

RESEARCH REPORT

Physical Therapists' Experiences with Patients with Traumatic Spinal Cord Injury

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ABSTRACT

Study Design: Qualitative design including inductive analysis. **Objectives:** Understand the experience of physical therapists (PT) when treating individuals with traumatic spinal cord injury. **Background:** Spinal cord injury (SCI) affects 12,000 Americans each year. Individuals with SCI spend an average of eighteen days hospitalized in the acute care unit, and, on average, an additional thirty-nine days are spent in the rehabilitation unit.¹ The relationship that develops between the physical therapist and the individual with SCI is both physical and psychological in nature. Little is known about how physical therapists interpret and experience their interactions with individuals with SCI. **Methods:** Interviews were conducted with four licensed physical therapists (two males and two females) with an average of 13.25 years experience working with individuals with SCI. The interviews were transcribed and evaluated for similar and unique clusters of statements. The clusters were grouped into similar categories. The categories were collapsed into themes. **Results:** Three themes emerged relative to the physical therapists' experience treating individuals with SCI: (1) Multifaceted nature of SCI and the inherent challenges it presents to PT and patient; (2) benefits and barriers; and (3) strategies physical therapists use to facilitate recovery. **Conclusions:** The findings from this study highlight the components of the experience of physical therapists who work with individuals with SCI. Greater knowledge about the complex relationship that exists between the PT and the individual with SCI may help to foster a more effective rehabilitation.

Background

Spinal cord injury (SCI) affects 12,000 Americans each year.¹ Individuals affected by varying degrees of SCI undergo traumatic physical, social and psychological changes. The consequences of a spinal cord injury force a person to reevaluate every facet of their existence. With normal cognitive function and intellectual ability usually intact, individuals with traumatic spinal cord injuries are catapulted into a new and programmed world of medical procedures and physical rehabilitation. Individuals with SCI spend an average of eighteen days hospitalized in the acute care unit, and typically an additional thirty-nine days are spent in the rehabilitation unit.¹ It is

in the hospital environment that individuals with SCI must begin to live with their injury and closely interact with the medical team that is positioned to facilitate a successful recovery.

Initial reactions to SCI are not well understood, but can be viewed as "normal reactions to an abnormal situation".² The immediate psychological consequences of spinal cord injuries are convoluted by the effects of medication, sensory deprivation and pain.² North² highlights a number of immediate emotions which include numbness, disbelief, anger, fear, hope and despair. During the preliminary period of recovery individuals may be in disbelief about their current state and have a

disordered outlook on the future.² It may take years for an individual to fully psychologically accept the injury. However, North² expresses concern that in routine clinical practice the detection of psychological problems in patients facing permanent disability has been estimated at less than ten percent. North² suggests that there may be a thought pattern prevalent amongst health care professionals in which the presence of psychological disorders in individuals with SCI is normalized. The physical therapists' (PT) expectation of psychological distress may lead to complacency in appropriately intervening when patients are not coping well.²

Carpenter³ interviewed ten individuals with SCI in a qualitative study. Her results suggest that individuals with SCI are categorized into two groups; 1) those who appear to cope or become "successfully rehabilitated" and 2) those who succumb to the "tragedy" of disability. By placing patients into these two groups, practitioners may neglect to appreciate the strategies of those individuals who perceive themselves as "ordinary people coping with extraordinary circumstances." Carpenter suggests that it is common for newly injured individuals to be presented with a routine battery of rehabilitation services that prove later to have failed to cater to the individual because the services were not adapted to each person's particular lifestyle and needs. Carpenter advocates a more cooperative rehabilitation setting in which PTs facilitate recovery and patients assume greater ownership.³ The findings of Carpenter's study imply that there may be a need for an education program for rehabilitation professionals to facilitate an appreciation of the broad and personal effects of traumatic spinal cord injuries to better tailor rehabilitation services to the needs of each individual.³

Curtis⁴ found that PTs may experience a conflict in role satisfaction because they must balance interactions that fulfill their care-giving role with situations that facilitate patient responsibility and decision making. In role deprivation, physical therapists may feel that their authority is threatened or that their services are undervalued by promoting patient independence.⁴ Curtis⁴ suggests that PTs should assume an information-giving rather than a decision-making approach to therapy in order to establish a non-dependent relationship and avoid personal stress when treating individuals with SCI. In this way, PTs can incorporate the context of the patient's past experiences into the rehabilitation process and establish a relationship of trust and open communication.⁴ Because role deprivation frequently occurs in PTs working in SCI rehabilitation, Curtis⁴ proposes that staff support groups and in-service training sessions should be made available.

