to normal levels (Garber et al., 2014). In the past, push-up lifts were recommended for pressure relief, but it was found that this was not as effective and could lead to upper limb injuries due to overuse and strain on the shoulder joints (Houghton, 2013). Maximum pressure reduction was reported with a forward-leaning technique and the lean being at least 45 degrees forward (Hougton et al., 2013). During the skills test, participants struggled to maintain pressure relief or weight shift for long enough. Unfortunately, no distinction was made in the current study between a push-up lift or a forward lean. It is suspected that the out-patients would, generally, still be performing the push-up lift as this is the technique that was taught in the past. If this is the case, it would be important to incorporate the more effective forward-lean weight shift into training for out-patients as well. Attention must be given to ways to teach persons to time the duration of the weight shift. Technology, like mobile phones could potentially be utilised to aid timing issues to ensure proper and effective weight shifts.

The question on the time it takes for a PU to develop with continuous pressure, scored the lowest of all the aspects covered in the PU knowledge section. This could indicate that the participants were not aware of just how rapidly a PU could start to develop. If one does not realise this, one might be much less vigilant in performing weight-shifting activities. The findings could also point to a lack of understanding of weight shifts and why they need to be done as often as recommended.

Guihan et al. (2012), Bloemen-Vrecken et al. (2007) and King et al. (2012) also found low adherence to weight shifting (55%). Guihan et al. (2012) explored participants' willingness to change their behaviour and increase adherence to the recommended practices. Of the practices investigated, weight shifting was the recommended practice that had the second highest percentage of participants willing to change their behaviour (Guihan et al., 2012).

The cause of pressure ulcers that most participants were aware of, was not turning in bed. The majority complied with the recommended practice of turning every two to four hours with 85% turning in bed regularly. The 85% may be inflated by the 100% of in-patients who responded positively to this answer, since turning in bed was being monitored by nursing staff.

5.4.2. Risk factors

The lack of knowledge with regard to risk factors is worrying. If a person does not know that poor nutrition, tight clothes, smoking, burns, poor posture and poor health increase the risk for pressure ulcers, they may not take care in these areas. None of the participants scored full marks for the question on nutrition. The lack of knowledge about the role of nutrition and a balanced diet is also shown in figure 4.7 where only 9.8% of participants indicated that maintaining a healthy diet could assist with the prevention of pressure ulcers.

Maintaining a healthy diet is also an important component of maintaining general health. The importance of good general health seemed to have become obsolete. Very few participants indicated poor health as a risk factor for pressure ulcers or the managing of medical conditions as a preventative practice.

Two other aspects that can negatively influence general health and increase the risk of pressure ulcers are smoking and substance abuse. Smoking increases the risk of developing a PU (Saunders, Krause, Carpenter & Saladin, 2014; Coleman et al., 2012; Gould et al., 2014). Smoking also impairs wound healing and, thus, the healing of existing PUs (Gould et al., 2014). The number of participants who reportedly smoked in this study (37% overall) was very similar to the results in the previously mentioned study by Guihan et al. (2012) where 33.6% of the participants reported being current smokers and the study by Saunders et al. (22,6%) where the smoking habits of 1076 participants with SCI was studied (Saunders et al., 2014). What is alarming in the current study, is that the participant group with the highest reported percentage of current smokers was the in-patient group (43%). This might indicate that more should be done at the rehabilitation centre to dissuade clients from smoking.

Drug and alcohol abuse were the two practices that had the highest overall percentage of adherence to the recommended practices for good skin care. Only four percent of participants admitted to using drugs and only ten percent reported drinking more than four alcoholic drinks in a week. In the Human Sciences Research Council report published in 2008, on the trends in substance abuse in the Western Cape, it was found that the Western Cape is the province, in South Africa, with the highest reported prevalence of risky alcohol abuse (16%) and the highest life-time prevalence of substance abuse (18,5%). In the study by Bombardier and Rimmele, conducted in 1998, it was found that drug and alcohol abuse pre-injury was much higher for people who sustained a SCI compared to the general population (Bombardier & Rimmele, 1998). Heinemann, Doll, Armstrong, Schnoll and Yarkony (quoted in Stroud, Bombardier, Dyer, Rimmele & Esselman, 2011) found that up to 75% of people who suffered a SCI and who had abused drugs and alcohol before their injury, return to these habits within 7 to 18 months after the injury. When considering these statistics, there seems to be a strong likelihood that the actual percentage of participants using drugs and/or alcohol could be much higher than reported. Interestingly, the peer supporters reported the lowest compliance with this recommended behaviour of not using drugs and/or abusing alcohol. This could be because the peer supporters might have felt more comfortable to be honest about their habits. Drug and alcohol abuse could have been under-reported because the participants could have felt that they did not want to answer those questions truthfully because the interviewers were regarded as figures of authority.

Of concern, in this study, was the finding that less than 10% overall and no in-patients indicated that not using a cushion increased the risk for pressure ulcers. While 50% of peer councillors identified using a cushion as a preventative practice, only 12% of out-patients and 2% of in-patients mentioned this. Despite this, 78.8% of participants believed that using a wheelchair cushion could make a significant difference in whether or not they developed a PU. The skills test showed that more than 90% of participants used their cushion correctly. In the same vein, 12% of in-patients and peer supporters indicated that poor posture increased the risk for pressure ulcers, while none of the outpatients indicated this.

Cushions play an important role in pressure-ulcer prevention and an integral role in optimal positioning (Garber et al., 2014; Houghton et al., 2013). Correct positioning assists with pressure relief and prevents shear and friction. In most of the best practice guidelines regarding PU prevention in people with SCI, it is reiterated that there is no one-size-fits-all approach to seating and seating support surfaces such as cushions (Garber et al., 2014, Houghton et al., 2013). It is recommended that the type of cushion chosen should be based on a thorough assessment of the person and his/her needs. The choice is influenced by the clinical characteristics of the person, the weight-bearing needs of the person and also personal choice. In a developing country, like South Africa, another important aspect is cost.

The care of the cushion is also important. Caring for the cushion extends its lifespan and ensures that the pressure-relieving properties of the cushion stays intact. It is worrying that only 14.4% of the participants knew how to take care of their cushions, as poor cushion care could decrease the pressure-relief properties of the cushion and increase the risk of developing a PU. In the practices section, 65% of participants reported checking the condition of their cushion at least once a week and 60% of the participants knew how to check if a cushion needed replacing. This could indicate that even though participants did not always know how to take care of their cushions, they would know when it needed to be replaced. Once a year, clients are followed up for a seating review at the WCRC. This is because the cushion most often issued to clients is cushions made of foam and foam cushions, generally, need to be replaced once a year. If the cushion is not properly taken care of and loses its pressure-care qualities without the user realising it, the user may be at an increased risk of developing pressure ulcers. An important aspect of cushion care is to protect it from moisture. Houghton et al. emphasised the use of a waterproof cover for a foam cushion to protect the cushion (Houghton et al., 2013).

Skin must be clean and dry to prevent PUs (NPUAP, 2010; Garber et al., 2014). Less than half of participants, in the current study, mentioned that moisture might increase the risk of developing a PU. A quarter of the participants said that one of the ways to prevent a PU is to keep the skin clean and dry and they also knew how to keep the skin clean and dry. Guihan et al. found that 30% of participants had regular problems with incontinence and only 51.2% reported bathing daily to clean the skin properly (Guihan et al., 2012). A limitation of this study is that incontinence issues were not addressed under the practices section of the questionnaire.

Skin checks form an important part of the PU prevention plan (Garber et al., 2014). Just over 10% of participants knew that regular skin checks could assist in pressure-ulcer prevention, while 80.3% believed it could make a difference. Around 60% actually performed skin checks twice a day. This could be a reflection of how the questionnaire was structured, as skin checking was not given as an option to choose in the knowledge section of the questionnaire and participants might have opted to rather name other options as answers.

