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PHANTOM
SENSATION AS
EXPERIENCED BY
PEOPLE WITH A
SPINAL CORD INJURY

By

Daren Drysdale

A dissertation submitted for the degree of Doctor of Philosophy of the University of Dublin, Trinity College Dublin, Dublin 2, Ireland. The research for the contents of this thesis was conducted in the School of Psychology.

DECLARATION

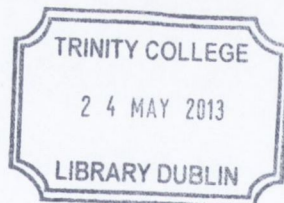
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SUMMARY

All the approaches in this thesis are linked by a common query: What is the meaning, structure and essence of the lived experience for a person with a Spinal Cord Injury (SCI) who perceives phantom sensation and/or pain? (See Figure 1).

The thesis will allow you to form an accurate impression of phantom sensation in the population of people with a spinal cord injury and it highlights some of the confusion surrounding the terms now in common use. As the thesis progresses, the review of the literature and the presentation of the research informs a change in the use of the term “phantom” for the reader.

Currently a regular dictionary definition of phantom pain/sensation is frequently limited and to be found only if you look under “pain”. If looking under “phantom” the reader will probably only find the term as it applies to an amputated limb or as it applies to x-ray technology (e.g. Dorland, 2011). The description of the phenomenon across different populations is similar but a precise definition difficult to narrow down. I began with the concept that any sensation apparently felt in a deafferented part of the body (amputated or not) is a phantom.

Chapter 1: Introduction and What’s Gone Before

The issue of phantom pain is confusing for most especially when considered with phantom sensation and this becomes obvious in the literature. It is the tendency of most taxonomies to either ignore phantom sensation (PS) completely or to treat both it and phantom pain (PP) differently. Added to this, the definition of phantom sensation and/or pain seems highly subjective with the operational definition varying significantly between articles.

This chapter will outline the key pieces of literature that have been presented about the phenomenon in this population and others. It will also introduce the discrepancy in the

definitions used by the researchers looking at people with an amputation and people with a spinal cord injury. The apparent confusion between pain and sensation is also highlighted.

Chapter 2: A Qualitative Study

This chapter focuses on the experience of 8 people who have a diagnosed complete injury i.e. they have no response to pinprick and no voluntary motor activity below their level of injury. However, they are not sensationless and describe their experiences in vivid terms.

All were interviewed and using a grounded theory method, their responses were gathered into six higher order categories. The categories are listed and examples are given of the responses from the interviewees that gave rise to the discovery of the categories.

Chapter 3: A Quantitative Study

In this chapter you will find details of a study that explores the associations between psychosocial states and the experience of unexpected sensory phenomena. 107 people responded to the survey. 96 completed the descriptive section with 65 leaving information both in the descriptive and episodic sections of the survey. The phenomena described are in paralysed areas and/or in areas tested as sensationless.

I outline the use of the Day Reconstruction Method for collecting data and briefly describe the method. The different procedures follow (ethics, confidentiality etc.). There is then a section describing the results and their potential meaning.

Chapter 4: Case by Case

One of the aspects of working in a patient centred setting is the tendency to begin to refer to people as their injuries. New clinicians are frequently advised that it is “Mr Smith with a broken leg in cubicle one” and not “the broken leg in cubicle one”.

In an effort to make sure that I avoid the same tendency, this chapter focuses on a sample of the people who have contributed to the studies. Information that helps us understand the lived experience associated with the phenomenon becomes apparent. Three

cases are chosen, two for further analysis from the day reconstruction study and one case from a person who expressed interest in contributing to the data questionnaire after it was administered online.

Chapter 5: General Discussion

This chapter serves to knit the previous chapters together using the central question of the thesis. It assists by specifically asking the data to expand on the meaning, structure and essence of the lived experience garnered from the previous chapters and by deconstructing the central question. The chapter finishes by making a simple recommendation borne out of the previous studies and arguments.

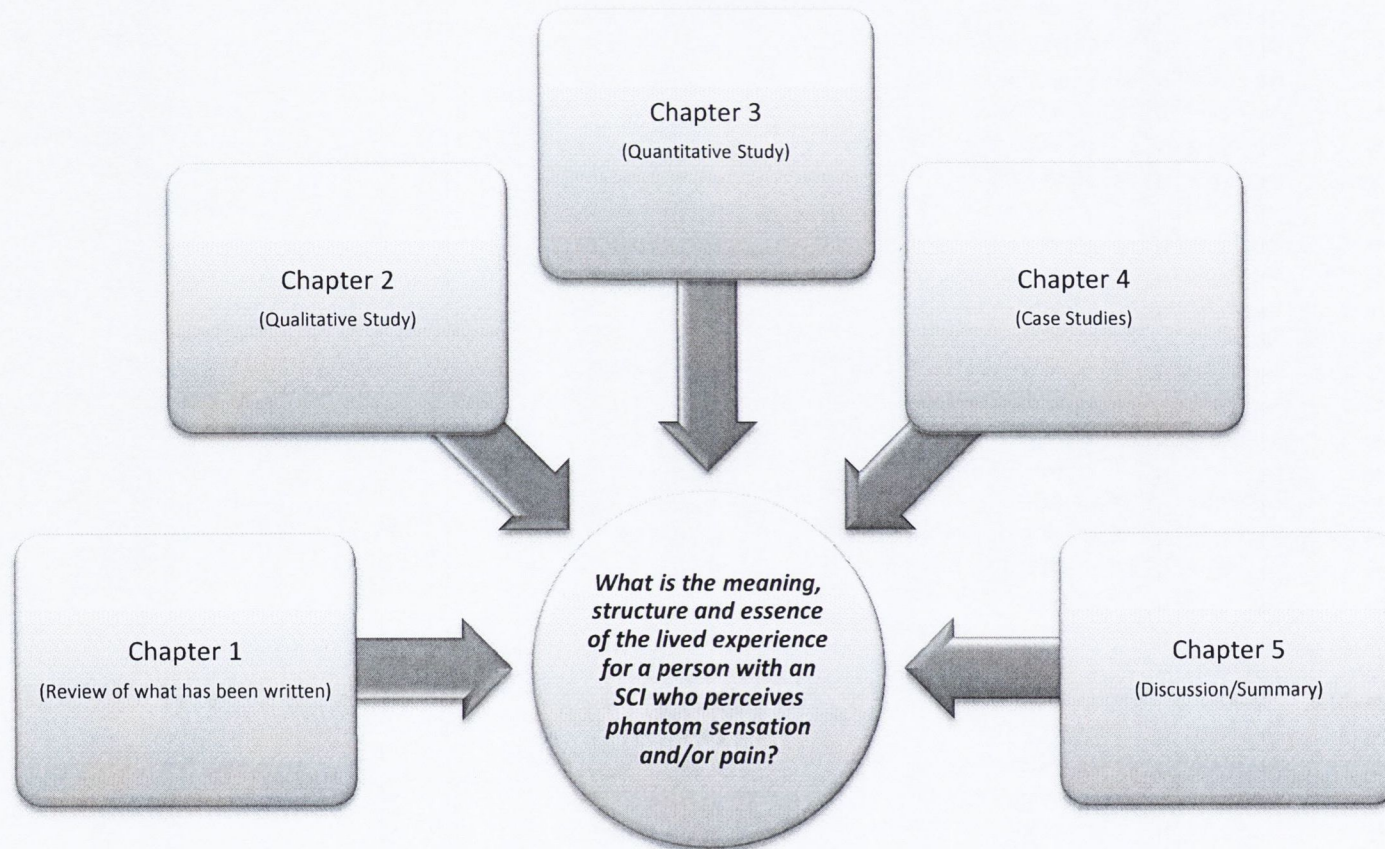


Figure 1: A simple graphic representation of the format of the thesis

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Thanks to my wife for making the time and space for me to focus on the work and more importantly for putting up with me while I tried to get it all done. It took a lot longer than we were planning for and she has been with me and even taking steps for me all of the way.

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LIST OF ABBREVIATIONS

| Abbreviation | Full | Note |
|--------------|---|---|
| ADL | Activities of Daily Living | The regular activities pursued by people as they live their lives. |
| AIS | ASIA Impairment Scale | A measurement scale to help assess the impairment caused to an individual after an SCI |
| ASIA | American Spinal Injuries Association | Multidisciplinary group of individuals dedicated to standards, education, research and communication between professionals in the SCI health arena. |
| CRPS | Complex Regional Pain Syndrome | Previously known as RSD. Painful condition affecting an apparently healthy area characterised by hair loss, inflammation, shiny skin and allodynia |
| DPO | Disabled Peoples Organisation | Various organisations that supply educational, research or other resources for people with a disability. They also frequently supply peer support services. |
| DRM | Day Reconstruction Method | Research method designed to ask a participant about an episode recalled from the previous 24hours |
| IASP | International Association for the Study of Pain | An international organisation consisting of professionals dedicated to the study of the mechanisms, nature and treatment of pain |
| LE | Lower Extremity | Leg and Thigh |
| LOI | Level of Injury | The level on the spine where the injury occurs. Frequently used interchangeably with LOL |
| LOL | Level Of Lesion | The level where the lesion occurs. May be different to the Neurological Level of Injury (Different disciplines prefer LOL or NLI) |

| | | |
|-------|-----------------------------------|--|
| NLI | Neurological Level of Injury | The neurological level of the injury. May be different of the Level Of Lesion. (Different disciplines prefer LOL or NLI) |
| PCA | Personal Care Assistant | Assistants to people with a disability to help with ADL's |
| PP | Phantom Pain | Pain apparently originating from a deafferented part of the body |
| PS | Phantom Sensation | A sensation apparently originating from a deafferented part of the body |
| RHI | Rubber Hand Illusion | A technique using an artificial rubber hand that demonstrates or measures the ability of a person to displace the sensations from their real hand to an artificial one |
| SCI | Spinal Cord Injury | A general term for a lesion or compression of the spinal cord resulting in the complete or incomplete loss of sensory and or motor control. It may be the result of disease, due to trauma or congenital processes |
| SCVMC | Santa Clara Valley Medical Center | The county hospital located in Santa Clara County in California |
| SIC | Spinal Injuries Centers | Centers of speciality that focus on the care of individuals who sustain an SCI from the moment of diagnosis to the end of inpatient rehabilitation |
| UE | Upper Extremity | Arm |
| ZPP | Zone of Partial Preservation | The area (dermatomes and myotomes) caudal to the neurologic level that remain partially innervated |

CHAPTER 1: PHANTOMS: AN INTRODUCTION/WHAT HAS GONE

BEFORE

CHAPTER 1 OUTLINE

The chapter starts by introducing the concept of “Phantoms”, both Phantom Sensation (PS) and Phantom Pain (PP). It talks about the interest that people have in the phenomenon and affirms that it is also present in the SCI population. This is followed by a statement of what is to come in this thesis then a review of the current and historical literature about phantom sensation and pain focussing on the phenomenon in people with an SCI. The significance of the research completed as part of this document and a quick overview of pain and sensation in the Spinal Cord Injury (SCI) community follow.

Sensations from Parts of Our Bodies That Are Missing

Most people are fascinated by the idea that we can have sensations coming from parts of our body that are obviously missing (Ramachandran & Blakeslee, 1998). Even more intriguing is the concept that these sensations can also be present when the body part is still attached. This becomes a reality for many individuals who experience a Spinal Cord Injury (SCI). It's highly likely that a person feeling sensations coming from part of their body that is apparently denervated can be at best confusing and very often depressing or anxiety creating.

These sensations are often referred to as "Phantoms" and unfortunately the term suggests that the sensations are not real. For some though, it's an affirmation that their body continues to function in some similar way to the manner it did before the injury.

What Does This Thesis Do?

Using a mixed methods approach (grounded theory methods, statistical analysis and case studies), the studies in this thesis look predominantly at the personal experience of sensory phenomenon in areas classified as sensationless in individuals with an SCI. They look for the possible connections between psychosocial events/states and the experience of phantoms. They examine more closely the individuals who experience this phenomenon and add to the existing body of research that has been conducted to date on these occurrences.

The major reason for utilising a mixed methods approach is that it afforded me multiple techniques for investigating a broad question. The different methods become the dominant focus of 3 of the chapters in this thesis.

The thesis is divided into chapters that are designed to address the central question: What is the meaning, structure and essence of the lived experience for a person with an SCI who perceives phantom sensation and/or pain? Or as a series of questions: What

experience does someone with an SCI have of phantom sensations, how do they explain them and are they associated with other psychosocial factors and/or pain? (See Figure 1).

The qualitative approaches address the experiences as related by people experiencing the phenomena and the quantitative approaches are designed to investigate any associations between PP/PS and psychosocial events/states.

The chapters and their functions are as follows:

Description: Chapter 1

This chapter lets you know what to expect in the thesis and is an introduction to PS and PP, how they appear in the literature and addresses the history and significance of the subject.

Description: Chapter 2

The initial study in the thesis uses grounded theory methods to examine the phenomenon in people with an SCI and how it is perceived. It illuminates the rather murky depths of this subjective event experienced by people with an SCI and allows participants to openly discuss their experience and have that discussion analysed in a systematic way. It also helps us better understand the manifestation of sensation below the level of the lesion and brings us closer to understanding the lived experience of a person with an SCI and PS. The chapter outlines the six core categories found in the data and quotes examples of the categories in the interviewees dialogue. It discusses the findings of the study as the categories emerge and ends with a section that merges the topics in a more cohesive way.

Description: Chapter 3

This chapter looks at the “when” of the phenomenon and what it may be related to. The information garnered from the qualitative study was incorporated into this phase of the research in order to inform many of the questions asked in the questionnaire.

In order to accomplish this I decided to use a technique that improved the accuracy of the participant's memory of cognitive and emotional states and the events that were happening at the time.

The Day Reconstruction Method (DRM). The DRM is an application of research design that minimises recall bias (Kahneman, Krueger, Schkade, Schwarz, & Stone, 2004; Khan, Markopolous, & Ijsselstein, 2008) and it helped me answer the questions: Do the sensations reported in the first study exist in another sample and do they change through the day. In addition, another research question posed was: Are the psychosocial states that a person with SCI experiences linked in any way with their experience of sensory phenomenon in areas that have been tested as sensationless?

I relied on the DRM to help pull out the information needed to highlight these patterns. A more detailed description of the approach is outlined in Chapter 3.

Description: Chapter 4

The individual cases outlined in this chapter add texture and fill out information missing from the previous studies. Two of the cases are selected from the previous studies and the third outlines the story of an individual who has had to face two major disability onsets in his life. The third study also highlights the density of the material that can be gleaned from online sources if a person with an SCI decides to use them.

All three also serve the purpose of helping to generate new queries and areas for exploration.

Description: Chapter 5

The last section of the thesis is a discussion about all of the approaches used in the thesis and the information that can be gleaned from them. The discussion arises from the

previous work in the thesis but there are also clinical recommendations based on the information garnered from the individuals encountered while conducting the research.

Phantom Phenomena from the Point of View of People with an SCI

In chapter 2 of this thesis and narratives such as "Still Lives" (Cole, 2004) we see that individuals with an SCI also describe the same type of phantom phenomena people with an amputation describe. And although PP is recognized as a potential source of discomfort in the SCI population it appears that the treatment of the problem is as challenging, if not more so, than it was for the amputee population a number of years ago.

The term "phantom" is value laden and as we will see it is difficult to pin down. If a person experiences a sensation from a part of their body that is no longer attached, diagnosing that the sensation as a phantom is easy. However, if that body part is still attached diagnosing is more complicated. This difficulty has led to a debate as to the definition of a phantom sensation (Brugger et al., 2000) and this is an issue which becomes obvious in the literature and throughout this thesis.

In addition, and perhaps counter intuitively, some research (Cole, 2004; Nepomuceno, Fine, & Richards, 1979) has also found that most people with an SCI would not like to give up the sensations, even if they are painful. This opinion was also expressed by many of the participants who were interviewed for the studies in this thesis.

Phantom Phenomena and Pain from the Point of View of the Professionals

For the professional the definitions (PS and PP) in the literature are variable especially as they are used in describing the phenomena in the SCI population. This makes it difficult to compare results of the studies as the operational definitions are sometimes unclear until some way into the article. For example, many professionals such as Sherman et al. (1997) accept the concept that any sensation or pain below the Neurological Level of

Injury (NLI) in a complete injury is a phantom. Others, such as Bryce and Ragnarsson (2000) who predominantly focus on describing pain, caution against using the term deafferentation pain as deafferentation alone may not explain pain below the NLI. Some such as Bockenek and Stewart (2002) only use PP in a situation where the person also has an amputation in addition to the SCI.

As a result of this variability phantom sensation categories are often found (when they are mentioned at all) in pain taxonomies. The phenomena are poorly understood and the painful aspect is often emphasised.

Alternatively, classifying pain post SCI has been seen as critical to treatment and rehabilitation and addressed in many taxonomies (e.g. Beric, 1997; Burke & Woodward, 1976; Donovan, Dimitrijevic, & Dahm, 1982; Frisbie & Aguilera, 1990; Maury, 1978; Michaelis, 1970; Segatore, 1992; Siddall, Taylor, & Cousins, 1997; Waisbrod, Hansen, & Gerbeshagen, 1984) but few specifically mention PP and PS rarely makes an appearance (not surprisingly as PS is considered benign). I'll discuss the more frequently used taxonomies later in the chapter.

Most treaters are not sure how to best use the available taxonomies and clinicians are hesitant to identify any pain as phantom. They fear that as soon as a patient hears the phrase they may automatically assume that "all in my mind" is a synonym. Possibly because of this, PP will frequently be documented as of pain of unknown origin and because of this its aetiology cannot be narrowed down through tests (Miner, 2007).

History and Background

Ambroise Paré, Rene Descartes and Lord Nelson

PP and PS in people with an amputation have been documented for centuries (Jensen & Nikolajsen, 1999). Stories about Admiral Lord Nelson and other famous amputees are oft told. Ambroise Paré and René Descartes mentioned it centuries ago and

continue to be referenced in both stalwart pain texts such as Wall and Melzack's "Textbook of Pain" (2002) and more popular texts such as "Phantoms in the Brain" by V.S Ramachandran and S. Blakeslee (1998).

Reluctance and Being Seen as Insane

Despite the apparent widespread familiarity with the phenomena the amputee community has learned that medical treatment of phantom pain is largely ineffective, mostly painful and frequently "embarrassing" (Sherman, Devor, et al., 1997, p. 10). If the intervention is surgical it will, at minimum, have the accompanying pain due to the surgery. Alternatively, if the intervention decided upon is pharmaceutical there are likely to be secondary effects. Also, until quite recently and probably embarrassingly for people with the amputation, it was highly likely that if a person reported PS or PP they would be unnecessarily sent for psychiatric evaluation (Sherman, 1997; Sherman, Sherman, & Bruno, 1987). Indeed, it was not uncommon to read that PS or PP was a manifestation of wish fulfilment (e.g. Solomon & Schmidt, 1978).

Possibly as a result patients with an amputation are reluctant to report these sensations because the individuals concerned feel they may be viewed as crazy (Sherman, Katz, Marbach, & Heermann-Do, 1997; Shukla, Sahu, Tripathi, & Gupta, 1982).

As we will see in the second chapter, the concern also exists in the population of people with an SCI. It too (according to many of the accounts in the qualitative study) results in a reluctance to report the sensations.

Where Phantoms are Also Reported

The term "Phantom" is most often associated with people experiencing a limb amputation however, in the last few decades the amount of literature regarding the phenomenon in other populations has increased dramatically (e.g. Björkman, Arnér, Lund,

& Hydén, 2010; Bors, 1951; Brugger, et al., 2000; Dorpat, 1971; Price, 2006; Ramachandran & Blakeslee, 1998; Ramachandran & McGeoch, 2007; Rothmund, Grusser, Liebeskind, Schlag, & Flor, 2004; Wade & Finger, 2010).

For example, burn victims frequently report pain in the area of the injury years after it has healed (Napoli, 2002), people who have a tooth removed still feel the tooth in place and pain emanating from it (Marbach, 1978, 1997; Rees & Harris, 1978; Schnurr & Brooke, 1992), removal of various internal organs (including the uterus, rectum, stomach and bladder) does not deter a person feeling sensations from the now missing organ (Brena & Sammons, 1979; Sherman, Katz, et al., 1997) and there are articles in the literature that attempt to better understand post-mastectomy phantom breast pain (Hansen, Kehlet, & Gartner, 2011; Rothmund, et al., 2004). However, in most texts about the phenomenon, populations other than amputees receive only an acknowledgement. This is not surprising given the dearth of information about the aetiology of phantoms and the difficulty in defining them.

In addition, people have reported supernumerary phantom limbs [perception of upper and/or lower extremities in excess of the usual number of limbs] (e.g. Curt, Yengue, Hilti, & Brugger, 2011; Halligan, Marshall, & Wade, 1993; Khateb et al., 2009).

For example, the study conducted by Curt, Yengue, Hilti and Brugger (2011) is a very in-depth study of a single case in the SCI field. They look at a 71 year old male who reports the frequent awareness of supernumerary limbs. They detail the use of the Rubber Hand Illusion (RHI) and its research and rehabilitation role in the course of this inpatient's post trauma/surgery rehabilitation. The paradigm is described more fully in Botvinick and Cohen's article (1998) but basically entails the tactile stimulation of a person's hand with the simultaneous touching (in the corresponding area) of a rubber hand. The major difference between both extremities is that the real hand is hidden from view but the rubber hand can be seen by the patient. The intriguing result is that the stimulation on the real

hand is stopped but the participant continues to feel the sensations as long as they see the rubber hand being touched.

The caution with this study can be applied to all case study designs: it is a bad idea to generalise the findings but an in depth awareness of the phenomenon and how it may present is necessary.

There is also the assumption in the article that the experience and aetiology of a phantom in SCI is the same as that of a person with an amputation i.e. that the phenomena are identical across all populations.

Most Widely Known Recent Account

Probably the most widely known recent account detailing PS is documented in Ramachandran and Blakeslee's book "Phantoms in the brain." (1998). They connect the incidence of both painful and non-painful phantoms into neuroplasticity and although the text deals mostly with the practices in the amputee population there seems to be general acceptance amongst most researchers and clinicians that the mechanism is the same or similar for all.

In the manuscript Ramachandran recounts one of his first experiences with the PS phenomenon in a person with an amputation and his initial thoughts about its occurrence: a recent Upper Extremity (UE) amputee was shaving when he noticed corresponding sensations in his phantom limb. Ramachandran, his physician at the time, postulated that because the area on the sensory motor cortex responsible for the cheek is located near the area responsible for the arm neuroplasticity, it was probably playing a role. Using a q-tip (cotton bud) and by gently stroking the facial skin, Ramachandran mapped the entire phantom hand on his patient's face.

The theory has taken hold and subsequent functional magnetic resonance imaging (fMRI) studies have shown both cortical and subcortical plasticity involved with the

phenomena (Moore et al., 2000). Subcortical remapping may explain the situations where the activity on the sensory motor strip is not adjacent to the location of the referral point on the Penfield map (Flor, 2002).

Neuroplasticity alone however, does not explain every case documented and it is likely that a combination of factors have to be considered. In this, it begins to resemble the treatment and research surrounding chronic pain.

Significance

Mechanism is Conjecture.

Certainly the physical mechanism that gives rise to sensory phenomena in sensationless areas following SCI is still conjecture (Siddall & McClelland, 1999). Even the mechanics of PS remains debatable, for now, in the amputee population. Indeed, given the multiple theories regarding its origin it is highly likely that there are multiple aetiologies and most certainly, multiple treatment options.

Flor (2002) outlines the major theories that curry favour at the moment. They involve neuroplasticity, peripheral nerve damage or memory of the pain being imprinted at various levels in the brain and spinal cord. It is highly likely though, that any one of these theories will only account for a percentage of the incidents or only explain a certain portion of every occurrence. Correct interpretation of the mechanism(s) involved is needed to clarify.

The Need to Clarify

While there is acceptance, by many, of the incidence of PP or PS in the SCI population, it is not immersed in the rehabilitation protocols that are most often used. These protocols include pharmaceutical treatments for both neuropathic and nociceptive pain below the Level of Lesion (LOL) (Wall & Melzack, 2002; Wrigley et al., 2009). The

pharmaceutical interventions can also suggest the low dose; off label use of tricyclic antidepressants such as amitriptyline for chronic pain (Dharmshaaktu, Tayal, & Kalra, 2012).

In addition to the pharmaceutical practices are the surgical interventions such as ablation of neuropathic tissue that may be irritated by proximity to the epidermis of the residual limb (in the case of a patient with an amputation as well as an SCI) or interventions that include resecting the cord at a higher level than the original injury.

There are also the interventions from the physiotherapy, occupational therapy, psychology and other allied health fields that would all benefit from understanding the incidence and nature of PP and PS in this population.

Although reports of non-painful sensory phenomenon are becoming even more widespread in the SCI population, and we see forays into nosology for this population (Siddall & McClelland, 1999), the study of PS is limited. “The clinical relevance of non-painful PS remains unclear” (Curt, et al., 2011, p. 594) but the need to establish the existence of a link or lack of link between PS and PP or pain in general, is evident.

Treatment Protocols Changing

If it can be shown that there is a connection between the pain process and the experience of PS as seems to be the case in individuals with an amputation (Sherman, Devor, et al., 1997), treatment protocols for people with an SCI may change. If the onset of non-painful sensory phenomenon in a deafferented area is an indicator that PP is likely, the treater is likely to be more aggressive in their approach to the PS. For example, if a clinician knows that the likelihood of PP is greater if the person experiences PS they may administer prophylactic pharmaceutical measures before PP manifests.

As more research is done with this population by interested parties, relationships between a person’s affective state, daily tasks, onset, duration and vividness of the

sensations will also emerge. These correlations will allow both clinicians and researchers more reliably predict the probability of a person developing PP. This will mean that suitable interventions for pain (Gatchel, Howard, & Haggard, 2011; Gatchel & Turk, 1996) can be applied sooner i.e. before the sensations become painful.

The Literature on Pain and Sensation in SCI

Pain in SCI

It is a surprise to many to learn that there is significant pain experienced by most individuals who have sustained an SCI (Beric, 1997; Frisbie & Aguilera, 1990; Hicken, Putzke, & Richards, 2002; Loeser, 2002; Maury, 1978; Segatore, 1992; Siddall, Yeziarski, & Loeser, 2000; Waisbrod, et al., 1984) - that the condition is frequently painful below, at and/or above the LOL. There are a myriad of different texts, papers and presentations about the subject (e.g. Bockenek & Stewart, 2002; Bryce & Ragnarsson, 2000; Burke & Woodward, 1976; Davis & Martin, 1947; Maury, 1978; Michaelis, 1970; Siddall, et al., 1997; Tunks, 1986; Waisbrod, et al., 1984; Wall & Melzack, 2002; Waxman & Hains, 2006) however, these sources of information have not made their way much out of the SCI/rehabilitation community. Most of the taxonomies are formed from the manifestation of the pain that is commonly reported and are created from the following:

General Pain in SCI individuals. These are pain types not necessarily linked to a somatic area and as such can manifest in a range of locations. They include:

Instability of the spine. A musculoskeletal pain secondary to ligament damage or bone fracture of the spine. Pain normally radiates out from the site of injury and treatment normally involves stabilising the spine by immobilisation, implanted rods, halo collar or spinal fusion.

Muscle spasm. Pain caused by intense spasm. The spasm is often located below the LOL but the pain can be felt above due to the strength of the spasm.

Visceral pain. Burning or cramping in the abdomen that fluctuates in intensity is generally referred to as visceral pain. Pain signals may be carried via the Vagus nerve which travels out of the brain and passes the injury site completely. For example, a person with an SCI may develop appendicitis and still feel it though they may not be able to tell from where exactly where the pain is originating. Because the autonomic nerves that convey visceral pain bypass the injury the pain is still felt.

Pain above the LOL. The pain is located in the region of sensory preservation above the LOL.

In addition to the familiar reasons for aches and pains that we all encounter like headaches or toothaches, a substantial number of people who find themselves in a wheelchair will begin to experience pain related to their specific situation. For example, repetitive strain injuries or overuse syndromes, cervical myofascial pain, bursitis and thoracic outlet syndrome. In areas such as their neck, shoulders, elbows or wrists pain becomes common (Elliott et al., 2008). Quite simply, operating a wheelchair forces a person to constantly repeat movements that under normal circumstances they would not need to undertake. This pain can be either neuropathic or myalgic i.e. nerve or muscle related. If the damage is incurred in a nerve (neuropathic), treatment can be very difficult. In fact neuropathies are often viewed as intractable pain generators (Wall & Melzack, 2002).

The person can also experience above level neuropathic pain associated directly with their injury. These painful sensations may be due to damage to peripheral nerves but can also be unrelated such as complex regional pain syndrome (CRPS). Depending on the origin the pain may be relieved by surgical interventions particularly if the pain is caused by compression of a peripheral nerve (Raja, Meyer, Ringkamp, & Campbell, 2002).

Pain at the LOL. Pain that normally covers two levels rostral to below the injury is frequently referred to as the girdle, transition zone, Zone of Partial Preservation (ZPP) or

the end zone pain (Bockenek & Stewart, 2002; Siddall, Yeziarski, & Loeser, 2002; Wall & Melzack, 2002). It is an unpredictable area with sensation being variable both over time and from person to person.

When pain is present in this area it also tends to be variable and dominantly neuropathic in origin. Depending on the diagnosis (nerve root entrapment, segmental deafferentation pain or syringomyelia) the treatment will change but the outcome tends not to be favourable.

Pain below the LOL. Again, pain in this area is dominantly neuropathic. It is often referred to as dysesthetic pain, deafferentation pain or central dysesthesia syndrome (Beric, Dimitrijevic, & Lindblom, 1988; Davidoff, Roth, Guarracini, Sliwa, & Yarkony, 1987; Davis & Martin, 1947). It is probably the most common of all the pain types in the SCI population and the most difficult to treat (Bonica, 1991).

Taxonomies for Pain in SCI

Although most will agree about the general types of pain, an agreed upon taxonomy for pain in SCI has eluded professionals working in the area. Many have proposed classification schemes over the years (e.g. Beric, 1997; Bockenek & Stewart, 2002; Burke & Woodward, 1976; Davis & Martin, 1947; Donovan, et al., 1982; Frisbie & Aguilera, 1990; Holmes, 1919; Maury, 1978; Segatore, 1992; Siddall, et al., 1997; Tunks, 1986; Waisbrod, et al., 1984). Indeed, Loeser (2002) identified 28 articles where the authors categorised painful sensations in people with an SCI. The problem is that the taxonomies disagree in their order of pain types and this leads to confusion in both the clinical and research arena. It can also lead to confusion in people with the SCI and as seen in Chapter 2 this confusion is often unspoken to professionals.

Frequently the phenomenon appears as part of a figure in the article depicting the taxonomy but an in depth description is lacking (e.g. Bockenek & Stewart, 2002; Bryce &

Ragnarsson, 2000; Desasri, 2003). We are left wondering if the PP referred to in the figure is pain associated with the SCI or if it only applies to the person if they have an amputation in addition to the SCI.

For example, the taxonomy outlined by Bockenek and Stewart (2002) divides SCI pain into nociceptive, neuropathic, visceral and other. It then divides the first three categories into pain above, at or below level. It does not divide the category 'other' into the same regions and the pain examples it gives fall into a range of regions that are not clearly defined. PP is found here. Both PS/PP are not discussed in the text.

Alternatively, the widely adopted taxonomy for pain in a person with an SCI proposed by the International Association for the Study of Pain (IASP) is much simpler than most and as a result easier to apply by people in the field (Siddall, et al., 2000). It consists of only 3 tiers with visceral pain being removed from the first tier of identification and making an appearance in the second tier (Siddall, et al., 2002). However, it does not mention PP specifically and according to the designers of the taxonomy there is an automatic assumption that it is not a necessary classification of pain in SCI though this is never specifically mentioned in the documentation. According to their rationale and confirmed by their primary author, PP can be viewed as pain below the level of the lesion (Siddall, 2006). This explanation leaves us in the dark regarding PS's and whether they should be considered in some way. It also leaves us wondering about pain experienced in an amputated limb above the injury.

Judging by the frequency that PP is mentioned either implicitly or explicitly in the taxonomies, we can assume acceptance of its occurrence in the community that the phenomenon is frequent. However, the majority of the research does not detail the experience from the point of view of the individual with an SCI.

In general, very little seems to be formally known despite its occurrence in the population. Waxman and Hains (2006) note the commonality of phantom phenomena in

their study which goes on to investigate the molecular aetiology or mechanisms involved. They continue by emphasising that parts of the central nervous system can become amplifiers and generators of pain and just treating the pain below the LOL will not suffice. They do not address the more benign sensory phenomena or discuss whether a relationship exists between PP and PS.

Loeser in an introductory chapter to an IASP text highlights that in general “physicians can describe pain in terms of broad categories but not on the basis of the underlying mechanisms” (2002, p. 5). This challenge can also be seen in the phenomena of PP and PS as no one has yet been able to confirm the underlying mechanisms for PP/PS even in the amputee population.

Sensation in SCI

Sensation is a principal concern for most people with an SCI and the health professionals involved with care. The classification schemes that exist enable the SCI community to begin the process of communicating function in an accurate fashion. The expectation that a person has regarding what they will be able to do begins with the classification of their injury. The information received by the person with an SCI has to be accurate and consistent (Matter et al., 2009). If not, the functional goals for the person with SCI will be unreasonably low or high. Because of this there has been a focus on classification schemes through the years.

Outline of common motor and sensation classification schemes. Classification schemes can roughly detail the levels of injury experienced by the individual and these can then be used to understand any functional boundaries a person with an SCI may experience. There are two commonly used classification schemes for SCI and both help illuminate the issues for both the observer and person experiencing the loss of function.

