

How do individuals living with a spinal cord injury in a rural area prevent pressure injuries?

The lived experience of intact skin.



(photo courtesy of AgrAbility website)

Catherine Brabrook

Occupational Therapist/Rural Spinal Cord Injury Coordinator
Rural Spinal Cord Injury Service (New England)

Hunter New England Local Health District
Tamworth Rural Referral Hospital
Locked Bag 9783
Tamworth NEMSC NSW 2348
Ph: 0267678350

Acknowledgements

A huge thankyou to all the participants who allowed me, a complete stranger, into their homes to ask very personal and probing questions. I enjoyed meeting you all and I thank you for your honesty.

Thankyous also:

To Emma who “got” my idea from the beginning and helped me achieve it.

To David who taught me so, so much...and all done with lovely humour.

To Kerith for your advice and encouragement to get me to the finish line.

To Anne for helping me to see a deeper level of meaning and to not be afraid of it.

To Anita my “closet academic” manager. Thanks for all your support and allowing me such flexibility in my work to be able to complete my project. And for your edits.

To Alyssa Rogan and Elizabeth Dalloway for sharing their knowledge and extensive experience in the areas of both spinal cord injury and pressure injury.

To Darren for making all the initial phone calls to the research participants.

To my family for their support and allowing me to take over the office and then the dining room table with all my research paraphernalia.

To HETI and Rural Research Capacity Building Program for giving me this opportunity. This journey has taken me from having not read a journal article in the last 20 years to being very, very keen to further my involvement in research in the future.

It was eye-opening for me having the opportunity to perform interviews without a “clinicians agenda” and to just be able to listen. The following is a quote from a book I was reading at the time of completing my research interviews and this rang so true for me:

“Interviewing is not what people imagine. Before you try it, you think it must be like pulling teeth. You approach each interview fearing that you will not get enough. But what you learn is that you must humble yourself before the other. You have to let go of your anxious desire to control and direct the encounter. You have to live for a while in the uncertainty of not knowing where it’s heading. You don’t lead. You learn to follow. And then you are amazed at what people are prepared to tell you.”

Helen Garner True Stories 1996¹

Table of Contents

Page 4:	Abstract
Page 5:	Executive Summary
Page 6:	Introduction
Page 6:	Literature Review and Rationale
Page 11:	Method
Page 13:	Findings
Page 20:	Strengths and Limitations
Page 21:	Conclusion and Recommendations
Page 22:	References
Page 24:	Appendix 1 – Glossary of Terms
Page 26:	Appendix 2 – Literature Search Process
Page 27:	Appendix 3 – Consent Form
Page 28:	Appendix 4 – Information for Participants
Page 29:	Appendix 5 – Sample Interview Questions

Definitions of terms used in this Report:

Pressure Injury - Pressure injuries are also known as pressure ulcers, sores, wounds or areas. A pressure injury can be defined as a lesion caused by unrelieved pressure resulting in damage of underlying tissue.

Spinal Cord injury – Damage to any part of the spinal cord or nerves at the end of the spinal canal causing permanent changes in strength, sensation and other body functions below the site of the injury.

Pressure relieving lifts – Voluntary movements specifically for the purpose of relieving pressure on the bottom and upper thighs when in a seated position.

Transfer – Movement of self from wheelchair to another piece of equipment or vehicle.

Autonomic Dysreflexia - Is a condition where the involuntary nervous system overreacts to external or bodily stimuli. This reaction causes a dangerous spike in blood pressure, racing heart, constriction of peripheral blood vessels, and other changes in the body's autonomic functions. Autonomic dysreflexia following spinal cord injury occurs when the spinal cord damage is at or above the level of T6.

Please find a Glossary of Terms in Appendix 1 further explaining the main terms used in this report.

Abstract

Title

How do individuals living with a spinal cord injury in a rural area prevent pressure injuries? The lived experience of intact skin.

Introduction

Those living with a spinal cord injury in a rural area are commonly viewed to be at risk of pressure injury due to their reduced access to specialised health care, specialised pressure care equipment and care in the home. However there are individuals living rurally who remain relatively pressure injury free over their lifetime. A qualitative study was used to explore the experiences of rural community dwelling adults who have had a long term spinal cord injury but have successfully avoided the experience of a major pressure injury.

Methods

Participants were recruited from the Rural Spinal Cord Injury (New England) database. Inclusion criterion were having a spinal cord injury for more than 10 years, having no motor ability below the level of injury, living at home and not having had a severe (grade 3 or 4) pressure injury. Five semi structured interviews were conducted in participants own homes. Three participants lived on rural properties (2 outer regional and 1 remote as per ASGC-RA Classification) and two lived in towns with a population greater than 10000 (inner regional). All participants were white, Caucasian males aged between 35 and 60. The average time since injury was 23 years. Qualitative analysis of the transcribed interviews was completed using a hermeneutic phenomenological approach. Interpretation of the data revealed three main themes and a number of sub themes as being integral to the research participants' ability to maintain their skin integrity.

Results

The major themes were "Skin not a separate entity", "Self-sufficiency" and "Minimise disruption to life". Research participants maintained their skin integrity through maintaining autonomy over their skin care management, flexibility and problem solving with regards to skin care management, proactive responses to minor body signals and completion of pressure relief within their activities of daily living rather than as a separate task. Participants were motivated to maintain their skin integrity due to fear of further incapacity and their strong sense of responsibility to others. Analysis revealed that participants' accessed equipment in an ad-hoc manner in the absence of local specialist spinal cord injury seating services although surprisingly this did not appear to have adverse effects on their ability to prevent pressure injury.

Conclusions

It is anticipated that these experiences and stories will inform education and management of those living with spinal cord injuries in rural areas with regards to maintaining skin integrity. The study strengthens the case for continued access to spinal specific services in rural areas through the Rural Spinal Cord Injury Service and also highlights the challenges for clinicians working with this client group.

Keywords

Spinal Cord Injury, Pressure Injury, Prevention, Community, Rural, Australia

Executive Summary

With the release of the NSW Agency for Clinical Innovation Model of Care for Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injury and Spina Bifida² in 2014 the focus of clinicians involved with the care of spinal cord injured clients is moving towards best practice for prevention of pressure injury. This study sought to understand the behaviours of long term spinal cord injured individuals who have been successful in maintaining intact skin. It is anticipated this information will inform clinicians in the education and management of spinal cord injured individuals living in rural areas with regards to pressure injury prevention.

The study highlighted a number of behaviours that appear to be protective of pressure injury for rural individuals and this information will be valuable for clinicians in their education and management of clients at risk of pressure injury. It also unfortunately highlighted the inequitable access rural clients have to specialised pressure injury services and equipment. In this study individuals had an ad-hoc approach to equipment acquisition in the absence of access to a specialised seating service. Although this approach had not had an adverse effect for this particular cohort at this point in time they had not taken into account changes that may occur with seating needs, for example due to development of co-morbidities or aging generally. This cohort also exhibited many protective factors for pressure injury risk. For those less successful at prevention of pressure injury and with higher risk factors access to timely and specialised equipment prescription is imperative in preventing pressure injury. This is particularly pertinent for our aging population of rural spinal cord injured patients who have changing needs with regards to skin care due to onset of comorbidities, more fragile skin and less opportunity for activity as they retire.

