



Phantom sensations in people with complete spinal cord lesions: A grounded theory perspective

Daren G. Drysdale, Kazuko Shem, Agnes Walbom, Maureen D. Miner & Prof. Malcolm MacLachlan

To cite this article: Daren G. Drysdale, Kazuko Shem, Agnes Walbom, Maureen D. Miner & Prof. Malcolm MacLachlan (2009) Phantom sensations in people with complete spinal cord lesions: A grounded theory perspective, *Disability and Rehabilitation*, 31:4, 267-276, DOI: [10.1080/09638280801923607](https://doi.org/10.1080/09638280801923607)

To link to this article: <https://doi.org/10.1080/09638280801923607>



Published online: 07 Jul 2009.



Submit your article to this journal [↗](#)



Article views: 150



View related articles [↗](#)



Citing articles: 1 View citing articles [↗](#)

RESEARCH PAPER

Phantom sensations in people with complete spinal cord lesions: A grounded theory perspective

DAREN G. DRYSDALE¹, KAZUKO SHEM², AGNES WALBOM², MAUREEN D. MINER³ & MALCOLM MACLACHLAN¹

¹Dublin Psychoprosthetics Group, School of Psychology, Trinity College Dublin, Ireland, ²Santa Clara Valley Medical Center, California, and ³South County Pain and Rehab, Gilroy, California, USA

Accepted January 2008

Abstract

Purpose. Phantom sensations are somatic phenomena arising from denervated parts of the body. There is very little research, and much diagnostic confusion, regarding such experiences in people with spinal cord injuries. In the case of ‘complete’ spinal cord lesions, phantom experiences may challenge, and indeed, contradict, the understanding that both clinicians and patients have of such injuries. This paper seeks to provide a better understanding of such ‘phantom’ sensations in spinal cord injury.

Method. We used grounded theory methods to explore ‘phantom’ sensations as experienced by individuals with complete (ASIA A) spinal lesions. Eight people with complete lesions, who were selected through theoretical sampling, participated in a semi-structured interview.

Results. Emergent themes included injury context, sensations experienced, the meaning of sensations, body connectivity, attitude and communication about sensations.

Conclusions. Our results provide an enhanced understanding of the embodied experience of phantom sensations, and important insights regarding self-construction and rehabilitative processes in people with spinal cord injury who experience such anomalous sensations.

Keywords: *Spinal cord injuries, phantom sensations*

Introduction

Phantom sensations are sensations apparently arising from regions that have been completely denervated [1] and although phantom sensations are mostly documented in individuals with amputations, they have also been recognized in other groups. For instance burn victims frequently report pain in the area of the injury years after it has healed [2], individuals who experience brachial plexus avulsions often report phantoms in their arms [3], people who have a tooth removed can sometimes still feel the tooth in place and pain emanating from it [4]; various internal organs have been noted to generate phantom pain after removal [5] and there are reports of post-mastectomy phantom breast pain [6]. This paper seeks to better understand the experience of people with a spinal cord injury (SCI) who have also

reported sensations below the neurological level of injury (NLI), sensations that may consequently be classified as phantom sensations [1,7,8].

The physical mechanisms that give rise to phantom pain or other phantom sensations in people with amputations remain conjecture [9–11] as do phantom experiences following SCI [1]. Theories attracting contemporary interest include suggestions that neuroplasticity, peripheral nerve damage, and ‘pain memories,’ play a role [12]. Price [13] attempts to harmonize apparently conflicting theories regarding the phenomena’s existence in people with amputations by hypothesizing that memories of the limb are laid down *in utero*.