The physical change associated with SCI is best understood by looking at two aspects of the injury. How high up the spine the injury has been sustained and to what level of completeness the spine has been severed or compressed.

The two most regularly used scales for doing this are the Frankel and the American Spinal Injuries Association (ASIA) classifications (also called the ASIA Impairment Scale [AIS]).

The Frankel classification scheme was in wide use by most specialists in the rehab community up until the mid-1990's. It was first published in 1969 (Frankel et al., 1969) but was added to and modified until there were so many versions of it in existence it ceased to be an entirely useful standard. It was difficult to compare the way it was used in one facility versus another without knowing how the clinicians or researchers were interpreting it. Indeed, the scale was even modified for the animal world (Levine et al., 2009).

The Frankel scheme was replaced by the ASIA classification. The newer scale is much more widely relied on at the moment and ASIA monitor the use of the scale and describe the parameters of the scale very specifically (see appendix E). Table 1.1 outlines both schemes and shows the difference between the two.

The major difference comes not in their absolute rating of the injury but in their dependence on measuring functionality to do it. The Frankel scale weighs the functional ability of the individual more so than the ASIA scale. The ASIA scale is more accurate anatomically and physiologically however, the Frankel scale uses terms such as “useful” and “practical” in its descriptors which are open to interpretation by both patients and health professionals (Tsou, Wang, Khoo, Shamie, & Holly, 2006). For example, a person with an SCI may have a flicker of activity in their wrist extensors in their left UE. By the physician using the ASIA system, the movement will be recognised but if a physician is using the Frankel system, it may not be. If the people involved in assessment do not feel the flicker of movement is ‘practical’ the movement may be ignored.

Table 1.1

Comparison of ASIA and Frankel classes

| *ASIA Scale (AIS) | Frankel Scale | Description |
|----------------------|------------------|--|
| A | A | <p>Frankel: No motor or sensory function clinically detected below the level of the injury.</p> <p>AIS: No motor or sensory function is preserved in the sacral segments S4-S5 (Anus)</p> |
| B | B | <p>Frankel: Preserved sensation only - no motor function clinically detected below the level of the injury; sensory function remains below the level of the injury but may include only partial function (sacral sparing qualifies as preserved sensation).</p> <p>AIS: Incomplete-sensory but not motor function is preserved below the neurological level and includes the Sacral segments S4-S5</p> |
| C | C | <p>Frankel: Preserved motor non-functional - some motor function observed below the level of the injury, but is of no practical use to the patient.</p> <p>AIS: Incomplete-motor function is preserved below the neurological level and more than half of the key muscles below the neurological level have a grade of less than 3.</p> |
| D | D | <p>Frankel: Preserved motor function - useful motor function below the level of the injury; patient can move lower limbs and walk with or without aid, but does not have a normal gait or strength in all motor groups.</p> <p>AIS: Incomplete-motor function is preserved below the neurological level and at least half of the key muscles below the neurological level have a muscle grade of 3 or more</p> |
| E | E | <p>Frankel: Normal motor - no clinically detected abnormality in motor or sensory function with normal sphincter function; abnormal reflexes and subjective sensory abnormalities may be present.</p> <p>AIS: Normal-motor and sensory functions are normal</p> |

*ASIA classification scheme available on the ASIA website (http://www.asia-spinalinjury.org/publications/2006_Classif_worksheet.pdf). Also available in Appendix E

As can be deduced from the scales, the amount of function diminishes as the level of the lesion moves up the spinal cord and it is also strongly influenced by the completeness of the lesion.

Complete versus incomplete. This begs the question: If a person experiences pain or sensation below the NLI is it by definition PP or PS if the functional diagnosis is an ASIA A (complete) lesion?

Jonathan Cole in his book “Still Lives”(2004) doesn't think so and neither do a number of the people with an SCI that he interviewed for the text. He discusses the incompleteness of the diagnoses and some of the ramifications to the labelling. I'll address this issue again in Chapter 3 and further consider the ramifications of the classification on both interview and survey respondents.

It is vital to stress however, to both clinicians and patients, that that the classifications are subject to change over time and that they are a gross measurement at best. Even when they are accurate they will not account for the diversity of injury type that people regularly manifest in clinics and frequently will not predict how much function an individual will recover after an injury.

However, it is important to realise that if paralysed to a point where a wheelchair is required all tasks are arduous and certain tasks have to be accomplished, sometimes expediently, no matter what the functional level of the person.

A taxonomy for non-painful sensory phenomena in SCI

The attempt to classify phantom sensation is confused by the fact that the sensations are also frequently painful. If the sensation is painful it will be classified using one of the pain taxonomies however, Siddall and McClelland (1999) have created classifications for the non-painful sensations commonly encountered by individuals with an SCI. They call these sensations “non-painful sensory phenomena” or “phantom

sensations”. This is the only taxonomy for non-painful sensory phenomena in a person an SCI.

The authors have, as in all taxonomies, divided the sensations into categories and subcategories. The categories used in pain taxonomies and Siddall and McClelland’s classification do not overlap in any meaningful way.

The first group of sensations they describe fall into a category they call simple sensations and include pressure, temperature and touch. These sensations are grouped together and classified as simple because they require only a single source of information from the nervous system.

The second category of sensations are the complex sensations which require more than one piece of information to assemble. They include volume, length, posture and movement.

These categories can help health professionals, individuals with an SCI and the wider community understand the PS’s that people with an SCI experience.

Phantom versus Real

It is not unusual to see researchers, clinicians and people with an SCI using the term phantom sensation to mean the non-painful sensory phantom phenomena (e.g. MacIver, 2009; Sherman, Katz, et al., 1997; Siddall & McClelland, 1999) but this leaves us wondering about how to categorise painful sensory phantom phenomena.

There is also a tendency when most talk about sensations below the NLI to divide them into “phantom” and “real” sensations; real sensations being sensations that have identifiable triggers and PS being sensations that don’t. From a subjective perspective, it makes no difference. The sensation is either felt or it is not.

Cady discusses the issue more fully in his article on pain experience (2009). He points out that the concept that the pain is subjective and that the realisation of this

potentially eradicates the need to establish whether the sensation is “genuine” – all sensations are real. Indeed, Ramachandran had previously noted similar issues and has taken it to its logical conclusion. He describes the mental image of our body as a “phantom body”(1998, p. 58) and discusses its malleability.

Because pain and sensation are inherently subjective experiences they are difficult to quantify. Many have tried though, particularly with the experience of pain. There have been a range of instruments that have been modified or created to help examine pain such as the McGill pain questionnaire (Melzack, 1975) or instruments that rely on a Visual Analogue Scale (Chapman et al., 1985) however, as Cady (2009) has pointed out, most professionals still rely on observing pain behaviours.

The definition of a phantom sensation is variable in the literature and often it is not until we read some way into the text that the operational definition becomes visible. For example some texts such as Bockenek and Stewart’s (2002) seem to classify PP as if it only applied to individuals with an amputation as well as an SCI and don’t mention PS at all. Other texts such as Sherman’s (1997) treat any sensation below a complete injury as a phantom.

Phantom Pain/Sensation and where it fits. It is important to realise that PP/PS is not a mechanism-based diagnosis. It is instead, a diagnosis based purely on the location of the pain and looks very like it fits under “pain below the LOL” as the IASP taxonomy implies. But it can occur in an amputated limb above the LOL. Katz even talks about pain memories existing in amputated limbs below the LOL (1996). Here is where the confusion becomes obvious for both the health professionals and people with an SCI.

The decision to call the pain experienced by the person “phantom” frequently, but not always, comes from the realisation that it is apparently coming from a denervated part of the body (normally an area that has been amputated). It may be nociceptive or neuropathic in the way it is felt. This is irrelevant to the diagnosis (though the medical

treatment will potentially vary). The question that should face most diagnosticians when working with someone with an SCI is whether the body part is truly denervated.

It is also useful to note that in the literature in many articles the operational definition relies on the concept that if the injury is complete the sensations below the NLI must be phantoms. The first study in this thesis followed the same convention assuming that as all participants had a complete cord transection any sensation felt below the LOL in all of the participants was by definition a phantom. But as the thesis progressed I began to realise that if the individual was even classified with a complete injury there was no way of confirming that a sensation signal was not bypassing the lesion in some way.

The Feature in Common

Physiologically speaking the common feature between both SCI and amputation of a body part is deafferentation of the area. In the case of an amputation, the evidence of deafferentation is obvious; the body part is quite simply not present. This sort of evidence is not present in the case of an individual with an SCI and as a result at least the phenomenological experience should not be assumed to be the same.

The nearest diagnosis in the SCI world that matches an amputation is ASIA A (complete) and this is frequently done (e.g. MacIver, 2009; Sherman, Devor, et al., 1997) but as mentioned earlier and again later by participants there are inherent assumptions made about this classification that may be erroneous.

The Rationale for the Methods Employed

In general there are three broad areas of research technique: Quantitative, qualitative and mixed methods. There are proponents of all three and all approaches have merits and flaws. When using any of the methodologies it becomes clear that they try to categorise the data in a way that makes it easier to analyse. The quantitative does so

numerically, the qualitative – using language and the mixed methods using methods from both approaches.

Quantitative

Description.In the quantitative world when a person is interviewed or surveyed the researcher transduces the information from language to numbers or mathematical symbols. They then begin to analyse the data. Most of the analysis will take place in the mathematical realm (Coolican, 2009).

Limits.Quantitative techniques, because they rely on statistical models, are limited by mathematical requirements. The transduction in this case is from language to numerical data and the approaches are frequently accused of trying to convert complex human behaviour into relatively simple models (Booth, Colomb, & Williams, 2003).

Merits.The benefit of doing this becomes obvious. Categorising participant responses is essential to converting the information into manageable chunks and quantitative methodology allows researchers to view patterns they ordinarily would not be able to see. In addition, the techniques following mathematical models, also allow the researchers to discern arrangements such as correlations. The methodology also enables the researcher to position the phenomenon within the population and using this approach infer similar behaviour in other samples or populations.

Qualitative

Description.There are many methods available to the qualitative researcher ranging from grounded theory to discourse analysis methods. These approaches can be broken down into epistemological approaches that reflect the world view of the researcher. They all have in common the central motif of recognising that the researcher influences the research and that this factor should be recognised in the process (Willig, 2004).

Limits. Qualitative techniques, because they rely more on language interpretation, can also be viewed as limited. Maintaining the meaning of the response is difficult throughout the analysis but even the process of understanding the response before analysis is challenging.

Merits. These approaches mirror the quantitative techniques in that there is a specific intention to understand the data and ask it to relinquish meaning but they do this by analysing the data directly trying to avoid the process of transduction. Because the data is being kept in the same form for analysis as it was in during collection the process this reduces the possibility of information being lost.

Using Mixed Methods in This Thesis

In order to maximise the benefits of both methodologies Creswell (2008) suggests combining both approaches in a mixed methods tactic inside the same study. One of the many possibilities open to the researcher is using the qualitative methods to inform the quantitative (Rossman & Wilson, 1985). This thesis does this in that the grounded theory study generates information that is further explored in the quantitative study both of which generate data that is examined even more thoroughly in the case studies.

Johnson, Onwuegbuzie and Turner (2007) describe the history and the broad approaches to mixed methods research in their article “Toward a Definition of Mixed Methods Research”. In the article they also describe the various definitions of triangulation and how they are applied. Denzin (1978) describes a methodological triangulation where the researcher uses multiple methods to investigate a research problem. The concepts of methodological triangulation were again broken down by Morse (1991) into simultaneous and sequential triangulation. The latter being a better description of the approach taken here where the results of one approach inform the next method chosen.

The quantitative approaches are very good at answering what is happening and how much it happens. They also address association between variables. The qualitative approaches are very good at obtaining insights into routine. They are also good at asking who, where, why and how and as a result highlight the meaning of the phenomenon being investigated.

As this thesis asks the question “What is the meaning, structure and essence of the lived experience for a person with an SCI who perceives phantom sensations/pain” a monomethod would limit the potential research. The research question is broad and because the two standard approaches look at the same phenomenon in different ways it make sense to use both if possible. Qualitative approaches would more easily answer the meaning and essence components of the question with the quantitative looking more deeply at structure.

An additional realisation is that, as far as I can tell, the studies in this thesis are the first of their kind applied to this population. As a result gathering information from potential precursor studies is premised on the idea that the phenomenon is the same in other populations as most of the literature comes from studying the phenomena in amputees. It is not unreasonable to assume that the manifestation of the phenomena is similar across populations but it is erroneous to assume the aetiology is the same.

CHAPTER 2: A QUALITATIVE STUDY

CHAPTER 2 OUTLINE

The chapter begins with outlining some of the challenges facing both clinicians and researchers when talking with people who have an SCI and who also experience phantom sensations. It then moves onto the decision to use grounded theory methods and gives a description of their application to this study. Participants are then described and the various procedures to protect them are outlined. The results of the interviews are analysed and six higher order or core categories are found (the categories are further described and discussed in Chapters 4 and 5). Finally the chapter ends in a short discussion and conclusion.

The Issue

The difficulty in classifying sensations, especially if they are painful, becomes obvious to any who try. This is largely due to the perception of sensation, particularly pain, being inherently subjective.

But even before even trying to fit signs or symptoms into a diagnostic taxonomy, clinicians, as part of their initial evaluation, will always ask what the reason is for the visit. Indeed, professionals from every discipline enquire about patient/client perceptions when they first appear for treatment.

The task faced by health professionals in correctly identifying sensations frequently makes any type of intervention challenging. Added to that, if the sensation or pain is also labelled “phantom” it can make the person undergoing rehabilitation very confused and occasionally confrontational.

Relatively few studies have explored the perception of phantom sensation afforded by considering the patient’s own experience and those that do predominantly look at the phenomenon in people with an amputation (Gallagher & MacLachlan, 1999; Gallagher & MacLachlan, 2001).

The presence or absence of painful sensations have been found to be the best indicators of a person’s ability to return to work after they have been injured or completed their inpatient rehabilitation (Rose, Robinson, Ells, & Cole, 1988). As a result the pain (frequency, duration and intensity) or identifying the type of painful sensation in people with an SCI is a major component of rehabilitation success.

Despite this, there is a dearth of information regarding phantom sensations or PP in individuals with an SCI and although pain below the neurological level of the lesion is noted in both clinical and research settings, there is great difficulty in finding that universally agreed upon taxonomy (e.g. Beric, 1990; Bryce & Ragnarsson, 2000; Davis & Martin, 1947; Desasri, 2003; Freeman & Heimburger, 1947; Guttmann, 1973; Siddall, et

al., 2002). Indeed, until recently, there were so many differing systems for identifying pain in SCI that it was noteworthy to find two specialists from different disciplines or institutions using the same system (Hicken, et al., 2002).

The individual continually constructs both internal and external images of the self (MacLachlan, 2004) and perhaps one of the greatest challenges to our self-construction occurs with the wrenching of our body schema from the sense of self in the form of an acquired SCI. The body remains visibly intact, yet non-functional and the sense of self in that functionality has to be re-negotiated. Therefore, in contrast to the individual with an amputation (Rybarczyk, Szymanski, & Nicholas, 2000) the person with an SCI has to construct an almost complete image of self.

In addition, there may be conflicting messages to be reconciled. Visually individuals can see themselves as whole and intact but do not feel any external stimulus (e.g. pinprick) yet they experience a host of sensations that can be both realistic and vivid.

It is also of note the rates of chronic pain reported in persons with an SCI have been reported as high as 94% and levels of pain that interfere with activities of daily living (ADL's) have ranged from 5% to 45% (Bryce & Ragnarsson, 2000). Pain that can hinder rehabilitation for a person with an SCI can be significant.

As stated, there are many different ways of constructing a taxonomy for pain in SCI but there has been a focus on classifying only pain types with a notable exception: Siddall and McClelland (1999). In their article "Non-painful sensory phenomena after spinal cord injury" they address non-painful sensory phenomenon directly. They propose a taxonomy which I used as one of the components for the interview guide (see Appendix A). The categories they proposed in their taxonomy were also some the criteria used in the analysis of the data to classify the different types of sensation reported. For example, they describe the perceptions that create either simple or complex sensations and I was able to use their descriptions to help me phrase questions that helped participants describe their experiences.

Creating a comprehensive taxonomy for both pain and sensation is beyond the scope of this thesis but the process should be informed by as many disciplines as possible. Fields such as psychology, occupational therapy, speech therapy, social work, respiration therapy, recreation therapy, physical therapy/physiotherapy etc. work extensively with people who have an SCI and their input is needed. This process has already been utilised in the development of the IASP taxonomy for pain associated with SCI (Siddall, 2006).

There are other qualitative studies on PP/PS particularly focusing on people with an amputation but I have been unable to find any articles that systematically analyse the phenomena in the SCI population outside of the afore mentioned case study of supernumerary phantom sensations (Curt, et al., 2011).

The Approach

With all of this in mind and in order to more fully understand the lived experience for a person with phantom sensation and an SCI this thesis approaches the issue from a psychosocial view. A qualitative methodology using grounded theory methods for the first foray of the research was chosen as appropriate.

There are a range of components in this methodology that are necessary to make data analysis systematic and given that the data generated from an interview can be unstructured it is vital that analysis is as organised as possible. As the data in this study were uncovered all of the techniques commonly used in grounded theory generation were used.

Grounded theory generation methods are an effective way of analysing data from an unstructured source in a systematic way. They hinge on the belief that data should be allowed to speak for themselves and supply researchers with a clearer series of steps to elicit meaning from the collected information. Because of this specificity the method lends itself to a qualitative researcher who wishes to mix methods. The method also takes away

some of the vagueness may face the researcher regarding the application of qualitative methodology.

The general technique for collecting and analysing the data generated by grounded theory method was initially proposed by Glasser and Strauss (1967) and after a frank exchange of views between them, was later modified by Strauss and Corbin (1998).

The later modification by Strauss and Corbin moved the initial method closer to a quantitative approach, thus making it more palatable to traditional investigators. Pidgeon and Henwood (1997) describe the differences between the method as described in 1967 and the methods described later.

The technique was proposed as a possible alternative to quantitative approaches, which deal more with the rate of occurrence, reliability or location within a population. The qualitative methods concern themselves more with the phenomena being investigated. The arguments for and against both approaches have been exhaustively dealt with in the literature and elsewhere (e.g. Booth, et al., 2003; Breakwell, Hammond, & Fife-Schaw, 2000; Creswell, 2008; Denzin & Lincoln, 2003; Glasser & Strauss, 1967; Pidgeon & Henwood, 1997; Ritchie & Lewis, 2003; Rossman & Wilson, 1985; Strauss & Corbin, 1998; Willig, 2004).

Grounded Theory Methods as Applied To This Study

Categories and How They Were Used

Categories are the basic “building blocks,”(Willig, 2004, p. 33) used by any researcher in developing a grounded theory. All incidents, processes or occurrences that share common features were grouped together or categorised. Initially, the categories tended to be descriptive but as the process continued, the categories became increasingly abstract. These categories became visible through appropriate coding. The generation of these categories allowed me to build a theory grounded in the data garnered from the

participants. This theory was then used to inform part of the content in the quantitative study that followed.

In this study, after distilling every sentence to its abstract form, there were 6 core categories that emerged from the data by the time the entire process was finished (detailed in the results section).

Coding the Material

First it was necessary to open up or unzip the corpus (in this case the interviews) for analysis and identification of the categories. The process helped me to place similar categories together.

It consisted of 3 major phases, open, axial and selective coding. The first set of tasks (open coding) allowed me to describe, label, identify and categorize the information that interviewees furnished. The second phase, referred to as axial coding, necessitated linking the concepts found when “opening” the data. The third, selective coding focused on identifying the core concepts that knitted everything together.

Each phase can happen at any point during the coding of the data. It is not desirable to first do the open coding; finish examining the interview then move on to axial, once again completing the entire interview and then move onto selective. The phases were not sequential in any way instead; all of the techniques were implemented contemporaneously.

Initially I coded the interviews on a line-by-line basis in order to elicit the maximum amount of information and to ensure the resultant theory was truly grounded. This technique increased the number of categories available for analysis. As the interviews continued I increased the size of the section of the coded text effectively moving from a line by line analysis to coding entire sentences or entire replies/statements.

Where possible the categories were titled in vivo (i.e. using terms that the participants mentioned while describing their experiences).

Potential participants were approached at either the clinic in Santa Clara Valley Medical Center (SCVMC) or a peer support group attached to the hospital. It was relatively easy to triangulate information by accessing the participants' medical charts, physicians' notes and field notes from Social Workers, Physical Therapists and Occupational Therapists. This was done as soon as participants gave written permission.

The Usefulness of Constant Comparative Analysis

Using constant comparative analysis while coding, I continually moved from identifying similarities to identifying differences between categories. This method allowed for the constant review of the categories used. This meant that as I coded the information the process continued to be dynamic. In this case, some of the statements from the participants easily lent themselves to categorisation and others moved from one category to another until they finally found a home. Frequently, as the categories formed, they would merge to form another more relevant higher-order category.

Negative Case Analysis

Another technique I relied on while coding was negative case analysis. This practice is designed to help researchers look at the data for cases that do not fit the categories. This highlights possible problems in category formation. When this is used correctly the researcher is effectively assessed by the process they are relying on. It is important to be able to let go of a category or a case if it is apparently incorrect.

Category Verification

In addition to my own assessment I identified neutral third parties and tested the discovered categories to verify their aptness i.e. I approached post-graduate students and clinical professionals and asked them to verify the appropriateness of the categories I had discovered. The statements from the interviews were randomly sampled and a selection of them were given to the verifiers on code cards. I then asked them to place the statements into the appropriate categories. Concordance was at 85% and the categories were adjusted until there was in excess of 90% agreement.

The Importance of Theoretical Sensitivity

It is imperative that the researcher be sensitive to the material on an abstract level (Strauss & Corbin, 1998; Willig, 2004). I accomplished this in three ways, reading the literature in the field, my own clinical experience and using the experience of the clinical staff in the facility where the study was conducted.

One of the great challenges facing any researcher using qualitative research is the ability to move from descriptive to abstract views of the data. I actively engaged the data by asking questions of it, creating opposites or making comparisons. This technique helped me extract meaning from the dialogue.

How Theoretical Sampling Helped

Once there were obvious concepts visible in the data from an individual's interview I consulted with the physicians who were involved with the study and we identified the next potential participant from those who had volunteered their time.

Theoretical Sampling is a process where future participants are chosen on the basis of the categories that have come to light. It is based on a simple premise. As an investigator becomes more familiar with the data presented, patterns begin to emerge

across the different interviews. Instead of just randomly sampling we looked for participants that displayed the properties that were under investigation. The emerging categories were checked against the real world by choosing samples that contradicted or reinforced the premise being examined. This meant that a case may have also been chosen because participant did not meet the previously identified concepts. This was done in order to challenge the categories. The properties of interest changed over the course of the interviews sometimes to such an extent that the original research question was modified.

It is here that we can see one of the more obvious aspects that differentiate grounded theory methods from quantitative research: There is no attempt to create a random sample. For this reason qualitative research in general will not elicit information about the incidence in the population of the phenomenon being studied instead it paints a comprehensive view of the phenomenon from the point of view of the experienter.

Theoretical Saturation and How It Was Used

In this study participants began to repeat concepts quite quickly. For example, the concept that pain and sensation were frequently felt below the NLI was common to all the interviews and strongly present even in the first conversation.

The model where the researcher continues to sample until no new categories are identified is called Theoretical Saturation. This process “functions as a goal rather than a reality.”(Willig, 2004, p. 35)

Theoretically, if a researcher were to interview a participant that responded with all the categories discoverable in the coding the study could be saturated from the first participant (however, this would effectively be impossible because the researcher could never be sure that the categories had been saturated and it is always possible for the researcher to modify a category or change perspective).

As a result of this, sample sizes in grounded theory research are frequently low and would not be advisable in quantitative studies (Creswell, 2008) as was the case here.

Memo-writing In This Study

Memo-writing is essential in every part of the process and it allowed me to see patterns in the data and organise them more clearly. It is a simple technique where the researcher takes note of thoughts, theory categories, concepts, operational details in the future etc. Actually, memo writing was probably the biggest single aid in completing this study.

All the above-mentioned techniques were used extensively in the research. They are the basic techniques but not the only ones necessary to identify information in the data and I relied on them heavily to help meaning emerge from the interviews that was not immediately obvious.

More detailed descriptions of the techniques can be found in Strauss and Corbin's 1998 book on grounded theory procedures (1998).

Research Design Choice

The various techniques in grounded theory method allow researchers to approach data in a different way to other quantitative methods. However, amongst the various approaches to qualitative research the generation of grounded theory stands out as being very structured. Descriptions of the method are very specific and lend themselves to use by researchers who may not have the experience to glean all there is to be gleaned from a simple conversation. In addition to using the method to help make sense of the data I also relied on the process to help generate hypotheses for the next study.

Another aspect and perhaps the primary reason for choosing from qualitative methodology was the realization that it was imperative for me to listen to people with an SCI who had experienced this phenomenon.

I felt that it was unnecessary to distil the data to a single theory but instead focussed on the realisation that it could be used to discover a host of different categories that could be further investigated in the following studies. In this, it is better considered as a qualitative study utilising grounded theory techniques.

Method

Qualitative approaches concern themselves with trying to understand the phenomenon as experienced by the individual or group undergoing the experience (Lyons, 1999) and not with looking at the incidence of the phenomenon in a population.

Participants

Using the inclusion criteria 14 potential participants were identified by the physicians and/or inquirer/investigator primarily in the outpatient clinic in SCVMC. They volunteered their time for the study. Unfortunately on closer inspection six of the potential participants met a component or multiple components of the exclusion criteria leaving eight participants out of the initial 14 identified. (Both sets of criteria are detailed later and a more comprehensive version of the identification process can be found in the section labelled "Sampling").

Participants were interviewed for the research project in a non-threatening environment of their own choosing e.g. the kitchen table at home. The researcher recorded the interviews with small micro-cassette recorder. Each participant was interviewed once. A third party later transcribed the interviews and the researcher verified and coded each script.

Inclusion criteria. Criteria for inclusion in the study were that the individuals were aged at least 18 years. They were spinal cord injured and met the criteria for an ASIA A diagnosis (meaning they had received a medical assessment of having a complete spinal cord lesion). They had to have at least a high school education and they had to be able to give informed consent.

Exclusion criteria. If the potential participant had a history of a psychiatric disorder that involved hallucinations or delusions, if the person was taking prescribed or un-prescribed medications that had hallucinatory effects or had poor English comprehension they were excluded as potential interviewees.

Sampling. All patients meeting the ASIA A (complete) diagnoses attending the clinics were asked if they perceived sensation below the level of the lesion and if so would they be interested in volunteering time to be interviewed at home. The ASIA A diagnosis was confirmed by evaluation or inspection of medical charts in any who had expressed an interest. In addition, individuals with an SCI were approached during their attendance at a peer support group. If necessary any volunteer from the peer support groups was re-evaluated by one of the SCVMC clinic physicians.

In order to be interviewed all the participants had to meet the inclusion criteria. It was also important that they had to have the ability to understand the interview questions and reply without the need of an interpreter. This stipulation is standard in a large number of California research facilities, where the research is based on interpretation of the responses. This issue is critical where even the state driving test is issued in 31 different languages (State of California: Department of Motor Vehicles, 2011). The requirement was also mandatory for the Institutional Review Board (IRB) in SCVMC to pass this study (See appendix C for documentation).

The physicians established that none of the medications that each participant was taking were hallucinatory in nature or had hallucinations as a side effect. At this time they

also verified that participants had no history of a psychiatric disorder that involved hallucinations or delusions.

As the phenomenon displayed itself with more clarity the sampling procedure was refined using theoretical sampling as detailed above and more fully in Strauss and Corbin (1998). However, the basic inclusion and exclusion criteria were always met.

Descriptive statistics of participants. Out of the eight interviewees that met all of the criteria, five were male, three female. All participants sustained their injuries in a traumatic manner. Five were tetra or quadriplegic, three with injuries sustained at a lower level. All had complete injuries i.e. ASIA A diagnosed. They averaged 46.25 years of age, ranging from 34 to 60. The time since injury ranged from three to 31 years averaging 16.75 years. Their age at the date of injury (DOI) ranged from 17 to 40 years old averaging 28. These characteristics are summarised in Table 2.1

Table 2.1

Summary of Participant Characteristics

| Characteristic | Number (total n=8) |
|------------------------------------|--------------------|
| Total | 8 |
| Male | 5 |
| Female | 3 |
| Tetraplegic | 5 |
| Neurological level: | |
| Cervical | 5 |
| Thoracic | 3 |
| Mean Age (range) | 46.25 (34-60) |
| Mean age at time of injury (range) | 28.75 (17-40) |
| Mean years since injury (range) | 16.75 (3-31) |

All procedures within the study were physically non-invasive however; we anticipated that there might be some emotional trauma associated with discussing the injury or reaction to the phenomena. The principal investigator (PI) and co-investigator were already clinical professionals familiar with the population and as the study was being

conducted under the auspices of the county of Santa Clara, participants could easily be referred to psychology services or the peer support group within the hospital.

General Procedure

Potential participants were identified and semi-structured interviews, involving the use of a simple graphic representation of the human body, a series of open ended questions and a focus on the descriptions of benign phantom sensations as detailed by Siddall and McClelland (1999) were conducted (see appendices A and B). The eight participants attended either a peer support programme or outpatient clinic at SCVMC. The referring physicians verified all diagnoses. The interviews were recorded on tape and the participants were asked questions pertaining to both general information about the injury and specific information about sensations experienced below the NLI.

All interviews were transcribed by a third party, verified by the interviewer and analysed by the interviewer/researcher in accordance with grounded theory method. Open codes were created using microanalysis. Categories of a higher order were noted and using the properties and dimensions of these categories, via axial coding, the concepts were brought together.

Initial coding was completed immediately prior to the selection of the next participant. The categories were tested using inter-rater reliability.

Interview procedure. In order for the interview to be fluid it was important that the locus of control be located in the interviewee as much as possible thus the interviews were conducted in various places but all were in locations conducive to casual conversation and all were of the participants choosing. In addition, the interviewer eliminated any travel costs associated with the interview by travelling to the participant.

The interviews were all semi-structured in that there was enough leeway for the interviewee to take the interview in any direction but the skeletal structure of the interview consistently returned the participant to the topic of the investigation. The structure was determined very generally for the first interview and became increasingly specific as the theoretical sampling technique made itself felt. The initial research question was “How is phantom sensation experienced by a person with a spinal cord injury?”

All interviews were recorded with a SONY M-200MC micro cassette recorder in meeting mode. The recorded portion of the interviews ranged from 0.5hrs to 1hr. The encounters from the moment of arrival to the moment of departure lasted approximately 2 hours.

Ethical Procedure

Permission for the study was obtained from two sources: Trinity College, Dublin School of Psychology Research Ethics Committee (SPREC), and the IRB for SCVMC in California. The Ethics Committee (TCD) granted permission from June 1st, 2003. The IRB eventually granted permission in late August of the same year but dated the study as having started in May. Due to the delay in authorisation from the IRB in California, it was deemed necessary to reapply for permission to the IRB to effectively extend the timeframe for the study in California. This process was continued until the information garnered from the participants was published and the study terminated. The IRB granted the first extension in May of 2005.

The requirements were similar for both committees with the notable exception that an additional informed consent document was necessary to meet federal standards in the U.S. The details of the requirement can be found in the United States' Health Insurance Portability and Accountability Act also known as HIPAA (104th US Congress, 1996). The study also had to be presented in a live setting with the Principal Investigator (PI) to the members of the board in California together with completion certificates issued by National Institutes of Health (NIH) for the online course "Human Participant Protections Education for Research Teams (see appendix C).

Participants signed each informed consent document, initialled each page and each manuscript was witnessed by a neutral third party. In addition, each participant signed a release in order to allow the researcher or anyone directly attached to the study, to access medical records.

All participants were judged by the referring physician and the interviewer to be mentally competent to give consent.

Process of consent. Attending physicians identified potential candidates and gave them the phone number to call for participation. The researcher then either returned the call or spoke immediately with the potential participant at the clinic or peer support group. The study was described in detail and all questions answered. If the individual was interested in participating and the diagnosis and classification were verified, the researcher then mailed them the informed consent documents (see appendix F and G for copies of the Informed Consent documentation) along with a stamped, self-addressed envelope. Once the participant returned the signed informed consent documents, the researcher then, via phone, scheduled the interview and addressed any other concerns the potential participant may have had. At the interview the researcher gave a copy of the informed consent to the interviewee and prior to the dialogue, encouraged questions about the process. All

information given by the participant was triangulated with existing information in the medical files or verified by the clinic physicians.

Participant comprehension. The potential participant was asked to verbally repeat the procedure and details of the study. They also had to verbally demonstrate knowledge of their rights to confidentiality and what they should expect of the research team. They did this by explaining the informed consent documents to the researcher before the interview began. If any points were not understood they were explained and repeated as many times as necessary by the researcher.

Documentation of consent. An SCVMC physiatrist/rehabilitation physician had the responsibility of being listed as the PI. This was done to meet the requirements of the IRB in Santa Clara County. These requirements clearly state that the principal investigator listed on the project shall be a county employee. There was one co-investigator listed, Daren Drysdale. Only Daren Drysdale or the PI were authorized to certify and document obtainment of informed consent.

Confidentiality.

Participants are guaranteed confidentiality in the informed consent documents (appendix F and G). Personal health information in the form of name, address, telephone, fax, e-mail, medical record numbers, brief family medical history, allergies, current and past medications, current and past therapies and recorded interviews was taken (see appendix H for summary documentation).

All participants were assigned an identification number which was used to recognise all research material that contained information about the individual. In all material that may be published the participant's initials are used. All hard copy files were and are kept in a locked file cabinet at all times. Only personnel directly associated with the project had access to the cabinet.