Currently in rural NSW spinal cord injured clients have access to specialised seating services only once or twice per year. At other times clients are reliant on their local occupational therapist to provide this service. Occupational therapists in rural areas have had improved access to spinal specific education via the Rural Spinal Cord Injury Service however seating and equipment prescription for the spinal cord injured individual is much specialised and requires a high level of specialised clinical skills. This impacts in various ways for the rural individual with a spinal cord injury. For example an occupational therapist servicing a small outer regional this population may only be referred one client every year requiring prescription of a wheelchair and it is thus very difficult to maintain clinical expertise in this area. Waiting lists for occupational therapy services also affect the timely access of clients to pressure care equipment, putting them at further risk of pressure injury. It is recommended that rural clients have improved access to seating and pressure care equipment prescription through a local health district dedicated service. ***Employment of an occupational therapist on a part time basis within the Rural Spinal Cord Injury Service (New England) would service this gap in access for rural individuals and assist in the prevention of pressure injuries in this client group.***

In rural NSW there are approximately 4500² adults living with a spinal cord injury excluding individuals living in the Illawarra and Hunter regions (the researcher did not have access to Hunter and Illawarra population data). Although not all of these individuals will be at risk of pressure injury, for example they may not be wheelchair dependent, there remains a high number (estimated at 30% at any one time²) who will develop a pressure injury. The cost to health services in terms of both bed numbers and intervention for managing pressure injury is very high and therefore prevention of pressure injury through appropriate education of community based clients and improving access to

specialised spinal seating services is likely to be cost effective for health services. Statistics for NSW admissions to acute hospitals indicate patients with a spinal cord injury admitted with a pressure injury have an average length of stay five times longer when compared to all patients admitted into NSW Health acute care facilities.² Findings of a 2011 study estimated annual treatment costs to be 260% higher for spinal cord injured patients with a pressure injury compared to those spinal cord injured patients without a pressure injury.²⁰

Introduction

Pressure injury has long been a focus of spinal cord injury research with regards to spinal cord injury due to the debilitating effects it has on those who develop them and because of the high treatment costs to health services.² Treatment can include months of bed rest to allow for zero pressure on the wound site, frequent community nurse visits to ensure healing of the wound, allied health involvement, hospital admissions and surgical intervention. Research regarding spinal cord injury and pressure injury exists around prevention, management and treatment but there is limited research regarding those who successfully maintain intact skin into the long term.

Those living with a spinal cord injury in a rural area can be at great risk of pressure injury due to their reduced access to specialised health care, care in the home and specialised equipment.³ Specialised expertise in both wound care and spinal cord injury are advocated³ as the best way to prevent and treat pressure injuries however access to both specialities in a rural area is difficult. Prevention of pressure injuries for those living in rural areas is particularly pertinent as long term bed rest (a common treatment protocol for resolving pressure injuries) can be a much more isolating and difficult protocol for rural individuals to manage. The severe disruption of client and family lives if they require surgery in a metropolitan centre with weeks or months of rehabilitation is also of concern.

The purpose of this study was to understand the experiences of persons living in a rural community who have had a long term spinal cord injury but have successfully avoided the experience of a major pressure injury. It is anticipated that these experiences and stories will inform education and management of those living with spinal cord injuries in rural areas with regards to pressure injury.

The author of this study works as a Rural Spinal Cord Injury Coordinator with the Rural Spinal Cord Injury Service (RSCIS). The position is based in Tamworth NSW and covers the northern sector of Hunter New England Health (Peel, Mehi and Tablelands Clusters). The RSCIS operates as a hub and spoke model of care, comprising a metropolitan-based multidisciplinary team (Spinal Outreach Service), supporting five Rural Spinal Cord Injury Coordinator positions across the state. The role of the coordinators is to support people with a spinal cord injury living in rural areas to achieve better health outcomes. The current (2013) data base of the service has approximately 600 rural clients⁴ with approximately 30 people (one third) with a new injury returning to live in rural NSW each year.²

Background

A pressure ulcer is a localised injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear.³ There is a standardised grading system used by health care professionals to assess the severity of a pressure injury. Pressure

injuries can be defined as: Grade 1 - Intact skin with non-blanch-able redness of a localised area up to Grade 4: Full thickness tissue loss with exposed bone, tendon or muscle or Un-stage-able with depth unknown.³ (Please see Appendix 1 for full standardised grading scale).

Persons with a spinal cord injury are at great risk of pressure injuries partially due to their inability to feel pain in a pressure area (due to poor or no sensation) and their inability to shift weight naturally (due to loss of mobility).⁵ The many other risk factors for pressure injury in this population include level and extent of injury, co-morbidities, fitness, smoking, age and a previous history of pressure injury.⁶ Duration since initial injury^{7,8} and poorly managed spasticity⁹ have also been shown to be predictive for pressure injury.

Prevalence of pressure injury in spinal cord injured population

Pressure injury remains a common occurrence in individuals with a spinal cord injury⁸ however reported rates of pressure injury in this population vary widely. Studies can vary in demographics, grades of wounds and acute versus community populations so they are difficult to compare. Other studies have included all persons with a spinal cord injury, including those who are ambulatory and therefore at much less risk of pressure injury, and again underestimate the prevalence.

Both recent⁸ (2012) and older published articles¹⁰ (1993) assessing prevalence of pressure injury report approximately 30% to 35% of the SCI population having a pressure injury. A summary of international data for pressure injury in the community is estimated prevalence at 34% (although this includes individuals with Spina Bifida).² Rates of 2.2 for new pressure injury incidences per person per year were recorded in a 2013 Canadian study which included all grades of injury.¹¹ The most severe pressure injuries (grade 4 or un-stage-able) in this study were reported to be acquired in the community.¹¹

There is an increasing spinal cord injury population in Australia and therefore an increasing prevalence of those at risk of a pressure injury. O'Connor¹² in 2005 estimated the age-standardised spinal cord injury incidence rate for Australia at 14.5 per million persons and predicts an increase in the prevalent population to between 10,500 and 12,000 by 2021. The decreased mortality and improvements in life expectancy have resulted in an increasing prevalence of patients living with spinal cord injury¹³ and therefore a possible increase prevalence of pressure injury.

Despite variations in reported rates of pressure injury occurrence individuals with a spinal cord injury remain at high risk over their lifetime and therefore it is imperative that they develop effective strategies for preventing pressure injuries.¹⁴

Effects of pressure injury on individuals living with spinal cord injury

Effects of pressure injury include social and economic impacts as well as long term physical and psychological consequences.² Severe pressure injuries affect an individual's quality of life as they require long periods of bed rest to heal (often many months), can result in systemic infection and, if not treated, can lead to mortality.²

A Canadian study on the impact of pressure injuries in the spinal cord injured population found individuals with a pressure injury report a lower quality of life than those without a pressure injury.¹⁵ The study found pressure injuries have a profound impact on participation in daily living activities as well as community activities.¹⁵

Clinical observations and research have demonstrated negative effects on general physical health, socialization, financial status, body image, and level of independence and control.⁶ This effect on

independence and control is particularly relevant as research has shown that autonomy is important to quality of life for an individual with a spinal cord injury.¹⁵

Relevance to rural and remote individuals living with spinal cord injury

Pressure injury prevention and early management is particularly relevant for rural spinal cord injury populations as surgical interventions and bed rest can be a much more isolating and difficult protocol for rural individuals to manage. The severe disruption to client and family life if they require surgery in a metropolitan centre with weeks/months of rehabilitation is also of concern.

In Australia acute spinal cord injury is treated in a specialist acute care facility in a major metropolitan city. This has presented difficulties for rural and remote patients as families need to relocate, social dislocation occurs and there is difficulty for clinicians in approximating rural and regional home environments.¹⁶ Research suggests that education received in acute care setting is de-contextualised and does not transfer well to the actual life settings.¹⁶ The information they receive regarding pressure injury prevention therefore may not be applicable to their specific home environment. These difficulties may also be applicable to the rural and remote patient who is treated for a pressure injury at one of the specialist spinal wards in a metropolitan hospital.