Physical therapists are placed in a sensitive position. They have been trained almost exclusively to treat physical impairments, yet are exposed in daily practice to varied psychological responses to injury. Papadimitriou⁵ found in her interviews with PTs that they define their "work" based on the physical aspects of rehabilitation and feel discomfort when sensitive emotional issues arise in the patient interaction. According to the PTs in Papadimitriou's study, the feeling of discomfort stems from the lack of formal training regarding psychological issues and the fear of crossing professional boundaries by extending beyond their scope of practice.⁵ The occurrence of emotional distress in individuals with SCI seems unavoidable due to the pain and foreignness associated with the rehabilitation process. Physical therapists are exposed to a barrage of psychological responses partly because they

witness the earliest stages of individuals coping with and assimilating a life altering injury. As Curtis and Papadimitriou suggest, PTs must balance the influence of their own emotional process and professional intentions with the specific psychological and physical needs of the individual patient.^{4,5}

To date, little research has examined the perceptions of physical therapists working with individuals with spinal cord injury. Understanding how physical therapists perceive and interact with individuals experiencing psychological distress post traumatic SCI was the primary objective of this study. With a better understanding of how physical therapists respond to psychological distress exhibited by individuals recovering from SCI, strategies and techniques might be developed to foster and facilitate positive interventions. The findings of this study may produce a more integrated perspective on the dynamic relationship between physical therapists and their patients. This qualitative study was guided by the search for answers to the following question: What is the psychological experience of physical therapists when providing rehabilitation for individuals with traumatic spinal cord injury?

Methods

Setting and Participants

Participants for this study were identified through discussion with Physical Therapy faculty at the first author's university. Names of male and female physical therapists in the area that had ample experience working with spinal cord injuries were requested. Four individuals were identified and contacted. After discussing the study and gathering consent a 30-60 minute interview occurred at a location convenient to the participant. All four consented to participate (see Table 1). All graduated from accredited Physical Therapy educational programs and worked at outpatient clinics. They had worked with SCI patients for an average of 13.25 years. Three of the participants indicated that they had work with 100 or more SCI patients during their careers. Participant Four did not indicate how many SCI patients she had rehabilitated. All the participants were Caucasian.

Data Collection

The first author was an undergraduate student at the time of data collection. This research was designed as a pilot study in an effort to link her undergraduate degree with her graduate studies in physical therapy. A research team was formed consisting of the

Table 1. Characteristics of Participants.

Participant ^a	Age	Sex	PT Experience (years) ^b	Experience with SCI (years) ^c
Sonya	40	Female	15	15
Jasmine	44	Female	19	19
Joe	38	Male	15	12
Derek	44	Male	14	7

^aPseudonyms have been used to protect the privacy of the participants. ^bYears of experience as a Physical Therapist. ^cYears of experience working with patients with spinal cord injuries.

author's faculty mentor (second author), a physical therapy faculty member, and a doctoral student. The author's mentor assisted in data analysis. The latter two members of the team did not formally analyze the data but were solicited for advice, guidance, and clarification. The first author conducted all the interviews. Each interview began with general background questions. Time was also spent building rapport and trust with each participant. These questions were followed by two specific questions designed to explore each physical therapist's experience of working with individuals with spinal cord injuries who were having a difficult time coping. Probes and follow-up questions were used to elicit further information.

The specific questions were:

1. What is it like to work with individuals who are having difficulties coping with their injuries?
2. Can you tell me about an experience in which an individual with a spinal cord injury expressed emotional distress during rehab with you?

Data Analysis

A phenomenological approach guided this research. Phenomenology assumes that there exists a perceived reality that contains common elements. The goal of phenomenological analysis is to describe the phenomena of interest.⁶ We were interested in understanding the common experiences of physical therapists who had treated spinal cord injured patients who had difficulty coping. Data analysis was guided by the process outlined by Creswell.⁷ Each interview was transcribed and read multiple times by the authors. The first reading was conducted to gain a general understanding of the phenomenon. A second reading was followed by a meeting between the two

authors to contextualize each interview. We then independently highlighted statements or sections of each interview that described the physical therapists' experience. The researchers then met and created clusters of similar and unique descriptions of the phenomenon into categories. These categories were labeled with a term that best captured the essence of each cluster. The categories were examined and consolidated further into themes.^{7,8} Each theme was given a representative label.