An important aspect of skin inspection is knowing how to do it correctly, when to do it and where the skin should be inspected. To know where to inspect the skin, people with SCI would need to know where the areas are that are the most vulnerable to PU development. According to the prevention guidelines (Vidal & Sarrias as quoted in Garber et al., 2014), the three most common sites for PU development is the ischium (28%), the sacrum (21%) and the trochanteric prominences. Current participants most frequently name the ischia as potential sites for PU (85%), but only 31% knew that the sacrum was a high-risk area. This could mean that the sacrum was not inspected by all and that a developing pressure ulcer forming in that area could be missed. The manner in which skin inspection was done, or should be done, was not assessed in this study.

The perceived benefits of good skin care most often chosen by the participants were feeling better physically (78,8%), prevention of PUs (81,6%) and satisfaction in taking care of themselves (85,9%). This indicates that good skin-care practices were being associated with PU prevention and that the participants realised the importance of these recommended practices. This might indicate that the reason for the low reported compliance with the recommended skin-care practices, was mainly due to a lack of knowledge and skills and not due to the belief that the practices would not help to prevent PUs.

Few participants expressed barriers to skin-care practices. The most common barrier identified by participants, was not having someone to assist them (18,3%), a barrier also experienced by participants in the studies conducted by King et al. (2008) and Guihan & Bombardierm (2012). The low reporting of barriers could indicate a lack of knowledge as participants might belief that they do not experience barriers, because they have believed themselves to be performing the recommended practices correctly.

According to the Veterans Association of the USA's guidelines on how to prevent and manage PUs, there are numerous possible reasons why a person could be doing recommended guideline practices incorrectly, or not at all. These could include a lack of knowledge or information on the practices and the reasons for doing them, being distracted because of psychological distress, incomplete or wrong information from the various rehabilitation professionals involved in the training and/or the wrong interpretation of information given to the participants (Liberman & Chaiken, 1992 as quoted in Garber et al., 2014). This is the reason why health literacy and testing health literacy is important as merely having all the knowledge is not enough. Knowing how to interpret and use that knowledge, is what constitutes good health literacy and translates much more effectively into doing the correct practices correctly (Villaire & Mayer, 2007).

Health literacy has been defined as: "[T]he degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000 as found in Villiare & Mayer, 2007:214). We can then see that the processes needed for appropriate health self-management is not only to have the information, but to understand the reasoning behind the practices, exactly how the practices work and, then, to be able to make correct decisions.

Chapter 6: Conclusion

6.1. Introduction

Treating pressure ulcers is not only costly to the state health department, but also to the person with the SCI and everything possible should be done to prevent the occurrence of pressure ulcers. Even though we do not always have access to advanced technology like pressure-alternating cushions and mattresses, basic preventative practices do not cost anything and if done correctly, could prevent many more pressure ulcers. However, as the researcher will argue in the conclusion, current study participants did not have the knowledge to effectively engage in preventative strategies. Before concluding arguments are presented, the limitations of the study will be discussed. Finally, recommendations to WCRC and for further research projects are made.

6.2. Limitations of study

Various limitations to the current study have been identified. These included:

- Participants were not randomly selected due to time and distance constraints. It would have been very difficult to do a random sample selection of the population of persons with SCI who were or had been clients of the WCRC due to the difficulty in reaching persons who might have lived far away. Random selection might have highlighted more out-patients, particularly those who has not been followed up at WCRC and who might have had PUs.
- Excluding persons who did not visit WCRC for follow up.
- Demographically, the study participants were comparable to participants in other studies conducted involving persons suffering from SCI in the Cape Town area and aligned well with demographic information about the Cape Town area. However, the possibility exists that due to a relatively small sample used, participants might not have fully reflected the study population. Thus, one has to be careful when making generalisations referring to all clients with SCI receiving rehabilitation at the WCRC.
- This study was done in an urban setting at a well-resourced rehabilitation centre. Thus, extrapolation of findings to rural or less resourced urban settings might not be possible,
- No socio-economic status was measured. Even though employment status was measured and socio-economic status could be derived from that information to some degree, socio-economic status of participants was not measured, specifically. This is important as one of the risk factors for PU development, found in literature is low socio-economic status (Saunders et al., 2012) and socio-economic status could play a role in the availability of resources and transport.
- Due to the learning effect of the questionnaire, intra-rater reliability could not be checked. Some of the questions in the beliefs and practices section of the questionnaire

answered some of the questions in the knowledge section, thus, there was a learning effect as a result of the questionnaire and this made testing for intra-rater reliability difficult.

- The client's perception of what a pressure ulcer was, was not check and/or inclusion of a "red area"/discolouration as an option in the pressure ulcer history options. More participants could have had previous PUs as researcher noticed that clients would often refer to having had a red area, but would then state that they had never had a PU before.
- Current PU status was not documented
- No age at time of onset of injury or specific cause of injury was documented. This is important information to have for epidemiological purposes.

6.3. Conclusion

A lack of comprehensive, recent incidence and prevalence studies on SCI and pressure ulcers challenge comparisons. However, overall, one can say that demographically and clinically, study participants mostly conformed to previously described populations. From study findings and previous studies it seems as if the demographic variables of being male and lower levels of education might increase the risk for pressure ulcers. One may, thus, cautiously postulate that the average client at WCRC already has an increased risk of developing a pressure ulcer. However, the current study participants may not accurately reflect the SCI population managed at WCRC and/or confounding variables may have impacted on findings.

Without comprehensive epidemiological information (i.e. mortality rates and causes, life expectancy) on SCI, in South Africa, it is difficult to interpret the information based on the percentage of participants who had pressure ulcers. While being lower than life-time incidence risk from other studies, results seems high for a group of participants of whom about 50% were less than two years post-injury. This is especially significant since the number of participants who had a pressure ulcer might be under-reported due to a lack of knowledge on what constituted a PU.

The lack of knowledge on the staging of PUs and, especially, not identifying a red area/discolouration as a stage 1 pressure ulcer, is worrying. If participants cannot identify a PU in the initial stages they will not be able to practice prevention and/or seek early assistance, an important aspect to ensure healing and prevent progression of the pressure area to a more serious stage 2, 3 or 4 ulcer. Even though most participants knew PUs could recur, none of the participants mentioned that a previous PU constituted an increased risk. This is a worrying fact, because then the person with SCI would not know to be more vigilant in detecting another PU.

Nutrition is something that persons with SCI can influence and change to assist with PU prevention, given the financial means to buy the recommended foods. Not knowing what the correct food is to eat for good nutrition could increase the risk of PUs instead of lowering it.

Knowledge about the role of body mass and general health in PU prevention must also be improved.

The knowledge about pressure ulcers and pressure-ulcer prevention of all three the sub-groups of study participants were poor. As a result, although participants generally believed pressure ulcers to be serious and that they could prevent pressure ulcers through preventative practices, a lack of knowledge might have prevented them from performing PU-prevention practices adequately. For instance, unrelieved pressure is the main cause of pressure ulcers and weight shifts are some of the main preventative practices. In accordance with these practices, most of the participants correctly believed that weight shifts made a difference in whether a person with a SCI would develop a PU. Despite this, the knowledge on how to do the weight shifts, the reported practices on how the weight shifts were done and the weight shift skills test, scored very low. Thus, it seems that although the importance of shifting weight was taught to participants, the actual performance of the activity, its frequency and duration were either not taught adequately, or not retained and implemented. Similarly, shear often occurred in the transfer skills test, but was identified by few participants as a cause of pressure ulcers. Wheelchair cushions play an important role in optimal positioning – an aspect that can decrease sheer and provide some pressure relief. It is essential that all persons with SCI know how to take care of their specific type of cushion and how to identify when it needs replacement.