Financial Procedure

There was no financial remuneration for participation in the study. In an effort to keep costs for the participants to a minimum it was decided that the researcher should bear the responsibility for travel. This also allowed the interviews to take place in a familiar environment to the participant.

Results

The data corpus was collected using semi structured interviews. The data was then analysed using grounded theory method as described above and laid out by multiple authors(e.g. Glasser & Strauss, 1967; Pidgeon & Henwood, 1997; Strauss & Corbin, 1998; Willig, 2004).

During the study, six higher order categories came to light as a result of subcategories being identified in the data. The higher order categories were: Injury context, sensations, meaning of the sensations, body connectivity, attitude and communicating about phantom sensations.

Injury Context

As previously stated, in all instances participants acquired the injuries that resulted in their paralysis. The injuries resulted from a variety of events such as being in a building that was hit by a tornado or involvement in motor vehicle accidents. This theme was elicited by a query or series of queries instigated by a guideline in the interview guide reminding the interviewer to establish the type of trauma (see Appendix A).

For most, the recollections of the injury onset were patchy and unreliable at best. RP, a 41-year-old, single man with a lesion at C5 secondary to a quad bike overturning, explained it this way:

I: . . . How much of the whole thing do you actually remember?

R: The (long pause) . . . I think most of I think has been put back from what people have kind of shared . . . with me. Emm, I don't say that I have a lot of recall but there are moments when I was in Dominican (hospital), then I will come to, but ahhh, I think a lot of that was still information given to me, that that I recall.

Another participant reported the complete absence of memory stating that her first recollection of the incident was waking in bed in the operating room:

And everything was just, ah, I couldn't move...and I must have blacked out and I remember them taking me out of the truck into the helicopter....And then I didn't remember anything after that and I remember waking up on the operating table
[TLV]

Continuing the issue of blacking out FS, a 46 year old married man with a lesion at C5-6 gave an alternative view:

But, I don't think that I really, uh, I, I, I don't think I lost consciousness at any point, um, I just remember talking to my wife and then there were three guys that we had met, uh, the day before we'd actually met on the airplane. And, uh, they were all (short pause)...well, t-w-o of them were retired police officers and one was a reserve police officer. Um, (pause) and so they were the ones that helped me out of the pool, or to the side of the pool and at what point the paramedics took over and-and physically got me completely out of the pool and so on, I'm not entirely... sure

Despite the claim to not losing consciousness his recollection of the event was still distorted and he seemed uncertain of the details, particularly time duration.

R: Um, actually they didn't, they didn't initially take me completely out of the pool, they just sort of stabilized me there in the pool. Now, at, what '(sighs)' how much time elapsed between that and when I was actually on, on the pool deck and talking to the other people and the paramedics, I'm not exactly certain. It...(long pause)...you know, recollection is that there was no time lapse at all, although the paramedics were there, so obviously there -

I: (Overlapping) There must have been time...

R: (Overlapping) Time had passed...

I also recorded narratives about injury onset that were told in a rather mechanical, and well-rehearsed way. The language used was sometimes impersonal and remote:

. . . and the vehicle flipped. And upon flipping we were going down the cliff or highway or should I say embankment. [RP]

The use here of the word "upon" stood out principally as the participant never used the word again in the interview. It was not in his usual conversation and it seemed as though he was retelling an account given in a formal setting such as a courtroom.

JK, a 60-year-old man who sustained his injury when he came off a motorcycle, also told his story but it was obviously brief and told frequently:

Motorcycle accident . . . I bought a motorcycle which was a little bit too big for me and got on it, and (short pause) actually I bought it in parts and put it together, and got on it one night and it wouldn't stop and I ran into a house. (Long pause). Very simple.

The tone he used could easily be described as one of boredom. This observation fits as one of the techniques frequently used by clinicians is to encourage clients to tell and retell the trauma in order to blunt its emotional and cognitive effects (Schnurr et al., 2007; Tuerk et al., 2011).

One of the more dramatic onsets of injury was related by JA, a 59 year old, married, woman with a complete injury at T12. She recounted her experience when as a child she experienced a tornado:

And so it picked up the building with me in it and crashed it over across the way and, um, I came down on my head and compressed the T12 vertebra which caused a spinal cord injury, bruising of the spinal cord...

Sensations

This category, common to all the interviews, is primarily descriptive in nature. It covers the physical sensations experienced by our participants post injury. Most of the sensations mentioned were painful either because of their intensity or because of their nature. Of note is that none of the participants used the term “phantom” to describe either the pain or sensations below the NLI.

In all interviews the participant was asked to describe the sensations they perceived and the responses were coded and fell into Siddall and McClelland’s (1999) taxonomy which added more credence to their categories.

The sensations were described in a range of different ways such as where the sensation was felt, what type and how vivid the sensation was, how long it lasted, when it happened, whether it was triggered by something that the participant could identify or whether it was painful or not etc. FS captured many of these concepts in this extract:

R: If I attempt to move my toes or move my feet at the ankle, sometimes they will feel like they’re moving. In fact, when I attempt to move my toes, they usually feel like they are moving, like they’re, like I can curl them.

I: So, the sensation is so real to you that unless you are looking you can’t be sure?

R: Um, you know, that’s funny. Uh, because now, and this is six years post, I still try to move my toes and my feet, thinking that well, trying to move it certainly can’t hurt

anything . . . And I don't expect it to move necessarily . . . I don't have to look at my toes to know that my toes aren't curling – just because I've done it so often.

Most of the comments made by the participants reflected this complexity of lived experience. Indeed, it was difficult to categorize many of the statements because the concepts were bound together so tightly in the participants' narrative.

The areas of the body where the sensations were felt were diverse, though as we were interested in phantom sensations, most of the interviews centred on both painful and non-painful sensations prevalent below the NLI. Despite this localization many of the participants reported that the sensations sometimes moved, both while they were being discussed with the interviewer and over a longer period. AH, a 44-year-old, single man who sustained his C5 injury while surfing spoke about the sensations moving while he was being interviewed:

I can tell you right now, and it's moved again, that (long pause) that the, that the feeling that I have of, of like something holding me or surrounding me has now shifted from my, um, upper part of my shin all the way down to into my toes.

Location. Also remarked on by some participants was an oddity in the location of the sensations in response to a stimulus. The incitement, such as a simple touch, administered to a denervated area of the body was experienced in a region with normal sensation. This phenomenon is quite common and frequently cited in the literature (e.g. Moore, et al., 2000; Siddall & McClelland, 1999), termed referred sensation.

R: I have had that sensation where somebody touched like my hand and I got a sensation in my shoulder . . .and then I have another (short pause) example of that and I think this is, this is something that is probably autonomic -um, but for instance, I had, a-at one point, I had a wound on my left heel and whenever that was irritated, for instance, uh, after I visited the podiatrist and they debrided the wound I would get

a clammy sensation on the back of my neck. Interestingly though, when my left foot was irritated, that clammy sensation would be on the right hand of my neck and I have had a similar thing happen, but reversed with the right foot on the left hand side of my neck. To the point where I could say my foot is irritated, my neck feels clammy, I need to put my foot up and then it goes away. [FS]

Complexity/Simplicity. The complexity or simplicity of the sensations was also commented on. Many of the participants reported sensations such as burning, pulling, buzzing, tingling pressure or numbness. These sensations are linked by the common concept that they cannot help the individual form a sense of where the body is in space. Although the sensation's location on the body was obvious to the participant, it was insufficient on its own to help the participant form all but a simple impression of what may be happening in the body part. In addition to the complexity, identifying whether the sensation is painful or not was also noted by most interviewees:

R: It's not necessarily pain, it's a buzzing sensation. The pain that I feel, if I may, is all limited to my hands.

I: Ok.

R: Everything else is sensation that I can't explain, except I do have in the back of my hip...

All of the participants also reported complex sensations such as movement or position of body parts. One participant recalled feeling her legs straight when they were, in fact, tucked under her. In contrast, another participant reported feeling that her legs were tucked in under her while she was sitting. TLV, a 44-year-old, single woman with a complete lesion at T8 caused by a motor vehicle accident described the sensations as follows:

I: What position do your legs feel like they're in?

R: My legs always feel like they're, like I'm sitting even if I'm laying straight in the bed.

I: You'll always feel like you're sitting. . .

R: Yeah.

JA who sustained her injury 41 years previously also reported a very similar phenomenon. She recounted first noticing the phantom sensation early on in her rehabilitation:

R:when I was first injured, for several months afterwards I felt like, you know, I was laying on my bed on my back on a (.....) electric bed and I felt like my knees were always bent.

I: Ok.

R: And they never were, but they always had the sensation of being bent up, so they...

I: They were in the air?

R: Yeah, they were in the air.

I: Ok, so it was like you were sitting down, lying down?

R: Right.

I: Ok. Alright. Do you get that sensation at all now?

R: No.

Vividness. The sensations were often so vivid, particularly in the case of movement that it was only after looking that the individual could be sure that the body part had not moved. JK spoke about the times she spent in bed trying to move a toe. "I used to lay in bed

and try and move my big toe and I would think it would be moving and I would look it and it wasn't moving".

Another participant observed that the only way he knew that his "foot is not moving is by looking at it". Even more dramatically some interviewees reported needing to ask a third party to inspect their limbs because they suspected their own proprioception to be inaccurate or they trusted the sensations to be accurate and were surprised when they found themselves mistaken. One interviewee reported a situation where she kept asking staff to "straighten my legs out".

SD, a 34-year-old, single man with a complete lesion at C5-6 secondary to a motorcycle accident described incidents in the early part of his rehabilitation where he was unable to see his legs because of being in a supine position:

I: Those sensations you were telling me about being different. What was different about them?

R: Um, (pause), well, for my legs, um, they would feel, um, like twisted or pointing to one side and I would ask somebody to check and they would just be upright.

He also spoke of the phenomena in his arms:

R: Um, (pause) same thing, ah (pause) basically it was in my legs and my arms.

I: Uh-huh.

R: My arms constantly felt like they were crossed over my stomach, or my chest.

Um, and they were straight out. So, and, it would be quite frustrating, really. It would feel like they were actually, my arms were actually crossed over me and putting pressure on me.

I: Right.

R: And, ah, but when I would ask somebody, my arms were straight out to my side

R: Yeah. I: And was it complete? Like, I mean could you. . .Did it feel like the way that your arms felt before the injury?

R: Yes

Triggers. Events that people identified as causing sensations were described in terms of internal and external cues. There were, however, a substantial number of sensations that seemed to happen spontaneously “I couldn’t say if it was like in the mornings or afternoon or after... But I know it was quite often” .

Many participants related the fact that they could identify an external stimulus that would give rise to a sensation such as hitting the person’s chair or bed. The response for one individual was the description of an electric shock working its way through his body.

The only thing I remember is when, and it still happens today, if somebody comes up and just hits my chair or hits the bed, I get this real surge of, it’s almost like an electrical shock type of thing. [FS]

Another respondent described that the sensations could be both volitional and spontaneous:

R: Emm ... (pause)... you know, It’d have to be completely unbeknown [to me] that something was going to happen...

I: Huh... Okay...

I: Have you noticed it [the sensation described] at any other time? Is it always after the startle?

R: Nope. I can do it myself as we sit here. [RP]

Internal events that could trigger responses were harder to identify. If the event was conscious such as a volitional attempt to move a body part the effects were much more easily attributable to a specific occurrence. FS described both the sensations and his ability to initiate them if he wished:

R: . . . I have sensations that generally start from my feet and sort of work their way up to about mid-trunk, that resemble pressure. Um, I don't really know how describe this except to say that other people that I've talked to have had similar sensation.

There is a, almost um (long pause) . . . it feels as though there is something sort of on the surface of my skin that sort of vibrates and runs up my legs into my mid-section.

I: Uh-huh.

R: Um, I've felt that from day one.

I: And is that constant as well?

R: (Overlapping) No.

I: Have you ever noticed a trigger?

R: Yes.

I: Okay, what?

R: I can trigger it. . . by . . . for instance, if I, uh, make at least a mental attempt to move my toes or my feet . . . (short pause) after-after that, I will get this sensation that sort of runs up my legs and sometimes up to as high as, like I said, mid mid-trunk.

I: Does the pain increase when you do it?

R: No.

I: No? There is no change in the pain level?

I: At all.

R: No. I, I should, I should say that it doesn't always happen as a result of this trigger. Sometimes it is spontaneous.

I: Okay. And you've never noticed any other trigger that could be outside of you or anything like that?

R: No. [FS]

This description was not unique. RP describes a general stinging sensation not necessarily in a specific body part: "I would say the, uh, movement attempt is what's triggering this, emm, stinging sensation".

Participants were frequently able to generate a sensation of movement by trying to move a body part and they often gave details of an electrical sensation that travelled through their body when they attempted to move. Individuals also reported that they stopped trying to move a body part, because after trying many times and not seeing a response, they just stopped checking to see if it was a movement they could sense.

Temporal information. Participants first noticed the onset of the phantom sensations at differing times. Some reported that they first noticed them within hours or days of the injury.

R: Now, I the the-the sensations that I described as, uh, that I could trigger-

I: Uh-huh. R: That . . . that . . . sort of is a . . . Yeah it kind of creeps up my legs. T-h-a-t I remember feeling very early on in San Diego

I: Uh-huh.

R: But, I can't recall whether I had that sensation as early as the day of or even the day after my, um, the actual injury.

I: Uh-huh.

R: But, very early on, I would say, certainly by within a couple of days, two-three-four days, very early on I remember that sensation; because I remember thinking that there must be some (long pause) there-there must be something that's still being transmitting there . . .that . . . that was a sign. [FS]

SD also recounted noticing them within a day or so after the injury “But I would say within a day or so after I got to the hospital I would start to have those feelings quite often.”

Others noticed phantom sensations much later. Sometimes it was many years after the injury. In one case the interviewee first became aware of such sensations eight years post injury:

Actually, it’s only been probably two years ago. I didn’t even think about it before and it’s just like, I’ll wake up and I think I’m sitting and I look and, you know, I’ll just look at my legs and think, it just feels weird. [TLV]

Another participant observed that the sensations only became noticeable once he discontinued his use of morphine as a pain suppressant:

I: ... how soon after the injury, while you were in valley (hospital), did you start noticing the sensations.

R: Ahhh, actually as soon as I, I came off the morphine. I was, I was talking about it. [AH]

This ties in with Sherman’s claim (previously mentioned) that there may be a connection between pain and phantom sensation (Sherman, Devor, et al., 1997).

The transitory nature of the sensations was also a recurring theme. For example FS expressed a difficulty in telling how long certain sensations continued.

R: And sometimes, you know, it sort of creeps up my, up my leg and sometimes like I said, reaches as high as my mid, mid-trunk. So depending on...I..I imagine it is a split second. I mean it’s hard to say. A second is actually a fairly long time.

I: Yeah

R: You think of a second as being very short, but for something like that to r-a-d-i-a-t-e up your body-

I: Okay.

R: It's probably just a split second.

But he continued talking about another phantom sensation saying that "It lasts longer than the period of time that I'm trying to move my foot." [AH]

Another respondent noted that "It's weird because I had it for the first two years and it went away."

AH commented on the fact that the sensations changed location even during the conversation:

I can tell you right now, and it's moved again, that (long pause) that the, that the feeling that I have of, of like something holding me or surrounding me has now shifted from my, um, upper part of my shin all the way down to into my toes.

He went on to be even more specific later in the interview stating that "They're shifting as we speak"

Other interviewees commented on the constancy of some of the sensations particularly if they were located in the ZPP:

R: And it's (pause), it's constant...I mean, it, it never seems to...when I wake up in the morning, it doesn't interrupt my sleep.

I: Uh-huh.

R: ...When I wake up in the morning, it's there and when I go to bed at night it's there. [JK]

Or another comment about constancy also by JK : ‘Yeah, I mean it’s the same today as it was forty years ago’.

There were times where respondents noted the complete absence of previously experienced phantom sensations:

Nothing. Right now there is nothing. But, as I stated, everywhere throughout my body where I do not have normal sensation, I will, at times I remember specifically having flowing water through my thighs, right through my muscles. [AH]

SD spoke about the sensations being vivid early on but that they had all but disappeared now:

I: ...do any of these sensations occur now? At all?

R: (Long pause) No.

I: But they were very vivid at the beginning of this instance...

R: Very, yeah.

Expected sensations. All of the people interviewed also reported expected sensations they associated with spasms, or autonomic dysreflexia (activity associated with the malfunctioning of the autonomic nervous system characterised by an increase in B/P)

Autonomic dysreflexia symptoms were noted as follows:

R: Because I do get, I get clammy if I have like my bladder is full, um, or with bowel movement . . .

I: Uh-huh.

R: . . . I get clammy, but that’s more all over . . .

I: Uh-huh.

R: This sensation that relates to the feet is very focused in an area maybe the size, not even of my fist; maybe the size of one of those lemons right there or a golf ball. [FS]

AH reported that as far as he can tell every muscle spasms but he can't feel the sensation directly if it is below his NLI however he does perceive some movement:

Interesting question. Um, (long pause). I haven't thought about it that way. (Long pause). I, I can state for sure that, um, for one I have spasms everywhere in my legs. My legs spasm, my toes spasm, my ankles spasm. Every muscle in my body as far as I can see still spasms. As far as knowing it? No. I would have to say no I don't, no, no it doesn't happen. Sometimes it feels like it's moving and it's not.

Meaning of the Sensations

The meaning of the sensations was not specifically asked for in the first set of guidelines but became very obvious fairly early in the series of interviews.

All of the interviewees assigned meaning in two different ways. The first was a description of what the feeling most resembled and the second a description of what the sensation implied.

As a result sensations meant a combination of different things to each individual. Sometimes the implication was neutral, but sometimes the sensations were vested with deeper symbolism. For example, many participants viewed feelings below the NLI as a sign of returning sensation or motor control.

Of course, you're looking for any sort of sign of return and early on even the doctors don't know what kind of return you can expect. So that was something, uh, that I was kind of clinging to that as being a sign of something coming back some, some recovery that I was going to have. [FS]

SD questioned the accuracy of the diagnosis

R: ... but to me I've just have had, um, too many feelings throughout my body.

I: if you question whether the injury is complete or not, have these sensations contributed to that questioning in any way?

R: (Long pause) I, I would say so, yes.

Even more explicitly JA expressed an early belief: “When I was first injured I was quite certain I could move my toes” She goes on to say, “I should be able to move my toes but they don’t move”

Other interpretations were more concrete and the sensations identified as being similar to something more mundane such as ‘It feels like I’ve got my shoes on most of the time’ [FS], “Right now I feel like there’s something – almost like there’s a hand wrapped around my ankle.”[AH]. SD noted that one set of sensations she encountered felt “like somebody shakes your hand and they squeeze your fingers together”. The drive to make sense of the sensation can result in descriptions that seem provocative “I, um, sometimes feel like there is something hot up my butt.”[AH].

Also expressed was an acceptance that involuntary movement was a part of the injury and that anything is better than nothing:

R: Well, I think psychologically, um, (short pause) they can kind of work both ways. Um, they can help from the standpoint of, for instance, I have this philosophy about spasms—

I: Uh-huh.

R: --that spasms are good—

R: ... because it’s better for something to work than to not work at all, even if it is involuntary.

I: Uh-huh.

R: And I don’t mean that just from the point of view of, um, ah-ah physiologically where there is a muscle response. That muscle is contracting, so it’s exercising, it’s

not going to atrophy as much—but also from a psychological point of view- to say well something's going on there.

I: Uh-huh.

R: So, I think, ah, these sensations, whether they be the hot/cold or the pressure, are similar in the sense that I, I have a feeling that having that sensation is better than not having it. [FS]

He goes on to speak to his acceptance of the sensations saying that he's "glad to have the sensations...some sensation is better than none. He expresses a difficult concept for those of us who have not experienced it, the idea that numbness is not sensationless: "Even though my body may feel numb, those other sensations still exist." JK also talks about this phenomenon: "Yep, it feels like it's, like if your hand is asleep." Alternatively RP mentions the effect of PS on his life saying that "This is never improved or anything, it is just...if anything, it may have affected some parts of my life, emm, specifically, you know, sleeping."

The difficulty for most of the individuals is separating "real" sensations from phantom. One interaction highlights this:

R: And the cold that I feel is, um, very faint.

I: Okay.

R: In fact, it's faint enough, I mean, I know that if I put my feet in ice water and I had normal sensation-that would be pretty shocking.

I: Yeah.

R: It's very faint and it's-it's faint to the extent that it may even just be—

I: Wishful thinking.

R: Something...yeah, it may be.

FS notes that the sensations "may be just a manifestation of – of something in your brain."

In certain cases there is also an emotion attached to the interpretation of the sensations. Many participants described some of the sensations as “frustrating”. Those same sensations, however, were not necessarily described as being “painful”. SD continued later in her interview to describe her reaction to the sensations where she perceived hands pushing into her chest.

R: Um, (long pause), well it’s just frustrating because it felt like pressure and I wanted to relieve that pressure of the hands on my chest.

I: Uh-huh.

R: But obviously I couldn’t.

I: But it never got to the point where you said something to the physicians to sort of say, “Hey, I’m having this experience. Can you do something about it?”

R: [Shaking her head] Probably because it wasn’t (pause) it was frustrating but it wasn’t painful.

I: Ok.

R: And I had a lot of other pain going on. [SD]

Some, if not the majority of the sensations that people experienced were painful but that some pain was not seen to signify anything is illustrated by AH: “The pain I could really do without. The pain serves no useful purpose”.

Body Connectivity

Once again, the topic of connectivity was not specifically mentioned in the initial guideline document, however a significant portion of the participants spoke of various attributes of their experience that began to coalesce under the body connectivity theme.

In one case this was very explicit:

It [sensation below the NLI] lets me know that I’m still in touch with my body. I, I, I don’t, like I said before, I don’t feel disconnected. I don’t feel a C5, that that’s all

there is, that I am only a mind now, that I'm not mind and body. I feel mind and body. I feel still connected to my soul. I've never let it go though either. And that's been very difficult. I'm speaking for myself. I know other people who I believe that are in the same situation who've let their bodies go. And they don't, they are disconnected. I just, you can see it when you look at them. People look at me and they go, "God, you look like you can get up and walk right out of your chair" and that's how I feel. [AH]

He also noted that he worked very hard both "mentally and physically to reconnect his body with his mind", though he didn't state how, other than he concentrated on making it happen while he was exercising.

The concept of distraction was explicitly mentioned by a number of participants. Distraction as a technique was used to deliberately attempt a disconnection between mind and body:

I: Would it go away, would the sensation stop?

R: (Long pause) I would almost have to say it would stop (pause) when I got involved in something else. Doctors came in and I was starting to talk to doctors. Friends came by.

I: And they would distract you?

R: Correct. [SD]

It is interesting that SD's perception is not that the sensation remained and she just ignored it but rather that it stopped completely. TLV, also in an attempt to deal with the sensations spoke about trying to "move her mind somewhere else".

Attitude

Most of the participants discussed their reactions and attitude to the pain, phantom sensation and to the injury itself. There were also a cluster of responses that were clearly indicative of the participants' general attitude to life. RP described his reaction and attitude to the phantom sensations in this way:

. . . you know, they they . . . early on it was really, emm an annoyance, emm, because it was frustrating that I would have the sensation of moving, but there is no motor control, emm.. I would have the sensation of moving, but I couldn't feel anything . . .

Another commented that he could live with the injury but what really bothered him was the pain. Yet another individual commented that even though it was six years post injury he still tried to move his toes and feet thinking that it can't hurt but he also mentioned the fact that it had taken him a "couple of months, perhaps more" to accept that he had a complete injury. FS commented on his relationship with the sensations of pain and how he rationalized the sensations:

R: If you sense, uh, a pain but you realize that it really does not relate to anything physical or that it is just pain for the sake of pain, then I'm not saying that makes it go away, but at least you don't worry about it as much (short pause). Now, as far as your question of how did I rationalize these sensations when I was being told that they weren't really sensations—

I: Uh-huh.

R: or something to that effect, um, (short pause). In one sense I probably still haven't completely rationalized that, because, um, I (long pause) I think that (long pause) I suppose there are, there are, and I've been told so this isn't completely just my own rationale, that there are the pathways for sensations. [FS]

He struggles to make sense of what his body is implying but doesn't seem to fully accept the theories or information he has absorbed cognitively. AH talked about his method for dealing with his situation. He maintained that he is a very "positive person", but notes that he has always been that way. It is also useful to note that he runs his own business. FS expresses a similar positive attitude and spoke candidly about his relationship with pain versus paralysis:

R: I would say that, ah, probably once or twice a week I'll have a day where I won't say I'm completely unproductive, but, um, I really have to fight to be productive . . . but-but in order to r-e-a-l-l-y function, you usually just kinda have to fight through it. Ah . . . I think generally (long pause) at least now, because I have come to realize that I can be productive and useful even with the injury . . . That I probably get down about the pain more so than the injury. In fact, I've thought about if someone were to offer me a partial cure—I: Uh-huh.

R: Um. . . let's say control of your bladder and bowels or walking or elimination of pain

I: You'd pick the elimination of pain

R: I might. I might. Which someone who's not in my position would probably think is nuts. Like, I-I would think that an able-bodied person's immediate or most obvious choice would be walk.

I: Uh-huh.

R: And everybody talks about, you know, even in the presidential campaign, you know, would stem cell, ah, ah, treatment, people like Christopher Reeves [sic] will get up and walk.

I: Uh-huh.

R: And Christopher Reeves [sic] would probably have told you that '(laughing)' there are a whole lot of other things that he might rather do before walking . . . Um. .

.I never heard him speak about that specifically, but I've certainly heard that from lots of other people. And, in fact, people with low-level, low-level paraplegics

I: Uh-huh.

R: Um. . . have said that. The wheelchair is not that big of a deal. You can get used to that, if these other things, things maybe like bladder and bowel function, that-that have such a drastic impact on your lifestyle. Not that-not that being in a wheelchair doesn't . . .um. . . and pain, pain is right up there . . . [FS]

Communicating about Phantom Sensations

The responses to a question specifically about who the person has told about the sensations are gathered in this category. The general response that that most participants had not spoken to medical professionals about phantom sensations was surprising.

One participant simply shook his head when asked if anybody had told him about or asked him about phantom sensations; another said she had not spoken about phantom sensation to anybody, including peers. A different participant declared "Nobody ever said anything about it." [JA].

FS points out that "burning pain is very common" which indicates that he must have mentioned certain sensations to his peers; and he clarified: "I have discussed these sensations with other spinal cord injured people because I know they don't think I'm nuts. I've discussed them with "civilians", if you will'. When asked, "What was the reaction of the clinical staff to the phantom sensations?" FS replied, "It was all negative". SD replied to a similar query: "I've also felt to disagree with the doctors about having a complete injury". He expanded upon the topic in the following exchange:

R: Um, you know, I don't know how that factors in, but, but to me I've just have had, um, too many feelings throughout my body.

I: So, has it influenced your acceptance of information from medical professionals? I mean, if you question whether the injury is complete or not, have these sensations contributed to that questioning in any way?

R: (Long pause) I, I would say so, yes.

He also expresses confusion as to why it was not a bigger issue: . . .Um, it was more, it was frustrating. Just because of the way it felt. Um, (pause), but no, I (pause) . . . Thinking back on it now, I don't know why, ah, it wasn't discussed with medical staff; or at least brought up. [SD]

FS also spoke of this hesitancy in bringing up the issue:

Ah (pause), but I always got a sense from the doctors that-that-that, I was nuts, that basically I had been diagnosed . . . and that they were testing me because I(pause) wanted them to, not because they really thought there was anything really going on [in the area affected].

Finally, JK expressed confusion at the conflicting messages he received early on.

R: When I was first in the hospital . . . Yeah, because I felt, I felt like they were, you know, that my toes were there because I was getting pain, so I was looking at them and trying to move them . . .

I: Uh-huh.

R: And they weren't moving.

I: And what was your reaction when you looked down and saw that your toes wouldn't move, but they felt internally like they were. .

R: (Long pause) I thought they were going to move.

I: Yeah.

R: I just thought that, you know, something was getting reconnected there because I was having pain, so it was something. . . ' cause they told me that I was complete and I thought, what does that mean? And they said, well, you won't, you won't be able to walk or you won't be able to feel anything. And then I instantly felt something, that's why I thought they were crazy. [JK]

This theme did follow from a specific question that was added to the guidelines as the interviews progressed. The participants were specifically asked who they had told about the sensations. Their responses were unexpected. I had expected that most would have had no problem discussing the phenomena with others.

Discussion/Summary

People sustain their injuries in many ways and the participants have outlined their own particular onset. As they related their stories two issues regarding onset became obvious. The first was the confusion of the memory around the inception of the injury, the second was how well rehearsed the stories were despite the confusion.

The largest of all the categories however, was undoubtedly "sensations". The participants detailed their experience of the sensations they most often felt. The sensations experienced below the NLI could be broken down into simple and complex sensations as outlined by Siddall and McClelland in their 1999 paper. But even more simply they could be seen as painful versus non-painful.

In addition to the level of complexity of the sensations participants also commented on the location (whether referred or not), the triggers and how vivid the sensations were. The concept that many of the sensations were so "real" respondents frequently had to check or get somebody to check is compelling.

I was struck however, by how many sensations people felt despite the fact that it is most people's impression that having an SCI is a sensationless state.

The meaning assigned to the sensations by the participants can easily be divided into implicit meanings and descriptive meanings. The descriptive meanings were more mundane and generally described what the sensation reminded the interviewee of or were analogous to. The implicit meanings often outlined what the sensations may mean for their prognosis. Because most people with an SCI are focussed on functional return, any potential sign of that return is viewed with great excitement.

Contrary to my expectation at the time, some people felt very connected to their bodies. One would assume that the higher the level of injury, the less one would be connected but this may not be the case. There seemed to be an aspect where a person, through an active act of will, deliberately reached out to their body to connect.

There was a volitional element in the perception of connectedness, if the sensation was unpleasant the participant would use distraction as a coping mechanism. Instead of trying to establish a stable association with their body, the person would try to distract themselves from the pain.

The attitude of the respondents to the sensations and to life in general also became obvious very quickly. It's not the level of injury but the attitude towards the injury and the sensations that go with it that are an indicator of the quality of life that a person with an SCI can expect post injury (Whiteneck et al., 2004).

The most surprising perception here is that if a choice were given between the removal of pain and the removal of the other issues that accompany an SCI such as walking and bladder control etc. some people would opt for the removal of pain. This becomes very apparent when reading the postings on various Disabled Persons Organisation (DPO) websites and is often noted in articles in the literature (e.g. Thietje, Giese, Kaphengst, Runde, & Schulz, 2010; Widerström-Noga, 2002) .

Acceptance of the injury is related to the adjustment to the limitations it might place upon a person (Arango-Lasprilla et al., 2010) and there are a number of concerns facing an individual who has sustained a spinal cord injury. They can be viewed through Maslow's hierarchy of needs (1943).

He developed a theory of motivation for human beings maintaining that people are impelled to work their way through a hierarchy of needs in order to maximise their potential or "self-actualisation". He later modified the hierarchy (Maslow, 1954, 1971) but the levels described remained the same. There are many versions of the hierarchy now in existence and it has been adapted multiple times (Duncan, 2010).

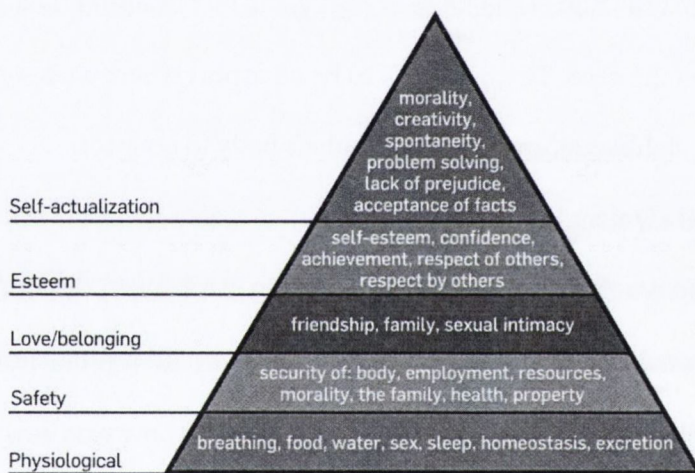


Figure 2.1 Maslow's hierarchy of needs in pyramid form

The concept is that in order to progress to self-actualisation a person must pass through and meet the needs outlined in the levels lower in the hierarchy. For most people with an SCI it can be argued that meeting these needs is more difficult. This difficulty can be seen by looking at the issues raised by the first level in the hierarchy.

The first level of needs (according to Maslow) contain the physiological requirements for all humans. Food, water, sex, breathing, sleep and excretion are listed in the figure above (fig 2.1). They are the most basic of all the needs as viewed through this

system. If the person has a SCI, meeting even these basic needs can be hugely difficult. For example, sleep onset and maintenance is problematic for significant number of people with an SCI as they cope with apnea, spasm, and/or pain (Biering-Sørensen, Jennum, & Laub, 2009; Burns, Rad, Bryant, & Kapur, 2005), breathing without the aid of a ventilator is impossible for anyone with an injury at or above C₄ (Charlifue et al., 2011), excretion, for most, becomes a matter of catheterisation (Cameron et al., 2011; De Ridder et al., 2005; Giannantoni et al., 2001), egestion may need digital stimulation (Chiodo et al., 2007; Kirshblum et al., 2007; Krassioukov, Warburton, Teasell, & Eng, 2009) and sex is hugely problematic for both partners (Chiodo, et al., 2007; Mary E, 1987; Reitz, Knapp, Tobe, Drack, & Schurch, 2003; Ricciardi, Szabo, & Poulos, 2007).

The categories of needs continue as can be seen in figure 2.1 but the difficulty in progressing through the hierarchy remains as problematic. Because meeting the needs in one category is contingent on meeting the needs of the level below, progression for a person with an SCI can be very slow.