In rural and remote areas individuals with a spinal cord injury also have less access to specialist wound care, equipment and care in the home. Access to spinal specific wound care is recommended as best practice³ however these services in NSW are based in metropolitan hospitals. Individuals living in rural and remote areas may have reduced access to skilled nursing care or specialised surgical management which may cause a delayed diagnosis or healing.¹⁷

Cost of pressure injury to health services

Pressure injury in the spinal cord injury population is very costly to health services. Treatment often involves long term bed rest and whether this occurs in the community or in an acute hospital intensive medical care is required. It has been estimated that pressure ulcers can account for approximately a quarter of the cost of care for individuals with spinal cord injury.⁹ Grade 4 pressure injuries are the most costly to health services¹⁸ as they take longer to heal and often result in surgical intervention with an associated lengthy period of inpatient rehabilitation. Although pressure injuries may only account for a small percent of readmissions to hospital¹⁹ for this population they can be the most costly in terms of bed occupancy. One study reported an average length of stay of 65.9 days for skin related issues.¹⁹ Statistics for NSW admissions to acute hospitals indicate patients with a spinal cord injury admitted with a pressure injury have an average length of stay five times longer when compared to all patients admitted into NSW Health acute care facilities.² Findings of a 2011 study estimated annual treatment costs to be 260% higher for spinal cord injured patients with a pressure injury compared to those spinal cord injured patients without a pressure injury.²⁰

In NSW, approximations of the cost of pressure injuries in the spinal cord injury population in community settings are difficult to establish. Costs for treatment in acute facilities in NSW are estimated at around 12.5 million per year.² The average cost of a community acquired pressure injury was estimated in 2009 to be \$124,327.00 (Us Dollars).¹⁸ However neither of these estimates account for the medical care in the community required before and after a hospital admission, transportation of patients or increased care in the home awaiting an acute admission. With the current waiting lists for a surgical bed in the specialist NSW treatment facilities, patients are managed for longer intervals in the community prior to surgery further increasing costs to health services.²

The high cost of pressure injuries in the spinal cord injured population is an incentive for health services to prevent and manage pressure injuries effectively in the early stages. Preventing pressure injury would be significantly less expensive than treating stage 4 pressure injuries and the associated morbidities.¹⁸

Prevention and management of pressure injury

Traditionally individuals with a spinal cord injury have been educated and encouraged to complete specific pressure injury prevention behaviours such as twice daily skin checks and regular weight lifts. These behaviours have continued to be encouraged when research as far back as 2001 having found weight shifts to be ineffective in reducing pressure injury.²¹ This study by Sheppard et al found that there was no relationship between these traditional skin health maintenance behaviours and the occurrence of pressure injury. When comparing persons who rarely with those who frequently sustained pressure injuries Jones et al reported two interesting findings.¹⁴ Firstly, activity and increased transfers rather than regular pressure relief movements were associated with the ulcer free group (although this study included subjects with some sensation so movements may also have been associated with discomfort). The second finding was that when comparing the ulcer group with the ulcer free group the ulcer group were more likely to daily skin check than the ulcer free group. The ulcer free group based their checking on need. Research by Clark et al in 2006 indicates that preventing pressure injuries in this population is a much more complex undertaking than just adhering to traditional methods and is individual to a person's unique set of life circumstances.⁶

When investigating risk for pressure injury Clark et al in 2009 investigated how individuals responded to the discovery of an early stage injury and produced a list of eight response categories that led to a more severe wound.²² These included procrastination, lacking adequate knowledge and diverting attention. The study concluded that clinicians should be focused on individual customised interventions in everyday settings rather than imparting generalised preventative information, for example specific weight shifts every 30 minutes. The researchers also recommended further research into the response characteristics of individuals who discover an early stage wound but it does not continue to a more severe stage.²²

Due to the development of a pressure injury being reliant on a very complex set of circumstances and risk behaviours there appears to be a shift to investigate protective behaviours versus risk factors when determining an individual's likelihood of developing a pressure injury.⁶ This study focused on the daily lifestyle influences on the development of pressure injuries and developed a number of data based models showing how this may occur.⁶ The study listed "liabilities versus buffers" in the areas of physical, health related, psychological, social/environmental and other (27 in all). The results indicated that a pressure injury was more likely to develop when a person with a high risk profile was exposed to a life disrupting event and the balance of "buffers to liabilities" was affected. This study reinforced the notion of a "change event" causing an increase in risk.⁶ Therefore it can be concluded that individuals who are flexible with their skin care routine and can proactively problem solve the need to change their skin care behaviours as needed are less likely to have a pressure injury.

Sheppard et al suggests protective factors may be more related to general characteristics (employment, years of education, marital status) rather than specific health maintenance behaviours.²¹ Although Smith et al found no difference in these characteristics as protective for pressure injury.²³ A 2013 Indian study found that manual workers (73%) had milder ulcers when compared to other employment categories and concluded that the physical activity in manual work

meant that they do not stay in the position for a long time.²⁵ This was consistent with Sheppard et al reporting that people with healthy skin histories were likely to perform more transfers per day.²¹

Taking responsibility for skin care is also associated with decreasing pressure injury risk. In the ACI NSW Model of Care² (published in March 2014) self-management is one of three key principals highlighted for the prevention of pressure injury. Self-management has also been proven to be effective in the management of other chronic illness, for example diabetes.²⁶ It is recommended that people with spinal cord injury also learn and incorporate effective and appropriate pressure ulcer strategies into their daily lives.^{6,9} This research also aligns well with a study investigating the quality of life among people with a high spinal cord injury¹⁵ finding that quality of life was dependent upon, among other factors, the opportunity to control their own life and care. A study investigating the skin care beliefs of individuals with a spinal cord injury recommended people should be encouraged to take control over their skin care from the time they are medically stable.²⁷

A recommendation from a previous study indicated more research is required with individuals with a spinal cord injury who experience few problems with pressure injury over their lifetime.¹⁴ The study recommended that research into the wellness behaviours of those with a spinal cord injury and fewer pressure injuries would be particularly relevant and could inform better education and management of pressure injuries in spinal cord injury populations living in the community.¹⁴ A number of key points from the SCIRE Project⁹ also indicated the need for more research regarding the best approaches for pressure injury prevention education and why some individuals adhere to prevention strategies and others do not. A Study that investigated that education of individuals with a spinal cord injury in regards to pressure injury advised that education should be community based and reinforced over time.²⁸ Other studies have concluded that community based pressure injury prevention efforts are strongly needed²⁹ and valuable³⁰ in the prevention of pressure injury. A study that analysed the educational needs of individuals with a spinal cord injury found one of the preferred education delivery methods was discussing the topic face to face with another adult with a spinal cord injury.³¹

In conclusion preventing and effectively managing early stage pressure injuries in the spinal cord injured population "... has the potential to eradicate enormous pain and suffering, save thousands of lives, and reduce healthcare expenditures by millions of dollars".¹⁸

Research Question

What is the lived experience of rural individuals with a long term spinal cord injury in maintaining intact skin? The aim of this research project was to explore how individuals who do not get pressure injuries manage their skin care.

Rationale for performing the study

- High prevalence of pressure injury in spinal cord injured population
- Long term psychosocial and physical effects of pressure injury on individuals
- Relevance to rural and remote individuals
- Cost of pressure injury treatment to health services
- Limited studies looking at community based individuals with a spinal cord injury who do not experience pressure injury
- No studies on rural individuals living with a spinal cord injury and their approach to pressure injury prevention

Method

Ethical approval for the study was obtained from the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District in August 2014.

Methodology

The chosen research approach was hermeneutic phenomenology as the research project explored the lived experience of individuals with spinal cord injury caring for their skin. As the research question relates to needing to understand several individuals' shared experiences, phenomenology was decided on as an appropriate choice.³¹ In this case the shared experience was living in rural NSW, having a long term spinal cord injury and not having had a severe pressure injury. It is the exploration of what individuals do and why, rather than what they know, that is the basis of this research study. Research suggests that real-world settings are the most robust method for assessing the effectiveness of prevention strategies in the case of pressure injury⁹ supporting this research being conducted with participants in their own homes.

Participants

Research participants were identified from a database held by the Rural Spinal Cord Injury Service (New England) ensuring that all participants who were chosen had a confirmed diagnosis of spinal cord injury and resided in a rural or remote area. To manage the possibility of coercion all Rural Spinal Cord Injury Service clients already known to the researcher were removed from the database list. For the remaining potential participants the following inclusion criterion was used:

1. Spinal cord injury present for more than 10 years
2. No motor ability below their level of injury i.e. Assessed as ASIA A or B (ASIA - American Spinal Cord Assessment – see appendix for definition)
3. Living at home
4. Had not had a Grade 3 or 4 pressure injury (This terminology was changed when enrolling participants as most were unfamiliar with the term grade 3 or 4 pressure injury – it was changed to “major” pressure wound and participants were included who had never been hospitalised or had surgery for a pressure injury)
5. Do not have a significant brain injury (as skin care routines are likely to not be self-managed, but initiated and managed by a carer).