The in-patients were interviewed within two weeks of their discharge dates and despite almost completing their rehabilitation programme, they only scored a mean of 40.4% in the knowledge section. This means that the in-patients did not have adequate knowledge to be able to prevent pressure ulcers once they went home. This is worrying in the light of the very few follow-up services available for persons with SCI as out-patients. In addition to inadequate knowledge on the impact of shear and trauma as causes of PUs, only half of the in-patients mentioned that sitting too long could cause pressure ulcers. In-patients believed pressure ulcers to be less serious, with a lesser impact on their activities than participants from the other two groups. A large number of them also felt themselves less likely to develop a PU. It is possible that their lack of knowledge, combined with a lack of practical experience of life with a SCI, might have influenced their beliefs.

The out-patients average knowledge score was 1% lower than that of in-patients. However, more of them saw themselves as likely to develop pressure ulcers, and a higher percentage believed it would seriously impact their activities. They suffered from the same lack of knowledge as in-patients, but personal experience of life with SCI and contact with others, might have influenced their beliefs over time. Even though out-patients achieved a similar mean knowledge score, a general impression that they might be more at risk of developing pressure ulcers than the other two groups, was created by the findings. They scored lowest of the three groups in each of the skills tests, they least often turned in bed every two to four hours and they scored lowest overall in incontinence-related strategies. The similar mean knowledge score to that of in-patients may imply that out-patients have retained the knowledge they received. However, the other findings seem to indicate that, as found in other studies, knowledge decreases over time.

Peer supporters had a higher mean knowledge score than the other two groups. They demonstrated more knowledge on the role of weight shift, nutrition, no smoking, body mass, managing incontinence, special mattresses, avoiding tight clothes and using a cushion in the prevention of pressure ulcers than the other two groups. Yet, their scores may have been too low to effectively prevent pressure ulcers for themselves and based on this knowledge score they may not have had sufficient knowledge to teach others PU prevention practices.

6.4. Recommendations

Recommendations to WCRC

- **Structured training programme:**
  The findings on participants' lack of knowledge suggest that the SCI rehabilitation programme at WCRC might benefit from implementing a structured PU-prevention programme. Such a programme should include the use of new, up-to-date video material with testimonials from other persons with SCI, group and individual discussions with use of techniques like 'teach-back' (Neptune, 2012), giving the clients something on paper to take home so they can refer to it at a later stage and the use of peer supporters in training.

  A lot of emphasis would need to be put on, not only showing or demonstrating techniques and preventative practices, but giving the clients a chance to practice these skills with someone present to guide them in the correct application of techniques. Emphasis would need to be put on general health maintenance as well as, for example smoking cessation and nutritional support as it seems as if the participants in the study did not understand the link between general health and well-being and skin health and the subsequent prevention of PUs.

- **Refresher courses for peer supporters:**
  It is recommended that the peer supporters undergo training to refresh and update their knowledge on PUs and PU prevention. This should be done on a regular basis and be based on a formal programme.

- **Other interventions:**
  Use of technology, like mobile phones to help with timing issues to ensure proper and effective weight shifts.

Smoking cessation interventions would need to be investigated and tested at the rehabilitation centre. Possible interventions include psychology groups on cessation, buddy-pairing and nicotine treatments.

Recommendations for future study

- Epidemiological studies on SCI and PU in South Africa.
- Epidemiological research on the profile of clients discharged from the WCRC. Such a study could include more detailed information regarding etiology, the prevalence and incidence of secondary complications and mortality rates and reasons for mortality. This could support and inform policy development in terms of resource allocation, but also prevention drives and campaigns. WCRC is the only state-funded rehabilitation centre in the Western Cape and valuable information regarding the client population could be gathered there.
- The development and piloting of a comprehensive training programme regarding PUs and PU prevention through action research. The effects of such a programme could be studied by repeating the questionnaire used in this study to ascertain if knowledge, practices, beliefs and skills have changed after the implementation of such a programme.
- Adapting the current tool to be used as a way of assessing PU risk and developing a cut-off score or score range that may be used to identify clients at high risk of developing pressure ulcers.
- Testing the knowledge, beliefs and skills of staff working at the WCRC about PU and PU prevention to ascertain if their knowledge is current and correct.

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Appendix A

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Do clients with spinal-cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, attitudes, practices and beliefs about pressure ulcers.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Adri Marica Visser

ADDRESS: Western Cape Rehabilitation Centre
103 Highlands Drive
Lentegeur
Mitchell's Plain
7785

CONTACT NUMBER: 021 370 2300 (w)

You are being invited to take part in a research project for clients with spinal-cord injuries. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. 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 at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study will be done at the WCRC. The purpose of the study to find out what clients with spinal-cord injuries know about pressure sores and how to prevent them. The study will also be looking at what clients with spinal-cord injuries are doing to prevent pressure sores from forming and what they belief about pressure sores. This information will hopefully assist the researcher together with the WCRC team to set up a better pressure care training programme at the hospital.

Why have you been invited to participate?

You have been invited to participate because you have a spinal cord injury and have certain knowledge and beliefs about pressure sores. Your input will be very valuable to help develop a structured programme for training pressure care. We need to know first what clients who has spinal-cord injuries know about pressure sores before we can know what and how we can make the training better.

What will your responsibilities be?

You will have to complete a questionnaire with the researcher or her assistant. At the end of the questionnaire you will be asked to perform 3 simple tasks to demonstrate what you know about pressure care. The questionnaire will take approximately 20 to 30 minutes to complete. Approximately 60 clients will be asked to participate.

Will you benefit from taking part in this research?

You will be sent/given information on pressure sores and pressure care once all participants have been interviewed. When structured training programmes regarding pressure care are put in place at WCRC in future, you will be invited to attend.

Your participation will help the staff at WCRC to adapt and change the training programme about pressure care to make it more understandable and relevant. This will benefit future clients to help them with preventing pressure sores.

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

There will be no personal risks involved by taking part in this study. Should the process cause any form of distress, further information will be provided.

Who will have access to your records?

All information will be protected and regarded as confidential. Your identity will remain anonymous at all times. Only the researcher and her assistant will have access to the information regarding your identity. No one will access your medical folder for the study. Research Ethics Committee members might need to inspect research records, but you will still remain anonymous.

Will you have access to information/answers?

Information regarding the study outcomes will be made available to you upon request.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there any thing else that you should know or do?

- You can contact Adri M Visser at 021 370 2300 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.

Declaration by participant

By signing below, I …………………………….….………. agree to take part in a research study entitled "Do clients with spinal-cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, attitudes, practices and beliefs about pressure ulcers"

I declare that:

- I have read or had read to me this information and consent form 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*) …………..……….. 2005.

....	....
Signature of participant	**Signature of witness**

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 a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .... on (*date*) .... 2005.

....

Signature of investigator **Signature of witness**

Declaration by interpreter

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

- I assisted the investigator (*name*) .... to explain the information in this document to (*name of participant*) .... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .... on (*date*) ....

....

Signature of interpreter **Signature of witness**

Appendix B

Pressure Care Knowledge, Beliefs and Practices questionnaire.