The levels of psychological acceptance may also come at a price. At least one study has shown that amongst the people who had accepted the injury the rates of alexithymia were very high. People who had accepted they're injury seemed prone to reducing their ability to describe or even experience the emotions attached to their experience 7 years later (Fukunishi, Koyama, & Tobimatsu, 1995).

In addition, actions necessary to meet these issues of limitation are assigned their weight by the patient, the medical staff and the people associated with the individual who has sustained the injury. Unfortunately, they may not be weighted in the same way and are not given the same credence by all the individuals concerned (Gerhart, Koziol-McLain, Lowenstein, & Whiteneck, 1994). Quite simply, what is perceived as relevant or essential from the point of view of the patient may not be viewed in the same way by the medical staff. Cole (2004) using interviews with former inpatients repeatedly discovers this

phenomenon. In another area Strauss and Corbin (1998) detail a situation where one of the authors makes observations about the data collected from pregnant women. She notes that behaviour, the medical staff considered dangerous, was not viewed in the same way by many of the participants.

I found evidence of another disconnect in this study. Participants reported a divide between sensations felt and their expectations of what “complete” really meant in relation to their injury. I termed this phenomenon “psycho-physiological dissonance” a state I postulate exists when a person’s proprioception of their own body contradicts their expectation. This can manifest as a person not trusting their body. Their expectation may be formed in many ways and is probably in place before the injury. A synonym for expectation in this case could be schemata or schema and it will probably change during the rehab process unless it is very accurate before the injury. I expand on this concept in the general discussion in chapter 5.

The temptation to relate the discovered categories to stages of rehabilitation or acceptance of the injury is strong. However, the categories that emerged from the data were not time contingent. Specific themes were not consistently found in people at a certain times after the injury. This observation adds evidence to criticisms of stage related theories of adjustment.

Another apparent aspect of this study is that although a grounded theory method was applied the data and category discovery was not consolidated until a theory became readily apparent. I did this to make sure the topic was not fully corralled and that the next two studies could more fully elaborate on the research question.

Conclusion

Using a qualitative methodology approach, the aim of the study was to provide descriptive information about the phenomena of phantom sensations in individuals who

sustained a traumatic, complete SCI. More information about this is uncovered in the following chapters. The information collected reflected the experience from the point of view of the individual with an SCI and by using grounded theory generation methods helped recognise and reduce the influence that the researcher may have had on the data.

A flotilla of categories was identified and after analysis, these categories lent themselves to identifying higher order categories of a more abstract nature. Identifying the core categories helps an enabled person understand a small part of the lived experience as it relates to sensory information coming from an apparently deafferented part of the body for a person with an SCI.

After looking at all of the categories, discovering more about when the sensations occur and whether they are related to predictable psychosocial events, is an obvious next step.

CHAPTER 3: A QUANTITATIVE STUDY

CHAPTER 3 OUTLINE

This chapter poses the question: When do the sensations occur and are they related to psychosocial events? It then moves on to procedures for choosing participants and lists the different organisations that helped recruit participants from non-clinical sources. Continuing in the method section it describes the survey including how the participants were chosen, the ethics, financial and data collection procedures. In the section on results it describes the participants and talks about the findings from the study. The relationships between the variables are explored. In the discussion section you'll find observations regarding studies that rely on the web and this study directly. Also discussed are the patterns that are immediately noticeable in the data. It then moves onto the conclusions drawn and invites you to move onto the next chapter.

Another Aspect

The aim of this chapter is to examine when during the day sensations below the NLI occur and are they related to specific psychosocial events? The previous study as a grounded theory method should) generated potential queries and hypotheses (Pidgeon & Henwood, 1997) and the information discovered in the study was used to inform the choice of questions in this enquiry.

To ascertain these patterns and relationships I used a quantitative approach, relying on a questionnaire that utilizes a method for improving the memory of a specific timeframe. This study adds to the central question of the thesis by searching for diurnal patterns of the phenomena and relationships between events.

The DRM

There are a multitude of studies, books and articles dealing with the various aspects of an individual sustaining a spinal cord injury. They look at issues ranging from pain in individuals with an SCI to acceptance/adjustment or life satisfaction following the injury (e.g. Angel, Kirkevold, & Pedersen, 2009; Beric, et al., 1988; Bockenek & Stewart, 2002; Fukunishi, et al., 1995; Gerhart, et al., 1994; Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2010; Kerr & Meyerson, 1987; Kortte, Gilbert, Gorman, & Wegener, 2010; Mariano, 1992; Nepomuceno, et al., 1979; Rose, et al., 1988; Siddall, Taylor, McClelland, Rutkowski, & Cousins, 1999; Siddall, et al., 2000; Tunks, 1986). They can be quantitative or qualitative however, I have not been able to find a study that applied this method to the SCI population.

The design of the DRM is based on the belief that the most accurate information regarding diurnal patterns and triggers is obtained using Ecological Momentary Assessment (EMA) techniques (e.g. Fahrenberg, Myrtek, Pawlik, & Perrez, 2007; Hektner,

Schmidt, & Csikszentmihalyi, 2007) such as a diary method or direct observation during the day such as the Experience Sampling Method(Larson & Csikszentmihalyi, 1983).

The ideal in many situations is to observe behaviour in a naturalistic setting but to do this effectively the method of observation should be minimally invasive (Bolger, Davis, & Rafaeli, 2003). Achieving this is difficult, with most of these methods requiring a certain amount of interruption to the participant's routine (Fahrenberg, et al., 2007).Most approaches require the participant to stop and note their activity and/or emotional response during the event or at specific intervals. Also, depending on the research design, an investigator may have to follow the participant to observe behaviour. These methods are financially and operationally prohibitive. As a result of the difficulties associated with the procedure the sample sizes tend to be small. The techniques that rely on a sampling technique will also miss events that occur between sample times.

A possible alternative is outlined in the form of the Day Reconstruction Method or DRM as proposed by Kahneman, Krueger, Schkade, Schwarz & Stone (2004). The basic concept is to prime the participant's memory by asking them to create self-defined episodes and asking questions about psychosocial events during the episode.

Using the DRM, the researcher can rely on a less invasive retrospective technique that utilises episodic reporting allowing participants to answer questions about episodes and psychosocial events that have occurred in the previous 24 hours. It helps participants recall episodes from their recent memory and helps them answer questions about events and their psychological state during the episodes. This allows the researcher construct an accurate map and diminishes the possibility of self-reporting and recall bias (Kahneman, et al., 2004).

The episodes are created to elicit an accurate measure of the time frame being analysed. The goal of the method is to provide an accurate picture of the experience associated with activities.

By its nature however, it is quite time intensive for the participant and although it could be used quite easily as a mechanism in a longitudinal study for this group the intensity could limit the sample size.

The DRM, by design, allows for larger sample sizes. In fact one of the reasons it was created was to encourage researchers who designed their data gathering around EMA techniques the option of accurately surveying larger numbers of participants (Kahneman, et al., 2004). It is important to realise that other factors will limit the sample size and although this method will allow for larger numbers in this study, the sample size was smaller than the technique would allow.

This survey was administered online and unlike many surveys was self-paced (a very important aspect to a person with an SCI). The concept that it could effectively be administered worldwide as it was placed on the web also made it desirable as an approach for an international SCI population. The idea that the sample also be nonclinical was important in that a number of participants in the previous study expressed reservations about discussing their own PS's with professionals involved in their care.

The use of the DRM permits larger samples to be drawn, again without incurring the expense associated with 24 hour monitoring studies. As the questionnaire was to be administered on line it was difficult to predict the response rate. However, it has been used previously for helping to investigate associations between affective states, tiredness and well-being i.e. the method had a track record of having been used for these variables and it was found to be valid and reliable (Dockray et al., 2010; Kahneman, et al., 2004; Stone et al., 2006). The method is frequently beneficial in the economics field particularly in this area of life satisfaction and well-being (Kahneman & Riis, 2005; Krueger & Mueller, 2010; Schwarz, Kahneman, & Xu, 2007) and has recently been used in the health psychology realm (Daly, Delaney, Doran, Harmon, & MacLachlan, 2010; Dockray, et al., 2010). Daly et al. also delivered their questionnaire online (the technique was effectively

piloted). In this study it was applied to affective states, tiredness and experiencing sensations in previously tested areas that had been rated as sensationless. I have been unable to find another example of the DRM being applied in SCI populations.

There is a large body of material that associates the perception of pain to a person's affect and a variety of other psychosocial events (e.g. Eimer & Freeman, 1998; Gatchel, et al., 2011; Gatchel & Turk, 1996; Keefe & Lefebvre, 2002; Thieme et al., 2006; Widerström-Noga, 2002). It is not unreasonable to assume that a similar association exists with phantoms, particularly with PP.PS's, both painful and non-painful, are often associated by both professionals and patients with fatigue and general stress levels. Arena et al. found this in their study in 1990 (Arena, Sherman, Bruno, & Smith, 1990)

Method

This study was cross-sectional applying the DRM however, the method followed the normal routine for statistical studies in that after gathering the information it continued with data preparation moved to descriptive and finally inferential statistics (Barnett & Ziegler, 1993; Coolican, 2009; Creswell, 2008; Field, 2009; Sternberg & Sternberg, 2010).

Questionnaire Design

The questionnaire, utilising the DRM and administered online, consisted of three different sections.

The first was the segment which most resembled a standard survey. It asked the respondents the expected demographic questions and continued with queries about the nature of their injury. The unifying aspect of this section is that the questions were not time dependant or likely to change over the day.

The next section of the survey consisted of the episodes that were used to map the day. The number of episodes was decided by the respondent and relied on his or her recall.

The episodes were of indeterminate length wholly decided by the participant. The respondent anchored the beginning and end of each episode by giving each episode a name and writing down the approximate times it began and ended. The indications of the beginning or end of an episode might be changing location, talking to someone or finishing one activity and beginning another.

The final section of the questionnaire consisted of the invitation to leave contact information, debriefing and thanks (See figure 3.1 for outline).

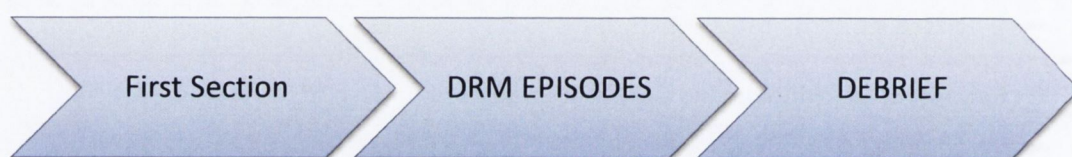


Figure 3.1 Questionnaire Outline. The ‘First’ section of the questionnaire consisted of demographic questions and questions pertaining to injury. The ‘DRM Episode’ section had 21 episodes comprising 10 questions reduced to eight (210-168 variables) if no sensations are noted and finally the ‘Debriefing’ section with an invite to leave contact information and thanks.

In order to create a familiarity for the respondents the questions followed the same format from episode to episode. The software however introduced a random element to the answer choice presentation in order to offset any potential order bias. Ten questions appeared in each episode. If the participant did not state that sensations occurred in tested areas in that particular time frame the number of questions presented was reduced to eight.

The participants were initially allocated space for seven episodes for each part of the day (morning, afternoon and evening) totalling 21 potential episodes per questionnaire/participant. The blank episodes remained invisible to the respondents unless they called for them by stating in the last question of the previous episode that they had more episodes to create (a logic statement was attached to the question in the programming of the questionnaire).As a result it was impossible to use a completion bar to let

respondents know how much of the questionnaire they had completed as the survey was of variable and unpredictable length. It also meant that printing the questionnaire was arduous as the redundant episodes that would never appear online would also be printed (this is the reason that the questionnaire does not appear in an appendix: in its printed form it would be huge).

If they needed extra episode reporting forms, on top of those available online, they were invited to request them from the research team. The majority completed a maximum of 3 episodes per section of the day and thus nobody asked for additional forms.

Each episode asked the participant a range of questions based on the questionnaire design by Kahneman et al. (2004). This was done to make the format of the questionnaire resemble a previously utilized survey that had already been validated. It began by asking respondents to name the episode (to aid their recall) and note the approximate time it began and finished. The next question appealed for information about their activity during the time frame giving them 19 options. Next they rated their affective state and tiredness during the episode. The scales ranged from 0 (no feeling) to 6 (very strong feeling). They also chose their location (3 options) and who they were interacting with (9 options). The next question had a logic statement attached: "Did you feel any type of sensation in an area of your body that has been assessed by a medical professional and found to have no sensation".

It was a simple dichotomous question and if the respondent answered "yes", two more questions were posed: They were asked what type of sensations they felt (9 options). The choices they were given were based on the criteria suggested by Siddall and McClelland(1999). After this they were asked if the sensations were painful.

If the person answered "no", the episode ended and the respondent could create another or move onto the next section of the day.

Participants

Choosing the sample. The respondents in the study were approached from a non-clinical source. The questionnaire appeal for completion was only available online. The participants, as a result were self-selecting and had no onus placed upon them to begin or finish the survey.

As stated, all participants were approached online via the World Wide Web. They either responded to an advertisement on a Disabled Person's Organisation (DPO) website or on a discussion board (see appendix I). The appeal directed them to the DRM questionnaire available online.

The websites used for the appeal spanned multiple countries. It was impossible, without breaking confidentiality and because it was administered online, to know what country the respondent accessed the questionnaire from. The relevant websites are listed in Table. 3.1

Table. 3.1

Websites used for appeals

| Website | Host Location |
|--|--------------------------|
| Australia and New Zealand Spinal Cord Injury Network (ANZSCIN) | Australia |
| National Spinal Cord Injury Association (NSCIA) | United States of America |
| Spinal Injury Ireland (SII) | Republic of Ireland |
| Spinal Injury Association (SIA) | United Kingdom |
| Canadian Paraplegic Association (CPA) | Canada |
| New Zealand Spinal Trust | New Zealand |
| Aparalyzed | United Kingdom |
| CareCure | United States of America |

| Website (cont'd) | Host Location (cont'd) |
|---------------------------------------|--------------------------|
| Spinal Injuries Scotland (SIS) | Scotland |
| Christopher and Dana Reeve Foundation | United States of America |

Note: Many of the DPO's required a copy of the permission documents issued by the research ethics committee.

Inclusion and exclusion criteria. Included in the survey was anybody who had access to the internet and to the websites listed above. As the websites are online presences for the DPO's the organisations also have a substantial presence in the offline world and occasionally directed members to their site which hosted the posting or appeal for participants.

All of the organisations focussed their attention on services offered in their own country or at least facilities offered in the first world area. This added a level of uniformity to the cultural and economic features encountered however, when looking at the data garnered from the survey it is important to factor this into the interpretation of the results and not generalise outside "developed" countries.

It is also important to realise that any exclusion criteria are difficult to administer using this method as the respondents are effectively anonymous.

Ethical Procedures

Ethics supervision. The ethical parameters of the study were overseen by the University of Dublin, School of Psychology Research Ethics Committee (SPREC). Before the survey commenced an application detailing the study in all aspects was submitted to the committee. A copy of the questionnaire, the informed consent and the debriefing document was also submitted. The study was cleared (see appendices C and D) and the creation of an online presence in order to gather data began in October of 2009. In addition to the creation of the survey the appeal for participants was created.

Process of consent. An informed consent document was included at the beginning of the questionnaire. To ensure that all participants agreed to the contents of the document, the questionnaire could not be accessed by anyone before they provided consent. If they declined the conditions of the consent document they would be rerouted to a message that thanked them for taking a look at the survey and ended the session.

Most DPOs also required a copy of the permission letter from SPREC before placing an appeal on their websites or their community forums (see appendix D).

Confidentiality Procedure

Confidentiality was ensured in that the contribution of every respondent was completely anonymous unless the respondent elected to leave basic contact information and a first name at the end of the questionnaire. This information was only used in the lottery process for the study.

The hosting company ensured that the IP addresses could only be used for one survey. Information containing IP addresses was protected by password. Access to survey responses was also password protected.

SurveyMonkey (the survey administrators) also have a comprehensive confidentiality policy. One of the more notable aspects is the use of SSL technology which ensures that all responses are transmitted to SurveyMonkey over a secure encrypted line. The company's security policy can be read in full at http://www.surveymonkey.net/Monkey_Security.aspx and the pages describe user, physical, network, storage, software and organizational security measures.

Financial Procedure

Instead of distributing limited funds across all participants each respondent who left contact information on completing the questionnaire was entered into a simple lottery for

€200. The winner of the lottery was chosen by randomly picking a participant who had left contact information at the end of the questionnaire.

Data Collection and Analysis Procedure

Participants accessed the survey online. The questionnaire was hosted by SurveyMonkey.com however the links to the survey were available to any who accessed the various DPO websites and that had volunteered to place a request on their website.

The data generated from the survey was collated by Survey Monkey and delivered to the researcher in either a format for Microsoft Excel (.xls) or as raw data (.csv). It was then converted to the SPSS format for more detailed analysis. It could also be accessed using the website's own interface.

The analysis of the data, after cleaning and recoding, entailed a descriptive phase on the appropriate variables followed by correlation or regression examination.

The elimination of the need to manually input the data from the questionnaire/data sheet into the chosen software (SPSS/PASW) eliminates a potential source of error but the data still has to be screened and cleaned. There is the possibility that as the researcher is relying on an automated system they will think that it is unnecessary to cast an intense eye over the data. For example, if there are errors or biases in the format of the questionnaire they will still have to be recognised in the missing data patterns, there are the decisions whether or not to create new values for the variables that list "other". These decisions are not removed just because the researcher decides to use an automated data gathering system.

Results

107 participants completed the informed consent documents, 96 people concluded the first 7 questions of the descriptive section, 86 completed the entire section and 65 left

information both in the descriptive and episodic sections of the survey. In total, the participants reported 210 episodes of information. Sensations in areas tested as sensationless were reported in 149 of the 210 episodes.

Descriptive Statistics of the Participants.

Over 92% of the participants sustained their injury in a traumatic way with their average age being 44 ($SD=11.77$). The average length of time since the injury was 11 years ($SD=10.05$). Of the 96 who specified, 56 were male and 40 female. Forty two per cent were married, close to nine per cent were in a long term relationship and 33% were single. The remainder were either divorced or widowed. Most (85.5%) had at least started a third level education with close to 17% having a postgraduate degree. The largest majority (50%) had no children with over 24% of the respondents living on their own. Almost 54% were either employed or worked as a volunteer. The most popular day for review was Monday (24.1%). 97.7% of participants reported feeling sensations in areas of their body where they didn't expect them. Table 3.2 describes the participants more fully:

Table 3.2

Characteristics of the sample

| Characteristic | Value |
|---|--------------|
| Total number of respondents who began the questionnaire | 107 |
| Gender | |
| % Male (n) | 58.3% (56) |
| % Female (n) | 41.7% (40) |
| Mean Age (Range) | 43.8 (19-71) |
| Mean years since injury (Range) | 11 (1-40) |
| Relationship Status: | |
| % Married(n) | 41.7% (40) |
| % Single (n) | 36.5% (35) |

| Characteristic (cont'd) | Value (cont'd) |
|---|---|
| % Long Term Relationship(n) | 9.4% (9) |
| % Widowed (n) | 1% (1) |
| % Divorced/Separated(n) | 11.5% (11) |
| Level of Education: | |
| % Some high/secondary school or less (n) | 3.1% (3) |
| % HS diploma or equivalent (n) | 11.5% (11) |
| % Some college/higher education/third level (n) | 31.3% (30) |
| % College diploma/degree (n) | 29.2% (28) |
| % Some graduate school/Post graduate study (n) | 8.3% (8) |
| % Post Graduate Degree (n) | 16.7% (16) |
| Offspring: | |
| No. of offspring (Amount- percentage of respondents) | 0 (50%), 1 (16.7%), 2 (16.7%), 3 (13.5%), 4 (3.1%), >4 (0%), |
| No. residing with participant | 0 (63.5%), 1 (21.9%), 2 (8.3%), 3 (6.3%), >3 (0%) |
| Total number of residents in the same house | 1(24%) 2(28.1%) 3(28.1%) 4(11.5%) 5(8.3%)>5(0%) |
| Method of injury | |
| % Trauma (n) | 92% (79) |
| % Congenital | 0% |
| % Illness(n) | 8% (7) |
| Employed and/or Volunteered | 53.9% (46) |
| Mean rating of job satisfaction | 5.3 (Scale: 0-6) |
| Mean rating of life satisfaction | 4.4 (Scale: 0-6) |
| Day described: | |
| Monday | 24.1% (16) |
| Tuesday | 18.4% (12) |
| Wednesday | 16.1% (10) |
| Thursday | 13.8% (9) |
| Friday | 4.6% (3) |
| Saturday | 8% (5) |
| Sunday | 14.9% (10) |
| Unexpected sensations | 97.7% (84) |

Note: Depending on the location of the relevant question in the survey the number of participants (n) answering the question changes

Diurnal Patterns of Sensations

In every episode the respondent was asked “Did you feel any type of sensation in an area of your body that has been assessed by a medical professional and found to have no sensation?” The responses were mapped and no clear diurnal pattern was noticeable except a suggestion of a trend towards declining sensory phenomena in tested areas as the day progressed (a visual representation can be seen in figure 3.2).

Linear or other relationships were visually checked but none were observable. In addition the linear (for an increase or decrease throughout the day) and quadratic effects (for a U shaped relationship) were analysed and are summarised in Table 3.3. and 3.4

Mean. Did you feel any type of sensation in an area of your body that has been assessed by a medical professional and found to have no sensation

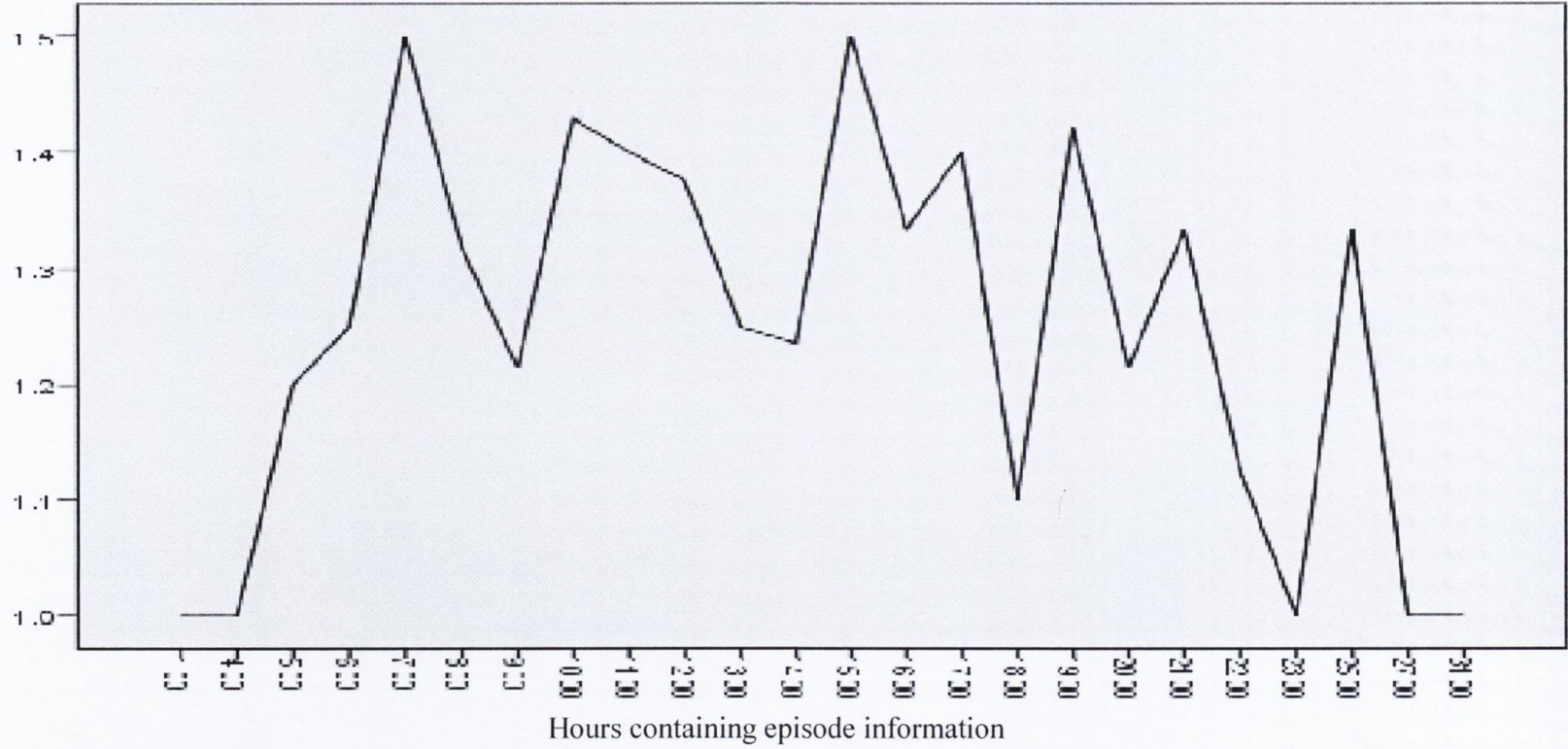


Figure 3.2 Diurnal pattern of reported sensations in areas tested as devoid of sensation. 31 hours listed as some respondents supplied information about episodes that went beyond the 24 hours due to sleep problems etc. I decided to let this information remain for the mapping of this pattern.

Table 3.3

Linear effects

| Model Term | Co-efficient | Std. Error | t | Sig. | 95% Confidence Interval | |
|------------|--------------|------------|-------|------|-------------------------|-------|
| | | | | | Lower | Upper |
| Intercept | 0.648 | 0.644 | 1.007 | .315 | 0.620 | 1.917 |
| Epmidhr | 0.041 | 0.042 | 0.997 | .320 | 0.041 | 0.123 |

Table 3.4

Quadratic effects

| Model Term | Co-efficient | Std. Error | t | Sig. | 95% Confidence Interval | |
|----------------|--------------|------------|--------|------|-------------------------|-------|
| | | | | | Lower | Upper |
| Intercept | 2.278 | 1.631 | 1.397 | .164 | -0.938 | 5.494 |
| Epmidhr | -0.223 | 0.245 | -0.910 | .364 | -0.705 | 0.260 |
| Epmidhrsquared | 0.009 | 0.008 | 1.093 | .276 | -0.007 | 0.026 |

Sensations

Participants were asked if they felt sensations in areas of their bodies where they did not expect to feel them, 97.7% of the respondents did. Sensations in areas of their body tested as having no sensation were reported in 71% of the episodes on the day. They were also asked if they felt sensations in areas that health professionals had designated as paralyzed - 87% of participants had done. There seemed to be a discrepancy between the expectations of the respondents and what they experience. How the respondents formed their expectations was not specifically asked.

Looking at the variables (age, gender, ed. level, number of offspring, residents in the house, job status and relationship status all which can be found on the first page of the questionnaire) and using a logistic regression none of the variables were related to whether a person felt sensations in a paralysed area or not.

Table 3.5

Prediction of sensations in paralysed areas

| Step 1 | B | S.E. | Wald | df | Sig. | Exp(B) |
|--------------------|--------|-------|-------|----|------|--------|
| Age | .041 | .037 | 1.226 | 1 | .268 | 1.042 |
| Gender | .135 | .744 | .033 | “ | .856 | 1.144 |
| Ed_Level | .412 | .271 | 2.318 | “ | .128 | 1.510 |
| No_of_offspring | -.062 | .352 | .031 | “ | .861 | .940 |
| Residents_in_house | .137 | .366 | .141 | “ | .708 | 1.147 |
| Job_status | .179 | .702 | .065 | “ | .799 | 1.196 |
| Married | .103 | .884 | .014 | “ | .907 | 1.108 |
| Constant | -6.271 | 2.865 | 4.791 | “ | .029 | .002 |

This is not surprising as there is little evidence from literature that any of these variables have been found to be predictive in any way.

Next I added the years since injury and whether the person is in a support group.

Table 3.6

Prediction of sensations with years since injury and peer support group participation

| Step 1 | B | S.E. | Wald | Sig | Exp(B) | 95% CI Exp(B) |
|--------------------|---------|-----------|-------|------|--------|---------------|
| Age | .079 | .049 | 2.613 | .106 | 1.082 | .983 1.191 |
| Gender | -.122 | .867 | .020 | .888 | .885 | .162 4.844 |
| Married | .389 | 1.059 | .135 | .713 | 1.475 | .185 11.758 |
| Residents_in_house | .454 | .492 | .852 | .356 | 1.574 | .601 4.128 |
| Job_status | -.502 | .832 | .364 | .546 | .605 | .118 3.091 |
| Peer_support_group | 19.706 | 8634.527 | .000 | .998 | 3.616 | .000 . |
| Ed_Level | .424 | .335 | 1.605 | .205 | 1.528 | .793 2.945 |
| Years_since_injury | -.120 | .061 | 3.899 | .048 | .887 | .787 .999 |
| No_of_offspring | .901 | .617 | 2.135 | .144 | .406 | .121 1.360 |
| Constant | -44.965 | 17269.054 | .000 | .998 | .000 | |

(N=82); $\chi^2 = 3.9$, $p < .05$ or .89 [95% CI= .787 -.999].

Additionally, using a simple bar chart with error bars it was easy to see that the cause of the injury was not a factor in whether a person experienced sensations in areas of their body that have been tested as paralysed or not.

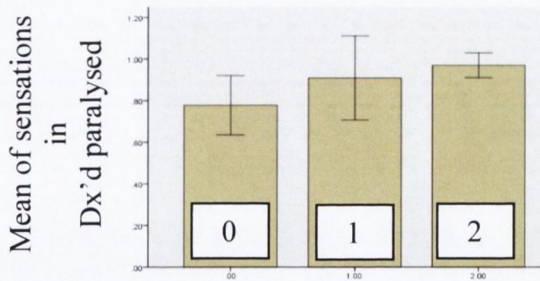


Figure 3.3 Mean of sensations by years since injury
(0 = 0-5 years, 1 = 6-10 years, 2 = 10+ years)

How consistent the sensations were for people (minutes, hours, days or constant) was the next variable analysed. Forty three per cent of the respondents claimed the sensations were constant with 32% claiming the sensations were intermittent lasting minutes to hours. Only 3% noted sensations that lasted days.

Sensations were slightly more constant for older people ($B=.053$, $SE=.029$, $t=1.825$, $p<.1$), those with less education ($B=-.441$, $SE=.222$, $t=1.990$, $p<.1$) and for those with fewer children ($B=-.540$, $SE=.281$, $t=1.921$, $p<.1$)

Table 3.7

Constancy of sensations

| Variables | Un-Std. Co-E | | Std. Co-E | | Sig. |
|---|--------------|------------|-----------|--------|------|
| | B | Std. Error | Beta | t | |
| What age are you? | .053 | .029 | .265 | 1.825 | .072 |
| What is your gender? | .010 | .598 | .002 | .016 | .987 |
| Married | -.155 | .681 | -.033 | -.227 | .821 |
| What is the highest level of education you have completed? | -.441 | .222 | -.248 | -1.990 | .050 |
| How many children do you have? | -.540 | .281 | -.298 | -1.921 | .059 |
| Including yourself, how many of people live in your household? | .378 | .268 | .198 | 1.410 | .163 |
| How did you become injured? | .398 | .494 | .098 | .806 | .423 |
| Are you involved with, a member of, or attend a peer support group? | .021 | .667 | .004 | .031 | .975 |

| Variables | Un-Std. Co-E | | Std. Co-E | t | Sig. |
|---|--------------|------------|-----------|-------|------|
| | B | Std. Error | Beta | | |
| Are you employed or do you regularly participate in volunteer work? | -.402 | .550 | -.088 | -.731 | .467 |
| How many years since your injury? - Please enter the number of years since you sustained your injury. | .002 | .029 | .010 | .083 | .934 |

It was decided to analyse only three episodes from each section of the day in order to accurately capture the data means. The reason for this is because the frequency levels/number of participants reporting activity in any episode past the third in any section of the day became excessively low and the calculations required for analysis could be too easily affected by outliers influencing the mean.

The number of people and percentage of participants in the first three episodes of each section of the day who reported sensation in tested parts of their bodies is listed in table 3.8. This is a simple breakdown, by episode, showing the percentage of participants' who experienced sensations in parts of their bodies that medical professionals had tested (and found the areas to be sensationless).

Table 3.8

| <i>Percentage per episode of sensations in areas tested</i> | | |
|---|--------------|-------|
| Episode No. | No of people | % |
| 1 (morning) | 46 | 71.9% |
| 2 (morning) | 16 | 76.2% |
| 3 (morning) | 10 | 83.3% |
| 4 (afternoon) | 29 | 64.4% |
| 5 (afternoon) | 6 | 66.7% |
| 6 (afternoon) | 3 | 100% |
| 7 (evening/night) | 27 | 67.5% |
| 8 (evening/night) | 9 | 75.0% |
| 9 (evening/night) | 3 | 75.0% |

Satisfaction

Respondents were asked to rate their life satisfaction on a scale from 0 (not at all satisfied) to 6 (very satisfied). This survey concurred with the previous findings showing that 75% of this sample ranked their satisfaction at or above the midpoint (mean = 3.4).

Females (presumably with an SCI) are more satisfied with life than any other group measured ($B=.739$, $SE=.367$, $t=2.014$, $p<.048$). This may indicate that women are more accepting of their injury. The ramifications of this are discussed later.