The ten year post injury time and completeness of injury were selected as length of time post injury and completeness of injury are high risk factors for pressure injury. Clients who were known not to meet the inclusion criteria were removed from the data base list (this is known through a regular case review process with the service manager and another rural coordinator). This left 41 potential participants for the research project.

Potential participants were sent a letter (See Appendix 4) outlining the project and asking for volunteers. As no response was received within 2 weeks of the mail out, a further culling of the list was then completed removing clients from the database list who did not have a known contact phone number. A colleague of the researcher then telephoned the remainder of the clients randomly selecting names from the 24 person list. Calls were made over a period of two weeks resulting in 6 potential participants. Other potential participants either did not answer the telephone, declined to be interviewed or advised of not being within the inclusion criteria. The

researcher then telephoned the potential participants to organise a home visit to complete the interviews.

The Interview

The interviewer was experienced in interview techniques, particularly with individuals with a spinal cord injury, as home visits and initial interview assessments formed part of her job tasks. Semi structured interviews were completed by the researcher in the participants own homes at a time of their convenience. Face to face interviews in participants own homes were identified as the most appropriate as:

1. Attending appointments can be a challenge for people with a spinal cord injury particularly those living in rural areas where public transport is limited and they may need to organise carers or community transport.
2. Having the interviews take place in a participant's home allows for easier establishment of rapport, ability for researcher to see how/when/where skin care is completed and the types of equipment used for skin care.
3. Some clients with a high level spinal cord injury have limited handwriting function and therefore answering a written questionnaire would be difficult.

Written consent was obtained prior to the interview (see Appendix 3 for copy of consent form). The interviews were all audio-recorded. In an attempt to establish rapport with the participant, all demographic, living situation and injury information was obtained prior to the formal taped interview.

A literature search (see Appendix 2) was completed prior to the research interviews to inform the types of questions to ask. An outline interview schedule was used (see Appendix 5 for example questions) however this was only a starting point and more in-depth questions were asked during the interview process.

Additional relevant information obtained from the participant either prior to or following the recording of the formal interview was included in field notes completed immediately following the researcher leaving the participant's home. All interviews were completed between October 2014 and January 2015. A variation form was submitted in April 2015 to allow the field notes to be used in the analysis as this was not included in the original research protocol. Approval of the variation was received from the Hunter New England Human Research Ethics Committee on 5th May 2015. The recorded interviews were transcribed by the researcher.

Data Analysis

The process of data analysis was informed by information gained from the Rural Research Capacity Building Program research workshops, discussion with the researcher's supervisor and mentor and Carole Grbichs book *Qualitative Research in Health: An Introduction*.³³ Each interview recording was transcribed by the researcher as soon as possible after the interview. Preliminary analysis occurred at this time to identify any gaps in the information or where further questioning would be an advantage in the following interview. This preliminary analysis allowed the researcher to start to form a framework of issues in relation to the topic and so inform the next interview questions and approach. The preliminary analysis also assisted in determining that saturation of data had been reached. Once all the interviews had been completed and transcribed the researcher met with her mentor to discuss the emerging themes from the preliminary analysis and explore their meaning.

Both the audio-taped and the transcribed interviews were listened to and reread many, many times to ensure the emerging themes were consistent across all interviews and that no further issues were appearing. A coding tree was developed and examples from each transcription (the majority being participant quotes) were aligned with each. The codes were grouped and regrouped until all information was a “fit” for a code. Definitions for each were completed and added to as the process unfolded. The codes were then also organised into sub-codes or categories to allow for increased understanding of the data. The researchers mentor was instrumental in exposing how the researchers own values and beliefs may be affecting the interpretation and the codes were adjusted by the researcher accordingly. This discussion was particularly focused on the fact that the researcher initially may have interpreted some of the data from a clinicians perspective but through this discussion and learning process was able to ensure the data remained true to the participants original answers and ensure it was seen through their eyes.

Findings

Six participants were interviewed for this research project. Following further questioning during the interview process, one participant was found to not meet the inclusion criteria (he had had surgery for a grade 3 pressure injury) and therefore his interview was not included in the analysis. The five remaining participants were all white, Caucasian males. Their average age was 45.8 years (range 35 to 58 years) and the average time since injury was 23 years (range 11 to 33 years). Three participants lived on rural properties (2 outer regional and 1 remote as per ASGC-RA Classification) and two lived in towns with a population greater than 10 000 (inner regional). Three participants identified as paraplegic and two as tetra-plegic. In three of the five interviews the participants’ carer (wife in two cases and mother in one) was also present and contributed to the data.

All participants reported no issues with co-morbidities or mental health and reported their pain, bladder and bowel routines and spasms as being well managed. Anecdotally all participants appeared to have a high level of self-efficacy as all five were independent with self-care to their full potential, three were employed full time and the remaining two reported levels of social and leisure activity that they were satisfied with.

Analysis of the interview transcriptions resulted in the following main themes and a number of sub themes being identified as central to the participants’ success in maintaining their skin integrity over the long term. The three main themes were: ‘skin not a separate entity’, ‘self-sufficiency’ and ‘disruption to life’.

Skin not a separate entity

The participants in this study did not see their skin as a separate entity or their skin care as a specific routine that needed attention. Skin care was embedded in their everyday activities. Participants demonstrated high levels of flexible thinking and problem solving abilities and intimate knowledge of their own bodies which assisted them to maintain their overall health including their skin integrity.

Completion of pressure relief within daily living tasks

All of the research participants reported that they did not complete specific or regular pressure relieving lifts to manage their skin integrity. One participant described everything he had to do to

maintain his health due to his spinal cord injury and therefore he said managing pressure relief within the tasks he already did made life easier.

Participant 5: “There are so many things we have to do and think about that one less thing (not completing specific pressure relief movements) is actually a lot”.

The majority of participants (four of five) advocated movement or activity performed within their everyday activities as their number one strategy for preventing pressure injuries.

Participant 4: “I don’t really have to think about pressure relief because I’m active”.

The only participant who didn’t advocate activity was a high level tetraplegic with minimal body movement although he also performed his pressure relief within his daily living routine rather than as a separate task. He used a power wheelchair for mobility with a tilt mechanism that could assist with pressure relief but he only used this in relation to self-care tasks or comfort – he did not regularly use it for the explicit purpose of pressure relief. When asked how often he used the tilt feature for pressure relief he replied:

Participant 3: “Oh time to time not very often (laughs) ... more for comfort than anything. Well I suppose every day I do because every time I tilt and stuff like that to empty the leg bag”.

Persons who are active throughout their day redistribute pressure automatically and within their functional activities. The Canadian Best Practice Guidelines³ advises that increasing daily functional activity may be sufficient to protect skin from excess or prolonged pressure. This study of rural individuals included those who were very active and gainfully employed and therefore pressure relief within daily activity worked for them. However rural individuals with a spinal cord injury generally have less access to suitable employment and leisure activities, for example wheelchair sports are generally organised in metropolitan areas. There may be some individuals therefore who may not be active enough to prevent pressure injuries. In this case clinicians need to be innovative when working with this client group to encourage access to activities that would allow them to obtain a level of activity that would prevent pressure injury. Examples might be encouragement to participate in volunteer work or increased participation in domestic tasks.

The three manual workers in this study reported fewer incidences of red marks than the two sedentary participants. The active participants reported frequent leaning forward, reaching and transfers to complete tasks. This was consistent with a 2013 study²⁵ that found manual workers have fewer incidences of pressure injuries than those with sedentary occupations.

Participants in this study appeared to have contextualised their knowledge and behaviours into their everyday lives. Care of skin in this cohort was particularly related to activity - the more active participants were with their daily routine the less specific skin care behaviours were performed. This confirms results of the Jones et al 2005 study¹⁴ that activity may be a protective factor against skin breakdown. This finding is relevant for clinicians in acute and community settings. In an acute setting there may be less opportunity for activity (e.g. not working, having assistance with self-care and domestic tasks) so specific pressure relief movements would continue to be relevant. In a community setting however it may be more relevant to instigate discussions with clients around activity levels rather than frequency of pressure relieving lifts.