Adapted from assessment tools used by Guihan and Bombardierm. Guihan M., & Bombardierm C.H. 2012. Potentially modifiable risk factors among veterans with spinal cord injury hospitalized for severe pressure ulcers: a descriptive study. *The Journal of Spinal Cord Medicine*, 35(4):240 – 250
Revised March 2015

☐in-patient ☐ out-patient ☐ peer supporter

Participant number: ☐☐☐

Demographics and medical information

1. Date of Birth | dd | mm | yyyy | Age ______________

2. Gender ☐ male ☐ female

3. Race ☐ African ☐ White ☐ Coloured ☐ Asian

4. Education level ☐none ☐primary school ☐some high school ☐high school ☐tertiary

5. Marital Status ☐ never married ☐ married ☐ divorced ☐ widow/er ☐ lives with partner

6. Employment status ☐ unemployed ☐ full time employed ☐ part time employed ☐ Pensioner ☐ Student/Scholar

7. Date of injury | dd | mm | yyyy | Time since injury ______________________

8. Type of lesion ☐ traumatic ☐ non-traumatic

9. Level of injury ☐quadriplegic ☐paraplegic OR level _____________

(ASIA classification if known) ☐A ☐B ☐C ☐D

10. Pressure sore History (choose only one appropriate category):
(This includes any pressure sores anywhere on the body)
☐ 1. Does not have, nor ever had a pressure sore
☐ 2. Pressure Sore immediately after injury/diagnoses (none since then)
☐ 3. Has had pressure sores once or twice since discharge home
☐ 4. Gets a pressure sore once a year. (Heals at home)
☐ 5. Has continuous problems with pressure sores (Often requiring hospitalisation)

(Ask client to transfer onto a plinth before interview if possible to transfer independently.)

We will now go through the questionnaire. There are 4 sections. I will explain the sections as we get to them.
(Where there is more than one option for an answer, only prompt for more answers twice)

Knowledge

This section is looking at what you know about pressure sores and how to prevent pressure sores. Answer it as fully as possible.
(Read question to client. Write down or tick answers that client gives. Write down answer in empty area if answer not on sheet. Do not read answers on sheet to client.)

1. What can cause pressure sores? (3 points total)
(*should name at least 3. 1 point for each correct answer. 3 point max***)**

☐ Sitting too long in one position
☐ Not turning/not doing weight shifts
☐ Shear/friction (sliding or being pulled across a surface)
☐ Trauma
Other ____

2. What things that you do every day can make your risk of getting a pressure sore more?
(*Should name at least 5. 1 point for each correct answer. 5 point max)*

☐ Moisture (eg. urine or sweat)
☐Tight clothes and/or shoes
☐ Poor diet
☐ Not using a wheelchair cushion
☐ Heat / burning
☐ Smoking
☐ Previous pressure sores
☐ Being over or under weight
☐ Poor sitting posture
☐ Poor health
Other ____

3. How many stages do pressure sores have? (*2 points***)**

____

4. What does the stages of pressure sores look like? Name the characteristics of each stage, what will you see or feel? (*Only prompt for the amount of stages given in question 3. E.g. only ask for stage 1 and 2 if answer to no. 3 was two. If did not know, skip question 5. Should name at least 1 in each stage. 1 point for each correct answer***)**

Stage I:
☐ Warm
☐ Discoloured (darkened, purple in darker skin; red on pink in light skin)
☐ Does not blanch (whiten) when pressure is applied
☐ May feel harder or softer (mushy) because of fluid (oedema) underneath
☐ No break in the skin
______________________________________ (other words used by participant)

Stage II:
☐ Abrasion or scrape
☐ Blister
☐ Shallow ulcer/sore
☐ Break in the skin (epidermis and dermis both)
______________________________________(other words used by participant)

Stage III:
☐ Break in the skin through both layers (epidermis, dermis and subcutaneous tissue below)
☐ Looks like a deep ulcer/sore with or without evidence of damage to surrounding tissue
☐ Full-thickness
☐ Necrosis/dead tissue
☐ Drainage/fluid seeping out
____________________________________(other words used by participant)

Stage IV:
☐ Full-thickness
☐ Very deep/could go to the bone
☐ Necrosis/dead tissue
☐ Drainage
☐ Could be infected
☐ May involve muscle and extend to tendons and joints
____________________________________(other words used by participant)

5. How can you prevent pressure sores/what can you do to prevent pressure sores from forming? (*Should name at least 5. 1 point for each correct answer. 5 points max***)**

☐

☐ Check skin
☐ Weight shifts/pressure relief in wheelchair
☐ Turning every 3 hours in bed
☐ Keep skin clean and dry(good personal hygiene)
☐ Eating a healthy balanced diet
☐ Use a cushion in good condition
☐ Don't sit too long in one position
☐ Use a special mattress
☐ Be aware of hot things on skin (coffee cups on lap, floor boards in cars and trucks)
☐ Don't wear shoes or clothes that are too tight
☐ Use a lotion on very dry skin
☐ Making sure all medical conditions e.g. diabetes are under control and managed correctly
Other : ____

6. What is the first sign that you have a pressure sore? What will you see or feel? (2 points total) *(Write down answer given… tick box only if correct one was given)*

☐

____

(☐ Skin would be discoloured (red, pink, purple) OR ☐you will feel a hard area.)

7. What should you do if you notice or are told that you have a pressure area or a pressure sore on your body? (*2 points total***)** *(Write down answer given… tick box only if correct one was given)*

☐

____

(☐ Get off it immediately. Or ☐ Go see your doctor or go to clinic immediately)

8. How many times each day should you inspect or look at your skin or ask someone to inspect your skin to look for signs of a pressure sore? (*2 points total***)** *(Write down answer given… tick box only if correct one was given)*

☐

____
(☐ Minimum: 2 times (once in the morning and once at night))

9. How often should you do a weight shift/pressure relief when you are in your wheelchair and for how long? (*2 points total)(Write down answer given, tick box only if correct one was given)*

☐

____

(☐ At least 2 minutes every 30 minutes)

10. On what areas on of your body will a pressure sore develop the easiest?
(should answer at least 5, 1 point each, 5 points total)

☐

☐ sacrum/coccyx (tailbone)
☐ ischial tuberosities (seat bones, buttocks)
☐ trochanters (side of hips/hips)
☐ heels
☐ ankles
☐ elbows
☐ top of feet when lying pr
☐ knees
Other ____

11. What foods or food groups can help build up muscle and help protect the skin?
(*1 point each correct answer, 4 points total***)**

☐

☐ fish / meat
☐ some beans
☐ some nuts
☐ eggs
☐ diary products
Other ____

12. What type of wheelchair cushion do you use and how old is it?
(*2 points if knows both***) (**Can give options if not sure)

☐

Cushion ☐ Foam ☐ Air-filled ☐ Gel Age__________________

13. What should you do to take care of your cushion? Name 2 things that you should do. (*2 points total***)** (*Client should be able to mention two ways to care for his/her cushion. If client answered wrong in question 13, mark for his own cushion, not the one chosen in 13)*

Foam cushions:
☐ Allow cushion to "air dry" after a day's use.
☐ Wash cover frequently (mild soap and water and air-dry).
☐ Do not submerge in water/ get it wet
☐ Do not expose to direct sunlight.
☐ Always use a cover when sitting on the cushion.

☐

Air filled cushions:
☐ Wash with mild soap and water and rinse well.
☐ Wash cover frequently (mild soap and water and air-dry).
☐ Minimize exposure to direct sunlight and heat.
☐ Check regularly for punctures
☐ Dry thoroughly.

Gel cushions:
☐ Wipe down plastic cover with water mixed with a little soap.
☐ Wash cover frequently (mild soap and water and air-dry).
☐ Store flat.
☐ Dry thoroughly.