Table 3.9

Life Satisfaction

| Variable | Un-Std. Co-E | | Std. Co-E | | |
|---|--------------|------------|-----------|--------|------|
| | B | Std. Error | Beta | t | Sig. |
| (Constant) | 3.360 | 1.442 | | 2.330 | .023 |
| What age are you? | .006 | .018 | .045 | .337 | .737 |
| What is your gender? | .739 | .367 | .239 | 2.014 | .048 |
| Married | 1.136 | .418 | .368 | 2.720 | .008 |
| What is the highest level of education you have completed? | -.148 | .136 | -.125 | -1.088 | .280 |
| How many children do you have? | -.011 | .172 | -.009 | -.062 | .951 |
| Including yourself, how many of people live in your household? | -.286 | .164 | -.225 | -1.741 | .086 |
| How did you become injured? | -.346 | .303 | -.128 | -1.141 | .258 |
| Are you involved with, a member of, or attend a peer support group? | .468 | .409 | .125 | 1.144 | .257 |
| Are you employed or do you regularly participate in volunteer work? | -.726 | .337 | -.238 | -2.153 | .035 |
| How many years since your injury? - Please enter the number of years since you sustained your injury. | .020 | .018 | .131 | 1.127 | .263 |

It is also interesting to note that there is no relation between satisfaction with life, and the tendency to feel sensations ($r = -.036$) or how long the sensations last ($r = .072$).

Illness

Participants also ranked their illness status on a scale from 0 (not at all ill) to 10 (very ill). The mean score was 3.18 with 78% of the respondents claiming average to good health (5 or less). For most, they were healthy on the day with only 19 people reporting ill health. The chronicity of their health measure was impossible to tell with this survey. After running a regression analysis the health measure appears unrelated to any of the demographic characteristics (relationship status, age, gender, ed. level, # of children, residents at home) or injury related variables (identified as paralysed, duration of sensations, time since injury and method of injury).

States/traits.

The state/trait condition of the respondents was calculated over the full 210 episodes recorded. The overall question comprised 6 scales running from 0 to 6 (0 as no feeling to 6 with a strong feeling). The scales (with their means in brackets) were Happy (2.98), Tense/stressed (2.18), Depressed/Blue (1.34), Interested/focussed (3.26), Calm/relaxed (2.84) and Tired (3.23).

Because the question was positioned as part of the episodes it was decided to limit the analysis to 3 episodes in each section (as explained earlier).

Table 3.10

Episode by episode averages affect State/trait and tiredness

| Episode No.[n] | Mean | SD |
|----------------------------|------|------|
| 1 (Morning) [64] | - | - |
| <i>Happy</i> | 2.64 | 1.79 |
| <i>Tense/Stressed</i> | 2.08 | 1.96 |
| <i>Depressed/Blue</i> | 1.59 | 1.90 |
| <i>Interested/Focussed</i> | 2.80 | 1.99 |
| <i>Calm Relaxed</i> | 2.80 | 1.82 |
| <i>Tired</i> | 3.02 | 2.07 |

| Episode No.[n] (cont'd) | Mean (cont'd) | SD (cont'd) |
|----------------------------|---------------|-------------|
| 2 (Morning) [21] | - | - |
| <i>Happy</i> | 3.00 | 1.73 |
| <i>Tense/Stressed</i> | 1.71 | 1.68 |
| <i>Depressed/Blue</i> | 1.33 | 1.49 |
| <i>Interested/Focussed</i> | 3.38 | 1.56 |
| <i>Calm Relaxed</i> | 3.14 | 1.71 |
| <i>Tired</i> | 2.81 | 1.86 |
| 3 (Morning) [12] | - | - |
| <i>Happy</i> | 3.08 | 1.08 |
| <i>Tense/Stressed</i> | 2.33 | 1.72 |
| <i>Depressed/Blue</i> | 1.42 | 1.16 |
| <i>Interested/Focussed</i> | 3.75 | 1.14 |
| <i>Calm Relaxed</i> | 2.67 | 1.83 |
| <i>Tired</i> | 3.00 | 2.00 |
| 4 (Afternoon) [45] | - | - |
| <i>Happy</i> | 3.18 | 1.45 |
| <i>Tense/Stressed</i> | 2.22 | 1.79 |
| <i>Depressed/Blue</i> | 1.22 | 1.41 |
| <i>Interested/Focussed</i> | 3.73 | 1.70 |
| <i>Calm Relaxed</i> | 2.78 | 1.68 |
| <i>Tired</i> | 3.09 | 1.81 |
| 5 (Afternoon) [9] | - | - |
| <i>Happy</i> | 3.22 | 1.86 |
| <i>Tense/Stressed</i> | 2.89 | 2.20 |
| <i>Depressed/Blue</i> | .78 | 1.39 |
| <i>Interested/Focussed</i> | 4.11 | 1.36 |
| <i>Calm Relaxed</i> | 2.33 | 1.66 |
| <i>Tired</i> | 3.00 | 2.00 |
| 6 (Afternoon) [3] | - | - |
| <i>Happy</i> | 3.00 | 2.00 |
| <i>Tense/Stressed</i> | 3.00 | 2.65 |
| <i>Depressed/Blue</i> | .00 | .00 |
| <i>Interested/Focussed</i> | 4.67 | .58 |
| <i>Calm Relaxed</i> | 2 | 2.65 |
| <i>Tired</i> | 1.67 | 1.53 |
| 7 (Evening/night) [40] | - | - |
| <i>Happy</i> | 3.38 | 1.86 |
| <i>Tense/Stressed</i> | 2.15 | 2.01 |
| <i>Depressed/Blue</i> | 1.37 | 1.89 |
| <i>Interested/Focussed</i> | 3.20 | 1.62 |
| <i>Calm Relaxed</i> | 3.22 | 1.85 |
| <i>Tired</i> | 3.83 | 1.96 |

| Episode No.[n] (cont'd) | Mean (cont'd) | SD (cont'd) |
|----------------------------|---------------|-------------|
| 8 (Evening/night) [12] | - | - |
| <i>Happy</i> | 2.25 | 1.54 |
| <i>Tense/Stressed</i> | 2.67 | 20.01 |
| <i>Depressed/Blue</i> | 1.50 | 1.88 |
| <i>Interested/Focussed</i> | 2.17 | 1.34 |
| <i>Calm Relaxed</i> | 2.08 | 1.73 |
| <i>Tired</i> | 4.25 | 1.81 |
| 9 (evening/night) [4] | - | - |
| <i>Happy</i> | 3.25 | 2.06 |
| <i>Tense/Stressed</i> | 1.75 | 2.22 |
| <i>Depressed/Blue</i> | 0 | .00 |
| <i>Interested/Focussed</i> | 4.25 | 2.22 |
| <i>Calm Relaxed</i> | 3.25 | 2.22 |
| <i>Tired</i> | 4.00 | 1.63 |

The awareness of the limits facing someone with an SCI encouraged me to distil the potential affect scales into the categories listed above. For analysis I further reduced them into positive and negative affect scales. For the positive affect scale the scales for “Happy”, “Interested/Focussed” and “Calm/Relaxed” were amalgamated. For the negative affect scale the measures for “Tense/Stressed” and “Depressed/Blue” were amalgamated. Tiredness was left free standing.

There was a need to create a variable for the episode times. For example, a person may report an episode that begins at 10am and finishes at 12pm. The midpoint would be 11am and that becomes the episode time.

Table 3.11

State/traits versus sensations in areas tested as sensationless

| Model Term | Co-efficient | Std. Error | t | Sig. | 95% Confidence Interval | |
|-----------------|--------------|------------|-------|------|-------------------------|-------|
| | | | | | Lower | Upper |
| Intercept | -0.206 | 1.924 | 0.107 | .915 | -3.999 | 3.587 |
| Age | 0.012 | 0.033 | 0.370 | .711 | -0.053 | 0.078 |
| Gender=1 | 1.152 | 0.745 | 1.547 | .123 | -0.317 | 2.621 |
| Episode time | 0.053 | 0.044 | 1.190 | .236 | -0.035 | 0.140 |
| Positive affect | 0.015 | 0.069 | 0.225 | .823 | -0.151 | 0.120 |
| Negative affect | 0.055 | 0.107 | 0.517 | .606 | -0.266 | 0.156 |
| Epl | | | | | | |
| Scale_Tired | -0.043 | 0.155 | 0.277 | .782 | -0.348 | 0.262 |

Location

The respondents had a choice of three responses for their location at the time of the episode: At home, at work or somewhere else. The majority of the episodes (75.2%) found the participants at home. Episodes with people at work totalled 13.3% and in 11.4% of the episodes the respondent was somewhere else.

Table 3.12

Location versus sensations in areas tested as sensationless

| Model Term | Co-efficient | Std. Error | t | Sig. | 95% Confidence Interval | |
|-----------------|--------------|------------|-------|------|-------------------------|-------|
| | | | | | Lower | Upper |
| Intercept | -0.453 | 2.035 | 0.222 | .824 | -4.465 | 3.559 |
| Age | 0.011 | 0.034 | 0.341 | .734 | -0.055 | 0.078 |
| Gender=1 | 1.158 | 0.752 | 1.539 | .125 | -0.326 | 2.642 |
| Episode time | 0.054 | 0.045 | 1.204 | .230 | 0.034 | 0.142 |
| Positive affect | -0.014 | 0.070 | 0.195 | .846 | -0.151 | 0.124 |
| Negative affect | -0.047 | 0.110 | 0.431 | .667 | -0.264 | 0.169 |
| Ep1 | | | - | | | |
| Scale_Tired | -0.054 | 0.158 | 0.344 | .731 | -0.367 | 0.258 |
| Location 1 | 0.312 | 0.774 | 0.404 | .687 | -1.214 | 1.839 |
| Location 2 | 0.152 | 0.965 | 0.157 | .875 | -1.751 | 2.054 |
| Location 3 | 0 | | | | | |

Note: Location 1= Home. Location 2=Work. Location 3=Other

Sensation and Type

In total, 71% of the respondents in the nine episodes reported sensations in an area of their body tested by a medical professional as sensation free.

Table 3.12 summarises the sensation types. The sensations are described using Siddall and McClelland's (1999) categories however respondents were presented in the survey with options for increase or decrease in temperature, referred, increase or decrease in pressure, position, length movement and other. People frequently felt more than one

type of sensation. All the descriptions were recoded by the investigator into the categories outlined by Siddall and McClelland

Table 3.13

Sensation types recoded and number of people experiencing

| Episode No.[n] | Number of people |
|------------------------|------------------|
| 1 (Morning) [64] | |
| <i>Simple</i> | 45 |
| <i>Complex</i> | 25 |
| <i>Referred</i> | 6 |
| 2 (Morning) [21] | |
| <i>Simple</i> | 15 |
| <i>Complex</i> | 15 |
| <i>Referred</i> | 3 |
| 3 (Morning) [12] | |
| <i>Simple</i> | 12 |
| <i>Complex</i> | 7 |
| <i>Referred</i> | 0 |
| 4 (Afternoon) [45] | |
| <i>Simple</i> | 24 |
| <i>Complex</i> | 19 |
| <i>Referred</i> | 4 |
| 5 (Afternoon) [9] | |
| <i>Simple</i> | 5 |
| <i>Complex</i> | 6 |
| <i>Referred</i> | 0 |
| 6 (Afternoon) [3] | |
| <i>Simple</i> | 10 |
| <i>Complex</i> | 0 |
| <i>Referred</i> | 0 |
| 7 (Evening/night) [40] | |
| <i>Simple</i> | 25 |
| <i>Complex</i> | 19 |
| <i>Referred</i> | 4 |
| 8 (Evening/night) [12] | |
| <i>Simple</i> | 7 |
| <i>Complex</i> | 7 |
| <i>Referred</i> | 2 |
| 9 (evening/night) [4] | |
| <i>Simple</i> | 2 |
| <i>Complex</i> | 3 |
| <i>Referred</i> | 1 |

Painful or Not

Out of the 210 episodes where sensation was experienced in areas assessed as being sensationless, 72.8% of the sensations felt were painful. The table below summarises the sensations using the 9 episodes previously discussed.

Table 3.14

Painful sensations in tested areas by episode

| Episode No.[n] | Painful |
|------------------------|---------|
| 1 (Morning) [64] | 70.5 |
| 2 (Morning) [21] | 68.8 |
| 3 (Morning) [12] | 70.0 |
| 4 (Afternoon) [45] | 75.9 |
| 5 (Afternoon) [9] | 66.7 |
| 6 (Afternoon) [3] | 33.3 |
| 7 (Evening/night) [40] | 77.8 |
| 8 (Evening/night) [12] | 77.8 |
| 9 (evening/night) [4] | 75 |

Discussion

The key findings of the study are discussed more fully below however, the study did not find any meaningful diurnal pattern of sensations, noted that many people felt sensations in areas that they felt should be sensationless and that the majority of participants were well educated. Also of note was that the number of participants that completed the survey was difficult to compute and that the level of life satisfaction was higher with women.

Diurnal Pattern

The small size of the sample may account for the lack of an immediately discernible pattern in a daily phenomenon. The suggestion in the data of a trend of diminishing sensations through the day bears further examination. It may well be that the pattern was beginning to emerge alternatively with a larger sample it may vanish

altogether. In order to achieve a sample size large enough to answer these questions with more certainty it may be necessary to access a clinical population.

Another possibility is that a pattern of sensations may not exist daily and that a pattern only exists over a longer period in which case the DRM in its current form will not capture the pattern.

Number of people reporting unexpected sensations

Very obvious in the data are the number of people who report sensations where they do not expect them. The initial values are tabulated from two questions in the first section of the survey. The first question asks if respondents feel sensations in areas they do not expect them. The second is more specific asking if they experience sensations in areas that health professionals have identified as paralyzed.

The discrepancy. There is a difference between the number of people who affirm these phenomena across both questions. More people claim sensations in areas of their body where they don't expect them (97.4%) than people have sensations in areas that have been deemed paralysed (87.4%). The difference is notable because it means that some people have sensations coming from areas of their body that they think of as beyond use but the body part has not been formally identified as being beyond the ability of the person with the SCI to receive sensations from.

The reasons for the apparent discrepancy can only be conjecture. Some of the sensations may be referred from other areas as detailed by Moore et al. (2000). Some of the areas may be adjacent to completely sensationless regions and the participant views them as paralysed erroneously. The body part could be located in an area of the ZPP. Another reason for the discrepancy could be simple survey error.

However, the finding does bolster the theory put forward from the previous study. This may be a manifestation of psychophysiological dissonance. The expectation of the

respondents is obviously out of line with their experience. They expect part of their body to be sensation free (for whatever reason) and it is not. It is certainly an area that bears further scrutiny.

Level of education

Another aspect of the survey that comes to attention is the educational level of the respondents. As reported, the majority of the sample (85.5%) attended at least some third level education. It is possible that this format (available only on the internet) has biased the sample ensuring that the average respondent has at least some computer awareness and although computer use is rapidly increasing in the SCI community it is not ubiquitous and still at approximately 69% (Goodman, Jette, Houlihan, & Williams, 2008). The same group also found that computer use increased with educational level and although the research was conducted in the US it is not unreasonable to assume that the trends, if not the numbers, are the same in other developed countries.

That observation leads to another, the bias that may exist in computer use/internet access between “developed” countries and those without easy access could easily taint the sample in ways not immediately obvious.

Life Satisfaction

This is a topic that most non-spinal cord injured people are intrigued by. Frequently researchers find that other factors are the dominant influences on life satisfaction and not the injury itself (Boschen, 1996; Tzonichaki & Kleftras, 2002).

As an aside, the premise around the screenplay for “Million Dollar Baby” was that life was not worth living if you sustain an SCI. It is better to be dead than to live with a disability (Shannon, 2005). In this study the average score for life satisfaction scale was

above the midpoint challenging the notion that a person who sustains an SCI will always be dissatisfied with life after an SCI

The finding that women with an SCI are more satisfied with life may come from a level of acceptance of the injury. An obvious next step is to establish what females were doing differently to their male counterparts but the necessary calculations examining issues such as who they were interacting with could not be completed because of sample size. This and their relationship to the injury need further exploration.

Participant Drop in Numbers. It became apparent very quickly that a large number of respondents were not making it all the way through this questionnaire. Figures on computer use in the SCI community have been reported (Goodman, et al., 2008) but data regarding incompleteness of surveys are difficult to find for the same group. It is generally accepted that web surveys will have approximately an 11% lower response rate (Manfreda, Bosnjak, Berzelak, Haas, & Vehovar, 2008) but this alone does not explain everything. There was a drop from 107 respondents who began the questionnaire to only 29 leaving contact information by the end of the survey. This was an apparent drop of 73%. This initially alarmed me however; it was quickly replaced by a realisation that the figures belied the situation.

The response rate. Calculating the success of dissemination, or lack of, when using a web based survey is very difficult without breaking confidentiality. In order to calculate the response rate two pieces of information are necessary: The number of completed units and the number of eligible units (Fan & Yan, 2010). We can easily obtain the number of completed surveys but as we have no idea how many people accessed the questionnaire it is impossible to calculate the number of eligible units (many more than completed the informed consent may have accessed the page and not gone any further and it was not possible to view this figure).

Looking more closely. A number of participants were not interested in leaving any contact information. Another aspect was that there was no onus placed on the respondents to complete the questionnaire added to which the numbers of participants who began the questionnaire was lower than anticipated. In addition, as the design of the survey is based on the DRM the finish point for the questionnaire can be different for each participant. As the contact information question was the finish point for SurveyMonkey's data tabulation it can leave the impression that far fewer participants completed the survey than actually did.

Some other possibilities. Part of the drop can be clarified by using Fan and Yan's (2010) criteria for examining factors affecting the response rates of web surveys.

They break the process into 4 basic steps: Web survey development, delivery, completion and return. All four criteria will affect this and every web survey but focussing on the factors surrounding web survey completion will give us an insight into the particular challenges for this population.

Survey fatigue. Groves, Cialdini and Couper (1992) demonstrated that various social considerations should be acknowledged when relying on a survey. They specifically mention survey fatigue in society in general but it is highly likely that the phenomenon is particularly noticeable in populations of interest such as people with an SCI. As can be seen on any of the DPO listservs, people with an SCI are frequently approached to participate in experimental, observational pharmaceutical device and survey research.

Physical limitations. A person with an SCI has a welter of tasks necessary for survival (Matter, et al., 2009), tasks that a person without an SCI would have no reason to be aware of. A prime example of a task common to all is the weight shift. This issue is invisible to most people without paralysis. Unless ill or aged with a mobility issue, a person without paralysis is constantly moving and decubitus ulcers (pressure sores) rarely develop. This is not so for a person with an SCI. Due to the lack of movement, skin breakdown is an issue that has to be dealt with from very early on in the rehabilitation

process (Chen, DeVivo, & Jackson, 2005; Krause, Vines, Farley, Snizek, & Coker, 2001; E. Martz, Livneh, Gontkovsky, & Stokic, 2010). It is so ubiquitous a matter that an app has been created for the i-Phone. It helps remind people with an SCI to change position on a regular schedule.

Needing assistive devices It also helps in understanding some of the challenges facing a person with an SCI using a computer to recognize some of the computer assistive devices that are frequently used by people who are paralysed. The issue here is that if a person is disabled to a point where they need to use an assistive device the chances are that the task will be onerous.

If the LOI is high (above C5), a device such as mouth stick can very quickly assume the role of the fingers when pointing and pressing and is one of a myriad of different devices that allow people with a high lesion to use a computer.

Another device frequently used is a mouse laser pointer which is attached to the head and allows a person with tetraplegia control the position of the pointer on the screen or a camera mouse that tracks head movement using a webcam and free software.

Other assistive devices such as voice control software which allows a person to both control the cursor and input text may be used. Of course, these devices are of little use to a person who is ventilator dependent and can't speak with the regular cadence.

All of these devices, if required, will add to the person's independence but at a cost of time. As soon as one of the devices is necessary to complete a task the length of time needed to complete the task increases dramatically.

The devices available are described for people with an SCI and health professionals in various places including catalogues and adaptive equipment supplier websites, particularly DPO websites previously listed.

Survey fatigue, physical limitations, and the need for assistive devices combine to make completing the computer task less than easy. These are just some of the limitations

that may face a person with an SCI when using a computer and when blended with the regular factors facing any respondent, need to be taken into account when a researcher is designing the survey.

Tasks such as these are invasive and time consuming and need to be completed whether the person is in the midst of another undertaking or not. It means that even if a person is completing a questionnaire on the computer they will have to interrupt the task no matter how engrossing.

In addition to the difficulties presented by the task above is the realisation that 95% of all of people with an SCI have at least one secondary medical condition with 58% reporting three (Ansen & Shepard, 2006; Chen, et al., 2005). This will add care issues specific to the secondary condition.

Lastly, is the realisation that not everyone wished to leave contact information and as this was the last question in the survey, relying on it to ascertain completion was in itself flawed. People didn't always access this question.

Generalising

The most apparent challenge to the generalizability of this survey or any web based survey is the applicability of the study to people if they don't have access to the internet (Couper, 2000; Fan & Yan, 2010; Fleming & Bowden, 2009). The ability to generalise the sample to the population in both experimental and survey based research is always open to scrutiny and all survey designers need to look closely at the basics of reliability and validity. For this study, as mentioned earlier, it is important not to generalise the information to countries where internet access is limited. This means that most of the findings in the study have to be confined to countries where people have access to the web.

However, as the ubiquity of internet access increases the question will become less relevant but more importantly for this group of rehabilitation service users the use of

computers with internet access is becoming a key in rehabilitation for those with an SCI (Goodman, et al., 2008). It was not unusual to observe 100% use of computers with internet access being utilised in most model systems of care in the US.

The result of the effort to keep the sample representative of the nonclinical population has resulted in a smaller than hoped for sample size and probably the biggest obstacle to generalising the results. This may be due to the lack of motivation to finish the survey because of the physical factors listed above. It may also be due to the participant not feeling obliged to begin or complete the survey as it is of nonclinical origin.

Using a Survey Administrator on the Web

It is also important to realise that the design of the DRM for management by a web based survey administrator (SurveyMonkey in this case) remains time consuming. The respondents in this study had the ability to create 21 episodes. Although most of the respondents did not need to avail of all the blank episodes in the questionnaire those episodes still had to be created.

In addition, it is also important to realise that the challenge of cleaning data still persists even after the apparent ease of downloading the responses from the survey administrator. The tasks facing a researcher in recoding and cleaning the data do not disappear because of a system that simplifies administering the survey.

Conclusion

The chapter has focussed on the quantitative nature and structure of the phenomenon called PS or PP in people with an SCI. It provided both descriptive and relational information. In the next chapter the information supplied in the first studies is expanded on by highlighting cases which add data to answer the central question.

CHAPTER 4: CASE BY CASE

CHAPTER 4 OUTLINE

It is hard to conceptualise the difficulties faced by a person who has a disability and more so when that person is instantly faced with the ramifications of the sudden onset of the disability (Cole, 2004).

This chapter begins with a brief introduction to specific cases that help round out our sense of the lived experience of somebody with an SCI and PS/PP. In the method section it talks about the research design choice and moves on to the procedures used for picking the cases. The measures used for data analysis such as triangulation, idiopathic outlook etc. are described next. In the results section each of the three cases selected is described, analysed and summarised. The chapter ends with a discussion and recommendations.

Choosing a Case

In one instant the person is “normal” and then suddenly everything has changed. The simplest issues that were invisible, such as opening a door, putting on the kettle, or using the bus, become an act of conscious will and have to be relearned. Concerns of a personal nature such as toileting, sexuality and basic hygiene become matter of open discussion with Personal Care Assistants (PCA’s) medical and rehabilitation staff.

The studies contained in this section of the thesis help us more completely understand the lived experience of a person with an SCI carrying on the process of elaboration begun in the previous chapters. The chapter will, to use a cliché, create a “face” for the participants.

These case studies are not approached in the same way as they would be at the beginning of a chain of studies in that they do not generate a specific hypothesis but serve to round out our perception of what it is like for a person with an SCI to experience sensations in areas where their expectation says they shouldn’t be.

There are three case studies in total, all with a slightly different focus. All will elaborate different aspects of what has come to light in the previous studies.

The first will expand on three of the six higher order categories that were discovered in the grounded theory study. The second case will say more about a single participant’s day as he reported it through the DRM. The third will focus on the remaining three categories from the first research study.

Method

Research Design Choice

The choice to look at case studies is dominantly informed by my background as a clinician. Although investigating data through exploring a case is not confined to a single method it is considered a valid approach (Willig, 2004, p. 70) and for many is the genesis

of all research hypotheses (Bromley, 1986). In this it has also helped generate more avenues for exploration in the future.

I began by further considering a participant who completed the semi-structured interview used in the first study. The research continued by looking more closely at a specific case from the DRM study that gives more information about 24 hours in the life of someone with paraplegia or tetraplegia. The final section comprises an analysis of data from a specific person who has a slightly different outlook on his life and injury.

Participants

Sampling procedures. Choosing the cases for additional inspection was governed by three factors: The research question governing the thesis, a wish to further explore the core categories and examining the life of a person with an SCI as it pertained to sensations in areas tested as sensationless.

In the case studies, as a sign of adjustment to the injury, I also looked for individuals who returned to work (or equivalent) post injury. I did this to decrease the possibility that the phantom sensations could be seen as wish fulfilment and dismissed (as evidenced historically in the amputee population [see Ch. 1]). Returning to work is frequently used as a gauge of rehabilitation success and often stated as a goal in rehabilitation programmes (Krause & Anson, 1996; Widerström-Noga, 2002). It is often measured in assessments such as the Functional Independence Measure or Functional Assessment Measure.

In addition to the return to work requirement, for the first case study I also searched for an interviewee that contributed substantially to the grounded theory research.

In the second case I looked for a participant from the DRM study that left information in both the descriptive and episodic sections of the survey. The information gathered goes some way toward helping visualise what a typical day in the life of a person

with an SCI might be like. Of course, the concept of a typical day for a person with an SCI is tempered with the realisation that there are no “typical” days and are they are frequently interrupted with a range of different medical complaints (Chiodo, et al., 2007; Haran, Lee, King, Marial, & Stockler, 2005; Liem, McColl, King, & Smith, 2004; McKinley, Jackson, Cardenas, & DeVivo, 1999)

For the third case I searched for a person who also showed an acceptance of his injury. I had been contacted by MP who expressed an interest in completing the DRM survey and I familiarised myself with his public persona. He is well known in both the SCI and enabled community and has chartered his life quite publically which allowed me to triangulate information relatively easily. Common to all three is the fact that all of the participants have a spinal cord injury. In addition to the SCI, MP is also blind.

Procedures

Data Analysis Procedure

The procedures for this section of the thesis entailed closely inspecting data already collected and in MP’s case also conducting a small unstructured interview. The data was then analysed using case study approaches to fill out the information received in the previous studies. The function of the case study in this document is not just to generate theory but because of its placement after the initial studies, to round out the findings in the previous studies.

The cases differed slightly across all three participants but by examining the individual cases I was able to perceive the subjectivity of the phenomena more clearly.

Using the case studies to examine the phenomena of interest. In all three case studies, as in all case study design, there is a concern with examining the phenomena of interest. The intensive study of these particular cases helps identify some of the factors that

may give rise to the occurrences of concern. The focus here is generated by the core research question i.e. understanding the lived experience associated with PS.

Triangulation. Particularly in the case of MP, triangulation was used extensively in order to examine the information from the various data sources. We can also see triangulation techniques in the examination of the selected case from the grounded theory study in that both the medical records and the semi structured interview were used as sources of intelligence. Triangulation of data sources was impossible for the respondent who completed just the anonymous web survey however, he and every participant in the survey was asked about the occurrence of PS in three ways in different sections of the questionnaire.

Idiopathic outlook. The individual cases were examined in their own right. The information garnered from the study was particular to that case and should not be generalised (Smith, Harre, & Van Langenhove, 1995). If we use as an example our single case from 107 chosen from the DRM study, the temptation to generalise to the rest of the sample is great; the temptation to generalise to the rest of the population is greater still. The same guideline holds for the other cases inspected. In the instance of MP, given the numerous sources of information the temptation is once again to generalise beyond the boundaries of the example. This has to be avoided.

In context. However, the examples were examined in a way that acknowledges the ecological validity of the cases. Here the challenge was great: To examine the cases for the phenomena of interest, not generalising but recognising the context from where it came.

Ethical Procedure

The ethical requirements such as the consent and confidentiality of each participant were guaranteed by the arrangements in the previous studies. For example, if the case

being analysed was originally part of the DRM research the ethical framework from that study covered the analysis done here.

Results

Case One

Selection. This person was chosen because, as a participant in the qualitative study, he particularly addressed three of the six concepts that came to light after coding and analysis of all the interviews. He spoke in depth about injury context, sensations and communicating about phantom sensations.

He was also the most expressive and thoughtful of all interviewees and seemed to have taken time previously to critically analyse his situation and the phenomenon of interest. As stated previously he also returned to work after his initial rehabilitation for the injury.

Description. FS was born in 1958; he is male, married and self-employed. At the time of the interview he had sustained his SCI 6 years, 6 months and 6 days previously. He was aware of and laughed at the significance of 6.6.6. He has been diagnosed as having an ASIA A (complete) injury at C₅₋₆.

Pharmaceutical and therapy history. He was on pharmaceutical courses of Trileptal (off label use, low dosage for neuropathic pain), Zanaflex (helps reduce spasms) and Prilosec (over the counter medication for heartburn).

He had completed rehabilitation on an inpatient basis at SCVMC five years previously. The therapies included Physical Therapy (PT), Occupational Therapy (OT), Respiratory Therapy (RT), Recreation Therapy (Rec Therapy), Aqua Therapy and Nutrition Therapy.

Family medical history. His medical family history was significant only for a stroke secondary to cancer affecting his father.

Surgical history. With the exception of a spinal stabilisation procedure and other surgeries related to his injury (such as suprapubic catheterisation) there were no other surgical interventions claimed or noted in his medical file.

Interview content. He began his account by detailing the sensations he regularly felt well below his LOI and by using a blank pain diagram (see appendix B) he systematically related information about the rest of his body. He also spoke at length (though we were both unaware of it at the time) about three of the six higher order categories later discovered in the data from all the participants.

During the interview he also brought up topics related to the other core categories but the material was minimal.

The higher order category: Injury context. He sustained the injury that left him quadriplegic (tetraplegic) in Mexico while on vacation. It was around 5:30 pm on the second day of his vacation and he dove into a swimming pool, hit his head and recalls “seeing ... bubbles in the water trying to float to the surface”. Very quickly, he discovered his inability to move while “trying to swim to the surface, but not being able to swim”. As a result he floated to the surface and a few people he knew helped him while he was in the pool.

When he described the event he used the phrase, “they stabilised me in the pool” which I suspect he heard from health professionals during rehab (the use of the word stabilised is widely employed by rehab and medical staff working in the area).

His wife and he had met three gentlemen on the plane the day before, two retired police officers and a reserve police officer. These “guys” in tandem with the paramedics lifted him from the pool.

His account, although more vivid than most, is still confused mostly about times he associated with different events.

Now, at, what... how much time elapsed between that and when I was actually on the pool deck and talking to the other people and the paramedics.....you know recollection is there that there was no time lapse at all, although the paramedics were there, so obviously there....time had passed. But I don't think I lost consciousness at any point...

This confusion about time may well have been due to shock secondary to the injury and is common amongst people after a traumatic event (Ford, 2009).

He was put in an ambulance and taken to a clinic which was closed. The paramedics then took him to a doctor's office but the physician's speciality was gastroenterology. FS felt that the doctor knew very little about SCI. He stitched FS's head, tested his sensation with a pin, catheterised him and left him for the night. He reports that he was awake for most of the night despite the fact that the doctor had given him some medication on arrival.

He informed me that there was a newly built hospital in Cabo San Lucas at the time "but from what I'm told they don't take gringos to the hospital".

Although recently challenged, it is generally held in most medical disciplines that the sooner a person experiencing a trauma is taken to a facility that can begin treatment, the better the outcome. This is often referred to as the golden hour (Berger, 2010; Little, 2010). Amongst the US model systems of care for people with an SCI the concept has been extended to the first 24 hours with the creation of Spinal Injuries Centres (SICs) (Jones & Bagnall, 2004). Despite this he did not express any anger, frustration or any negative emotions while discussing the fact. It is possible that he was not aware of the principle around the time of his injury but he is sure to have encountered it during his early rehab or from peers.

His journey continued when his wife arranged to have him flown to UC San Diego from the airport in Cabo San Lucas.

Uh, so they took me there next morning. Um, and then I spent about three weeks in San Diego in intensive care before they decided that I was more or less medically stable.

After San Diego he chose SCVMC to complete his initial rehabilitation programme as it was located about 10 blocks from his house. On examining his chart in SCVMC, I noted that early interventions, spinal stabilisation etc. had been previously completed at the hospital at UC San Diego. He continued with an intensive round of therapies which began after it was established that his injury was stable.

The higher order category: Sensations. During the interview he described sensations both above and below the NLI. He also discussed sensations from the ZPP or the transition region between the two.

Using the taxonomy created by Siddall and McClelland (1999) it was possible to categorise all of the sensations below the NLI into simple and complex but this taxonomy does not discriminate between painful and non-painful.

He started by describing burning sensations in his feet that continue to his midsection particularly on the right. He notes that he feels hot and cold in his feet providing the external stimulus is extreme enough, such as a bath of ice or an electric heater. Despite being responsive to these extremes in temperature he is completely unreactive to pinprick in these areas of his body. He does note though that the responses he has to heat and cold are so slight that sometimes he wonders if they are just wishful thinking.

He defines the burning sensation as painful and almost constant. When the pain is not present it seems to be “spontaneous” in that he has not been able to identify a trigger for either its appearance or infrequent disappearance. He also describes it later in the discussion as it being very similar to sunburn that has been slapped.

He notes a sensation or sensations of pressure that move up his legs from his feet. In addition, in the same area is a vibration that again runs up his legs and continues into his mid-section.

The vibration is not constant and is volitional in that he has noticed that he can cause it to happen by attempting to move his toes. The sensations became obvious early on, he noticed them first when he was in San Diego before he was moved to SCVMC.

As he is describing these phenomena he is interrupted by both his dog (barking) and his wife in pursuit of the dog.