Proactive response to body signals

All participants reported cues from their bodies as a catalyst for investigating issues with their health. Participants had an acute awareness of small changes or symptoms that might hint of

something more severe. When they identified a physiological change they proactively looked for a reason, including checking for skin irritation or excess pressure. Participants reported spasms, perspiration and symptoms of low grade autonomic dysreflexia as key signs for increased skin checking.

Participant 2 “Yeah if I’m starting to get a spasm or something for some reason you know if I’m sitting there and for some reason I’m getting a different spasm that’s when I’ll check it and I think is there something going on with my bum?” Line 35

Participant 4 “I get symptoms, what is it called again? You probably know spasms and sweating around the back of the neck?” “Autonomic dysreflexia?” (Researcher) “Yes that’s it. I get a few symptoms and check what is going on”. Line 77

All participants also had a good knowledge of what an early stage wound might present as (usually just a small red mark). They were proactive in attending to these small skin changes by removing pressure or utilising short term bed rest to resolve them. Participants had a plan for being able to continue with work or activities of daily living while managing their newly discovered red area/early stage injury.

Participant 2 “I’d do a couple of hours work or whatever then I’d go lay down for a couple of hours, put me bum up in the air. Just keep doing that all day on and off ‘til it sort of went away”. Line 135

Participant 4 “I’ve had the odd time where I might have an afternoon or day in bed taking the pressure off”. “Or a couple of times you’ve had more than a day” (wife). “Yeah if I’ve been worried I might do it for a bit longer”. Line 30

“Attention to bodily warning signs” is described in one research study investigating the relationship between “buffers and liabilities” as a buffer i.e. a protective factor against pressure injury.⁶ Interpreting cues from the body and modifying pressure injury prevention behaviours accordingly, as these research participants did, is also associated with being an effective problem solver.¹⁴

A study that looked at response factors leading to progression of wounds found that procrastination and diverting attention were two factors that led to individuals not managing an early stage injury. This is in contrast to the participants in this study who did not procrastinate with regards to immediately taking pressure off their early stage injury and had not had wounds that had progressed to a severe stage.

The participants in this study had lived with their spinal cord injury for many years and therefore knew what felt and looked right to them. Patients in the early years of their injuries may not have this acute awareness of their body signals. They may need encouragement and reminding of acknowledging small changes and proactively following up on the cause as a means of preventing larger problems. This may need to be reiterated to patients as they transition back to their communities.

Flexibility and problem solving

All research participants completed traditional skin care techniques (skin checks and specific pressure relief movements) on an as needed basis only. They were flexible with their self-care routines and were able to problem solve the need to change to more vigilant checking or increased

pressure relief movements following participation in risky behaviours. When their day to day routine changed so did their pressure injury prevention behaviours.

Participants who rarely performed specific checks or movements when at home were much more diligent when away from home or travelling long distances.

**Participant 2 “Whenever I go away I take a mirror in my toiletry bag so I check it that way”.
Line 99**

Participant 5 “Sometimes I drive back from Sydney by myself and I do stop and I move around then...”

The two participants who were less physically active (one due to being a high level tetraplegic and the other due to spending most of his time inside completing sedentary tasks) were much more diligent with daily checking of skin than the more active participants. They reported more incidences of red marks requiring frequent monitoring.

Participant 6 “Like every time I lie down, even if it is only an hour, I’ll check it (skin). Like not the whole body, like just where your pressure areas are like under your bum, under your heels”.

The 3 participants who were very active on a day to day basis only checked their skin regularly if something about their routine changed for example spending longer on the quad bike than usual.

Participant 2 “...if I know I’ve been, you know, clambering through the bush and things like that yeah I’ll check it when I get back”.

Another example of the participants ability to problem solve was their care with transferring from their wheelchairs to other equipment. The active participants reported completing many transfers per day which can be a risk for pressure injury as there is more chance of scraping/bumping during transfers. However participants reported care with transfers and were able to independently resolve the issue of difficult transfers.

Participant 4: “Oh about half a dozen (transfer per day). I’ve got a modification to the bike I’ll show you after that helps me transfer across”.

Participant 5: “I am careful getting on and off the bike. I use a cushion over the wheel of the wheelchair”. (This participant also had an electronically operated ramp for his wheelchair that lifted him up so that the transfer from the wheelchair to the quad bike was on the same level).

Participants also responded to change events in their lives whether this was a change in routine or a change in their symptoms they responded in a very timely manner. A previous study found that not responding to a change event can be a catalyst for skin breakdown and increase risk of wound progressing.⁶ Their ability to be flexible and problem solve issues were protective factors in prevention of skin breakdown. This confirms previous research that persons should be educated to alter behaviour when life circumstances change and to anticipate situations that may hinder care.²⁸ This aligns with data based models looking at change as catalyst for skin breakdown and increase risk of wound progressing.³

Within the acute care model there is less opportunity to practice problem solving and flexibility with skin care regimes as appropriate equipment is provided, skilled personnel are on hand to answer questions and skin care is monitored at a close level by staff. Rural and remote patients have less likelihood of day or weekend leave during rehabilitation to go home and practise their skin care in a

real life context. They may therefore require increased follow-up following discharge to encourage flexibility in managing their skin and ensure they have adequate problem solving abilities for their own context.

Self-Sufficiency

Independence

All participants showed a high degree of autonomy and responsibility for their own skin care. Three of the five participants independently completed their own self-care including responsibility for skin care management. The two remaining participants were tetra-plegic and required assistance with self-care however they both maintained responsibility for their skin care regime.

One tetra-plegic participant required twice daily assistance of a care agency for his self-care. He used an agency where by the client takes full responsibility for recruiting and training of the carers. He had changed to this type of care agency following dissatisfaction with a previous agency and their tendency to take over.

Participant 3: “Yeah it was terrible when I first started; just with the care provider that I had they were a bit domineering and yeah made life difficult.”

Following the change of care providers the participant developed a routine for the carers to check his skin and he and his wife trained the carers in what to look for when assessing his skin. If the carers found a mark of any sort, they would then take a photo of it with a mobile phone for the participant to check and for him to decide on the most appropriate course of action.

Participant 3 (Wife): “They (carers) tell him what they’re seeing and then he makes the judgment.”

Participants appeared to gain confidence over time with their skin care management and reported they were more forthcoming with what they knew to be right for their individual requirements. This particularly related to when they were hospitalised and being confident to tell the nursing staff what their needs were, particularly with regards to skin care.

Participant 3: “Probably one thing is trust your gut a lot more ... Now I’ve got the confidence to say hey no hang on a minute. Like state your case”. Line 279

Participants in this study achieved their autonomy through knowledge of skin care, confidence in knowing what was right for them and being the decision maker from when an early stage injury was discovered rather than relying on the opinions of others. These participants exhibited a high degree of self-efficacy has been proven to be a strong predictor of effective self-management in other chronic conditions.²¹ Their self-sufficiency or self-management was present in all aspects of their lives not just concerning skin care. It is a possibility that their rurality was a factor in this behaviour as they have had to be independent in the absence of support however this is not a conclusive finding. Their independence may also be related to the personalities of this small group of participants. However it does appear that this autonomy and self-sufficiency has contributed to their success in maintaining their skin integrity.

Interaction with services on their own terms

Four of the five participants had attended a specialised spinal seating service over the last 2 years and all but one had attended a rural spinal outreach clinic in the last 2 years. The client who had not attended the rural outreach clinic had maintained contact with his acute treating rehabilitation team

(in another state). Participants were positive about their interaction with these services with regards to skin management however reported very little regular association with local health services other than their GP. Many of the participants reported negative experiences with local health services when they were first home from acute rehabilitation. This initial negative experience appears to have coloured their future contacts with local health services, in particular community and allied health services.

Upon discovery of an early stage wound none of the participants indicated that they would contact local services except possibly their GP. Some participants saw contacting the local occupational therapist (OT) as part of a process that they had to go through to have equipment paid for rather than relying on them as an expert in equipment prescription:

Participant 6: “So the OT comes out and sees you?” (Researcher) “Yes we go through all that process”.