Methodological Rigor

Methodological rigor was established in the following ways. The content of the interview guide was examined by the entire research team. This was the first qualitative study conducted by the first author. She took great care to seek the advice and guidance of other members of the team who had experience conducting phenomenological qualitative studies. Multiple meetings were held regarding sampling, the structure of appropriate interview questions, and strategies of data analysis. In the initial stages of each interview time was afforded to building trust and ease between the interviewer and each physical therapist. This allowed for honest sharing of information and unique contributions from each participant. Each interview was open-ended which minimized researcher control and researcher bias. Each participant freely exchanged information rich data. To ensure data dependability all transcripts were meticulously maintained and an audit trail was created so that categories of data could be traced back to their origin and contextualized and confirmed. Each description of the phenomenon was labeled with the name of the participant and the page number of the interview transcript from which it originated. Finally, to further reduce possible researcher bias the first and second

author analyzed the transcripts independently and then met to discuss their respective interpretations of the data.

Results and Discussion

Three general themes emerged including: (1) Multifaceted nature of SCI and the inherent challenges it presents to PT and patient; (2) benefits and barriers; and (3) strategies physical therapists use to facilitate recovery.

Multifaceted nature of SCI and the inherent challenges it presents to PT and patient.

The general theme that SCI is a multifaceted injury emerged as a result of the compilation of many categories, including patient specificity, variation, tailoring, crashing post rehabilitation, level of psychologist involvement, false hope, intimacy, and degree of family/social support.

It became apparent that spinal cord injuries presented a unique challenge to the physical therapists and stood apart from most other injuries as a result of the broad, sweeping impact that SCI has on the individual. Derek commented on the *specificity, variation, and tailoring* by commenting, “And it is so patient specific so, you can’t take any two spinal cord injured patients and put them through the same, you can’t put them into a cookie cutter. They may have the same injury, they may be the exact same age but emotionally they are at two different places. So, I think every patient, you need to tailor the whole program to them.” While treatment of spinal cord injuries might be similar the participants emphasized the individuality of their interactions with patients. This finding contradicts Carpenter’s finding that PTs tend not to cater to the needs of individual patients.³

The term “*crashing*” appeared in two interviews and in both cases the participants were referring to the idea that once patients leave the supportive environment of the rehabilitation facility after their inpatient stay they are prone to depression and social isolation. This result is largely unavoidable from the PT perspective because it is impossible to predict or assess which patients are experiencing adaptive recoveries and which are not. This finding seems to contradict Carpenter’s suggestion that PTs tend to categorize patients into those doing well and those who succumb to the injury.³ It was suggested in the interviews that certain patients may enter outpatient rehabilitation with a seemingly positive and adaptive attitude, but later prove to be the ones that crash the hardest after leaving the hospital. It is also possible that those patients that display maladaptive behaviors during treatment may be better suited to withstand life post rehabilitation as a result of already beginning the coping process while support is available. Derek illustrated this idea when he said, “And a lot of times it’s the patients that put up that, ‘Oh I’m just going through this is, you know, I can do this.’ This gung-ho kind of no problems. I don’t have any issues. Then they get out and they crash because then reality hits and ‘Oh I’m in a wheelchair.’” Sonya concurred by stating, “Even the people that look like they are doing fabulously well are going to go home and crash.” The inevitability of crashing did not seem to be accompanied by complacency as suggested by North¹. The participants seemed to recognize the difficulty of recovery and attempted to be prepared for each patient’s individual response.

Another common experience that may present itself during treatment is that of *false hope*. Due to the promise of technology and the unpredictability of nervous system

return, many patients enter rehabilitation with the firm conviction that they will walk again. Physical therapists are therefore presented with the challenge of balancing the current reality and the often idealistic hopes of the patient. The participants suggested that it is important to not give the patient false hope, and equally important not to take any hope away from the patient even if there is a one percent chance that they may walk again. Jasmine highlighted how she approaches this when she said,

And I, always in seeing these patients and seeing longer term outcomes, I know what wonderful lives these people can have and how positive the experience can be. And so, I always have a really hopeful positive outlook and I make it a point to never give false hope, you know, by saying "It will be OK. You'll walk again." ... I think that I reinforce that what is truly important is now and maximizing now, and every moment along the way. ... we're just going to keep progressing and prepare this individual to take advantage of everything that presents itself along the way.

Another integral component of the rehabilitation process is the *involvement of the psychology team*. All of the participants agreed that the presence of the psychology team was beneficial and many suggested that the degree of involvement could even be increased. However, there were differing views on whether all patients were receptive to psychologists. It appeared to be a common experience for the participants to take on the role of a psychologist because most patients feel more comfortable releasing emotionally to the PT with whom they are familiar and comfortable.