14. How would you know if your cushion was worn out and needed to be replaced? What would be the signs you need to check for?(*Only needs to give one answer. Tick at their appropriate cushion. 2 points total***)**

☐

Foam cushions:
☐ finger pressure test grade 3 (cannot wiggle fingers)
☐ cushion has bottomed out

Air filled cushions:
☐ cushion does not inflate properly any more/at all
☐ cushion loses air in less than a day

Gel cushions:
☐ gel is leaking out of pad
☐ cannot re-position gel anymore

15. How can you prevent hot temperature injuries/burning your skin/burn wounds? (*Should name at least 4. 1 point for each correct answer, 4 points total and maximum***)**

☐

☐ Do not use heating pads or electric blankets
☐ Do not sit close to fireplaces, heaters or campfires
☐ Do not reach across hot burners
☐ Check bathwater temperature with your hand before getting into bath
☐ Use cup holders for warm drinks
☐ Check sun-heated surfaces before contacting skin
☐ Avoid sun-tanning
Other ____

16. If you were using a specialty wheelchair cushion, would you still need to do pressure relief or weight shifts while sitting on your wheelchair? (*2 points for yes, none for no***)**
☐ Yes
☐ No

☐

17. If you had a pressure sore before, how can you make your risk of developing another pressure sore less or prevent a pressure sore returning after it has healed? (*Should name any 2. 1 point each correct answer, 2 points total***)**

☐

☐ Keeping pressure off the area
☐ Do pressure relief/weight shifts regularly as directed
☐ Follow good skin care practices
☐ Having good eating habits
☐ Keeping other health conditions (e.g. diabetes, heart disease) under control
☐ Participating in an exercise program (staying active)
Other ____

18. After how long could you develop a pressure sore if you stay sitting without doing any pressure relief? (2 points) *(Write down answer given… tick box only if correct one was given)*

____

(☐ 30 to 60 minutes)

☐

19. If you have bladder or bowel incontinence, including leaking of urine or diarrhoea every now and then, what should you do to decrease your risk of developing a pressure sore? (*Should name any 2. 1 point each correct answer, 2 points total, 2 points maximum*)

☐ Wipe up soiled and damp areas with a dry cloth.
☐ Consider it to be a temporary situation that will resolve on its own
☐ Clean soiled skin with soap and water, rinse well and pat dry.
☐ Use protective cream in areas that come in contact with urine or stool
Other ____

20. Can pressure sores come back after they are healed? Do you think it is possible for you to develop another pressure sore after one that you have/had has healed?(*2 points*)

☐ Yes
☐ No

Total marks : (out of 60) ☐

Beliefs

This section is about your beliefs/understanding around/about pressure sores. There is no right or wrong answer. Just choose the option that best fits/describes what you belief.
(Read question to client and give possible answers. Client must choose one)

1. How serious do you believe a pressure sore would be for you if you were to get one in the future? (choose one)

Not serious	Fairly serious	Very serious	Life threatening

2. How likely do you believe you are to get pressure sores? (choose one)

Very likely	Fairly likely	Somewhat likely	Not very likely

3. How much do you believe pressure sores would interfere with your daily activities? (choose one)

None	A little	Somewhat	A lot

4. How difficult do you believe pressure sores are to treat…
In the beginning stages?(choose one)

Easy to treat	Somewhat difficult to treat	Difficult to treat	Not treatable

In the end stages?(choose one)

Easy to treat	Somewhat difficult to treat	Difficult to treat	Not treatable

5. To what degree do you believe you can prevent the development of pressure sores? (choose one)

Completely	A little	Somewhat	Not at all

6. To what degree do you believe that daily skin checks make a difference in whether or not you develop a pressure sore? (choose one)

None	A little	Some	A lot

7. To what degree do you believe that weight shifts make a difference in whether or not you develop a pressure sore? (choose one)

None	A little	Some	A lot

8. To what degree do you believe that limiting your sitting time makes a difference in whether or not you develop a pressure sore? (choose one)

None	A little	Some	A lot

9. To what degree do you believe that using a wheelchair cushion makes a difference in whether or not you develop a pressure sore? (choose one)

None	A little	Some	A lot

10. What benefits do you think comes from following good skin care practices/from looking after or caring for your skin? (Read options to participant. Choose all that apply)

☐ Feeling better physically
☐ Preventing pressure sores
☐ Allowing unrestricted activities
☐ Pleasing my doctor or other medical professionals
☐ Pleasing my family members or friends
☐ Peace of mind, not worrying
☐ Satisfaction that I'm doing the right thing by taking care of myself
☐ Other ____

11. How difficult is it for you to follow good skin care practices/to take good care of your skin? (choose one)

Not difficult at all	Somewhat difficult	Fairly difficult	Very difficult

If client answered not difficult in question 11, skip question 12.

12. Why do you think it is difficult to follow good skin care practices/to take good care of your skin? (*Read options to participant. Choose all that apply***)**

☐ They take too much time
☐ They take too much energy
☐ They cost too much money
☐ They are unpleasant
☐ They are not safe
☐ They are too much trouble
☐ I don't understand how to do them
☐ I don't have the proper equipment
☐ I forget to do them
☐ I don't believe they will help
☐ I don't want to do them
☐ I have too many other problems
☐ I don't have anyone to help me
☐ Other ____

13. Do you think that over the past 5 years (or if recently injured, since injury) the frequency of your pressure sores has been: (choose one)(*Skip if never had a pressure sore)*

Increasing	Decreasing	Not changing	No pressure sores in the past

Practice

This section is about what you do in your everyday life. There is no right or wrong answer. Answer as honest as possible. You can choose not to answer certain questions.
(Read question to client and give possible answers. Client must choose one)

1. How often do you look at and touch your skin in all the areas where bones are close to the surface of the skin (buttocks, lower back, hips, heels, ankles, shoulder blades, and elbows)?

Never	Once a week	Once a day	Twice a day

2. How often do you do pressure relief or weight shifting when you are sitting?

Every 15 min/4 times an hour	Every 30 min	Every hour	Less than once per hour

3. How often do you check if your cushion is still in a usable/good condition?

Never	Once a month	Once a week	Once a day

4. How many alcoholic drinks do you have on average per week?

None	1-4 drinks	5-8	8-11	More than 12

5. How often do you use street drugs such as marijuana, cocaine, meth/speed, heroin or tik?

Never	Once a month	Once a week	Once a day	More than once a day

6. How often do you smoke cigarettes or use other tobacco products?

Never	Max 2 times a week	Once a day	2 to 3 times a day	More than 3 times a day

7. When you are in bed, how often do you turn or are turned?

Never	Once a night	Every 2 to 4 hours	Every 5 to 6 hours	Every 6 hours

8. When you notice new or worsening skin breakdown, how soon do you go see the doctor or nurse at the clinic?

Never	After a month	After a week	After a day or two

9. When was the last time you or a caregiver inspected your skin?

Today	Yesterday	More than 2 days ago	More than a week ago

10(a). Do you or your caregiver slide/drag your body across the bed, wheelchair ,toilet, or other surface during a transfer?

☐ Yes **If 10(a) is answered "Yes" ask question 10(b)**
☐ No (skip 10(b))

10(b) How often do you or your caregiver drag your body across the bed, wheelchair, toilet or other surface during a transfer?

Rarely	1 to 2 times a month	Once every week	Few times a week

Skills tests

Now we will look at a few things that you do every day with regards to your wheelchair and cushion.

1. Correct cushion use.

(Put a wheelchair and cushion similar (or as close to similar) to the one used by the client in front of him/her. Ask the client to show you how the cushion gets put into/on the wheelchair correctly)

☐ right side up
☐ right way around.

2. Transfer.

(Ask the client to transfer from his wheelchair to a bed/plinth. Ask him to do it the way he does it at home. Provide him with transfer board or assistance as needed and directed by him/her. Check that no shear or drag occurs between the skin and the surface.)

☐ safe transfer
☐ no shear or drag between the surface and the skin.