Another participant only contacted the local community nurse in relation to having dressings paid for:

Participant 3 “We’ve spent a lot of money on that stuff (dressings) so now we try to, if I get a bad one, we get the community nurses purely to get the gear”.

Participants who were financially able to purchase their own equipment (either through an insurer or due to a compensation payout) tended to purchase equipment in an ad hoc manner without expert input or trialling of equipment and with little regard for changing needs e.g. aging skin, changes in body weight.

Participant 4: “How do you access equipment?” (Researcher) “Just ring them up really. I do it myself. If you’ve been in a wheelchair for as long as I have you know what you need.” “So you don’t involve an OT or anything?”(Researcher) “No I just order it and XX (the insurer) pays”.

Participant 2: “I just went into the wheelchair type shop they’ve got in town here, they don’t sell too much. I said ‘What’ve you got in the way of cushions? She said ‘We are selling this one and I said ‘That’ll do me, get me one in’ and it’s probably the best cushion I’ve had so far”.

During the interview process participants were asked why they thought they had maintained their skin integrity over time. Participants replied with comments like “luck” or having “good skin”. They identified they did not look after their skin utilising the traditional methods taught to them in rehab.

Participant 5: “I’m probably not the one to ask, I’m not a good example....I probably don’t do anything by the book”.

Participant 2: “When the subject comes up well I’ve never had one so no point in telling me how to care for one if I’ve never had one”.

Although this ad-hoc approach to equipment generally worked for them in the short term participants acknowledged that when they had access to a seating clinic appointment they utilised it. Participants particularly liked the pressure mapping capabilities of the seating service and felt this was one way they could see for themselves what equipment would suit their own pressure care needs.

In rural areas community health workers may only have one or two spinal cord injured clients therefore specialised clinical skills like customised wheelchair prescription may be difficult to maintain. The Canadian best practice guidelines³ state that the individual needs of a person with a spinal cord injury are very specific and require much expertise in the assessment and prescription of equipment. With these expertise only available to rural clients once or twice a year, it does not encompass the needs of spinal cord injured individuals with regards to pressure care needs in a timely manner.

Participants appeared reluctant to let someone with unknown spinal expertise into their lives. This is understandable given their long term spinal cord injury. As reported in the literature there is a fine balance between protective factors and risk of pressure injury and these participants appeared very protective of accepting generalised advice with regards to skin care. This seeming distrust of non-specialist spinal services has been documented previously by Middleton et al¹⁷ in 2008 and informed the introduction of the Rural Spinal Cord injury Coordinator positions and annual spinal specific education opportunities for rural health staff in NSW. This research cohort were experienced as well as successful in looking after their skin and therefore disinclined to relate to a service where they did not perceive they were receiving expert help or possibly that help was even necessary. It is therefore important for clinicians to acknowledge the expertise of long term spinal injured clients in looking after themselves. Learning from these individuals about what they actually do on a day to day basis, as opposed to what they have been told to do, is vital to furthering knowledge of prevention of pressure injuries in this population.

Minimise Disruption to Life

Participants were motivated to maintain their skin integrity through fear of further incapacity and their sense of responsibility to others.

Fear of further incapacity

When asked what motivated them to look after their skin all five participants related a story of someone in a similar situation who had a pressure injury. Participants identified as being “scared” of pressure injuries however when questioned further about what they were scared of it wasn’t just the wound itself but also the knowledge that long term bed rest could be the possible treatment. All the stories related by the participants were in context to the participants own situation:

Participant 5: “What really scared me was XX said she was seeing a farmer who had been in hospital for over 6 months and he still had an ulcer that was six by six inches sort of thing so that was pretty scary”

Participant 2: “There’s an old bloke I used to know who had a property out at XX and he used to get quite a few pressure sores because he’d, you know he was a farmer, and he’d leave his pliers in his pocket and sit on them and forget about them and he had quite a few breakdowns so sort of maybe subconsciously I do things that relieves me all the time and that’s why I’ve never had any”.

It is interesting that this ‘fear’ was specifically related to in-context stories. The effect of peer influences with regards to education is well reported³¹ and these findings support the involvement of in-context stories and peer influence. It would therefore be valuable to have in-context i.e. rural stories when educating both acute and community rural clients with regards to pressure injury. It may be useful for clinicians to have stories of how rural people manage their skin well within their daily routines as well as the “scary” stories.

Responsibility to others

Research participants were concerned about the long term effects pressure injury would have on their families and also their ability to earn an income. They advocated short term bed rest as a much preferred management technique to waiting until long term bed rest or surgery might be required.

Participant 4: “I can’t afford the time in bed. So then XX (wife) would have to do everything. You don’t want to be seen as dragging the chain.”

In a recent study, patients continuing with their lives and ignoring early stage pressure injury due to work and other life pressures has been cited as a reason for progression of a pressure injury²² however in this cohort responsibility was the catalyst for proactively looking after their skin. These participants were much more concerned of the effects pressure injuries (particularly long term bed rest or surgery) than a few hours or days in bed would have on their finances and families. This sense of responsibility prompted them to be proactive with management of minor skin problems.

Strengths and Limitations

To the authors knowledge this study is the first to seek to understand the lived experience of intact skin amongst rural spinal cord injured individuals. It looked at success stories as a means of informing the research rather than those with or with a history of ulcers as is common with research in this area. A second strength is the setting for the study being a ‘real world setting’ rather than an acute hospital and this allows for the information to more relevant to community dwelling individuals. Another strength is the study only included participants with a long term spinal cord injury and the fact they had been successful over a long period of time should strengthen the validity of the findings.

A limitation of this study is its very small sample size however this can be countered by the saturation of the data responses. Information gained may not be able to be generalised to the whole spinal cord injury population however these insights will still be relevant to rural consumers and clinicians. The aim of the study was to report on the experiences of a particular cohort rather than make overarching hypothesis with regards to preventative behaviours and this has been achieved. A second limitation is the self-reported pressure injury history of the participants. The researcher did not access medical history files or have contact with participants’ medical practitioners to confirm their pressure injury history although it does not appear that participants had anything to gain by not reporting their history accurately. The reported characteristics of this small sample may also be a limitation. All five participants reported no co-morbidities, being non-smokers and appeared to have good levels of self-efficacy – previous research has shown that these attributes reduce the risk for pressure injury. It is possible these characteristics alone may have contributed to the non-occurrence of severe pressure injury rather than the behaviours reported in this study however it is more likely that both contribute to the success of these individuals in maintaining intact skin.

Conclusion

Although the participants in this research project had a number of characteristics that put them at risk of pressure injury – age, time since injury, living rurally and completeness of their spinal cord injury – as discussed, they also shared a number of behaviours that appear to be protective of pressure injury. The information from this study is consistent with previous research outlining the complexities of pressure injury prevention and management in the spinal cord injured population.

This study identified relevant information to inform clinical education and intervention with rural clients with regards to pressure injury prevention and management.

Recommendations for consumer education and intervention include:

- Engagement of rural clients with Rural Spinal Cord Injury Services immediately following discharge from acute units to ensure they can adapt skin care practices to the context of their own environment.
- Assess the community dwelling individual's activity levels – the more active the client the less pressure lifts and skin checking may be required.
- Where activity is lacking encourage increased activity through volunteer work, leisure pursuits or increased participation in domestic tasks.
- In the early stages of spinal cord injury individuals may need prompting to respond to body signals until an awareness of their “normal” is achieved. It is not enough for them to be able to identify the signals, a proactive response is needed.
- Reinforce the need for flexibility with skin management, including responding quickly and appropriately to any change in daily routines.
- Where problem solving abilities are compromised, for example in the presence of a brain injury, clinicians may need to assist the problem solving process with flow charts, plans for action, when to utilise short term bed rest, who to contact or the increased education of carers.
- Encourage clients to take charge of their skin care from as early in the rehabilitative process as possible. As this study showed even those that require full self-care assistance can still be in control of their skin care and make decisions of what to do when an early stage pressure injury is discovered. For clients who are unable to self-manage, the collaborative or supported self-management models as outlined in the ACI Model of Care might be more appropriate.
- Avoid generalisations regarding skin care when educating individuals with a long term spinal cord injury. Advice and information needs to be relevant to that person and their context to be effective and for rapport building. Clinicians need to respect the expertise of these individuals in managing their own health.
- Individuals in this study appeared to have adapted to the lack of specialist spinal cord injury equipment services however this is not an ideal situation. For clients who have more risk factors than these research participants or who do not exhibit the protective behaviours as outlined in this research timely access to expert prescription of equipment is essential. A local health district specialised seating service would ensure timely access and evidence based equipment prescription.
- Use in-context stories involving rural individuals with a spinal cord injury as an effective means of communicating risk and consequences. Long term “success” stories like those of these research participants should be promoted as well as the “scary” stories.