The participants remarked that the fusion of both physical and psychological aspects in treatment produces a unique environment

between the PT and patient. The PT may become a confidant and support person which creates an *intimate interaction* that was suggested by the participants to be at times overwhelming and emotionally exhausting. Sonya suggested that,

As a physical therapist you are there with them in very intimate environment. You are touching them, you are helping them with skin care, you are holding on to them when they are trying to stand up. So, I think that you develop a very close relationship and I think that people, I mean patients don't have a defined boundary as I'm your physical therapist, but I'm just your physical therapist and so, when you leave here you need to find other people to support you. And I think that a lot of us therapists don't have a clearly defined boundary either. So, I just became a confidant, kind of.

The participants suggested that they play an important supportive role during the rehabilitation process that is both physical and emotional in nature. Sonya's quote however, does suggest the potential for role conflict and the difficulty PTs have in establishing an effective boundary with their patients.^{4,5} However, it was also suggested that it becomes imperative that the patient has a supportive network to assist with the reintegration process back into life and society, post hospitalization.

The degree of *family/social support* for each patient varies immensely. Sonya summarized the sentiments of all of the participants when she said,

You would hope that great family support would make their transition easier but it doesn't seem to necessarily work that way. Because, I think, it is equally as hard for the family, they don't want to make it hard for the patient, and the patient doesn't want to

make it harder for the family. So, I have noticed a lot of time that there isn't the communication that there may have been even before the injury. ... I have seen a lot of patients have wonderful family support crash harder than anybody else. And people that are all alone and end up going to a nursing home do better than anyone else. So, I think it is just kind of what's inside. I think family support helps but I don't think that that is the only criteria. I think it's helpful but there is a lot more that we don't even understand.

This sentiment reinforces the idea that spinal cord injuries are patient specific and varied and the quality of the recovery hinges on many interrelated variables.

Benefits and Barriers.

Rehabilitating individuals with spinal cord injury is very challenging. In this theme the physical therapists discussed the benefits and barriers of the process of rehabilitation. The categories comprising this theme were rewards, challenges, coping, personalization, and relationship building.

The physical therapists mentioned many *rewards* that they experienced by being a part of the rehabilitation process. Being able to witness people walk into the clinic years later that couldn't walk before, observing people grow, watching families come together and participating in real human interaction, are examples of the rewards that they experienced. Prior research has focused on the difficulties of rehabilitating individuals with spinal cord injury. The participants in this study were quite conversant about how powerful it was to witness patients grow from the experience. The comments from the participants suggest that the elements that make treating SCI special seem to stem from the fact that the injury takes the individual to a primitive

level functioning and the rehabilitation that the PT provides facilitates dramatic, positive personal growth that results in some higher level of existence for the patient. Jasmine summarized the varied responses of the participants regarding their experiences when she stated that,

We get to see the rebuilding and the progress back to a fulfilling life and that is just a spectacular process to see the progressive skill building and strength, endurance and the thing that is the most incredible is just seeing that hope and that will to go on and that will to do and participate and get back in life is so powerful, its really wonderful.

The rewards associated with successful rehabilitation seemed to be measured by whether the PT brought the individual to that next level, whether they were able to return to school, work, recreation, or simply back into life. By bringing the patient to the next level or back to their pre-injury level, physical therapists are able to offer the patient a starting point from which they can successfully leave the hospital environment.

With the immense rewards and satisfaction that comes with treating SCI, there are also many *challenges* for the PT. Derek spoke about his initial transition into SCI as being "hard" and "scary" when he explained,

Just because it was a whole different ball game. Spinal cord injury is a whole, it's different than any other type of therapy because you have so many, you've got the emotional, the psychological, the social aspects and a lot of these folks don't have the good family support. So, you've got psychosocial things, you've got financial aspects you have to look at. You're not just a therapist. You wear all kind of different hats. And so, it can definitely be overwhelming.

Because there is a lot to work on and a very limited time to do it.

Derek's quote supports Papadimitriou's finding that PTs experience a measure of discomfort with the psychosocial challenges that patients present.⁵ Physical therapists are required to take on many roles which spread the capacity of the individual PT across the physical and psychosocial realms of treatment. The participants mentioned becoming drained physically and emotionally because of circumstances, such as the need to talk to patients about things they may not want to hear, not having adequate training or background in the psychology of injury, maintaining motivation and the actual physical demands of rehabilitation. It becomes a delicate balance for each PT, in which they decide how much to give and how much to guard.

Each participant *coped* in their own personal manner, however there was a common avenue of team coping, in which the participants received support from other rehabilitation team members. Team coping consisted of case conferences in which all members of the team, including the psychologists, were present for informal discussions in which the participants could express frustrations or concerns.