Despite the research into phantom sensation in people with amputations, there is a relative dearth of information regarding phantom pain and sensation in people with SCI. This may be due to the difficulty

in classifying pain below the level of the lesion. In particular the classification of phantom pain in SCI is controversial, not very well explicated and not universally accepted [14,15]. For instance, in some SCI pain classification systems, such as Bockenek and Stewart's [16], it is noted; yet in others, such as Bryce and Ragnarsson's [17], or the International Association for the Study of Pain (IASP) taxonomy, proposed by Siddall et al. [15], it is absent; or at least assumed to be under another category such as pain below the level of the lesion. The use of the different classification systems leads to confusion both clinically and in research. For example, the rates of chronic pain reported in persons with SCI have been reported as high as 94% and levels of pain that interfere with activities of daily living (ADLs) have ranged from 5–45% [17].

Relatively few studies have explored the perception of phantom sensation afforded by considering the patient's own experience of these phenomena and the studies that do exist predominantly look at the experience in people with amputations [18]. Here we seek to better understand phantom sensations in SCI by asking those people with these experiences about them.

The individual continually constructs both internal and external images of the self [19] and perhaps one of the greatest challenges to our self-construction occurs with the wrenching of the 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 invested in that functionality has to be renegotiated amidst a series of physical, social and psychological losses. Therefore, the SCI individual, in contrast to the individual with an amputation [20], has to reconstruct an almost complete image of self, post injury. 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.

Method

We chose a convenience sample from patients attending physicians attached to the study and individuals making use of the SCI peer support network in Northern California, USA. The research was qualitative in nature, in that we interviewed people with spinal cord injuries. The time since injury varied across the participants. Our concern was with understanding the phenomenon as experienced by the individuals themselves.

We used grounded theory methodology as initially proposed by Glasser and Strauss [21] and later modified by researchers such as Strauss and Corbin [22].

Participants

In order to meet inclusion criteria, participants were men or women over 18 years of age who had experienced a spinal cord injury and had been diagnosed with a complete spinal cord lesion. In order to establish this we used the American Spinal Injury Association (ASIA) taxonomy. They have outlined a standard neurological classification scheme for spinal cord injury that helps all members of the SCI community better understand the anatomical and physiological parameters of different lesions in the spinal cord. The impairment scale ranges from 'A' through to 'E', with 'A' being classed as 'complete: no motor or sensory function preserved in the sacral segments' and 'E' classed as 'normal'.

Participants also had to have the ability to understand the interviewer without an interpreter, have completed a second level education and be able to give informed consent. All material used by the study in recruitment data collection and analysis was examined and cleared by the Research and Human Subjects Review Committee in Santa Clara Valley Medical Center and by the Trinity College Dublin, School of Psychology Ethics Committee.

All patients meeting ASIA 'A' criteria and attending the physicians attached to the study were asked if they perceived sensation below the NLI. If so and they expressed interest in volunteering, they were further evaluated for the study. Other participants attended peer support groups in the South Bay area just outside San Francisco, California.

Participants were excluded if they had a history of a psychiatric disorder that involved hallucinations or delusions. The referring physicians established that none of the medications that the participants were currently taking were hallucinatory in nature.

There were eight interviewees, five of whom were male, three female who met the criteria within the study. 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 34–60. The time since injury ranged from three to 31 years averaging 16.75 years. Their age at the date of injury (DOI) ranged from 17–40 years old averaging 28 (as summarized in Table I).

All interviews were recorded with a SONY M-200MC micro cassette recorder in meeting mode. The recorded portion of the interviews ranged from 30 min to 1 h. There was also a standard diagram of the human body used as an aid by the interviewer to ensure that all areas below the NLI were discussed. The interviewer could mark off each area as it was discussed with the participant. The encounters, from

Table I. Summary of participants' 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 time since injury (range)	16.75 (3–31)

the moment of arrival to the moment of departure, lasted approximately 2 h.

Sampling procedure

Patients who met the basic criteria (ASIA 'A') for inclusion were informed of the study by their physicians while they were attending the outpatient clinic for individuals with SCI in Santa Clara Valley Medical Center (SCVMC). In addition, the peer support groups that were in place and previously set up by the hospital's TBI/SCI Grant Project and rehabilitation department were approached by one of the researchers. Anyone who met the basic criteria for the study was given contact information and asked to call if interested. There was also a pamphlet circulated in the outpatient department, the hospital and the peer support groups, explaining the study and asking for volunteers.