A style of language begins to become more obvious as he elaborates. He obviously relies on the grammatical third person. It can be seen in phrases such as “So when you try to move your toes so that...” instead of: So when I try to move my toes so that... It seems that he may be trying to distance himself in some way. The use of the personal pronoun is only employed when he is describing certain types of sensations.

He goes on to elaborate the volitional component of the PS he feels. The movement attempt that never generates pain:

If I attempt to move my toes or move my feet at the ankle, sometimes they will feel like they're moving. In fact, when I attempt to move my toes, they usually feel like they are moving, like they're, like I can curl them.

The concept that the sensations are both vivid and very realistic is repeated throughout the interview.

He felt a “bit of sensation” at the tips of his toes which he first noticed while at SCVMC. (Note that he used the first person to describe these particular sensations):

I remember feeling at one point when I was at Valley Medical, and this was probably two months post-post injury, I remember feeling a little bit of sensation at the tips of my toes. When they put on or took off my socks. And, in fact, I have sensation in the tips of my toes, um, sort of like the pressure sensation. Actually, they're-they're kind of very hypersensitive. An example is, when my toenails are trimmed, it feels like they are cutting off the whole end of my toe. They are hypersensitive.

He describes sensations with an identifiable external trigger using personal pronouns but if the sensation is spontaneous having an unidentifiable trigger they are described in the third person. This pattern repeats throughout this and other populations. It is interesting to note that therapists are trained to look for this concept of using the third person in order to distance oneself from pain (Martin, 1989).

He also maintains the sensations, even if painful, are better than not having anything but that he could do without having the pain especially if the pain serves no useful purpose. If the sensation is useful it's a bonus, for example he mentioned the tips of his toes again which he can use to tell if he bumps into something. In addition the pressure sensation he feels in his lower limbs responds to external stimuli, if only lightly and he can use it to tell if he has wedged his legs under his bed.

He discussed the concept of referred sensation where he had noticed in particular a stimulus (wound on his left heel) well below his NLI but felt a clammy sensation on the right side of his neck as it was debrided. He also outlines a regular occurrence where he has been touched on a hand and felt it in his shoulder.

There are also sensations that he describes as autonomic in that he is aware that they tie into autonomic dysreflexia (AD). For example, he is aware of the fullness of his bladder by the "clammy" sensation he gets in general. He was probably taught to look for this during his initial inpatient rehab as autonomic dysreflexia (AD) can be life threatening. (AD results in a sudden hypertension potentially leading to seizures, stroke, coma and even death. It can be triggered by any irritation below the level of injury an overfull bladder or rectum (Dorland, 2011). AD is not a problem for a person with an injury below T₅₋₆)

In order to manage the pain more successfully he has tried hypnotism. He discovered that he got major relief from the pain while he was "under" but this reprieve was short-lived in that as soon as he began interact with his environment the pain would return as quickly as it had disappeared.

He also claims that in general the sensations are beneficial in rehabilitation therapy process but sometimes they can be a hindrance as well. He felt that they could have a psychologically beneficial influence though he did not elaborate.

Spasms are good as far as he is concerned. This concept correlates with the world view of many therapy approaches such as “Project Walk” based in Carlsbad, California (ProjectWalk, 2011). As he reports they can be used to help a person stand but the very least they can halt atrophy in the area that spasms.

He moves to sensations from more personal areas of his body but just before he does he claims that if he was offered a choice between walking and pain elimination he might choose the latter. This not the first time that this has been expressed in the SCI community added to which he said that pain is the single biggest reason he stops work. This concept is another expression of what Rose, Robinson, Ells and Cole (1988) discovered in their postal survey.

In this section he begins to discuss both painful and non-painful sensations originating in his penis.

He describes that the focus of the pain he experiences is here, although he is aware that this area is more sensitive than most. He can also separate out non-painful sensations though and they are perceived as pressure. He notes surprise:

Again, it's pressure, but that is c-o-m-p-l-e-t-e-l-y separate from pain. As a matter of fact, what's interesting is if I'm feeling pain in the penis and I touch it—It feels as though those are coming from two different places, yet somehow they are strangely superimposed in the same place.

The area has not been tested but he thinks, as he has some sensation there, that the injury could be ranked as incomplete in that area. He uses the phrases “complete” and “incomplete” in a manner consistent with their common use but his ASIA categorisation would not change even if the sensations were verified. (The description of the ASIA scale is explained more fully in Chapter 3).

He describes the feeling as similar to the sensation that he notices in certain areas in his legs but he is incapable of feeling an erection which also happens occasionally. He states that unfortunately the erection seems to be completely spontaneous and is in no way a response to sexual arousal.

He then focuses on the sensations coming from his “glutes”. He feels as if he can tighten them and they feel as if they are tightening but he has not had them reassessed since he was first categorised. He states that he hasn’t thought to talk to anyone about it.

Keeping one eye on the diagram he moved into his lower abdomen and up to his nipple line. At this point he is describing the ZPP. He states that the painful sensations extend as far as his lower abdomen but not any further and that he doesn’t get any pain between the lower abdomen and the nipple line. This is notable as many people with an SCI report pain in the ZPP as prevalent (Bockenek & Stewart, 2002).

The last area he addresses is his arms and hands. The evaluation of dermatomes and myotomes in this area is confusing. This is generally because of the tendency of rehab staff, medical staff and patients to switch attention from sensory information coming from the skin to motor control of muscles. He is aware of the potential confusion but is quite insistent on speaking about one last area of pain. He maintains that the pattern of sensation in his Upper Extremities (UE) is consistent with his level of injury but the most intense area of pain in his body is the back of his thumb on his right hand.

It hurts “all the time” and was the first place he felt pain. It responds to external triggers and is hyperaesthetic (painful response to a non-painful stimulus with the response in the same category). He has noticed that even blowing on it causes a burning pain (allodynia or painful response to a non-painful stimulus with the response being of a different category).

He claims that the painful sensations were not present until a few months into his rehab and that for the majority of the pain he feels that applying pressure seems to help.

The higher order category: Communicating about phantom sensations. He describes his reluctance to discuss the sensations with health professionals and anyone else outside the SCI population.

He mentioned that he seemed to have sensation in his toes while he was at SCVMC and he was retested to see if there was any perineal response and he could be categorised from ASIA A to ASIA B. He got the sense from the Doctors that he was nuts.

I have discussed these sensations with other spinal cord injured people—because I know they don't think I'm nuts. I've discussed them just with civilians, if you will.

He reports that it is his impression that they are quite common in the SCI community but people seem to have different manifestations of the sensations. He has never discussed any sensations of movement with either other people with an SCI or health professionals.

Case summary and discussion. FS was one of the participants from the initial study that focussed on using grounded theory methods. He also addressed the other categories discovered in the grounded theory study (meaning of the sensations, attitude and body connectivity) but only to a minor degree. The three remaining categories are better elucidated in Chapter 2 and in the information found and given by MP.

The lack of disgruntlement expressed around his injury is notable. It may be that his ability to accept the issues around receiving the injury are in some way connected to his ability to return to work.

He details the sensations he feels, particularly the painful ones, below the NLI but although rehab would be seen as successful, his knowledge of why some of these sensations are present is lacking. Some of the sensations he encounters would be lot less mysterious and potentially anxiety provoking to him if he had a more in depth knowledge of his injury.

The people he chooses to share information with will only be able to help in non-informative, though probably supportive, way. He is hesitant about sharing specific information with his attending health professionals.

During the interview he addressed many issues but certainly added to or embodied three of the higher order categories discovered in the corpus of the research. He spoke vividly about how he was injured as his memory of the event was not clouded by loss of consciousness. He went on to speak about the sensations he routinely feels below his NLI and then gave us an idea of who he had spoken to about the sensations.

Case Two

Selection. The focus of the second case is on a day as experienced by a participant with an SCI and phantom sensation. He was chosen because he fits the image of being part of the typical nuclear family. He also returned to work after the injury, filled out both episodic and demographic information and gave information about the beginning of his work week. Most notably he perceived, along with all of the interviewees in the qualitative study, sensation in areas of his body that had been tested as sensationless.

Description. The 56th participant who entered information into the survey is a married, 43 year old, male with a third level education. He has a spouse and they are responsible for one child who lives with them. He sustained his injury in a Motor Vehicle Accident (MVA) 11 years ago and like a substantial number of respondents in the survey he feels sensations in areas of his body where he does not expect them. Indeed, he feels sensations in areas of his body that have been identified as paralysed and they last hours at a time. He is involved with a peer support group and reports that he is very satisfied with both his life and work. He maintains that he has a good recollection of the previous day (Monday). He details beginning at 6:25 am and finishing at 10:50pm and that he did not feel himself as ill.

His day.

Morning. During the first episode of the day he recounts that he was at home and interacted with his wife and child. He prepared food, ate and spent some time focussing on his toilet/bowel programme (it's worth noting here that these tasks are usually time consuming and onerous for anyone with an SCI, particularly the bowel programme). He observes that he felt tired (4/7) but did not feel depressed or blue. Despite feeling tired he reported feeling calm and happy. Most significantly he reports that he felt no sensations in deafferented areas of his body at this time.

During the next episode he drove to work. He remains at the same level of tiredness but seemed to be feeling flat or apathetic with all of the emotional measures at 1/7 for intensity. He was commuting alone and did not feel any sensory phenomenon in areas tested as sensationless.

He then rates his morning at work in the office. His emotional measures are no longer flat led by a rating 5/7 in interest and focus. His tiredness level has dropped significantly for this episode which ends at 12:55pm. He has been interacting with clients/customers and work colleagues. He once again reports no PS during this episode.

Afternoon. In this episode he starts his afternoon at 1:00. He begins by eating lunch and checking his email. He claims no feeling of being depressed or blue but his stress level is at 4/7. Once again no PS but they do make an appearance in the next episode.

He now outlines his early afternoon, he is still at work on the phone and interacting with colleagues and customers. He continues to report no level of depression although he feels stressed but focussed. His level of tiredness remains a 2/7. During this episode he feels non-painful PS's and using Siddall & McClelland's (1999) taxonomy descriptions he notices movement and an increase in pressure. He describes that the sensations feel like "tight bandages wrapped around my lower legs".

He then moves on to describe an episode later in the afternoon finishing at 6pm. The dominant event was commuting again however for some of the episode he was working. His tiredness level has increased to 3/7 and he notices that his stress level remains high at 4/7. During this episode he interacted with his boss, work colleagues and clients. He continued to feel PS in his lower body again describing movement, pressure and bandages. However, this time he uses the “other” section in the relevant question to describe the bandages as “warm” not “tight”. This may mean that there is a temperature component in the sensations as well. Once again the sensations are not painful.

Evening/night. The next set of episodes came from later in the day. In them he relives his evening, in this case, at home.

He spent this particular episode (6 pm-7pm) with his wife and child. He helped prepare the food and then ate. His stress levels have reduced to 1/7 but his tiredness level remains at 3/7. His depression level has remained low all day (1/7) and he notes that his focus is a little less intense. PS's are again present but non-painful. The sensations are consistent in their presentation and once again he notices an increase of pressure, movement and the description of the bandages remain. This time they are both warm and tight.

The penultimate episode of the day covers “late evening” finishing at 10 pm. He watched TV, used the computer and generally relaxed spending most of the time with his spouse. His tiredness levels increase to an intensity of 6/7. He reports being calm, relaxed and happy. The PS's remain and once again are consistent with the episodes from the afternoon.

During the last time frame he reports that he went to bed. The episode ends at 10:50. Interestingly, he reports an absence of PS's during this time frame. His level of tiredness increases to 6/7. He ranks the emotions he has experienced during the day as pretty typical

Case summary and discussion. This case, one of many from the questionnaire responses, details a small sliver in the daily life of a person who contributed information left in the DRM survey. He left material that allowed the assembly of his day but it is important to realise that certain aspects of his routine are not commented on. It is impossible for any survey to capture every event during a period and much less so for a method that relies on the participant's memory (even if designed to minimise recall bias).

Also, because of the nature of the survey there was little ability for the respondent to elaborate on his responses. However, he used the "other" response in the episode questions pertaining to the sensation descriptions and I address this later.

Some of his responses and trends bear extra comment. He reports his satisfaction with life and work as very high. He also notes that his health was good on the day he details. It is highly possible that the satisfaction with life he reports is contingent on his health level but as this survey does not ask how often his daily health is good it is impossible to tell if there is a relationship.

He felt no sensory phenomenon in areas previously tested until early in the afternoon and the sensations were non-painful but lasted through the entire day. They eventually disappeared in the final episode of the day. He describes the sensations as pressure and although he also reports sensations of movement he never elucidates. He compares the sensations (the core category from the ground theory study: Meaning of the sensations) to a warm tight bandage.

His depression levels are low all day but his reported stress levels increase dramatically when he goes to work and continue high until he returns home. There are the expected elevated levels of happiness towards the end of the day. It's possible that that the material was influenced by social desirability. The behaviours weren't being directly observed by a neutral third party and the pattern of happiness falls into the socially expected phenomenon of being happier in the evening while with family.

Case Three

Selection. MP contacted me after viewing the appeal for participants on various DPO community forums. I was interested in examining a case where the level of acceptance by the participant was high. MP at a glance seemed to meet the criterion. There were many reasons for treating his survey separately to the responses from the rest of the participants in the quantitative survey. The primary concerns were that he expressed an interest only after the online version of the survey had been closed, the questionnaire had to be administered by a third party because of his blindness and I had met and spoken to him personally.

The final three categories discovered by the grounded theory study are meaning of the injuries, attitude and body connectivity. These areas are further elaborated by examining the various sources of information MP has placed in the public domain, examining a short debriefing interview for the survey and by looking at the data generated by the questionnaire.

Description. MP is a 35 year old, single male who describes himself as an adventurer, author and motivational speaker. This description is at the top of the page on his personal website. He finished his formal education receiving an MA from Trinity College Dublin. He is currently in a stable relationship, has no children and became blind in his 3rd year at university when he was 22. He also sustained an ASIA A (complete) SCI at T9 in April 2010. Given the ease of identifying him from his websites etc. (his website uses his name in the URL) I asked him to sign an additional waiver in addition to the informed consent documents at the front of the questionnaire (See appendix J).

Information sources. He has created at least three websites and populates two Facebook™ pages, two Twitter™ pages, one YouTube™ channel, a podcast channel and authored a book with a co-writer. All these are useful sources of information and combined with his survey response and a short interview gave me an insight into how he has adapted,

to date, to having an SCI. It has also allowed for the construction of a comprehensive chronological history of MP since he first became blind (See figure 4.1 on the following page for an outline)

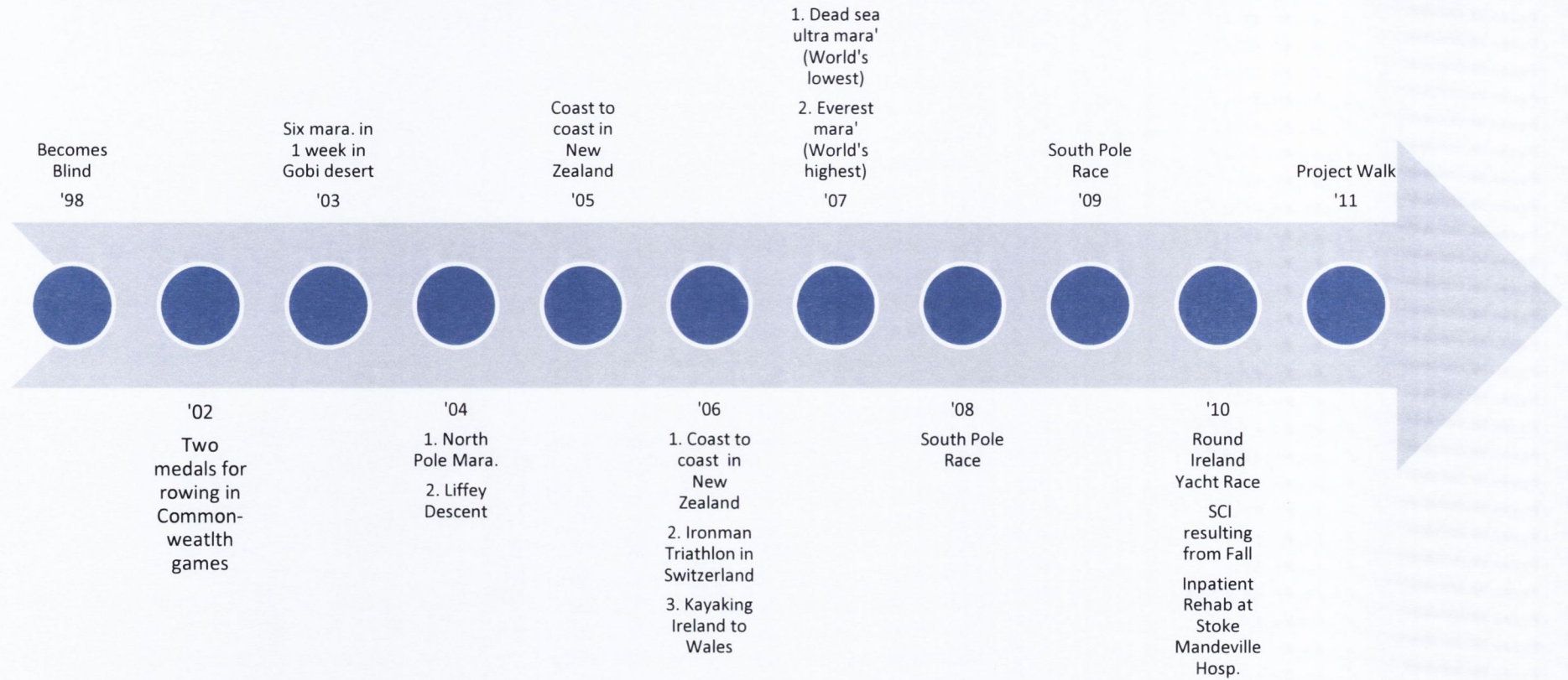


Figure 4.1 A basic timeline for MP constructed from information on/in websites, blogs, videos and DRM survey completion.

On searching the web there were also written accounts from people who have been involved with his activities, newspaper articles and testimonials from people and organisations who he has addressed as a motivational speaker. It is also quite easy to find video and audio podcasts of various interviews and presentations produced by BBC and RTE.

His websites. MP designed his first website to function as a point of reference for both his financial backers and his “team”. It also acts as an information source for any who care to access it.

The primary site was created before he sustained the SCI and together with the text on the site there are links to his story before and after the incident in video and blog form. As such, it is a comprehensive source of information although how he sustained the both injuries is never mentioned here. However, the incidents are discussed in other online sources.

The second site serves as an online face for the trust which functions as a financial safety net and has allowed him to pursue avenues of rehabilitation not open to many. In a section about his life he gives more detail about the time around the injury that resulted in his paralysis (he fell from a 2nd story window on the 2nd of July, 2010 breaking his back in a number of places, fracturing ribs and his skull).

The remaining site is specifically given over to his South Pole race and consists of text, links to video and audio diary entries.

His blog. The blog spans a period and takes the reader from October 2010 to June of 2011. It consists of a series of diary entries that cover the time between the onset of his SCI to three months after his return from “Project Walk” (a physiotherapy organisation based in the US). It consists of both text and video and details events and his reaction to them over the same time period. At time of writing it has nine entries.

His videos. He has peppered his blog and websites with various videos the focus of which varies depending on the need of the website or blog entry. In addition, many of his entries in Facebook™ and Twitter™ link or mention the videos which are all available on YouTube™ in one place. For example, in a series of videos taken while he was with “Project Walk” in Carlsbad, California, he demonstrates some of his current exercise regime which is intensive. In another blog entry/video he demonstrates a device in trial called a Brainport

It allows blind people to perceive objects using a camera mounted on glasses which sends the image to an electrode held on the tongue. The tongue receives the pixels of the image as current which the brain sends to the visual cortex to decipher (2011).

All of the videos available on the various sites are also available on his YouTube™ channel.

His social media sites. Twitter™, Facebook™ and YouTube™ are also used extensively. He uses two accounts on both Twitter™ and Facebook™. One account has been set up as a communication aid for the trust he has established and the other linked to his website. The YouTube™ site functions as a central site for all the video posts in the various online forums he maintains.

In total there are 15 videos available on his You Tube™ channel and numerous others recorded by yet other individuals. In addition, he has recorded several audio and video files as part of his South Pole race diary.

His book. MP has also authored a book which was published prior to sustaining the SCI but after his trek to the South Pole. The book contains 8 chapters and 130 pages and puts the proposition to the reader that we all make excuses and should always be, as the title of the book proposes “Making it Happen”. Interestingly, the book is only available online and is printed on request (Pollock & Whitaker, 2010).

His survey. Due to his blindness and the unavailability of the questionnaire online MP completed a paper version of the DRM survey. It was a simple print out of the .pdf version. It was administered by his PCA and although he was given the same instructions and information as respondents using a computer the information he gave was not statistically analysed with the rest of his cohort. A brief description of his responses follows:

In general. In addition to the responses that allow him to be described (see above) he documented his previous 24 hours. In this case the day he scrutinised was a Tuesday. He woke around 9am and went to sleep around 9:30pm noting that he felt well all day. This is unusual given the number of serious infections he has sustained secondary to the permanent catheter he has had implanted. Both the infections and the catheter operations are documented on his website blog. For example:

I wrote the above paragraph only hours after I posted my last blog, which detailed how my fight was waning. But, after my short reprieve from infections (enough of a reprieve for me to insist I be moved from the acute ward), on day 1 in rehab I was exhausted... another infection was brewing.

But as the tide of positivity was rising, I was hit with another infection. And then another. And another. IV drips, fluids, antibiotics, fevers, vomiting and a couple of weeks in bed each time. I had lost three stone and with it the will to go on. It was too exhausting to experience...

He reports that he was not at home all day and when conducting a short debriefing session I met him in the Burlington hotel where he is currently residing while he waits for his new home to be completed to his unique specifications. He rates his satisfaction with life at 2/6.

He experiences sensations that last minutes in areas of his body where he doesn't expect them and also feels sensations in areas of his body that health professionals have identified as paralysed.

He divides the day into eight episodes – three in the morning, two in the afternoon and three in the evening.

Morning. The morning section containing three episodes begins with the first episode of the day where he interacted with health professionals, parents and friends via phone while in bed. He notes that he felt sensations of movement and they were complex enough to be able to tell position but none of the sensations were painful. The sensations took place in areas that have been identified as sensationless by medical professionals. His levels of tiredness are high (6/6). He reports a feeling of being tense/stressed (3/6) with no feeling of being happy or calm/relaxed. Interested/focussed is reported at 3/6 with only a low level of depression (1/6). It is interesting to note that he has the same level of tension as interest. This may be viewed (in combination with his stated history of participating in adventure athletics) as fitting the arousal theory of motivation (Yerkes & Dodson, 1908).

The second episode consisted of him preparing for the day, showering and dressing etc. It takes us to 11am. He reports no PS during this part of the day. His tiredness levels remain high and his stress levels move up to 6/6. The remainder of his emotional levels continue as before (the possible reason for this is that the more mundane Activities of Daily Living ADL's in this episode do not carry an emotional load).

The last episode of the morning before noon finds him meeting with his social worker. His focus has increased to its maximum reported level as has his tension however his tiredness levels have diminished almost entirely. He did notice sensory phenomenon that were vivid enough for him to perceive movement but none of the sensations were painful. He also noted spasm but the questionnaire was not specific enough to ascertain if it was a sensation he felt or an event he experienced.

Afternoon. In the afternoon he has used two episodes to describe this section of the day. The first stretches from 12:00pm to 2:00pm. During the time he used the phone and computer. He also ate and relaxed.

His tiredness levels continued to be very low but his feeling of depression increased strongly. He noted sensations below the NLI once again feeling movement.

Between 2:00pm and 5:15pm he had multiple meetings with health professionals. Interestingly, his level of happiness increased to its highest level of the day (6/6) as did his focus. His tension level/stress dropped to 3/6. He felt no level of depression at the time. Overall this episode seemed beneficial resulting in him feeling most of the emotions associated with a positive outlook he also felt no sensations below the NLI at the time.

Evening/night. The sixth episode of the day begins his description of the evening. It begins approximately at 6:00pm and runs to 8:00pm. During the episode he eats, relaxes while watching TV, spends some time on the phone and naps.

His tiredness level begins to creep up from the previous episodes to 2/6. He has dropped his focus and there is also a drop (0/6) in his tension levels. His depression levels increase slightly to 1/6 but these are offset by his happiness levels of 2/6.

During the penultimate episode he relaxes with his partner describing the events during the episode as socialising. His levels of tiredness and focus/interest increase to 6/6 and 3/6 respectively. This increase in both factors seems counter intuitive. I would expect that as tiredness increased the levels of focus would decrease but the point may be explained by observing that he was interacting with his partner at the time. It may also be explained by his interaction with a medical professional (he currently classifies his PCA as a medical professional) and these events require him to focus more.

The last episode of the day details the time from going to bed until 12am. As expected he reports very strong feelings of tiredness with all of the emotional scales at zero. He does not claim any sensations below the NLI.

The survey acts as an excellent information source but by its nature is limited. The rather more open quality of the other sources allowed me to piece together information that was missing from the survey.

His debriefing. The debriefing is the last of sources accessed in order to establish his opinion. It was very brief and functioned more to act as an opportunity for him to ask questions about the survey. All respondents were given the same opportunity but in the case of the online participants the debriefing had to take place as part of the survey, via e-mail or phone.

The debriefing lasted about 20 minutes and began with issues regarding the process of answering the survey. The process tended to be a bit more complicated due to his blindness. He needed a person there to transcribe his answers and read the questions (which he felt sure did not alter his responses but may have felt an obligation to respond in a certain way due to increased social desirability).

The rest of the time during the meeting he discussed other factors regarding his new status as a person with an SCI and I took some notes regarding statements he made about the core categories (meaning of the sensations, his attitude and body connectivity) discovered in the grounded theory study.

Discussion

Given the number of different sources of information it was possible to put together a profile of his approach to life and sensations below the NLI.

The information can be divided into data that was publically available (online, TV, Radio etc.) and data that is more private (survey and debriefing). It was possible that there could have been a conflict between data from the public and the private sources. There was however, a consistency of viewpoint across sources that increases confidence in the analysis.

Using the categories from the qualitative study, I applied a framework or filter to the data from the various sources.

The Meaning of the Sensations.

The meaning he assigns to the sensations can be gleaned primarily from his survey responses and his debriefing session post survey. During the debriefing he described the sensations using “simple” adjectives, the term used by Siddall and McClelland (1999) to describe sensations such as pressure, tightness or temperature etc. In the survey, in addition to simple sensations, he also described movement which would fall into the classification of complex sensation. After describing the sensations he then moved onto their implication.

The suggestion that there may be a connection between his brain and areas below the LOI was very important to him. The possibility that the sensations were evidence of this connection was stated very clearly.

They indicate to me that there's some connection between my brain, past my injury down to the legs and therefore there's a hope or chance that I might be able to strengthen those connections and gain some function.....

For most people with an SCI the implied meaning of the sensations is bound very closely with the meaning of the injury as a whole. It is not uncommon encounter people asking: What's going to happen to me? Will I ever walk? What's my life going to be like? etc. Perceiving sensations in areas where they are not expected may feed the dissonance in the influence relationship the person has with their health-care providers.

The first meaning assigned to the SCI tends to be more concrete although it frequently takes the form of being goal or progress orientated (Angel, et al., 2009). In his book, MP addresses this concept but as the book was written before he became injured it is in regard to his blindness. He speaks about his drive to return to his fitness level pre-blindness and wonders if this is the reason for all of the adventure sport challenges he set for himself (Pollock & Whitaker, 2010).

In regard to sensations in these studies, the range of meanings tended to follow similar lines to those expressed by the interviewees in Chapter 2. His replies can also be divided into implicit and descriptive categories.

Attitude

The major source of insight regarding his attitude comes from the book he has authored. The book was written predominantly for the business world and those interested in motivation. Because of this it is a very useful source of data regarding his attitude to a multitude of different events.

Acceptance. Some of the quotes from the various chapters indicate the importance of the concept to him:

“The thing that leads us out of self-pity is finding acceptance.” (Ch2, P25)

“When we reach acceptance we have reached the true understanding of the problem, difficulty or challenge facing us” (Ch2, P25)

“However, as soon as we accept reality, we can move forward and build a life more satisfying than any comfort zone we could ever create.” (Ch2, P26)

“You must accept your current reality before you can take control of your life.” (Ch2, P29)

“Once you have accepted the truth of where you are, you are ready to take the steps towards where you want to be.” (Ch3, P47)

“Blaming other people and being angry about the result are not going to change it. And feelings sorry for myself is not going to turn the clock back and reward me with a second chance. Only by accepting that is has happened can I even consider moving on.” (Ch8, P120)

There are many more references in the book to the need for acceptance of the reality of the situation you find yourself in and the importance of the theme repeats itself in many of the data sources though not as explicitly. The insight into the degree of acceptance needed for rehabilitation seems to come from a coping mechanism probably honed when

he became blind. He has applied it to his general attitude and it has become a major part of the approach he teaches to corporations. It also appears as a cornerstone concept in rehabilitation protocols (Henwood, et al., 2010; Kortte, et al., 2010; Low et al., In Press; Erin Martz, Livneh, Priebe, Wuermsler, & Ottomanelli, 2005).

Lack of acceptance. Contrary to the acceptance he espouses prior to his SCI he does not accept at least some components of what the implicit meaning of the injury might be. In a statement from one of his blog entries he asserts his lack of willingness to accept his potential future.

Conventional wisdom suggests that I will not walk again. The script seems to read that I've been saved from death, stabilised in hospital and now I will remain in a wheelchair. But I'm not ready to let conventional wisdom determine my future.

He also describes himself as "broken" in one of the entries. It is possible that he is experiencing a discrepancy between his belief system and his current situation.

Acceptance versus the lack of it . His competitive nature (as can be implied from the number of endurance based competitions he participated in up until his SCI) will not allow him to give up. This attitude seems to influence his acceptance of a future he does not wish to accept. Here he confronts a fine line that faces both professionals and individuals with an SCI. "Do I accept to the point where I just give up?"

Perseverance. From twitter he posts, "how do 100m sprinters train for years to shave hundredths off their times...maybe I'm a sprinter now training for tiny gains over years." This seems to fit with his apparent ability to stick with something once he has determined that it is something he wishes to achieve.

Asking for help and independence. One of the more difficult areas for somebody with an SCI to face is the drive that most people have to be independent versus the need to ask for assistance (Kerr & Meyerson, 1987). Prior to the injury MP presented to people in companies. As part of his presentation, he counselled that we should to put a "team"

together: A team that would help you in some way But before you can do this effectively you have to accept that you need help. He addresses the same concept in his book:

I had to swallow my pride, I accepted that I would have to through the process of doing things that I really didn't want to do. I had to ask for help...I wanted to live an independent life. An "independent life" for me at the time meant being able to do the same things I did before I became blind. (Ch3, P32)

Most SCI rehabilitation protocols will focus on this ability and he has to apply it now to his newly acquired injury. It is important to be able to balance the need for independence with the need for assistance. He needs to put another team together.

There are countless other skills that anybody who experiences a sudden onset disability has to develop and the issue in this case is that they have already been developed to help him cope with his blindness but now he needs to access them again for another disability.

The question that arises is whether MP has accepted his injury and the decrease in function that goes with it. According to many models associated with adjustment (e.g. Angel, et al., 2009; Gerhart, et al., 1994; Low, et al., In Press; Erin Martz, et al., 2005) his actions don't readily fit the expected behaviour of a person who has accepted their injury (In an update to his videos he can now be seen surfing in San Diego and walking with the aid of an exoskeleton while in Northern California.) However, his theories regarding motivation do.

Body Connectivity

Looking at the connection to his body the immediate question that comes to mind is whether he is more or less aware of it now? He addresses this aspect of the injury in his blog but he also discussed the topic during the debriefing session for the survey. He noted that he was more conscious of his body now than previously (pre and post the onset of the SCI) but only while he was exercising. The exercise regime associated with "Project

Walk” is intensive and he has found that he has to pay particular attention to his body while completing the prescribed exercises. In his blog he notes that

Working my paralysed legs over the past four weeks has provoked a connection to my legs...The feelings are not normal but rather a general sense of my legs, a connection with the ground and sometimes a feeling of warmth and pulse...I feel a sense of connection through my legs that does not happen when I don't try to use the muscles below my injury level.

He also noted that the act of completing the survey forced him to pay more attention to this apparently sensationless area of his body. This act of attention is very similar to the ideas espoused in mindfulness training (Kabat-Zinn, 1991). The training advocates the benefits of consciously attending to an event and is very similar in approach to the act of consciously attending to a body part.

In addition to the conscious attention he pays to his body while exercising is the awareness of the sensations below the NLI. “I’m not sitting on air, there is something there”, summed the concept up for him. The area below the LOI had not disappeared from his awareness.

Communicating about PS

MP does not seem to have any problems about communicating his experience of sensations below the LOI. In his video blogs he displays the exercise regime put in place while he was with “Project Walk” and he is quite open about talking about any sensations below the LOI. In the blog text he talks of the sensations not “being normal” but the fact that he mentions it on a public forum seems a long way away from the recalcitrance expressed by FS.

Conclusions

Analysing specific cases garnered from the various studies was a way to personalise the information gathered from the research. It also enabled me to gain additional insight into the lived experience of people with an SCI who perceive PS or PP. This insight comes in the form of aiding the reader to visualise some of the personal experiences of a person with an SCI who feels PS.

The first and last case studies help us to understand the role acceptance may play in adjustment. In the first case FS also detailed his experience highlighting three categories discovered in the grounded theory. He gave a plethora of information that allows us to understand his experience with PS i.e. how he sustained his injury, the sensations he feels and who he tells. He addresses the issue of how he perceives the sensations sometimes wondering if it is just “wishful thinking”.

In the case of M.P. his apparent acceptance of the limitations imposed by his SCI, acceptance previously learned with the onset of blindness while in college, was pivotal to his adjustment to the injury.