3. Pressure relief.

(Ask the client in his wheelchair to show you how he does pressure relief the way he does it at home for the same time he usually does it at home. Client can either lift or lean forward or sideways. A carer is allowed to help. Time the client.)

☐ correct technique (adequate pressure relief)
☐ 2 min or longer.

Thank participant

Appendix C

Changes to questionnaire after pilot studies

Pilot study 1

Pilot study 1 was done by the researcher independently to iron out issues relating to timing, working and practical considerations.

Changes to the questionnaire after this pilot included:

- Removing the question in the demographic section asking participants where their previous PU was along with the picture to indicate the area.
- Changing the wording in questions 1, 2, 4, 5, 8, 10, 12, 14, 16, 17, 18 and 20 in the knowledge section to simplify the question and make it more understandable.
- Removing question 11 from the knowledge section as it was deemed irrelevant.
- Changing question 19 in the knowledge section to an open-ended question without options for ease of asking the questions
- Changing the beliefs question 12 to skip that question if irrelevant depending on the answer in beliefs question 11.
- Changing the practices question 3 from how to check if a cushion is worn-out to how often the check is done as this related to a specific practice.

Pilot study 2

The rest of the pilot studies was used for training of the research assistant and to check for interrater reliability. This was done in the following way:

Pilot 2: Researcher does interview. Researcher and research assistant both score client on answer sheet.

Pilot 3: Research assistant does interview. Researcher and research assistant both score client on answer sheet.

Pilot 4: Researcher does interview. Researcher and research assistant both score client on answer sheet.

Pilot 5: Research assistant does interview. Researcher and research assistant both score client on answer sheet

Changes to questionnaire resulting from these pilot studies:

- Added an “other” option to all of the knowledge questions to allow the interviewer to write down any answers that was given, but was not on the answer sheet.

Pilot study 3

This pilot study was done by the researcher as a last check to iron out practical, wording or timing issues. It was also done with the official translator of the hospital to familiarise her with the questions. No changes were made to the questionnaire after this pilot.

Appendix D

Collapsing of categories

To enable meaningful correlation studies to be done on the data some of the data categories needed to be collapsed. This was done as follows:

Time since injury vs the belief about how serious a PU is believed to be

	Not/fairly serious	Very serious/life threatening
Injury <1year ago		
Injury >1year ago		

Time since injury vs how likely the participants belief themselves to get a PU

	Likely (very, fairly, somewhat)	Not likely
Injury <1year ago		
Injury >1year ago		

Time since injury vs the belief about how much a PU would interfere with activities of daily living

	None/a little	Some/a lot
Injury <1year ago		
Injury >1year ago		

Time since injury vs percentage total skills test score

	Skills Score <50%	Skills Score >50%
Injury <1year ago		
Injury >1year ago		

PU history vs belief about the degree to which a PU can be prevented

	No PU history	History of a PU
Can prevent to some degree (completely, somewhat, a little)		
Cannot prevent (unable to prevent)		

PU history vs age

	No PU history	History of a PU
Younger than 40		
Older than 40		

PU history vs gender

	No PU history	History of a PU
Male		
Female		

PU history vs race

	No PU history	History of a PU
African		
White		
Coloured		

PU history vs education level

	No PU history	History of a PU
Did not complete high school education		
Finished High school & Tertiary education		

PU history vs marital state

	No PU history	History of a PU
Living without partner		
Living with partner		

PU history vs employment status

	No PU history	History of a PU
Unemployed		
Employed/Pensioner/student		

PU history vs time since injury

	No PU history	History of a PU
Injury <1year ago		
Injury >1year ago		

Reported frequency of skin inspection practice vs PU history

	No PU history	History of a PU
Does twice daily		
Less than twice daily		

Reported correctly done pressure relief vs PU history

	No PU history	History of a PU
Every 30min or less		
Every hour or more		

Reported smoking vs PU history

	No PU history	History of a PU
Does not smoke		
Smokes		

Safe transfer skill vs PU history

	No PU history	History of a PU
Transfer safe (Skills2score = 2)		
Transfer not safe (Skills2score = 1 or 0)		

Correct pressure relief skill vs PU history

	No PU history	History of a PU
Pressure relief correct (Skills3score = 2)		
Pressure relief not correct (Skills3score = 1 or 0)		

Knowledge on pressure relief vs reported pressure relief

	Every 30min or less	Every hour or more
Answer correct		
Answer wrong		

Knowledge on pressure relief vs pressure relief skill time component

	Weight shift <2min	Weight shift >2min
Answer correct		
Answer wrong		

Education level vs percentage knowledge score

	Score <50%	Score >50%
Did not complete high school		
Finished High school & Tertiary		

Time since injury vs percentage knowledge score

	Score <50%	Score >50%
Injury <1year ago		
Injury >1year ago		

Appendix E

Research Assistant confidentiality form

TITLE OF THE RESEARCH PROJECT:

Do clients with spinal-cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, beliefs and practices about pressure ulcers.

REFERENCE NUMBER:S14/10/213

PRINCIPAL INVESTIGATOR: Adri Marica Visser

ADDRESS:
50 Dolphin Square
Dirkie Uys street
Somerset West
7130

CONTACT NUMBER: 0842587754

I (*name*) ________________________________ herewith declare that I will treat all participant information and data related to and collected during the study as confidential and protected. I will not disclose any information or data that I obtain from study participants or the researcher as part of the above mentioned research study. I will uphold each participant's right to confidentiality and to be treated in a fair and just manner at all times.
Signed at (*place*) __________________ on (*date*) __________________2015.

______________________________ ______________________________

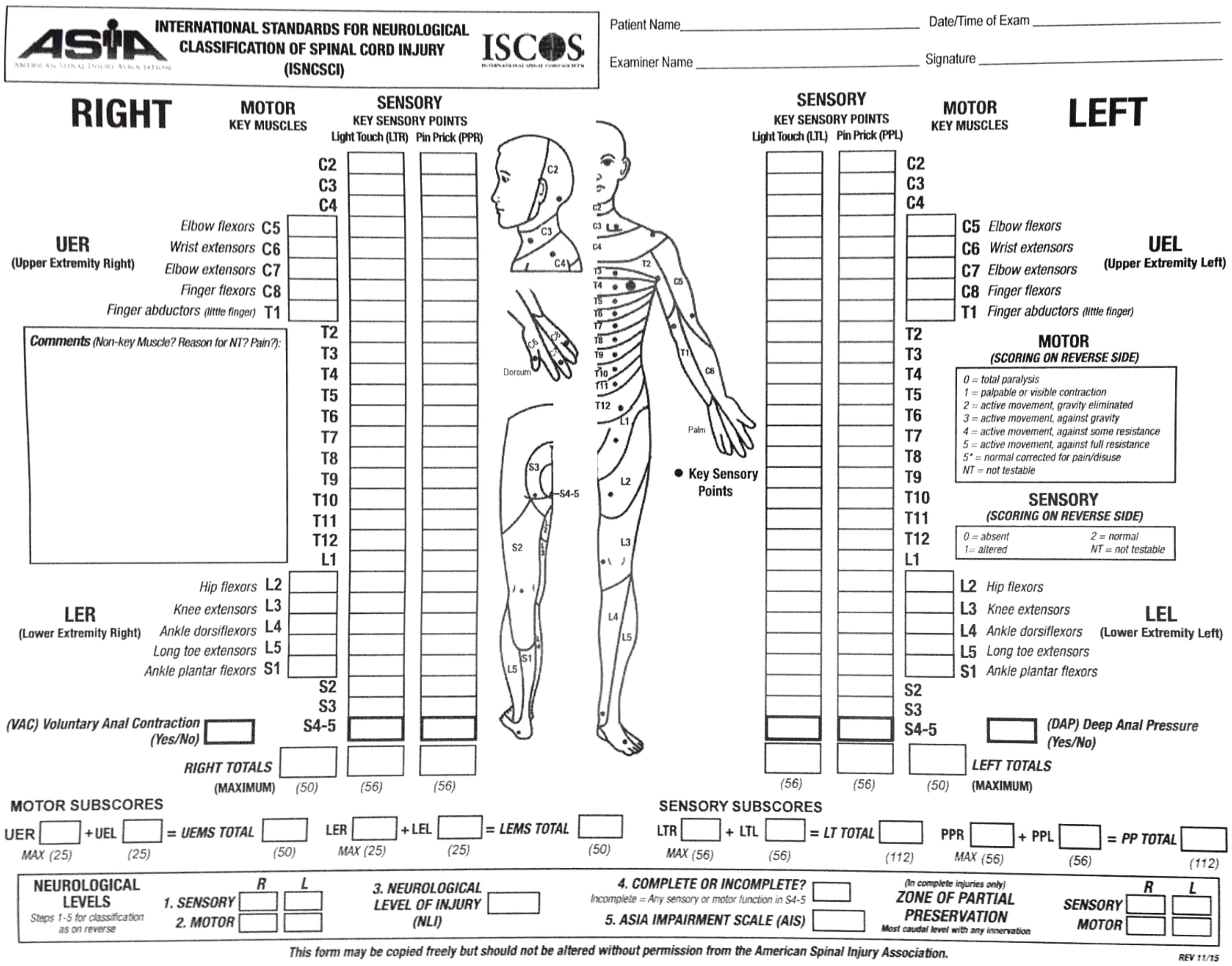
Signature of research assistant **Signature of witness**