Fourteen individuals who met the ASIA 'A' criteria volunteered their time for the study. Over the course of the study this group was narrowed to eight because some of the individuals did not meet all of the inclusion criteria or the process of theoretical sampling ruled them out. The diagnosis and inclusion criteria were confirmed by the treating physicians or by accessing patient charts after potential participants had expressed an interest in being interviewed. All participants from the peer support groups were either re-evaluated by one of the study's referring physicians or the medical charts were examined to ensure the diagnoses.

As the phenomenon displayed itself with more clarity, the sampling procedure was refined using theoretical sampling as detailed by Strauss and Corbin [22] and although the initial research agenda was chosen by the researchers, as concepts became clearer due to coding, the next participant was chosen based on those concepts. For example, a participant may have described a certain type of phantom sensation and the next candidate was chosen to further explore this phenomenon.

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 locations were conducive to casual conversation and of the participants own choosing. In addition, the interviewer eliminated any travel costs associated with the interview by travelling to the participant.

Interviews were informal in that there was enough leeway for the interviewee to take the interview in any direction; however, the topic under investigation was always returned to, i.e., phantom sensation. The interviewer used two general approaches to aid the interview. All interviews began by asking the participant to recount the history around the onset of the injury. This was followed by asking each participant to describe the sensations in a particular part of the body. As an aid, the interviewer used a standard visual representation of the human body in order to make sure that every part of the body under the NLI was covered during the interview. Our area of interest is described by the question 'What is phantom sensation as experienced by a person with a spinal cord injury?' This enquiry was the central issue for all interviews. In addition to referring to the diagram, interviewees, in order to spur on the interview, were also asked if they experienced any feelings of volume or length below the NLI, if a limb felt like it was in a particular posture or position, if movement was ever felt and if so was it spontaneous or could it be deliberately triggered. There were also questions about onset of the sensations, the emotional reaction to the sensations and the effect they had on the person's life, if any.

Data analysis

The interview was coded as soon after the conversation as possible in order to allow theoretical sampling. In addition, it was micro, or line by line, analysed after all interviews were completed. We used grounded theory methodology as laid out by various authors [21–23]. Categories were uncovered and meaningful concepts and quotes noted. The relationship between categories was fully explored and final categories were established via discovery. We tested the reliability of the higher order categories by asking a neutral third party to place interview phrases into the relevant categories. Twenty phrases were picked randomly from the interviews and an independent rater was asked to place them into one of the six higher order categories. As a result one of the categories was refined and the title changed from 'Acceptance' to 'Attitude'. This change resulted in a 100% inter-rater reliability.

Results

During our 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, connection to my body, attitude and who I've talked to about phantom sensation.

Injury context

As previously stated, in all instances participants acquired the injuries that resulted in their paralysis. The injuries resulted from a range of events such as being in a building that was hit by a tornado or involvement in a motor vehicle accident.

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 hospital.

We also recorded narratives about injury onset that were retold 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]

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 well rehearsed:

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.

Sensations

This category, common to all the interviews, is descriptive in nature. It covers the physical sensations experienced by our participants post injury. Most of the sensations mentioned were painful

sensations 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.

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 is a 46-year-old, married man with a lesion at C5-6 which happened while diving into a swimming pool. Many of these above concepts are captured 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 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.

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.

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]

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. All of the participants also reported 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.
 I: When did you notice that?
 R: Notice?
 I: That, that the position of your legs, at least lying there in the bed...
 R: 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.

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. Indeed, as stated earlier, one participant observed the 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 propriocep-

tion to be inaccurate or they trusted the sensations to be accurate and were surprised when they found themselves mistaken. 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

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.

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 that a sensation 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]

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 to

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. 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.

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]

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

The transitory nature of the sensations was also a re-occurring theme. There were times during the interviews where respondents noted the complete absence of previously experienced phantom sensations.