The second case opened up a day for us which explicitly gave us a view of how many different factors are at play in the daily life of someone with an SCI. Our respondent gave us a window into his day, tells us who he spent it with, outlined his perception of the phenomena he experienced and shared some of the emotions he felt during the day. Analysing a specific response adds texture to the information aggregated in the quantitative study.

MP also volunteered to let us into his life for a brief moment He permitted us to glimpse some of the understanding he has about disability and motivation to help him cope with his new set of challenges. In addition, he shares a significant amount of himself and his opinion online in the various forums he populates.

However, an experience they all share is a disconnect between their expectations and their lived experience of their own bodies. FS discusses a reluctance to speak about so called phantom sensations, the survey participant informs us that he feels sensations he does not expect, and MP notes the same in his survey responses.

CHAPTER 5: GENERAL DISCUSSION

CHAPTER 5 OUTLINE

The last chapter in this thesis serves to summarise and bring together the thoughts and findings in the previous chapters. It begins by restating the central research question and using its components as a template. It continues by looking once more at the core categories from the grounded theory study and using them to help amalgamate the conclusions from the various chapters. It completes the document by making recommendations for health professionals who may be working in the rehab arena. It also adds recommendations for researchers to expand on or clarify some of the issues raised by this thesis.

The central question in this thesis, the query that drove all the subsequent research questions bears repeating: What is the meaning, structure and essence of the lived experience for a person with an SCI who perceives phantom sensations and/or pain?

The components of the research question are further elaborated below and their applicability to the thesis will become more obvious.

The use of the term “meaning” is reasonably self-explanatory. The “structure” of a phenomenon is its arrangement of and relations between its own components. The “essence” speaks to its intrinsic nature.

The first study captured and gave us an insight into all the components of the research question, the second study addresses structure very thoroughly, and the third-essence

The question provides a template for application to all the findings. To start we can deconstruct the question: “Meaning” is the first concept it contains.

Meaning

The meaning of the phenomena in the health professional’s world seems very much at odds with the meaning assigned by the people with an SCI. How a person with an SCI may view the meaning of the sensations below the LOI is well described by one of the core categories discovered in the grounded theory study (meaning of the sensations).

Broadly speaking the responses in the survey can be divided in two, with implicit and descriptive meanings. The descriptive meanings are direct portrayals of the events with most respondents using analogies to describe the sensations (e.g. It feels like hot sand running...). The implicit meanings or the meanings implied by the sensations tended to revolve around signs of return. Any sensation that could be interpreted as a sign that feeling or motor control was resuming was greeted with enthusiasm. The dominant implicit

meaning assigned by the participants to the sensations can best be summed up by the responses from FS where he interprets any sensation he perceives below the LOI as a sign that something is “returning”. He also stated that when he was closer in time to the injury or “early on” he was more inclined to interpret the sensations as being a sign of return.

This interpretation could well be a sign of the degree of acceptance of the injury. The degree of acceptance is generally held to be a good indicator of adjustment (Angel, et al., 2009; Arango-Lasprilla, et al., 2010; Fukunishi, et al., 1995; Kerr & Meyerson, 1987; Korte, et al., 2010)

Other meanings of the sensations included the idea that the sensations were fundamentally a good thing but that emotionally they could be frustrating particularly if they were painful.

The emotional state of the person will affect rehabilitation (Thietje, et al., 2010). It is likely that any dissonance between an individual’s expectations and their experience will affect their emotional state.

Some of data gathered from the DRM survey helps here as well. Participants were asked if they felt sensations in paralysed areas of their bodies. They were also asked if they felt sensations in areas where they didn’t expect to feel them. In addition, in each episode created, they were asked if they felt sensations in areas that a medical professional had assessed as sensationless.

There were a range of answers that described both simple and complex sensations (Siddall and McClelland’s (1999) categories). There was also an option called “other” which allowed participants describe sensations they felt in their own words. After the replies had been re-coded there was a list of descriptions that did not easily fit the choices given. They included warm sand running down legs, fizzing in the buttocks and bad

abdominal pain. One entry stood out in that there was a lot of mostly explicit meaning associated with the sensations:

I can feel blood flow in my legs and spasms in specific muscles. I can feel a relief from the blood leaving my legs. By the end of the day my ankles were swollen (normal) and I can feel the blood flow as it leaves my legs. Not my pulse but blood flow and relief of pressure. (Anonymous entry in survey)

There are obviously the simple sensations associated with the decrease in pressure but here the person feels a sensation that they interpret as the blood “leaving my legs”. This is a very vivid description that the respondent has interpreted in a specific fashion.

From the second example in the case studies chapter we can also analyse his answers to the question about sensations he experiences. The focus in the case study was on his day but he details the sensations he feels in areas that have been tested as sensation free. He interprets the sensations in an explicit way not expanding on them to elucidate their potential prognostic meaning. In the “other” response he compares them to warm tight bandages wrapped around his lower legs. All of the descriptions fall neatly into the simple sensation category (Siddall & McClelland, 1999).

However, in the debriefing discussion with MP he also supported the concept that any sensation can be a sign of return. The majority of the sensations he described both in the debriefing and in the survey fell into the arena of simple sensations however, it does not matter to the perceiver whether the sensations are simple or complex. If the implied meaning is that return is possible whether the sensation is simple or complex matters little to the person experiencing the sensations.

Additionally, we can see the fine line that has to be walked between acceptance of the injury and hope for a cure (e.g. Arango-Lasprilla, et al., 2010; Fukunishi, et al., 1995; Henwood, et al., 2010). The clinical challenge is to represent the new restrictions presented

by the injury in such a way that the person accepts the limitations but is still positive about their own future.

This juxtaposition is highlighted by looking at MP's case. He dealt with his blindness by pushing himself physically. His history since the onset of the blindness has been to challenge himself by setting very challenging goals but with the SCI the achievements he was used to aiming for are rendered impossible. This is common to all people experiencing an SCI but I suspect they may be evenly more acutely felt here.

Pivotal to the opinion he espoused while speaking professionally was the concept he described as the red dot (Pollock & Whitaker, 2010). This is the dot you see on a map that says "you are here". The concept he advocates is the idea that in order to progress you must accept where you are. The challenge facing him now is to accept where he is but to do it without losing the desire to change.

Meaning is subjective, the implication of the sensation will change demonstrably from person to person but if the meaning of the sensation is taken to be a sign of return or potential return it is highly likely that rehabilitation will be influenced.

Structure

The relationships between the components of the experience are explicitly explored and reported in Chapter 3. In addition, the associations between concepts are the bedrock of the analysis when coding the data in grounded theory analysis (Booth, et al., 2003; Breakwell, et al., 2000; Creswell, 2008; Strauss & Corbin, 1998). The grouping together of the concepts into higher order categories is the exploration of relationships and can be viewed as the equivalent of the search for relationships between variables in a quantitative study.

A focus of the quantitative study was to find out if there was a diurnal pattern of sensation experienced in a part of a person's body that a medical professional had deemed sensationless. Despite the fact that the majority (97.7%) of people felt sensations in areas where they didn't expect them the day didn't reveal any blatant pattern. This is an avenue for further research. There was a trend towards a decrease in sensations in tested areas as the day progressed but is highly likely that a larger sample is necessary. The DRM was specifically designed by Kahneman et al. (2004) to be administered to large samples and maintain the richness of data quality similar to an ESM technique. In this case, the focus on making sure the sample was non-clinical resulted in the sample being smaller than could easily be accommodated by the method.

One of the aspects worth noting is that some of the measures were possibly developing into trends and need further examination. For example, looking at the plot for the time since the injury versus the number of episodes where PS was reported there seemed to be a potential association developing. As the length of time since injury increased the number of times people reported sensations below the NLI also increased. This concurs with the finding that as time progresses since the Date of Injury (DOI) the number of incidents of pain increases (Mariano, 1992; Siddall, et al., 1999; Siddall, et al., 2000; Smeal et al., 2006; Wrigley et al., 2007)

Another of the findings noticeable in the data from the quantitative study was that women with an SCI were more satisfied with life than their male counterparts. This also needs more scrutiny. The OECD reports both women and men as having very similar levels of satisfaction in most countries (OECD, 2012). This finding is bolstered by Beutell (2006) though he adds that life events proximal to the measurement can strongly influence the measurements. Chipperfield and Havens (2001) showed that life satisfaction declined in women who were married versus men unless they encountered a major transition event

such as the death of a spouse. If they did encounter a major transition the life satisfaction in both genders declined but more so for men. These relationships between the various factors encountered in life continue to be investigated but one particular aspect needs further investigation here: Is satisfaction with life indicative of adjustment to the injury?

One of the approaches might try to examine the difference in expectation of functional return. Using an approach such as the DRM would seem to be without merit. Finding a measure that could measure expectation retrospectively would be a challenge.

Essence

Looking at the “essence” or the intrinsic nature of the lived experience is the next step in deconstructing the question. The concept of “essence” is difficult to define.

Understanding some of the philosophy behind the research helps.

Phenomenology versus Positivism.

The idea that it is impossible to separate reality from the observer has been debated for many years. The argument between those who favour qualitative methods of research and those who favour quantitative highlights this apparent divide.

Pure positivists argue that we can be completely removed from that which we are observing (Willig, 2004) and that it is indeed possible to measure something both objectively and without influencing it. Indeed, most of the natural sciences seem reliant on the concept. However, as a sceptic might point out, even when we measure the temperature of a glass of water the simple act of placing a thermometer into the container will change the temperature of the liquid. Indeed, pure phenomenologists will argue that even the choice what to observe/measure is fundamentally a subjective act.

Similar arguments can also be observed in the debate surrounding embodiment. Here we find the rather obvious, though difficult to conceive, concept that reality experienced by an individual is governed by their physical state (MacLachlan, 2004). It is impossible for an individual to experience anything unless it comes in the form that the individual can process. In order for something to be perceived it has to be experienced by our bodies and if the object of our observation cannot be perceived in its natural form it must be transduced into a form that can. For example, although an object may be too small to see unaided we can build an instrument to bombard it with electrons and convert it to a visual representation that we can then see on a screen.

According to this view everything we experience is governed by our own ability to perceive it. My interaction with my universe is completely reliant on my body. Imagine what it must be like if suddenly and irrevocably my body is changed. My universe will change too. This happens to someone who sustains an SCI. Quite simply, their entire universe shifts because the object used to make sense of that universe has changed.

Avoiding the Argument

To avoid getting sucked into the positivism versus phenomenology argument this thesis has dealt with both qualitative and quantitative methodologies. The concept of talking with a person who has an SCI and experiences sensations below the level of their lesion, seems self-evident and quantifying it in some way; essential. Mixing methods in a cohesive way is a solution to the problem posed by the two methodologies frequently portrayed as being at odds (Creswell, 2008). The essential nature of PS can only be completely discovered using both approaches. In this thesis the qualitative tells us what we are seeing, the quantitative the when and the case studies weld them together.

The aetiology of the concept of PS needs to be challenged here though. The idea expressed by most is that because a person is ASIA A (complete) any sensation or pain below the NLI is a phantom. This is flawed. Unfortunately, PS is a term used by researchers, clinicians and people with an SCI, under the assumption that any sensation below the LOI (if the lesion is complete) must be phantom. There is a problem here; there are a few sensations that have been identified as originating above the LOI including the apparently odd situation where, for example, a person may feel lower back pain despite the fact they may be paralysed from the thoracic region. The realisation that the enervation point for the para-spinal muscle that may be involved is above the injury or that the muscle is enervated by at least two nerve roots at two different levels, begins to help the person with the SCI understand why there are apparently sensations originating from the paralysed area.

There is also the situation where a person can feel sensations from their viscera (such as appendicitis pain) because the pain signals bypass the spine completely being carried by the Vagus nerve which is the 10th cranial nerve and originates directly from the medulla just above the inferior cerebellar peduncle (Netter, 2003; Tortora & Grabowski, 1993) thereby originating from a point above the injury.

This means we can never be 100% sure that the sensation experienced is a “phantom”. Communicating this idea to person with an SCI can be difficult.

So at best there is a question about the essence of the phenomenon as we can't be sure (currently) whether the phenomenon is the same across all populations?

The Lived Experience

To further address the central question, acknowledging the higher order or core categories makes sense. “Meaning of the sensations” obviously fits the earlier part of the

question which specifically asked about the meaning of the concept. However, there are a number of concepts that arose from the grounded study phase of the thesis and when grouped together gave rise to the core categories: Injury context, sensations, meaning of sensations, body connectivity, attitude and communicating about phantom sensations. Each category gave rise to a number of issues most of which were discussed in Chapter 2 and examined from other perspectives later in the thesis. We can use these categories as another guide to move us more towards understanding a portion of the lived experience for person with an SCI feeling sensations below the NLI.

Injury Context

When looking at injury context we can easily see the confusion around the memory of the onset of the injury. This was apparent in the responses given by the interviewees when recorded. Even when the account of the incidents surrounding the onset of the injury were seamless in their delivery they very much sounded rehearsed. There was also no way to verify if the memories were of the incident or planted there later (Nourkova, Bernstein, & Loftus, 2004). It became obvious that most people in the survey, the grounded theory study and the cases had reflected on the onset of their injury, whether they remembered it directly or not.

It is also interesting to note that 100% of the participants in the qualitative study sustained their injury in a traumatic fashion and 92 % of the respondents in the quantitative study sustained their injury in a similar way.

The way a person became injured was not a condition of control for either the qualitative or quantitative research i.e. the type of injury was never used as a condition in the theoretical sampling and was never an inclusion or exclusion criteria for the survey. The studies here found no relation between the possibility of experiencing PS and the

nature of the SCI cause. This should be verified by other studies dealing specifically with people with an SCI

It is possible that the nature of the injury is related to whether the person has a higher or lower chance of experiencing sensory phenomena in an area that has been tested as sensationless. There have been a few studies designed to ask whether SCI pain is a factor of the type of injury i.e. does the way a person sustains the SCI influence whether they experience on-going pain (e.g. Mariano, 1992; Nepomuceno, et al., 1979; Wrigley, et al., 2009). The question that is never answered is whether the pain below the NLI is a phantom.

In the quantitative study presented as part of this thesis the number of people who had sustained their SCI in a non-traumatic fashion made it impossible to calculate if the way a person sustained their injury was related to whether they felt a sensation below the NLI or not. This is an avenue for further research and can only be done accurately if the sample sized is increased.

Sensations

The sensations reported from the various sources were complex and muddled by the perception of pain. Even the most complex of the taxonomies in widespread use do not discriminate easily between pain and sensation (Beric, 2002). For example, one of the most widely accepted texts on the subject (Bockenek & Stewart, 2002) divides SCI pain by type and then location. It mentions PP explicitly and places it with headache, psychologic pain and complex regional pain syndrome under the category of “other”. The taxonomy used by members of the IASP and proposed by Siddall et al. (2002) does not mention it at all.

As far as I have been able to find (using SciVerse, Psych Articles and Info, PubMed and Ovid etc.) phantom sensation in people with an SCI is only used to describe

non-noxious events below the LOI or if the person has a limb amputated in addition to the SCI. There is little reference in the texts to painful phantom sensations just PP

PP is again reserved for pain below the level of the injury but it is frequently only described as pain without the term “phantom” appended (not a bad idea give the value laden nature of the term as seen by the reluctance of people to discuss it).

The category was large when discovered in the interview transcripts and in the survey the incidence of sensation in a part of the body that a medical professional said to be sensationless was over 87%. In addition, the people in all three of the cases examined experienced sensations that could be classed as phantom.

Once again using this category to further analyse the phenomenon I was struck by the apparent confusion around classifying or defining it. In future studies it would be helpful if the operational definition of the phenomenon was stated clearly and near the beginning of the article.

Body Connectivity

Body connectivity was discussed by AH during the interview stating that he connected with his body more efficiently while exercising. MP also noted this during his debriefing. He also asserted that people he knew claimed that they had just become a floating head. He maintained that there are a large number of sensations perceived as originating from below the LOL and that they would make it impossible for him to consider his situation in the same way.

The linking factor here seems to be exercise and exploring further to clarify correlation from causation is necessary. Assuming the concept is correct, do people who exercise more connect with their bodies more efficiently or do people who connect more efficiently just do more exercise?

Attitude.

Attitude is a more intangible category than most of the others. Almost every statement made by the interviewees can tell us something about the attitude of the person who delivers it.

However, the primary source for information on this category came from the analysis of MP's online data sources and his book. The online sources describe his attitude to both his life and injury but most interestingly we can see his attitude changing depending on his mood or activity. The book was written post onset of his blindness but pre the onset of his SCI. The attitude he expresses would be considered healthy by most but this attitude has been tested extensively since his DOI.

It is generally held in the rehab community that attitude is a great predictor of outcome. More exploration into this is required. Is there some component of attitude that is a better predictor of outcome. How does locus of control fit? It's well established that if the person's locus of control is internal the ability of the person to recover from an illness is much improved (Boschen, 1996). Does this relate to attitude...How?

Communicating about PS

It is here that we explicitly see the reluctance that most of the participants had about conveying the experience of PS to anyone. If the sensation is painful (and as a result will be classified as pain not PS) the reluctance seems to be diminished. They will talk about it to each other and health professionals but if the sensations are not painful FS tells us that he has only talked about them to "civilians".

The survey does not address this topic directly and MP does not seem to be aware of any problem speaking about it. During his debriefing session he mentioned his time in

“Project Walk” and that he was actively encouraged to both discuss the sensations and generate them if possible. The theory in approach being that any sensation is beneficial. A very similar view to that expressed in the grounded theory study.

Psychophysiological Dissonance

One of the major findings that came from the studies is the concept of psychophysiological dissonance. The ASIA A categorisation is specific (the details of the scale are described in appendix E). The diagnosis however, of a person having a “complete” injury is not as precise as most would think. The evaluation is still occasionally applied incorrectly. Most importantly the meaning assigned to it by most people with an SCI seems to be at odds with the descriptions of the classification from ASIA. The tension or dissonance a person experiences when they believe they should be sensationless but have feelings in apparently denervated parts of their body is what I have called psychophysiological dissonance.

It is similar to the dissonance state outlined by Festinger (1957) but the dissonance instead of being purely cognitive in nature predicts that anxiety is created when physiological sensations are out of line with a person’s belief system or self-concept i.e. this dissonance is created when a person’s expectation is out of line with their experience.

Both theories share the idea that a person will be motivated to reduce the dissonance. In the case of psychophysiological dissonance they can only do this by challenging the external source of information or accepting that their expectation is wrong. It seems, judging by the responses in the grounded theory study, that for a number of people challenging their primary information source is preferable to challenging their own expectation.

An area for further research is to create an instrument to find and/or measure this dissonance. An area arising from finding it in an individual is to create an evidence based intervention to decrease the dissonance.

General Observations

I found when designing the questionnaire that it was appropriate to address some of the higher order categories directly. This can be seen in the choice of questions/variables in that they mirror many of the concepts found in the grounded theory study. The core categories of sensations and meaning of the sensations are particularly noticeable.

Observations on web surveys in general. There are implicit and frequently explicit criticisms of using the web to gather information from participants. It is frequently held that the responses garnered could be affected by the presentation of the website (Azar, 2000), can be non-serious (Azar, 2000; Buchanan, 2000), could be adversely affected by anonymity (Buchanan, 2000; Skitka & Sargis, 2005), may not be diverse enough (Azar, 2000; Buchanan, 2000; Krantz & Dalal, 2000) or that most of the respondents are socially maladjusted (Kraut et al., 1998). Gosling et al. (2004) suggest some of the more frequent disapprovals. Table 3.12 outlines some of the more common preconceptions and the major arguments against them.

Table 5.1

Six preconceptions and Gosling's et al. findings

| Preconception | Gosling et al. Findings |
|---|---|
| Internet samples are not demographically diverse (e.g. Krantz & Dalal, 2000) | Internet samples are <i>more</i> diverse than traditional samples in many domains (e.g., gender), though [as with most samples] they are not completely representative of the population. |
| Internet samples are maladjusted, socially isolated, or depressed (e.g. Kraut, et al., 1998) | Internet users do not differ from nonusers on markers of adjustment and depression. |
| Internet data do not generalize across presentation formats (e.g. Azar, 2000) | Internet findings replicated across two presentation formats of the Big Five Inventory. |
| Internet participants are unmotivated (e.g. Buchanan, 2000) | Internet methods provide means for motivating participants (e.g., feedback). |
| Internet data are compromised by anonymity of participants (e.g. Skitka & Sargis, 2005) | Internet researchers can easily take steps to eliminate repeat responders. |
| Internet-based findings differ from those obtained with other methods (e.g. Krantz & Dalal, 2000) | Evidence so far suggests that Internet-based findings are consistent with findings based on traditional methods (e.g., on self-esteem, personality), but more data are needed. |

Source: (Gosling, et al., 2004)

As the internet becomes more freely available however, the potential benefits of the method far outweigh the potential downsides.

Legal compliance. Another issue worth noting is that when designing a computer based internet questionnaire that will be administered internationally it will be hosted in one country but it may also have to be compliant with another countries' disability policy. For example, the policy covering design/accessibility of a computer survey in the US is Section 508 of The Rehabilitation Act (USGovernment, 1998). This effectively means that although this questionnaire was designed in Ireland it had to meet the standards of the

countries that it was administered in. The practical application is that if the questionnaire meets US standards, where it is hosted, it will also currently meet all international accessibility requirements.

Finding participants. The initial challenge when commencing the quantitative phase of the research was finding a suitable body of people who were willing to participate in the study. There is normally no problem with finding people with an SCI but the vast majority of studies are conducted with current users of the medical system.

Non-clinical. The participants in each episode of the study were asked if they had felt sensations in a part of their body that had been assessed by a medical professional and found to have no sensation. This question was created directly from the finding in the second study that people were experiencing sensations that they had never spoken to their health care professionals about.

Additionally, in the first section of the survey they were also asked if they had felt sensations in their body that a medical professional had identified as paralysed. Because of their placement in the questionnaire the former asked about the phenomenon happening during the episode whereas the latter asked about the phenomenon happening at any time.

The sensation question in every episode also acted as the pivotal question with a logic statement attached. (It was a dichotomous question and if the person answered “No” they were presented with no more options and the episode terminated).

The possibility that a self-serving bias would be manifest in a clinical sample was of concern and eliminating any possibility that the respondents might be conservative with their answers seemed imperative. If participants viewed their answers in any way influencing their care in a clinical setting, this was to be avoided.

However, given the apparent difficulty in recruiting a nonclinical sample it would be advantageous to apply this method to users of clinical services with the caveat that all

questionnaires are anonymous and that this is conveyed to respondents in a clear and deliberate fashion.

Using mixed methods. The application of a mixed methods approach to the initial understanding of this research question is optimal. A quantitative approach converts the data into numerical form for analysis, a qualitative approach analyses the data in language and mixing both approaches will give the researcher the benefits of both (Creswell, 2008). Understanding the connection between variables, what is happening and how much it happens are the areas where quantitative approaches excel and answering who, where why and how are the areas where the qualitative approaches shine.

To fully understand the phenomenon both on a subjective and objective level it is preferable to combine both approaches in some way. In this thesis the quantitative approach (application of the DRM) lent itself to analysing the “structure” element of the research question. The qualitative approaches were applied to better understanding the “meaning” and “essence” of it.

What ASIA A Implies

There is a confusion for both professionals and people who experience an SCI regarding what is a complete injury and what is not. And even if the injury is classified as complete what does it mean?

This confusion can be seen in the exchanges in the grounded theory study, particularly when SD discusses who he has communicated with about the sensations. He also notices that he “has felt to disagree with the physicians about having a complete injury”. He feels that he has had too many sensations throughout his body for the diagnoses to be accurate. The disagreement displays that he has an external locus of control and is comfortable being at odds with health professionals but the disagreement could easily be dissipated if it was explained to him that having a complete injury does not mean that he

will be sensationless below the NLI. The application of the ASIA scale amongst health professionals is not uniform. The ubiquitous adoption of the ASIA system has moved the medical community a long way towards a unifying classification scheme but even though it has replaced the previous schemes (e.g. the Frankel scale) it is still open to interpretation. This is frequently commented on in both online information sources for people with an SCI (e.g. Young, 2010) and in texts from the field (e.g. Wall & Melzack, 2002).

The confusion seems to arise when the terms “complete” and “ASIA A” are used synonymously by either a medical professional or somebody with an SCI.

As can be seen from the studies, in many cases the perception of the person with an SCI is that they will be sensationless from below the injury but significant numbers are not.

A simple conversation early on and repeated during rehabilitation with the person who is experiencing the injury seems appropriate. The content of this conversation should be focussed on the probability that the person will experience very vivid sensations in areas of their body that may have been tested as sensationless. This needs to be done in such a way as to not feed false expectations and to minimise psychophysiological dissonance but at the same time to be sure that any sign of return is not missed.

Research Artefacts

The concept that an ASIA A (complete) classification is a guarantee of perfect deafferentation in a body part is debatable. Even physicians that are familiar with the ASIA classification maintain that it is at best an imperfect measure of function or even more importantly an indefinite prognostic guide (Kirshblum, Memmo, Kim, Campagnolo, & Millis, 2002; Savic, Bergstrom, Frankel, Jamous, & Jones, 2007; Young, 2010).

The participants for the grounded theory study were selected on the basis of their ASIA A classification which now seems unnecessary. If a person has had a complete

injury it is impossible to know if the area is completely deafferented. Ascertaining that the area where the “phantom” is being perceived is sensationless (negative to pinprick etc.) is the best we can achieve, the completeness of the injury is irrelevant. This realisation is becoming obvious with articles about “phantoms” associated with SCI looking at people with incomplete injuries (e.g. Curt, et al., 2011)

Recommendations

In the Research Realm

In order for research to improve a very clear operational definition of PS should be stated. The potential uncertainty of the term “phantom” in this population could make any future research about this topic in this population challenging.

As the number of people in the quantitative study who sustained their SCI in a non-traumatic way was so low and the appropriate analysis could not be conducted. The relationships should be researched further in this population. There have been studies that speak to the incidence of PP being associated, or not, to the aetiology of the amputation in the population of people with an amputation (Probstner, Thuler, Ishikawa, & Alvarenga, 2010; Schley et al., 2008) but there is a dearth of the similar studies looking at the SCI community.

A further analysis of the material provided by MP is indicated. The sources of data, most notably his blog and YouTube™ material, are constantly being added to and could easily lend themselves to a more longitudinal approach.

Another aspect that could be addressed is the size of the sample in the quantitative study. The survey could be administered through a clinical setting with hopefully an increase in sample size. In order do this effectively I feel that the participant must believe

that their care will not be influenced by their responses in any way. I would suggest that the researcher/inquirer not be a member of the treatment team.

The redesign of the questionnaire is also an avenue to pursue. The burden it places on a person with an SCI is high. Redesigning the questionnaire or administering it so that it becomes even more self-paced would be optimal. For example ensuring that that if administered in a clinical setting the tasks listed in the questionnaire are more specific to that setting and the options are decreased. In addition, it should be possible for the participant to return to the questionnaire during the day in order to maximise their ability to self-pace the survey.

In the Clinical Realm

Throughout the different research studies there is a discrepancy between the expectations of the individual with an SCI and what he or she feels on a moment to moment basis. The levels of confusion about what is and what is not a phantom sensation are rife both amongst people with an SCI and in the medical profession.

This could be addressed by making sure the SCI patient/client was aware of the limitations of the ASIA classification.

Avoiding the potential confusion caused by lack of comprehension in the patient/client is paramount. This could be done by implementing the same approach as is required for research participant comprehension in SCVMC. In the research field the participant is asked to repeat their rights back to the researcher. Ask the patient/client to repeat the information regarding their injury back to the deliverer, in this way the health professional can be sure that the patient/client has heard the information correctly.

It is of note that similar concerns have been addressed in the amputee population. A focus group of 32 health professionals were interviewed about their interactions with

individuals with an amputation. The authors noted “that the information given to patients on phantom phenomena is inconsistent and insufficient.” (Mortimer et al., 2004, p. 221)

Conclusion

All chapters are linked by the central question: What is the meaning, structure and essence of the lived experience for a person with an SCI who perceives phantom sensation and/or pain? This question then acts as the binding enquiry for everything else in the in chapters.

The change of the operational definition through the different aspects of the thesis of a “phantom” is notable. Indeed, this challenge facing researchers is posed in the simple question: What exactly is a phantom sensation. There does not seem to be an agreed definition of when a pain or sensation is a phantom and until then it is advisable that researchers lay out what a phantom is as early as they can in their article.

In the first study I only interviewed people with a complete injury deeming it necessary to ensure that the sensation was indeed a phantom. In the second and third studies applying exclusion criteria was impossible. After the results from the first study and some more reading of the literature I began to notice that if a person felt sensations in areas of their body where they weren’t expecting them or experienced them in an area previously assessed a sensationless this would make the sensations phantom.

Another issue that stands out is summed up in the phrase “psychophysiological dissonance”. The concept that a person can operate with a mental image of what having an SCI means versus what they feel. Their existing schema may have been in place before they sustained the injury or may be created as they interact with their new peers or as a result of their experience in a clinical setting.

Understanding phantom sensations, both painful and non-painful may well improve the rehabilitation protocols we currently use but we need more research to help us classify the somatic sensation people experience below the NLI in an SCI situation and how such sensations differ or are similar to phantom sensations in other conditions.

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APPENDICES

Appendix A: Interview Guide

Qualitative Study to Establish a Grounded Theory on Phantom Sensation in Individuals with a Spinal Cord Injury

(Field notes and interview guide)

- Gather the usual identification and basic medical history material from the chart or verbally and fill in the information in the participant information sheet. Confirm by triangulation. Use the information gathering as an ice breaker.
 - Fill out and verify the patient contact information etc.
 - Location of interview: _____
 - Date of interview: _____
 - Time of interview: _____ AM/PM
-

Establish type of Trauma.

- Ask the participant about the nature of the accident that resulted in the SCI
- Brief story of the accident as told by the patient

Establish the presence and nature of phantom sensation now or in the past

- Is the patient currently experiencing any sensations in part of his or her body that has been shown using standard protocols to have a complete sensory deficit to external stimuli?
 - Are these sensations painful or non-painful?
-

Description of the sensations

Complex sensations:

Volume

- Can you feel substance anywhere in the area below the LOL?

Length

- If you feel a limb do you perceive its length?

Posture/position

- Is the area of the body in which you feel the sensations in a particular posture or position?

Movement

- Does the movement happen without thinking about it (spontaneous)
- Can you make it happen deliberately?
- If the movement is without premeditation have you ever noticed any triggers?
- If you try to move the body part does the sensation change in any way

OR

Simple sensations:

Pressure?

- Can you feel any pressure without an apparent external source anywhere below the LOL?

Temperature?

- Can you feel any temperature without an apparent external source anywhere below the LOL?

Touch?

- Have you ever noticed a situation where you have touched or had touched one area of your body and felt it somewhere else?

Use the diagram.

Temporal nature

- When did you first notice the sensations?
- Did you ever experience any of these sensations before the injury
- Are the sensations continuous?
- Is there any pattern to their appearance or disappearance?
- Have the sensations changed over time?

Establish how these sensations affect the participant's life

- Do the sensations described affect ADL's in any way?
- Have they or do they affect rehabilitation in any way?

Establish any emotional reaction to the sensations

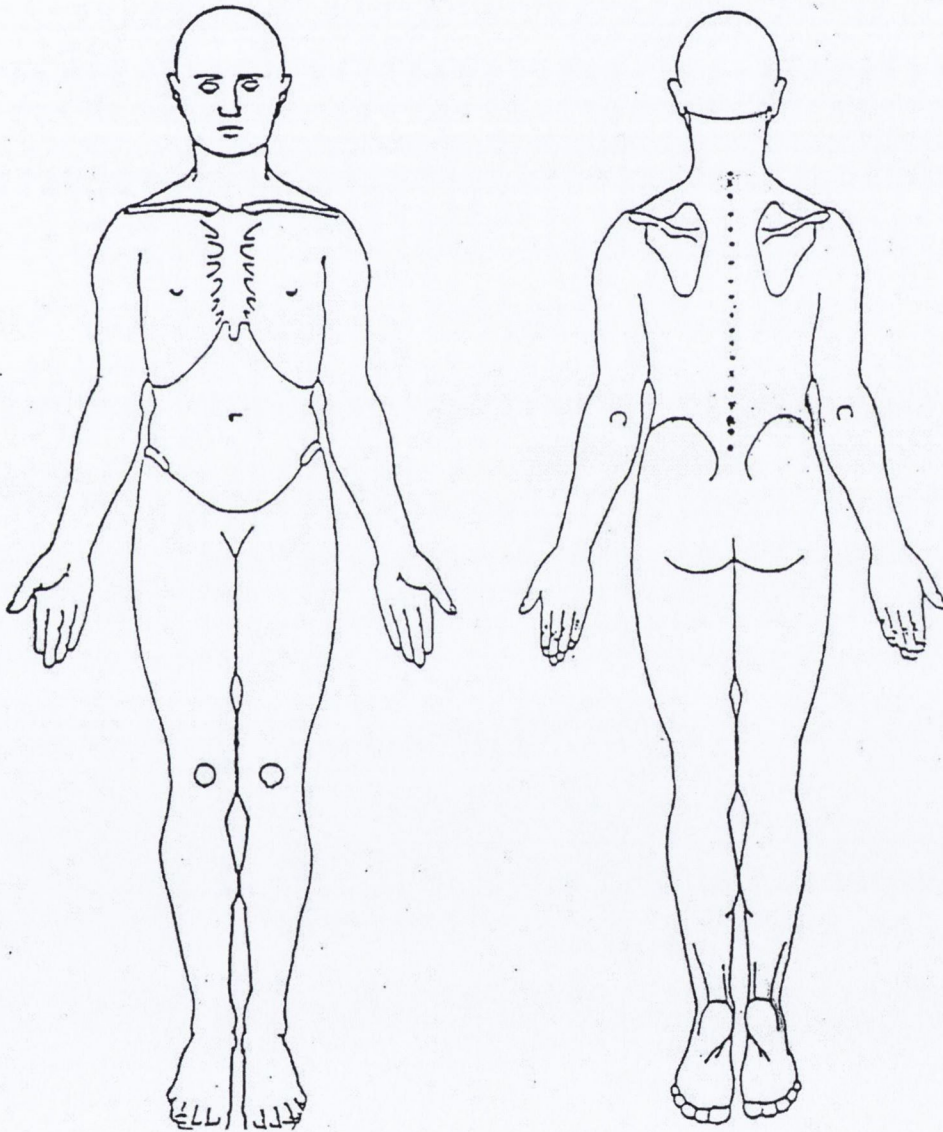
- How do you feel about the sensations?
- What do they mean to you?
- Have you ever told anyone about the sensations?
- Have they influenced your ability to accept the information you were getting from medical staff?