______________________________ ______________________________

Signature of investigator **Signature of witness**

Appendix F

ASIA Scale



ASIA AMERICAN SPINAL INJURY ASSOCIATION

INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY (ISNCSCI)

ISCoS INTERNATIONAL SPINAL CORD SOCIETY

Patient Name____________ Date/Time of Exam ____________

Examiner Name ____________ Signature ____________

RIGHT

MOTOR KEY MUSCLES

SENSORY KEY SENSORY POINTS Light Touch (LTR) Pin Prick (PPR)

C2
C3
C4

UER (Upper Extremity Right)

Elbow flexors C5
Wrist extensors C6
Elbow extensors C7
Finger flexors C8
Finger abductors (little finger) T1

Comments (Non-key Muscle? Reason for NT? Pain?):

T2
T3
T4
T5
T6
T7
T8
T9
T10
T11
T12
L1

LER (Lower Extremity Right)

Hip flexors L2
Knee extensors L3
Ankle dorsiflexors L4
Long toe extensors L5
Ankle plantar flexors S1

S2
S3
S4-5

(VAC) Voluntary Anal Contraction (Yes/No) ☐

RIGHT TOTALS (MAXIMUM) ☐ (50) ☐ (56) ☐ (56)

LEFT

SENSORY KEY SENSORY POINTS Light Touch (LTL) Pin Prick (PPL)

MOTOR KEY MUSCLES

C2
C3
C4

C5 Elbow flexors
C6 Wrist extensors
C7 Elbow extensors
C8 Finger flexors
T1 Finger abductors (little finger)

UEL (Upper Extremity Left)

T2
T3
T4
T5
T6
T7
T8
T9
T10
T11
T12
L1

MOTOR
(SCORING ON REVERSE SIDE)

0 = total paralysis
1 = palpable or visible contraction
2 = active movement, gravity eliminated
3 = active movement, against gravity
4 = active movement, against some resistance
5 = active movement, against full resistance
5* = normal corrected for pain/disuse
NT = not testable

SENSORY
(SCORING ON REVERSE SIDE)

0 = absent
1 = altered
2 = normal
NT = not testable

L2 Hip flexors
L3 Knee extensors
L4 Ankle dorsiflexors
L5 Long toe extensors
S1 Ankle plantar flexors

LEL (Lower Extremity Left)

S2
S3
S4-5

☐ **(DAP) Deep Anal Pressure (Yes/No)**

☐ (56) ☐ (56) ☐ (50) **LEFT TOTALS (MAXIMUM)**

MOTOR SUBSCORES

UER ☐ + UEL ☐ = UEMS TOTAL ☐
MAX (25) (25) (50)

LER ☐ + LEL ☐ = LEMS TOTAL ☐
MAX (25) (25) (50)

SENSORY SUBSCORES

LTR ☐ + LTL ☐ = LT TOTAL ☐
MAX (56) (56) (112)

PPR ☐ + PPL ☐ = PP TOTAL ☐
MAX (56) (56) (112)

NEUROLOGICAL LEVELS
Steps 1-5 for classification as on reverse

	R	L
1. SENSORY	☐	☐
2. MOTOR	☐	☐

3. NEUROLOGICAL LEVEL OF INJURY (NLI) ☐

4. COMPLETE OR INCOMPLETE? ☐
Incomplete = Any sensory or motor function in S4-5

5. ASIA IMPAIRMENT SCALE (AIS) ☐

(In complete injuries only)
ZONE OF PARTIAL PRESERVATION
Most caudal level with any innervation