All of the people interviewed also reported sensations associated with spasms, autonomic dysreflexia (activity associated with the malfunctioning of the autonomic nervous system) and sensations caused by expected reactions to external stimuli. 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]

Meaning of the sensations

Sensations meant different things to each individual. Sometimes the meaning was neutral, but sometimes the sensations were vested with deeper symbolism. 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]

Other interpretations were more concrete: 'It feels like I've got my shoes on most of the time'. SD noted that one set of sensations she encountered felt 'like somebody shakes your hand and they squeeze your fingers together'.

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 his interview to describe his reaction to the sensations where he perceived hands pushing into his 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: 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]

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

Participants spoke about their connection to their bodies. In one case this was very explicit:

It [sensation below the NLI] let 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 stay 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 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

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

I: 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]

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'.

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]

Finally, 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].

Discussion

The experiences described here were clearly vivid and compelling, indeed sometimes they were so compelling that the body had to be 'checked' to ascertain whether feelings of movement corresponded to what could be seen as happening. Other sensations were painful or just noted, some could be located in certain parts of the body, others not. This exploration of the 'lived body', grounded in the experience of people with complete (ASIA 'A') spinal cord lesions, presents several challenges to our understanding of SCI. For instance, is there any such thing as a 'complete' spinal cord lesion? Are these anomalous sub-lesional sensations accounted for by remnant un-lesioned pathways, or by pathways not yet understood? The answer to such questions,

raised by our participants' reported experiences, is however beyond the scope and focus of the present research. Equally fundamental issues can however be informed from our data. For instance, who has the legitimacy to give an authentic 'reading' of the anomalous experiences reported by our participants? The fact that such experiences are beyond the scope of our present diagnostic and descriptive nomenclature for SCI suggests that clinical professionals still have much to learn from those they seek to help. Although we have used the term 'phantom' to describe denervated body experiences, it should be noted that our participants did not use this term, even when they were aware of it, possibly because the term implies a degree of unreality. Participants in our study frequently noted that their reading of the clinical context implied that their sensations below NLI were somehow not authentic. Some of the most salient issues they raised are now briefly noted.

As all injuries in this study were acquired suddenly and under stressful conditions it is likely that participants experienced memory loss [24]. As a result, for many, it is probable that memories from this time frame are gained from a third party. This may partially account for interviewees retelling of the event responsible for their injury in a somewhat rote and distant manner. It may also be part of the healing process necessary for most people to move through [25]. The SCI person may not only feel a disconnect with aspects of their body functioning, but also with the events which led up to their injury, leaving them living with the bodily consequences of a strangely vicarious-like trauma.

A striking element of the interviews is the amount of sensation or pain experienced by all individuals interviewed in a condition that is considered, by many in the general population, as being sensation free. Certainly, the majority of people who sustain a SCI will enter the condition with a set of preconceived notions about the injury which will be reinforced or disproved as they prepare themselves for re-entry into the world beyond the hospital. It is reasonable to assume that most individuals begin their post injury act of self-construction, believing paralysis to be sensation free. When individuals experience sensations from parts of the body that they believe should be devoid of feeling, the belief that the clinical staff, or the patient herself or himself, are 'crazy' is not difficult to arrive at. Discounting their clinician's diagnosis may well have serious implications for the relationship between clinician and patient, and indeed limit the ability to reach optimal rehabilitation goals. Phantom sensations have previously been classified by Siddall and McClland [1] as simple and complex and we found that participants described

sensations in ways that could easily be broken down in a similar fashion but they did not relate them in this way. The sensations experienced were often described as being complete and vivid, but because of their apparent reality, this may give rise to potential problems. In a situation (hospitalization) that easily feeds a state of learned helplessness [26], the act of needing to ask a third party about the position of our own body, may further contribute to this: Patients are learning to distrust their embodied sensations; sensations from their own bodies. Such distrust in one's own judgement may eventually lead people with SCI to become overly trusting and dependant on the judgement of others, and thus deny their own agency; a key feature of successful rehabilitation.