References

1. Garner H. **True Stories**. Melbourne: Text Publishing; 1996.
2. **Model of Care for Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injury and Spina Bifida**. NSW State Spinal Cord Injury Service. Agency for Clinical Innovation Published: March 2014
3. Houghton PE, Campbell KE and CPG Panel. **Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury. A resource handbook for Clinicians**. 2013. Accessed at <http://www.onf.org>
4. Barker J, Brabrook C, Johnston S and Rogan A. **Reflections on the Evolution of a Rural Service**. Australian New Zealand Spinal Cord Society 2013 Conference Poster Presentation.
5. Krause J S, Broderick L. **Patterns of recurrent pressure ulcers after spinal cord injury: identification of risk and protective factors 5 or more years after onset**. Arch Phys Med Rehabil. August 2004; Vol 85.
6. Clark FA, Jackson JM, Scott MD, Carlson ME, Atkins MS, Uhles-Tanaka D et al. **Data-based models of how pressure ulcers develop in daily-living contexts of adults with spinal cord injury**. Arch Phys Med Rehabil. 2006 Nov; Vol 87.
7. Marin J, Nixon J, Gorecki C. **A systematic review of risk factors for the development and recurrence of pressure ulcers in people with spinal cord injuries**. Spinal Cord. 2013; 51, 522–527.
8. Eslami V, Saadat S, Habibi Arejan R, Vaccaro A R, Ghodsi S M, Rahimi-Movaghar V. **Factors associated with the development of pressure ulcers after spinal cord injury**. Spinal Cord. 2012; 50 Vol 12.
9. Henzel MK, Bogie KM, Guihan M, Ho CH. **Pressure ulcer management and research priorities for patients with spinal cord injury: Consensus opinion from SCI QUERI Expert Panel on Pressure Ulcer Research Implementation**. J Rehabil Res Dev. 2011; Vol 48.
10. Fuhrer MJ, Garber, SL, Rintala DH, Clearman R, Hart KA. **Pressure ulcers in community-resident persons with spinal cord injury: prevalence and risk factors**. Arch Phys Med Rehabil. 1993; Vol 11.
11. Deena L, Fré'déric S, Dumont S, Leblond J, Houghton PE, Noreau L. **Impact of pressure ulcers on individuals living with a spinal cord injury**. Arch Phys Med Rehabil. 2014; Vol 95.
12. O'Connor P. **Prevalence of spinal cord injury in Australia**. Spinal Cord. 2005; Vol 43.
13. Norton L. **Spinal cord injury, Australia 2007–08**. Australian Institute of Health and Welfare. 2010. Injury research and statistics series no. 52. Cat. No. INJCAT 128. Canberra: AIHW.
14. Jones, ML, Marini, I, Slate JR. **Prevention practice differences among persons with spinal cord injuries who rarely versus frequently sustain pressure injuries** Rehabilitation Counselling Bulletin; Spring 2005; Vol 48.
15. Whalley-Hammell K. **Quality of life among people with high spinal cord injury living in the community**. Spinal Cord. 2004; Vol 42.
16. Booth S, Kendall M. **Benefits and challenges of providing transitional rehabilitation services to people with spinal cord injury from regional, rural and remote locations**. Aust. J. Rural Health. 2007; Vol 15.
17. Middleton J W, McCormick M, Engel S, Rutkowski S B, Cameron I D, Harradine P, et al. **Issues and challenges for development of a sustainable service model for people with spinal cord injury living in rural regions**. Arch Phys Med Rehabil. October 2008; Vol 89.
18. Brem H, Maggi J, Nierman D, Rolnitzky L, Bell D, Rennert R, et al. **High cost of stage IV pressure ulcers**. Am J of Surg. 2010; Vol 200.
19. Middleton J W, Lim K, Taylor L, Soden R, Rutkowski S. **Patterns of morbidity and rehospitalisation following spinal cord injury study at RNSH**. Spinal Cord. 2004; Vol 42.
20. Stroupe K, Manheim L, Evans C, Guihan M, Ho C, Li K, et al. **Cost of treating pressure ulcers for veterans with spinal cord injury**. Top Spinal Cord Inj Rehabil. 2011; Vol 16.

21. Sheppard R, Kennedy P, Mackey CA. **Theory of planned behaviour, skin care and pressure sores following spinal cord injury.** J Clin Psychol Med Settings. 2006; Vol 13.
22. Dunn CA, Carlson M, Jackson JM, Clark FA. **Response factors surrounding progression of pressure ulcers in community residing adults with spinal cord injury.** Am J Occup Ther. May/June 2009. Vol 63.3.
23. Smith BM, Guihan M, LaVela SL, Garber SL. **Factors predicting pressure ulcers in veterans with spinal cord injuries.** Am. J. Phys. Med. Rehabil. 2008 Vol. 87.
24. Krause JS, Vines CL, Farley TL, Sniezek J, Coker J. **An exploratory study of pressure ulcers after spinal cord injury: relationship to protective behaviours and risk factors.** Arch Phys Med Rehabil. 2001; Vol 82.
25. Mathew A, Kumar S, Radhika S, Elango A. **Engagement in occupational activities and pressure ulcer development in rehabilitated South Indian persons with spinal cord injury.** Spinal Cord. 2013; Vol 51.
26. Hunt CW, Wilder B, Steele MM, Grant J S, Pryor ER, Moneyham L. **Relationships among self-efficacy, social support, social problem solving, and self-management in a rural sample living with Type 2 Diabetes Mellitus.** Res Theory Nurs Pract. 2012; Vol.26.
27. King RB, Porter LS, Balfanz Vertiz K. **Preventative skin care beliefs of people with spinal cord injury.** Rehabil Nurs. July/August 2008; Vol. 33.
28. Maria H, Larcher C. **Spinal cord injury and pressure Ulcers.** Nurs Clin N Am. 2005; Vol 40.
29. Vaishampayan A, Clark F, Carlson M, Blanche E I. **Preventing pressure ulcers in people with spinal cord injury: targeting risky life circumstances through community based interventions.** Adv Skin Wound Care. 2011 June; Vol 24.
30. Ghaisas S, Pyatak EA, Blanche E, Blanchard J, Clark F. **Lifestyle changes and pressure ulcer prevention in adults with spinal cord injury in the Pressure Ulcer Prevention Study lifestyle intervention.** Am J Occup Ther. Jan/Feb 2015; Vol 69.
31. Schubart J R, Hilgart M, Lyder C. **Pressure ulcer prevention and management in spinal cord-injured adults: Analysis of educational needs.** Adv Skin Wound Care. July 2008. Vol. 21.
32. Creswell J. **Qualitative Inquiry and Research Design: Chosing Among Five Approaches 2nd Edition.** Thousand Oaks: Sage Publications 2007.
33. Guihan M, Garber S L, Bombardier C H, Durazo-Arizu R, Goldstein B, Holmes SA. **Lessons learned while conducting research on prevention of pressure ulcers in veterans with spinal cord injury.** Arch Phys Med Rehabil. 2007; Vol 88.
34. Grbich C. **Qualitative Research in Health: An Introduction.** Allen and Unwin. 1999.

Appendix 1 - Glossary of Terms

Pressure injury:

Pressure injury can be listed as pressure ulcer, sore, wound or area. They are also known as decubitus ulcers, ischemic ulcers or bed sores.