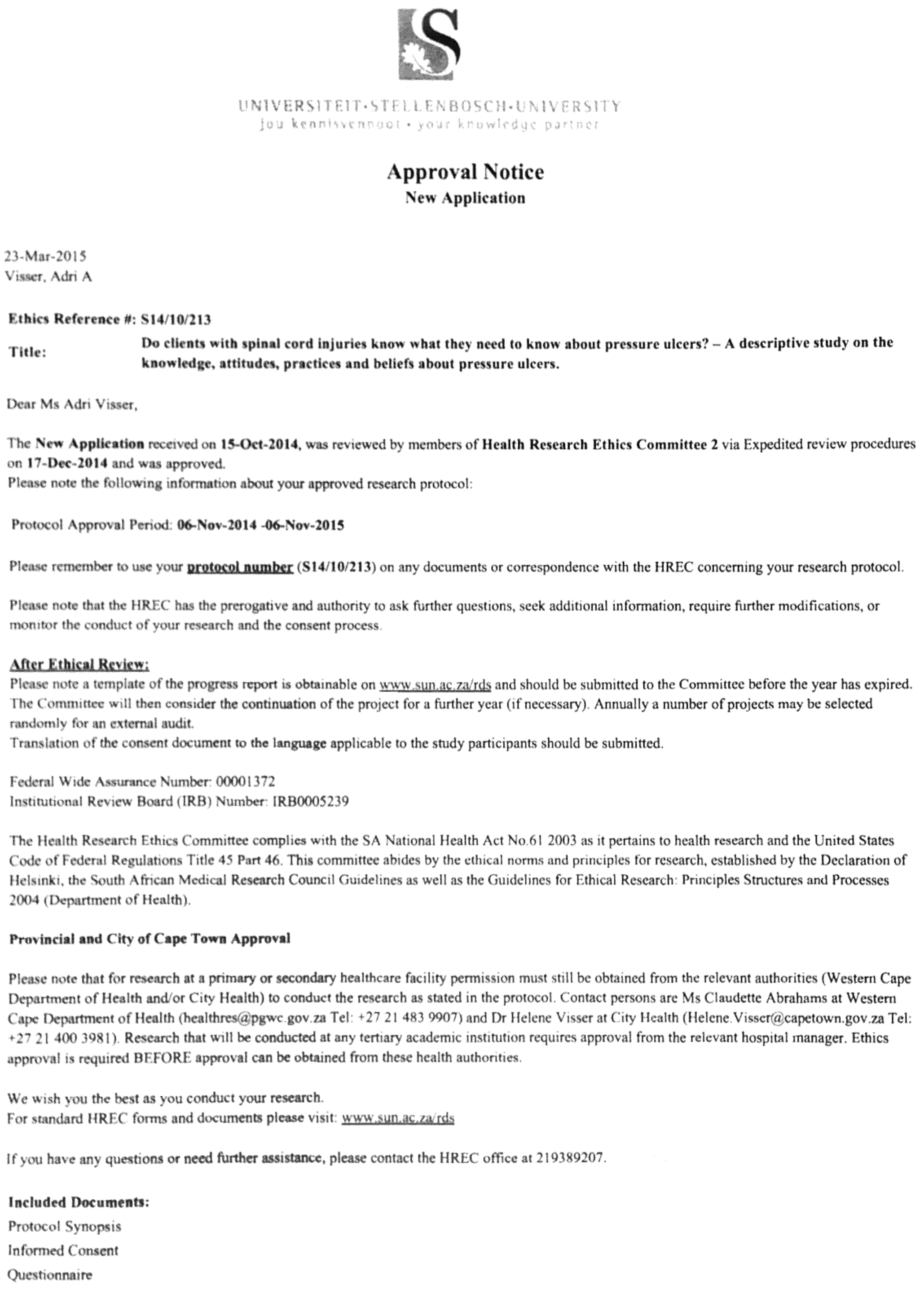
	R	L
SENSORY	☐	☐
MOTOR	☐	☐

This form may be copied freely but should not be altered without permission from the American Spinal Injury Association.

REV 11/15

Appendix G

Ethics Approval



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Approval Notice

New Application

23-Mar-2015
Visser, Adri A

Ethics Reference #: S14/10/213

Title: **Do clients with spinal cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, attitudes, practices and beliefs about pressure ulcers.**

Dear Ms Adri Visser,

The **New Application** received on **15-Oct-2014**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **17-Dec-2014** and was approved.
Please note the following information about your approved research protocol:

Protocol Approval Period: **06-Nov-2014 -06-Nov-2015**

Please remember to use your **protocol number** (**S14/10/213**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:
Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.
For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 219389207.

Included Documents:

Protocol Synopsis
Informed Consent
Questionnaire

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Ethics Letter

10-Dec-2015

Ethics Reference #: S14/10/213
Title: Do clients with spinal cord injuries know what they need to know about pressure ulcers? – A descriptive study on the knowledge, attitudes, practices and beliefs about pressure ulcers.

Dear Miss Adri Visser,

The HREC approved the following progress report by expedited review process:

Progress Report dated 22/01/2015 - 26/10/2015

The approval of this project is extended for a further year

Approval date: 09 December 2015

Expiry date: 09 December 2016

Kindly be reminded to submit progress reports two (2) months before expiry date

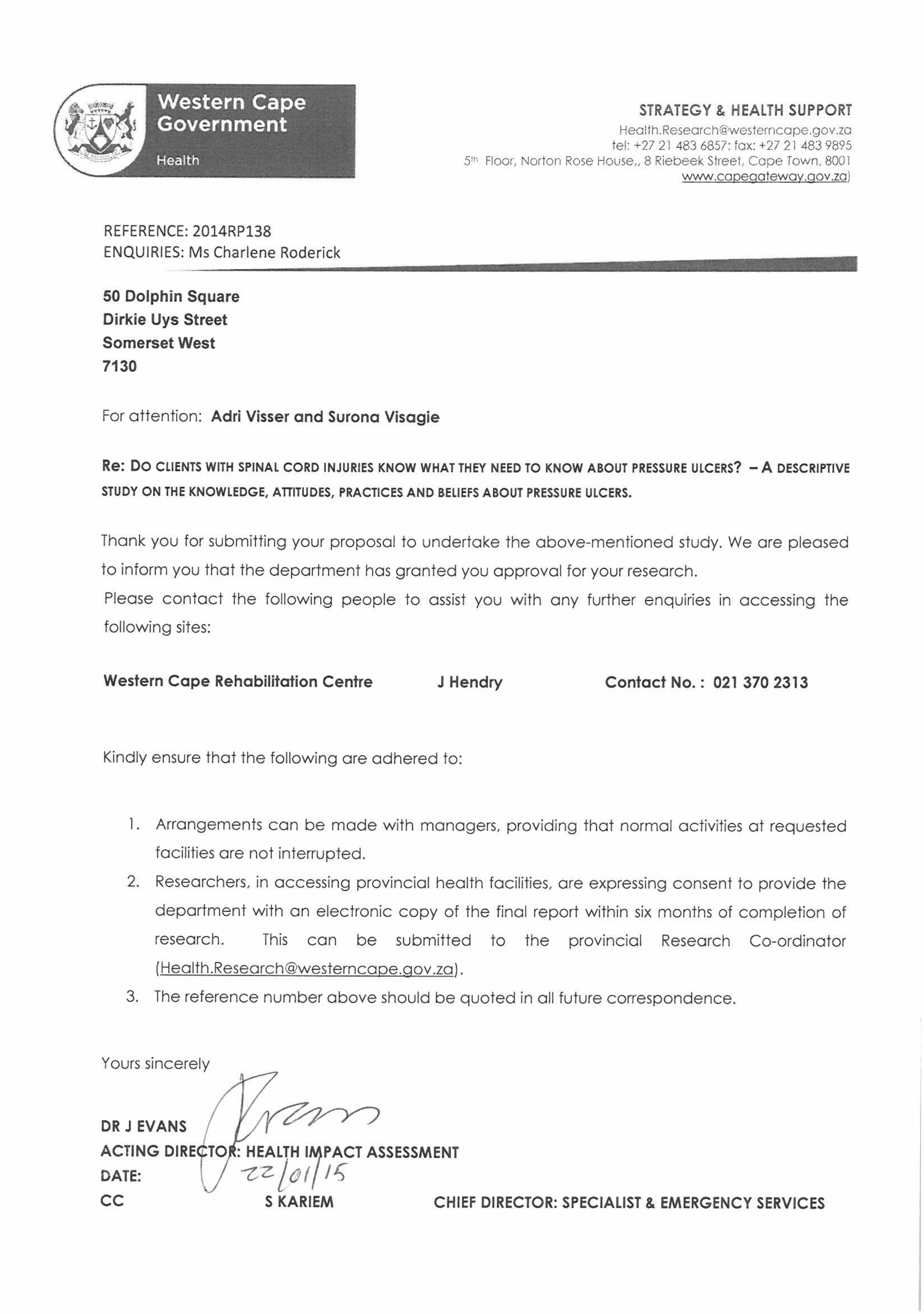
If you have any queries or need further help, please contact the REC Office 219389819.

Sincerely,

REC Coordinator
Ashleen Fortuin
Health Research Ethics Committee 2

Appendix H

Letter of approval Department of Health



Western Cape Government
Health

STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: 2014RP138
ENQUIRIES: Ms Charlene Roderick

50 Dolphin Square
Dirkie Uys Street
Somerset West
7130

For attention: **Adri Visser and Surona Visagie**

Re: DO CLIENTS WITH SPINAL CORD INJURIES KNOW WHAT THEY NEED TO KNOW ABOUT PRESSURE ULCERS? – A DESCRIPTIVE STUDY ON THE KNOWLEDGE, ATTITUDES, PRACTICES AND BELIEFS ABOUT PRESSURE ULCERS.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries in accessing the following sites:

Western Cape Rehabilitation Centre **J Hendry** **Contact No. : 021 370 2313**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR J EVANS
ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 22/01/15
CC **S KARIEM** **CHIEF DIRECTOR: SPECIALIST & EMERGENCY SERVICES**