In the attempt to medicate pain below the NLI clinicians may be overlooking something significant in the rehabilitation experience. For instance, the onset of 'phantom' sensations was attributed to the discontinuation of morphine by one of our participants but whether this was a positive or negative event is not clear. For people with an amputation the ability to feel a phantom limb has been beneficial to their ability to adjust to a prosthetic device [19]. Could there be any benefit to phantom sensations experienced by someone with an SCI? Does it really matter if we suppress with medication, non-painful sensations as well as painful ones? Both the reported onset and transitory nature of the 'phantom' phenomena in our sample reflects well established findings in individuals with an amputation.

AH noticed that he was more closely connected to his body now than he was prior to the injury. This may be because he was more aware of his body [19]. Increased 'bodily vigilance' may indeed make people more aware of internal bodily processes, processes that could perhaps be interpreted in others ways. Perhaps this suggests the need for greater dialogue between clinicians and patients about bodily experiences below NLI, their occurrence, interpretation and signification, including possible further deterioration of their condition. Painful sensations are a recurring problem for many with an SCI. They have been found to be an additional 'handicap' to the spinal cord injury with the majority of people who had returned to work claiming that the pain adversely affected job function [27]. The extent to which such pain includes 'phantom' or below NLI pain is unknown. As acceptance or adjustment stands as a major component in many SCI adaptation models [28], it is important for optimal rehabilitation that patients and clinicians share an understanding of sensations experienced below the NLI, particularly painful sensations, which may adversely affect the rehabilitation process both within and beyond the hospital setting.

Conclusion

One of the most interesting ideas to arise from our grounded theory analysis is what might be termed an experience of 'psycho-physiological dissonance', that is, operating with a mental model of what it means to have a SCI – which tells you certain physical experiences are not possible – while simultaneously experiencing physical phenomena that contradict the mental model: There is a disconnect between what the person 'knows' and what they 'feel'. Not alone is this confusing, and sometimes worrying, but the fact that some people with SCI experience a wide range of sensations post injury and do not discuss them with clinicians, is of concern for the rehabilitative process. Understanding the 'phantom' experiences of people with SCI may teach us much about the nature of embodiment, as well as enhancing their rehabilitation. Considerable research is needed to further explore the appropriateness of our classification systems for somatic sensations below the NLI, to what extent the label 'phantom' is appropriate for such sensations, and if so, how such sensations differ or are similar to phantom sensations in other clinical conditions.