Appendix B: Graphic Aid

PAIN DRAWING GRID ASSESSMENT

Draw the location of your pain on the body outlines using the appropriate symbols.

| ACHE | BURNING | PINS & NEEDLES | NUMBING | STABBING | OTHER |
|------|------------|----------------|------------|------------|------------|
| //// | BBB | ---- | XXX | ZZZ | 000 |
| //// | BBB | ---- | XXX | ZZZ | 000 |



Appendix C: Ethics Documentation for Qualitative Study
 SCVMC Research and Human Subjects Review Committee approval and continuance.

*Dedicated to the Health
 of the Whole Community*



*Research and Human Subjects Review Committee
 Office Annex Building, Room 127
 751 South Bascom Avenue
 San Jose, California 95128
 Tel: 408/885-4013 Fax: 408/885-4306
 e-mail: carol.guthrie@hhs.co.santa-clara.ca.us*

May 16, 2005

Kazuko Shem, MD
 Associate Chief, Department of PM&R
 Santa Clara Valley Medical Center
 751 South Bascom Avenue
 San Jose, CA 95128

RE: Project entitled "Qualitative Study to Establish a Grounded Theory on Phantom Sensation in Individuals with a Spinal Cord Injury"
 IRB Study Reference #5/13/05-09

Dear Dr. Shem:

During a convened meeting on May 13, 2005, the following action was taken by the Research and Human Subjects Review Committee of Santa Clara Valley Medical Center, a duly constituted Institutional Review Board [IRB] that operates in compliance with the Common Rule under a Federalwide Assurance #00001437, regarding the above-referenced project.

- Approved on a renewal basis for a period of one year with the proviso that you respond to the following and agree to comply with the conditions for approval set forth below.
- Approved having you serve as the Principal Investigator of this study at this site.

Status Report

It is unclear from the numbers reported whether any patients remain on study, as the numbers do not calculate correctly. Please clarify.

Informed Consent Form

Update the consent form by placing the following at the bottom of each page. A copy of the new version must be submitted for the Committee's study file. Please know that the new version supersedes all previous versions and must be used, henceforth, when enrolling new patients on study.

Study Approved: 5/13/05
 Study Approval Expires: 5/12/06
 IRB Study Reference #5/13/05-09

HIPAA Privacy Document

Please forward, electronically, the hipaa consent form to the following web site
carol.guthrie@hhs.co.santa-clara.ca.us .

IRB Study Reference Number: The new number assigned to this project is **5/13/05-09**. It is important that you reference this number when corresponding with the Committee regarding this project.

Kazuko Shem, MD
Page 2
May 16, 2005

CONDITIONS FOR APPROVAL

Educational Training: In accordance with this Institution's Federalwide Assurance through the Office for Human Research Protections (OHRP), National Institutes of Health, the Research Committee requires that any person, who proposes to involve patients as subjects in research, be required to complete an educational program on research ethics and become certified prior to conducting the research.

This applies to principal investigators, co-principal investigators, co-investigators, sub-investigators, study personnel involved in the consent process, and any person involved in analyzing study data who will have contact with participants and/or access to confidential and identifying information.

If any of your study personnel have not completed the Educational Training Program, you are requested to comply with this requirement at this time. The following web site may be accessed to complete the Program. When completed, a certificate must be provided for the Committee's file.

<http://cme.cancer.gov/clinicaltrials/learning/humanparticipant-protections.asp> (this program offers CME credits to those who qualify).

Expiration Date: This project's approval will expire 5/12/06. If the project is to continue beyond the expiration date, it must be renewed in accordance with the Committee's renewal instructions. As a courtesy reminder, a renewal application will be mailed to you one to two months prior to the expiration date. If the project is terminated or completed prior to the expiration date, the Committee must be notified in writing and provided with a final report.

Changes/Amendments to Project: Approval is required prior to implementing any change(s) in the research except where a change is necessary to eliminate an immediate hazard to study subjects in which case the Committee must be promptly informed of the change following implementation and a protocol amendment submitted for approval. To avoid any delay in having a request for changes considered by the Committee, it is strongly recommended that you contact the IRB Office to inquire of the Committee's instructions for submitting changes.

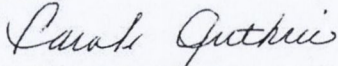
Reporting of Problems/Adverse Events: Promptly report any study-related problem(s) or adverse event(s) having to do with subject safety whether physical, psychological, or social and whether or not thought to be study related. Any death must be reported immediately upon your knowledge of such event.

Deviation from Protocol: Promptly report any significant or relevant deviation that is made from the approved version of the study protocol.

Data Retention: All study-related documents must be retained for a period of three years following completion of the research. Your funding agency, department, or other entities may impose additional requirements of which you should be aware.

Questions: Should you have any questions or require clarification of the above, please contact the IRB Office at 408/885-4013.

Sincerely,



Elisabeth A. Mailhot, MD, Chair
Research and Human Subjects Review Committee

EAM/cg

cc: Committee Members

National Institute of Health required certification for IRB clearance in CA



Human Participant Protections Education for Research Teams

Completion Certificate

This is to certify that

Daren Drysdale

has completed the **Human Participants Protection Education for Research Teams** online course, sponsored by the National Institutes of Health (NIH), on 10/02/2003.

This course included the following:

- key historical events and current issues that impact guidelines and legislation on human participant protection in research.
 - ethical principles and guidelines that should assist in resolving the ethical issues inherent in the conduct of research with human participants.
 - the use of key ethical principles and federal regulations to protect human participants at various stages in the research process.
 - a description of guidelines for the protection of special populations in research.
 - a definition of informed consent and components necessary for a valid consent.
 - a description of the role of the IRB in the research process.
 - the roles, responsibilities, and interactions of federal agencies, institutions, and researchers in conducting research with human participants.
-

National Institutes of Health
<http://www.nih.gov>

Application for approval of qualitative study to SPREC

| |
|--|
| Office use only Application number: Date of receipt: |
|--|

**Department of Psychology
Ethics Committee**

Application for approval

| | |
|-----------------------------------|--|
| Name of applicant | Daren Drysdale |
| Date: | May 7 th 2004 |
| Contact details (e.g e-mail) | darendrysdale@ireland.com, ddrysdale@mindspring.com, or drysdald@tcd.ie |
| Status (Staff, post-grad. etc) | Post grad |
| Title of project | Qualitative study to establish a grounded theory of phantom pain in the spinal cord injury population |
| Supervisor (if appropriate) | Prof. Malcolm McLachlan |
| Date of proposed start | June 1 st 2004 |

(Please note: You may exceed the space provided if necessary)

- | | |
|---|---|
| 1. What is the research question to be addressed? (max 30 words) | How do individuals with a spinal cord injury experience phantom sensation from a bio-psycho-social perspective? |
| 2. What is your proposed method of data collection? | Please attach copies of all non-standard questionnaires/ interview schedules. (We do not require copies of standard/ published questionnaires) <i>Tick here to confirm attachment</i> <input checked="" type="checkbox"/> |
| 3. Participant group | 1. Students only <input type="checkbox"/> 2. Other non-clinical groups (e.g. subject panel) <input type="checkbox"/> 3. Clinical groups*, i.e. any person who is receiving care/treatment presently or in the past. (No consent will be given without approval from the relevant Medical Ethical Authority) <input checked="" type="checkbox"/> |
| How many participants are required? | 10 to 16 max. *if marked please attach the following 1. Letter from clinically responsible person confirming agreement and that numbers of participants proposed will be forthcoming. <input type="checkbox"/> <i>Tick box to confirm attachment</i> Copy of application to relevant hospital ethics committee <input checked="" type="checkbox"/> <i>Tick box to confirm attachment</i> |
| 4. What design/ methodology will you use? How will reliability and | Methodology in detail can be found in the protocol document attached and concurrently under review by Institutional Review Board for Santa Clara County. |

- validity be assessed? It is a qualitative study based on a single interview. The techniques outlined by Strauss and Corbin will be used to code the interviews. Mathematical/Statistical measures of validity will not be applied.
- 5. Where will participants be tested / interviewed? At Santa Clara Valley Medical Center inpatient facility or outpatient clinic. Otherwise at a place of the SCI individual's choosing.
- 6. How long (per participant) will the testing/ interviewing take? Approx. 60 to 70 minutes.
- 7. Will participants be paid? What is the rate of payment? Participants will not be paid
- 8. With reference to the Freedom of Information Act what measures will you take for data storage? Ireland's FOI protocols are also incorporated in the U.S.' HIPAA regulations. Two Informed consent documents are required to be signed and verified by the principal investigators. Both documents are attached.

The following information is required

- 1. Consent form Tick box to confirm attachment
- 2. Information/ debriefing sheet for participants (this should be no more than 150 words, in very accessible language)
Tick box to confirm attachment
- 4. What is your debriefing procedure? After all the interviews have been conducted, a report of the findings will be sent to each participant.

11. Declaration of applicant
I confirm that I have read and will abide by the Department of Psychology Ethical Guidelines and the Psychological Society of Ireland guidelines on Ethical Research.

Signature of applicant

Daren Drysdale.

12. Declaration of supervisor
I have read through and approved the contents of this application to the Ethics Committee.

Signature of supervisor

.....

School of Psychology
Ethics Committee

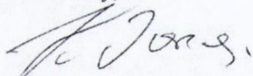
02/04/2006

Dear *Daren Daysdale*.

The School of Psychology Ethics Committee met recently to consider your application entitled
Psychophysiological dissonance and phantom sensation
in individuals with SCI

I am pleased to inform you that the Committee has approved your application.

Yours sincerely,



Kevin Tierney (Ph.D.)
Chairperson,
School of Psychology Ethics Committee

Appendix D: Ethics Documentation for Quantitative Study



COLÁISTE NA TRÍÓNÓIDE, BAILE ÁTHA CLIATH
Ollscoil Átha Cliath

TRINITY COLLEGE DUBLIN
The University of Dublin

F.A.O. Daren Drysdale

School of Psychology Research Ethics Committee

7th October 2009

Dear Daren,

Following receipt of amendments to your original application as prescribed by the Committee I am pleased to inform you that your application entitled "Psychosocial experiences and sensations in people with a spinal cord injury" has been approved by the School of Psychology Research Ethics Committee.

Yours sincerely,

Dr. Tim Trimble
Chair
School of Psychology Research Ethics Committee

SCHOOL OF PSYCHOLOGY
Aras an Phairsaigh
Trinity College
Dublin 2

Scoil na Siceolaíochta,
Dámh na nEolaíochtaí Sóisialta agus Daonna,
Áras an Phairsaigh, Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

School of Psychology,
Faculty of Arts, Humanities and Social Sciences,
Áras an Phairsaigh, Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1886
F 353 (0)1 671 2006
psychology@tcd.ie
www.psychology.tcd.ie

Patient Name _____

Examiner Name _____ Date/Time of Exam _____



INTERNATIONAL STANDARDS FOR NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY ISCOS

MOTOR
KEY MUSCLES
(scoring on reverse side)

| | | | |
|----|--------------------------|--------------------------|--|
| | R | L | |
| C5 | <input type="checkbox"/> | <input type="checkbox"/> | Elbow flexors |
| C6 | <input type="checkbox"/> | <input type="checkbox"/> | Wrist extensors |
| C7 | <input type="checkbox"/> | <input type="checkbox"/> | Elbow extensors |
| C8 | <input type="checkbox"/> | <input type="checkbox"/> | Finger flexors (distal phalanx of middle finger) |
| T1 | <input type="checkbox"/> | <input type="checkbox"/> | Finger abductors (little finger) |

UPPER LIMB TOTAL + =
(MAXIMUM) (25) (25) (50)

Comments:

| | | | |
|----|--------------------------|--------------------------|-----------------------|
| L2 | <input type="checkbox"/> | <input type="checkbox"/> | Hip flexors |
| L3 | <input type="checkbox"/> | <input type="checkbox"/> | Knee extensors |
| L4 | <input type="checkbox"/> | <input type="checkbox"/> | Ankle dorsiflexors |
| L5 | <input type="checkbox"/> | <input type="checkbox"/> | Long toe extensors |
| S1 | <input type="checkbox"/> | <input type="checkbox"/> | Ankle plantar flexors |

(VAC) Voluntary anal contraction (Yes/No)

LOWER LIMB TOTAL + =
(MAXIMUM) (25) (25) (50)

| | LIGHT TOUCH | | PIN PRICK | |
|------|-------------|---|-----------|---|
| | R | L | R | L |
| C2 | | | | |
| C3 | | | | |
| C4 | | | | |
| C5 | | | | |
| C6 | | | | |
| C7 | | | | |
| C8 | | | | |
| T1 | | | | |
| T2 | | | | |
| T3 | | | | |
| T4 | | | | |
| T5 | | | | |
| T6 | | | | |
| T7 | | | | |
| T8 | | | | |
| T9 | | | | |
| T10 | | | | |
| T11 | | | | |
| T12 | | | | |
| L1 | | | | |
| L2 | | | | |
| L3 | | | | |
| L4 | | | | |
| L5 | | | | |
| S1 | | | | |
| S2 | | | | |
| S3 | | | | |
| S4-5 | | | | |

TOTALS + =
(MAXIMUM) (56) (56) (56) (56)

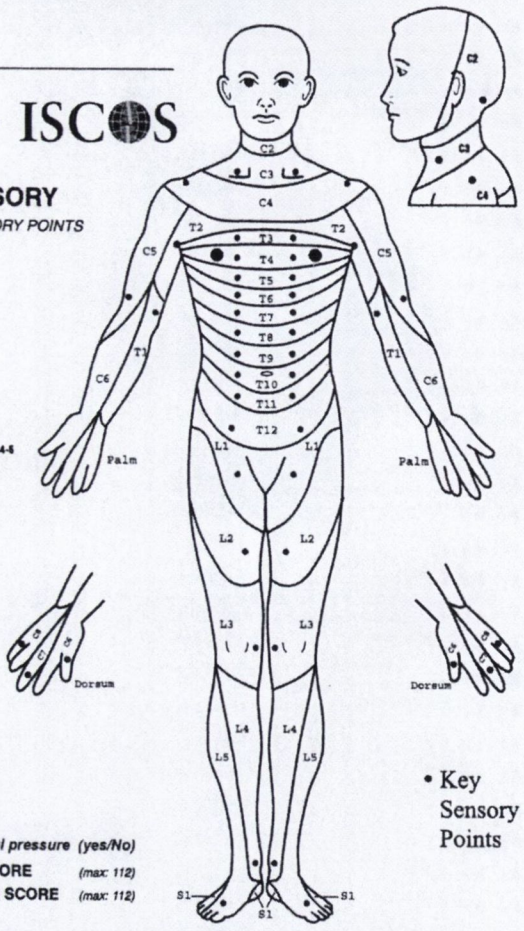
SENSORY
KEY SENSORY POINTS

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

(DAP) Deep anal pressure (yes/No)

PIN PRICK SCORE (max: 112)

LIGHT TOUCH SCORE (max: 112)



• Key Sensory Points

| | | | | | | | | | | |
|---|---------|----------------------------|----------------------------|---|--|---|--|---------|----------------------------|----------------------------|
| NEUROLOGICAL LEVEL The most caudal segment with normal function | SENSORY | R <input type="checkbox"/> | L <input type="checkbox"/> | SINGLE NEUROLOGICAL LEVEL <input type="checkbox"/> | COMPLETE OR INCOMPLETE? <input type="checkbox"/> Incomplete = Any sensory or motor function in S4-S5 | ASIA IMPAIRMENT SCALE (AIS) <input type="checkbox"/> | (In complete injuries only) ZONE OF PARTIAL PRESERVATION Most caudal level with any innervation | SENSORY | R <input type="checkbox"/> | L <input type="checkbox"/> |
| | MOTOR | R <input type="checkbox"/> | L <input type="checkbox"/> | | | | | MOTOR | R <input type="checkbox"/> | L <input type="checkbox"/> |

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

REV 04/11

Appendix E: ASIA Classification Diagrams

Muscle Function Grading

- 0** = total paralysis
- 1** = palpable or visible contraction
- 2** = active movement, full range of motion (ROM) with gravity eliminated
- 3** = active movement, full ROM against gravity
- 4** = active movement, full ROM against gravity and moderate resistance in a muscle specific position.
- 5** = (normal) active movement, full ROM against gravity and full resistance in a muscle specific position expected from an otherwise unimpaired person.
- 5*** = (normal) active movement, full ROM against gravity and sufficient resistance to be considered normal if identified inhibiting factors (i.e. pain, disuse) were not present.
- NT** = not testable (i.e. due to immobilization, severe pain such that the patient cannot be graded, amputation of limb, or contracture of >50% of the range of motion).

ASIA Impairment (AIS) Scale

- A = Complete.** No sensory or motor function is preserved in the sacral segments S4-S5.
- B = Sensory Incomplete.** Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5 (light touch, pin prick at S4-S5; or deep anal pressure (DAP)), AND no motor function is preserved more than three levels below the motor level on either side of the body.
- C = Motor Incomplete.** Motor function is preserved below the neurological level**, and more than half of key muscle functions below the single neurological level of injury (NLI) have a muscle grade less than 3 (Grades 0-2).
- D = Motor Incomplete.** Motor function is preserved below the neurological level**, and at least half (half or more) of key muscle functions below the NLI have a muscle grade ≥ 3 .
- E = Normal.** If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

**For an individual to receive a grade of C or D, i.e. motor incomplete status, they must have either (1) voluntary anal sphincter contraction or (2) sacral sensory sparing with sparing of motor function more than three levels below the motor level for that side of the body. The Standards at this time allows even non-key muscle function more than 3 levels below the motor level to be used in determining motor incomplete status (AIS B versus C).

NOTE: When assessing the extent of motor sparing below the level for distinguishing between AIS B and C, the **motor level** on each side is used; whereas to differentiate between AIS C and D (based on proportion of key muscle functions with strength grade 3 or greater) the **single neurological level** is used.

Steps in Classification

The following order is recommended in determining the classification of individuals with SCI.

1. Determine sensory levels for right and left sides.
2. Determine motor levels for right and left sides.
Note: in regions where there is no myotome to test, the motor level is presumed to be the same as the sensory level, if testable motor function above that level is also normal.
3. Determine the single neurological level.
This is the lowest segment where motor and sensory function is normal on both sides, and is the most cephalad of the sensory and motor levels determined in steps 1 and 2.
4. Determine whether the injury is Complete or Incomplete. (i.e. absence or presence of sacral sparing)
If voluntary anal contraction = No AND all S4-5 sensory scores = 0 AND deep anal pressure = No, then injury is COMPLETE. Otherwise, injury is incomplete.
5. Determine ASIA Impairment Scale (AIS) Grade:

Is injury Complete? If YES, AIS=A and can record ZPP (lowest dermatome or myotome on each side with some preservation)

NO ↓

Is injury motor Incomplete? If NO, AIS=B (Yes=voluntary anal contraction OR motor function more than three levels below the motor level on a given side, if the patient has sensory incomplete classification)

YES ↓

Are at least half of the key muscles below the single **neurological level** graded 3 or better?

NO ↓

AIS=C

YES ↓

AIS=D

If sensation and motor function is normal in all segments, AIS=E
Note: AIS E is used in follow-up testing when an individual with a documented SCI has recovered normal function. If at initial testing no deficits are found, the individual is neurologically intact; the ASIA Impairment Scale does not apply.

Appendix F: Informed Consent Documentation (Qualitative Study)

SANTA CLARA VALLEY MEDICAL CENTER Consent to Participate in a Research Study

TITLE: Qualitative Study to Establish a Grounded Theory on Phantom Sensation in Individuals with a Spinal Cord Injury.

INVITATION TO PARTICIPATE: You are being invited to participate in this study. The following information is provided to help you make an informed decision about whether or not to participate. If you have any questions, please do not hesitate to ask.

BASIS FOR SUBJECT SELECTION: You are being invited to participate because you have experienced a traumatic spinal cord injury. In addition, you meet the following characteristics: you have reported feelings or sensations in areas of your body that, due to your spinal cord injury, should not have any feelings or sensations; you have a high school education, and you have the ability to converse easily in English.

PURPOSE OF THE STUDY: The purpose of the study is to help us define common theories about your experience of phantom sensations. Grounded theory methods will allow us to find common ideas or patterns of thought and physiological similarities between you and other participants who report the same type of sensations.

EXPLANATION OF THE STUDY PROCEDURES: After you have been contacted by a research associate and have had the study explained to you, you will be asked to read and sign this consent form if you decide to participate. Once this form is signed, an interview will be scheduled at a time and place convenient to you. The interview will take about 1 hour of your time, but definitely no more than 70 minutes. At the beginning of the interview we will review the documentation you have signed and make sure any questions you may still have are answered. The interview itself will be recorded for note taking purposes and may later be transcribed. There are no predetermined questions that will be asked, rather the discussion will center on your experience of sensations in areas of your body that have been tested as completely lacking sensation. Types of questions that may be asked are:

- What do these sensations feel like?
- Do they come and go?
- How do they affect you?

POTENTIAL RISKS/DISCOMFORTS: There are no known risks associated with this study. Discomfort may be experienced only to the extent that some of the questions may be of a more personal nature and that the longer interview may require about 70 minutes of your time.

POTENTIAL BENEFITS TO SUBJECTS: WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY. However, possible benefits might be the opportunity to talk about a little discussed area of spinal cord injury and your experiences before and since. You may also be helping other individuals with spinal cord injury in the future.

ALTERNATIVES TO PARTICIPATION: The alternative to participating in this study is to not participate.

CONFIDENTIALITY: Every effort will be made to maintain your confidentiality during this study. Your medical records, your study file, and the consent form signed by you, will be reviewed by the study investigators. These documents may also be reviewed by the Research and Human Subjects Review Committee of Santa Clara Valley Medical Center, and for purposes of financial auditing and billing. Because of the need to release information to these parties, absolute confidentiality cannot be guaranteed. The information obtained in this study may be published in scientific journals or presented at scientific meetings, but your identity will not be revealed.

FINANCIAL OBLIGATIONS: Participation in the study is on a voluntary basis and does not involve any cost to you.

COMPENSATION IN CASE OF INJURY: We do not expect any injury to occur; however, if you feel you have been injured as a result of your participation in this study, you should know that it is the policy of the Research and Human Subjects Review Committee and Santa Clara Valley Medical Center not to provide for medical care or any form of compensation for any injury you experience as a result of your participation in this study. If you feel you have been injured as a result of your participation in this study, please contact Dr. Agnes Wallbom or Dr. Kazuko Shem at 408/885-2000. Know that this disclaimer does not affect any legal rights or redress you might have to compensation or medical treatment. By signing this consent form you have not waived any of your legal rights.

VOLUNTARY PARTICIPATION AND WITHDRAWAL: You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the study investigator(s) or Santa Clara Valley Medical Center. Your decision will not result in any loss of benefits to which you are otherwise entitled.

OFFER TO ANSWER QUESTIONS: If you have any questions, please do not hesitate to ask and they will be answered at this time. If you think of any additional questions later, please feel free to contact one of the study investigators listed at the end of this consent form.

The Research and Human Subjects Review Committee of Santa Clara Valley Medical Center has reviewed this study and will review any concerns you may have regarding your participation in the study including your rights as a research subject. The Committee is not associated with the sponsor nor the investigators and has no authority to provide for any form of compensation or reimbursement to you.

The Committee may be reached by calling the office from 9:00 a.m. to 5:00 p.m., Monday through Friday, at 408/885-4013, or by writing to the Research Committee, Santa Clara Valley Medical Center, Office Annex Building, Room 127, 751 South Bascom Avenue, San Jose, California 95128.

DOCUMENTATION OF INFORMED CONSENT: You are voluntarily making a decision whether or not to participate in this research study. Your signature certifies that you have decided to participate having read and understood the information presented. Your signature also certifies that you have had an adequate opportunity to discuss this study with the investigator and you have had all your questions answered to your satisfaction. You will be given a copy of the signed and dated consent form to keep. Thank you for your interest in this study.

Signature of Subject

Date Signed

Subject's Name (Typed or Printed)

My signature as witness certifies that the subject signed this consent form in my presence as his/her voluntary act and deed.

Signature of Witness

Date Signed

In my judgment the subject is voluntarily and knowingly giving informed consent and possesses the legal capacity to give informed consent to participate in this research study.

Signature of Investigator/Designee

Date Signed

IDENTIFICATION OF INVESTIGATORS

Principal Investigator: Kazuko Shem, M.D.
Associate Chief, Department of PM&R
Santa Clara Valley Medical Center
751 South Bascom Avenue
San Jose, CA 95128
408/885 2000

Co- Investigator: Daren Drysdale, BCIAC, Fellow
16615 Lark Avenue, ste 203
Los Gatos, CA 95032
408/821 7420

Appendix G: HIPAA Informed Consent Documentation

Santa Clara Valley Medical Center
Research Subject Authorization
Confidentiality & Privacy Rights

Protocol Title: Qualitative Study to Establish a Grounded Theory on
Phantom Sensation in Individuals with a Spinal Cord Injury

Principal Investigator: Kazuko Shem, M.D.
Associate Chief, Department of PM&R
Santa Clara Valley Medical Center
751 South Bascom Avenue
San Jose, CA 95128
(408) 885 2000

Co- Investigator: Daren Drysdale, BCIAC, Fellow
16615 Lark Avenue, ste 203
Los Gatos, CA 95032
(408) 821 7420

You have agreed to participate in the study mentioned above and have signed a separate informed consent that explained the procedures of the study and the confidentiality of your personal health information. This authorization form gives more detailed information about how your health information will be protected and includes:

- What personal health information about you will be collected in this study
- Who will use your information within the institution and why
- Who may disclose your information and to whom
- Your rights to access research information about you
- Your right to withdraw your authorization (approval) for any future use of your personal health information

By signing this document you are permitting the Santa Clara Valley Medical Center to use your personal health information collected about you for research purposes within our institution. You are also allowing the Santa Clara Valley Medical Center to disclose that personal health information to outside organizations or people involved with the processing of this study.

What personal health information is collected and used in this study, and might also be shared (disclosed)?

The following personal health information will be collected, used for research and may be disclosed or released during your involvement with this research study:

- Name;
- Street address, city, county, zip code;
- Telephone numbers, fax numbers, and electronic mail addresses;
- Medical record number;
- Family medical history;
- Allergies;
- Current and past medications or therapies;
- Information from interviews with you that may be significant to understanding your experience of phantom sensations.

Why is your personal health information being used?

Your personal contact information is important for the Santa Clara Valley Medical Center research team to contact you during the study. Your health information and results of tests and procedures are being collected as part of this research study and for the advancement of medicine and clinical care. The Principal Investigators may also use the results of these tests and procedures to treat you.

Which of our personnel may use or disclose your personal health information?

The following individuals and organizations may use or disclose your personal health information for this research project:

- The Principal Investigators and the Co-Investigator's study team (other Santa Clara Valley Medical Center staff associated with the study)
- The Human Subjects and Research Review Committee of Santa Clara Valley Medical Center which is the Institutional Review Board of the Santa Clara Valley Medical Center (the committee charged with overseeing research on human subjects)
- Authorized members of the Santa Clara Valley Medical Center workforce who may need to access your information in the performance of their duties (for example: to provide treatment, to ensure integrity of the research, accounting or billing matters, etc.).

Who, outside of the Santa Clara Valley Medical Center, might receive your personal health information?

As part of the study the Principal Investigators, study team and others listed above, may disclose your personal health information, including the results of the research study tests and procedures to the following:

- Other collaborating academic research centers(s): Trinity College Dublin, Psychoprosthetics Group who are specialists in this phenomenon in other populations.

The Principal Investigators or study staff will inform you if there are any changes to the list above during your active participation in the trial. Once information is disclosed to others outside the Santa Clara Valley Medical Center the information may no longer be covered by the federal privacy protection regulations.

In all disclosures outside of the Santa Clara Valley Medical Center, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier unless disclosure of the direct identifier is required by law.

In records and information disclosed outside of Santa Clara Valley Medical Center, you will be assigned a unique code number. The Principal Investigator will ensure that the key to the code will be kept in a locked file. The key to the code will be destroyed at the end of the research study.

How long will the Santa Clara Valley Medical Center be able to use or disclose your personal health information?

Your authorization for use of your personal health information for this specific study expires on December 31st, 2010. This information may be maintained in a research repository (database) or in hardcopy. However, the Santa Clara Valley Medical Center may not re-use or re-disclose your personal health information collected in this study for another purpose other than the research described in this document unless you have given written permission for the Principal Investigator to do so. However, the Institutional Review Board at Santa Clara Valley Medical Center may grant permission to the Principal Investigators or others to use your information for another purpose after ensuring that appropriate privacy safeguards are in place. The Institutional Review Board is a committee whose job it is to protect the safety and privacy of research subjects. Results of all tests and procedures done solely for this research study and not as part of your regular care will not be included in your medical record.

Will you be able to access your records?

You will be able to access your medical records at any time during the study.

Can you change your mind?

You may withdraw your permission for the use and disclosure of any of your personal information for research, **but you must do so in writing** to the Principal Investigator at the address on the first page. Even if you withdraw your permission, the Principal Investigator for the research study may still use your personal information that was collected prior to your written request if that information is necessary to the study. If you withdraw your permission to use your personal health information that means you will also be withdrawn from the research study.

You will be given a copy of this Research Subject Authorization Form describing your confidentiality and privacy rights for this study. You will also be given the Santa Clara Valley Medical Center's Notice of Privacy Practices that contains more information about the privacy of your health information.

By signing this document you are permitting the Santa Clara Valley Medical Center to use and disclose personal health information collected about you for research purposes as described above.

Subject's Name **[print]**

Subject's Signature

Person obtaining authorization **[print]**

Person obtaining authorization Signature

Appendix H: Additional Study Chart Documents**Potential Participant Checklist**

ID Number: _____

Is the potential participant ASIA A? Yes

Is the potential participant over 18 years of age Yes

Has the potential participant completed high school Yes

Hx. of delusions or hallucinations None

English verbal/comprehension skills are good Yes

None of the medications the potential participant is taking
are hallucinogenic in nature None

Informed consent given Yes

Participant History/Details

Participant ID Number: _____

Sex (Circle): Male Female

Age at time of study: _____

Date of Birth (day, month, year): _____, _____, _____

What level is the lesion at: _____

Date of injury (day, month, year): _____, _____, _____

Date of interview (day, month, year): _____, _____, _____

Length of time since the injury: (years, months, days): _____, _____, _____

Medications currently taking:

Medications Hx:

Current Therapies:

Past Therapies:

Allergies:

Family Medical Hx:

Current Medical Treatments and Practitioners:

Chart release for study ref #05/13/05-09

Qualitative study to establish a grounded theory on phantom sensation in individuals with a spinal cord injury

This document allows investigators associated with this study to access my medical records related to my injury. We will also call to get verbal permission prior to accessing any information.

Signature

Date

Appendix I: Online Appeal

Page 1

Phantom Sensation Online Survey (Links to the second page with more detail)

Psychosocial experiences and sensations in people with SCI

Sensations (painful or otherwise) below the level of injury in people with a spinal cord injury are puzzling. We want to know more. We have already asked and published what people with an SCI feel about the sensations they experience. If you are interested in helping just click [this link](#) (links to the survey URL:

<http://www.surveymonkey.com/s/NFJ3ZSJ>) and it will bring you straight to the questionnaire and help us find out more.

Page 2

When you complete the survey you can leave your contact information and I will enter you into the draw for €200. If you are not comfortable with leaving any identifying information and not participating; that's fine. You can withdraw from the survey at any time without giving any reason for doing so.

I am a clinical psychophysiologicalist and a mature PhD student based in Trinity College Dublin. As part of a [research group](#) (Links to the Dublin Psychoprosthetics Group URL: <http://www.tcd.ie/Psychoprosthetics/index.html>) I've been looking at phantom sensations in many groups of people. We're interested in looking at this phenomenon in people with a spinal cord injury.

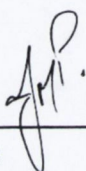
The survey helps break the previous day down into chunks or sections and helps you remember very accurately. Then we ask you questions about those chunks of memory. If you have noticed painful or non-painful sensations below your neurological level of injury, give it a try. We are looking at daily patterns and if there are any connections between the sensations and activities of daily living. If you are interested all you need to do is [click here](#) (links to the survey URL: <http://www.surveymonkey.com/s/NFJ3ZSJ>). If you have any questions please give me call or email me:

Daren Drysdale
Aras an Phiarsaigh
School of Psychology
Trinity College Dublin
Dublin 2
Ireland

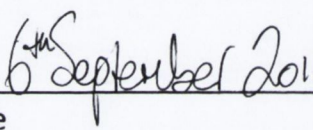
drysdald@tcd.ie
+353 (0) 86 872 7668

Appendix J: Mark Pollock Release

In addition to the conditions outlined in the study above do you give permission to the principal and co-investigators to access and analyse the material publically available at www.markpollock.com, You tube etc



Signature



Date