They have been defined as a “*localized injury to the skin and/or underlying tissue usually over a bony prominence as a result of pressure or pressure in combination with shear and/or friction*” (NPUAP 2007). The primary cause of pressure ulcers is felt to be externally applied pressure for a prolonged period of time over bony prominences such as the sacrum and ischial tuberosity. This applied pressure leads to decreased blood supply to the overlying soft tissues; tissue ischemia and can ultimately lead to tissue necrosis.

National Pressure Ulcer Advisory Panels (NPUAP) updated pressure ulcer staging system (NPUAP 2007):

Stage:	Description:
Deep Tissue Injury (Suspected) Stage	Purple or maroon localized area of discoloured intact skin or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. The area may be preceded by tissue that is painful, firm, mushy, boggy, warmer or cooler as compared to adjacent tissue.
Stage I	Intact skin with non-blanchable redness of a localized area usually over a bony prominence. Darkly pigmented skin may not have visible blanching; its colour may differ from the surrounding area.
Stage II	Partial-thickness loss of dermis presenting as a shallow open ulcer with a red pink wound bed, without slough. May also present as an intact or open/ruptured serum-filled blister.
Stage III	Full-thickness tissue loss. Subcutaneous fat may be visible but bone, tendon, or muscles are not exposed. Slough may be present but does not obscure the depth of tissue loss. May include undermining and tunnelling.
Stage IV	Full-thickness tissue loss with exposed bone, tendon, or muscle. Slough or eschar may be present on some parts of the wound bed. Often includes undermining and tunnelling.
Un-stage-able	Full-thickness tissue loss in which the base of the ulcer is covered by slough (yellow, tan, grey, green, or brown) and/or eschar (tan, brown, or black) in the wound bed.

The following definitions are taken from the Spinal Cord Injuries Australia website:

<http://scia.org.au/sci-resources-and-knowledge/health-and-sci-facts/what-is-spinal-cord-injury-sci>

This website is aimed at consumers and therefore the definitions use common language to explain these scientific terms. More in depth medical definitions can be found on the Agency for Clinical Innovation NSW Spinal Cord Injury website: <http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury>

Paraplegia: refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, due to damage of neural elements within the spinal canal.

Tetraplegia: (also referred to as Quadriplegia) refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal.

ASIA (American Spinal Injury Association) Scale: The degree of function after injury is measured according to the five-level ASIA Impairment Scale. They are:

- **A - Complete:** No motor or sensory function in the lowest sacral segment (S4-S5).
- **B - Incomplete:** Sensory function below neurologic level and in S4-S5, no motor function below neurologic level.
- **C - Incomplete:** Motor function is preserved below neurologic level and more than half of the key muscle groups below neurologic level have a muscle grade less than 3.
- **D - Incomplete:** Motor function is preserved below neurologic level and at least half of the key muscle groups below neurologic level have a muscle grade 3.
- **E - Normal:** Sensory and motor function is normal

Participants presenting with ASIA A and B were interviewed for this research project as they are more at risk of pressure injury than ASIA C D or E.

Autonomic Dysreflexia: Autonomic Dysreflexia can occur in an individual with a spinal cord injury at or above T6. It arises due to the loss of control mechanisms for blood pressure and heart function. It causes the blood pressure to rise to dangerous levels. Autonomic Dysreflexia can be caused by any bodily pain or discomfort. Common causes are a full bladder, bladder infection, severe constipation, or pressure sore. Anything that would normally cause pain or discomfort below the level of the spinal cord injury can trigger dysreflexia.

Appendix 2 - Literature Search Process

The literature search was completed primarily utilising the NSW Health Clinical Information Access Portal (CIAP). CIAP provides access to clinical information and resources including journals, guidelines and books. Where full text articles could not be obtained via CIAP the Hunter New England Health librarians (Tamworth) were able to source them for the researcher.

Only reports researching pressure injury in relation to spinal cord injury were sourced (not pressure injury generally).

The search terms used were:

Pressure + injury or + ulcer or + wound or + area or + sore

+ Spinal Cord or spinal cord injury or tetraplegia or quadriplegia or paraplegia

In conjunction with:

Prevention

Re-occurrence

Progression

Client + factors or + perspective

Patient + factors or + perspective or + journey

Self-management

Community

Home

Education

Rural

Australia

The references lists of other research publications were also explored for relevant papers including the NSW ACI Model of Care for Prevention and Integrated Management of Pressure Injuries in People with Spinal Cord Injury and Spina Bifida (2014), Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with Spinal Cord Injury (2013) and Pressure ulcer management and research priorities for patients with spinal cord injury: Consensus opinion from SCI QUERI Expert Panel on Pressure Ulcer Research Implementation (2011).

Due to high number of articles pertaining to pressure injury and spinal cord injury the search was contained to those articles published after 01/01/1997 (last 15 years).

Only reports available in English were sourced.

Appendix 3 – Consent form

Rural Spinal Cord Injury Service
Locked bag 9783
Tamworth NEMSC NSW 2348

Consent Form for the Research Project:

The Lived Experience of Intact Skin

(How do individuals living with a spinal cord injury in a rural area prevent pressure injuries?)

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project and do not have to give any reason for withdrawing.

I consent to a face to face interview with the researcher and understand it will be audio recorded.

I understand that my personal information will remain confidential to the researchers and the transcription of my interview will be de-identified.

I have the opportunity to have questions answered to my satisfaction.

I understand that in no way will my answers affect my ongoing service from Hunter New England Health or the Rural Spinal Cord Injury Service.

Signed: _____

Date: _____

Print Name: _____

I have informed the above person about this research and am sure that they understand both the content of the information statement and the additional information I have provided.

Signed: _____

Date: _____

Print Name: _____

Appendix 4 – Participant Information

Rural Spinal Cord Injury Service
Locked bag 9783
Tamworth NEMSC NSW 2348

Research Project:

How do individuals living with a spinal cord injury in a rural area prevent pressure injuries?

You are invited to participate in this research study conducted by Catherine Brabrook from the Rural Spinal Cord Injury Service at Tamworth Rural Referral Hospital and sponsored by the Health Education and Training Institute.

You have received this information as a person with a spinal cord injury on the database of the Rural Spinal Cord Injury Service.

The research project is aimed at understanding how people living in rural areas with a spinal cord injury maintain good skin health. We want to understand how you approach skin care and pressure injury (wound/ulcer) prevention. It is hoped this information will be used to better educate both clinicians and patients regarding pressure injury prevention.

The research project is particularly seeking people who have had their spinal cord injury for more than 5 years and have never had a severe pressure injury.

Participation will involve a face to face interview for about 1 hour at your home. The interviews will be audio recorded (taped) and transcribed at a later time. Participants can request to review the tape and ask for questions to be edited or erased during the interview. The interview questions will explore what you do on a day to day basis to maintain healthy skin and how you access information about pressure injury prevention. The interview transcriptions will be de-identified and individual participants will not be identified in any reports arising from the project.

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your service from Rural Spinal Cord Injury Service or Hunter New England Local Health District. If you do decide to participate, you may withdraw from the project without giving a reason.

If you would like to be involved in the study or would like further information please contact Catherine Brabrook on 0429473944 or 0267678350 or catherine.brabrook@hnehealth.nsw.gov.au

You may also receive a phone call asking if you would like to be involved.

Thank you for your consideration to being involved in this project.

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 14/08/20/5.04 Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to:

Dr Nicole Gerrand
Manager Research Ethics and Governance,
Hunter New England Local Health District
Locked Bag 1, New Lambton NSW 2305
Telephone (02) 49214950, email Hnehrec@hnehealth.nsw.gov.au

Appendix 5 – Interview Questions

The following are examples of questions used to initiate discussion with participants:

What do you do on a daily basis to look after your skin?

How, why...do you do this?

Tell me more about why you can't, don't...?

Why is that important?

How did you come to know that?

What equipment do you use to ensure your skin health?

How do you access equipment?

Why do you think you haven't experienced a major pressure injury?

Have you made any changes over time? (E.g. due to aging or other health problems)

What would you do if you found a red area on your backside?

Who would you contact?

How have you learnt to care for your skin?

How do you access skin care information?

Would you have liked more education or information?

What would your top tips be for looking after your skin?