References

- Siddall PJ, McClelland J. Non-painful sensory phenomena after spinal cord injury [Electronic version]. *J Neurol Neurosurg Psychiatry* 1999;66(5):617–623.
- Napoli M. Phantom burn pain gains recognition. Available at: http://www.findarticles.com/cf_dls/m0815/2002_March/83677779/p1/article.jhtml (Retrieved 9 April 2004). LookSmart; 2002.
- Giraux P, Sirigu A. Illusory movements of the paralyzed limb restore motor cortex activity. *NeuroImage* 2003;20(Suppl. 1):S107–111.
- Marbach JJ. Potential mechanisms of phantom tooth pain. In: Sherman RA, Devor M, Casey Jones DE, Katz J, Marbach JJ, Heermann-Do K, editors. *Phantom pain*. New York: Plenum Press; 1997. pp 59–88.
- Sherman RA, Katz J, Marbach JJ, Heermann-Do K. Locations, characteristics and descriptions. In: Sherman RA, Devor M, Jones CDE, Katz J, Marbach JJ, Heermann-Do K, editors. *Phantom pain*. New York: Plenum Press; 1997. pp 1–31.
- Rothmund Y, Grusser SM, Liebeskind U, Schlag PM, Flor H. Phantom phenomena in mastectomized patients and their relation to chronic and acute pre-mastectomy pain [Electronic version]. *Pain* 2004;107:140–146.
- Bors E. Phantom limbs of patients with spinal cord injury. *Arch Neurol Psychiatry* 1951;66:610–631.
- Conomy JP. Disorders of body image after spinal cord injury. *Neurology* 1973;23(8):842–850.
- Desmond DM, MacLachlan M. Psychosocial perspectives on postamputation rehabilitation: A review of disease, trauma and war related literature. *Crit Rev Phys Rehabil Med* 2004;6(2):77–93.
- Horgan O, MacLachlan M. Psychosocial adjustment to lower-limb amputation: A review. *Disabil Rehabil* 2004;26(14/15):837–850.
- Sherman RA, Devor M, Casey Jones DE, Katz J, Marbach JJ, Heermann-Do K. Phantom pain. In: Ray W, editor. *The Plenum Series in the Behavioral Psychophysiology and Medicine series*. New York: Plenum Press; 1997. p 264.
- Flor H. Phantom-limb pain: Characteristics, causes, and treatment [Electronic version]. *The Lancet Neurol* 2002;1:182–189.
- Price EH. A critical review of congenital phantom limb cases and a developmental theory for the basis of body image. *Consciousness Cognit* 2006;15(2):310–322.
- Desasri MD. Taxonomy of pain syndromes. In: Prithvi Raj P, editor. *Pain medicine: A comprehensive review*. St Louis, MI: Mosby; 2003. pp 17–21.
- Siddall PJ, Yeziarski RP, Loeser JD. Taxonomy and epidemiology of spinal cord injury pain. In: Yeziarski RP, Burchiel KJ, editors. *Spinal cord injury pain: Assessment, mechanisms, management*. Seattle, WA: IASP Press; 2002. pp 9–24.
- Bockenek WL, Stewart PJ. Pain in patients with spinal cord injury. In: Kirshblum S, Campagnolo D, De Lisa J, editors. *Spinal cord medicine*. Philadelphia: Lippincott, Williams & Wilkins; 2002. pp 389–408.
- Bryce TN, Ragnarsson KT. Pain after spinal cord injury. *Phys Med Rehabil Clin N Am* 2000;11(1):157–168.
- Gallagher P, MacLachlan M. Adjustment to an artificial limb: A qualitative perspective. *J Health Psychol* 2001;6:85–100.
- MacLachlan M. *Embodiment: Clinical, critical and cultural perspectives on health and illness*. Maidenhead, UK: Open University Press; 2004.
- Rybarczyk B, Szymanski L, Nicholas JJ. Adjustment to amputation. In: Frank RG, Elliott TR, editors. *Handbook of rehabilitation psychology*. Washington, DC: American Psychological Association; 2000. pp xiv, 727.
- Glasser BG, Strauss A. *The discovery of grounded theory*. Chicago, IL: Aldine Publishing Company; 1967.
- Strauss A, Corbin J. *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: Sage Publications; 1998.
- Pidgeon N, Henwood K. Using grounded theory in psychological research. In: Hayes N, editor. *Doing qualitative analysis in psychology*. Hove, UK: Psychology Press; 1997. pp 245–273.
- Cavenett T, Nixon RDV. The effect of arousal on memory for emotionally-relevant information: A study of skydivers. *Behav Res Ther* 2006;44(10):1461–1469.
- Livneh H. Psychosocial adaptation to chronic illness and disability: A conceptual framework. *Rehabil Counsel Bull* 2001;44(3):151–160.
- Seligman ME. Depression and learned helplessness. In: Friedman RJ, Katz MM, editors. *The psychology of depression: Contemporary theory and research*. Washington, DC: John Wiley & Sons; 1974.
- Rose M, Robinson J, Eells J, Cole JD. Pain following spinal cord injury: Results from a postal survey. *Pain* 1988;34:101–102.
- Heinemann AW. Spinal cord injury. In: Goreczny AJ, editor. *Handbook of health and rehabilitation psychology*. New York: Plenum Press; 1995. pp 341–360.