Most of the participants seemed to *personalize* the experience to some degree, whether that meant placing themselves in the patient's situation or realizing that SCI can strike anyone without selectivity and this could be their friend or family member. Jasmine revealed her perspective when she said,

It made me just realize that these people are just like me on a day to day basis just going through life with dreams and plans and goals and one day bam their life changes.

And that really was an emotional shock for me. I really had great compassion for these people and I really personalized it myself like, "What if that was me? What would I do? How would I handle that?" And I think at that point, that impacted the rest of my career and it does every day because I mean I just personalize these individuals as valid, wonderful human beings. You know, my brother, my mom, my sister, me in that situation and I never forget that that this is someone that has had a life change and how incredibly challenging that must be in that circumstance.

An alternate view came from Sonya when she stated that, "...I can recognize that this is the patient and it is not my life, it is their life and so when I go home, I can leave it at work."

Aside from whether the participants personalized the injury or not, they all suggested that they *build a strong relationship* with their patients. The relationships that develop arise out of the quality of the interaction that takes place between the PT and the patient. The PT has the opportunity to get to know the patient on many levels because they are often an emotional confidant and a significant support person during the preliminary steps toward recovery. Sonya spoke about her experience with SCI patients when she said, "They are tough. They work so hard. They become so motivated to get a close relationship with their families. And you really have better rapport I think. You get to know their dogs and their brothers and their sisters and you really get to know them as people." The relationship and often eventual friendship that develops between the PT and patient seems to arise spontaneously from the raw and honest human interaction. The experiences of the physical therapists in this study were laden with rewards and

challenges and also characterized by a desire to provide the same quality care that they would give to a friend, family member or even to themselves. The ability and the willingness of the physical therapists to build this relationship becomes one of the primary and most important contributions that they give to the rehabilitation process. However, the depth of the relationship does seem to present a possible issue for the PT in terms of role conflict and defining an appropriate boundary with the patient.^{4,5}

Strategies physical therapists use to facilitate recovery.

In discussing their experience with individuals with spinal cord injury the physical therapists spoke of the tools and tactics they used to facilitate recovery. This theme comprised the categories of tactics, listening, honesty, and outside connection. The *tactics* that were used by each participant to interact with individuals with SCI comprised a spectrum of approach styles, techniques and personal philosophies. All of the participants suggested that they offered support and then each explained the ways in which they accomplish that, whether it be by tapping into the machismo, giving a challenging task, treating their patient like an athlete, finding common ground, showing compassion, being their advocate, teasing, joking, etc.

Out of all of the contributions mentioned, the one that was voiced by all the participants was that of *listening*. When asked what they offer their patients in times of emotional distress, all of them answered that they simply listen. Joe said,

I try to just be a good listener and I try to reflect on what they are saying and I try not to rush through it, you know what I mean? And give them time and I am pretty straight up with the fact that I have done this forever

and I have seen just about all there is to see and I still have no idea what it is like to go through what you are going through. That is about all I can offer I think.

This statement exemplifies the consensus of the participants, that because they are not trained as counselors, the best thing they can give their patients in instances of emotional distress is their undivided attention.

Another primary contribution that the participants provided was *honest* information about what their patients could expect for their lives and offering every positive view point possible. This was expressed by the participants in the form of providing their patients with other patient's positive experiences and helping to make *connections* for their current patients within their communities. Connecting people, engaging peers, integrating patients into the community all seemed to be extremely beneficial contributions that the physical therapists were able to offer.

Conclusion

The primary goal of this study was to attempt to understand how physical therapists perceive and interact with patients who are experiencing psychological distress post spinal cord injury. To understand the phenomena it was necessary to first gain insight into the far-reaching impact that SCI has on the effected individual. Physical therapists that treat SCI must adapt to handle the various situations presented in spinal cord injury rehabilitation and remain dynamic and balanced in their treatment. Certainly not every accomplishment in the process of recovery can be gained in the preliminary months in rehabilitation. Rather it can take years or possibly the remainder of the lifetime of the patient to fully accept the injury. The physical therapist can only

manage to do their part in the short time that they have to prepare the individual for life outside the hospital and hope that there is a safety net of social support to facilitate the continuing recovery of the patient.

The physical therapist in this study went beyond sharing solely how they interact with their patients in the wake of emotional distress by revealing the rewards and challenges stored in all aspects of treatment. It became clear that the experience of physical therapists in this study were grounded in a relationship with their patients that allowed them to deal with not only the physical, but also the emotional response to injury in a constructive and positive manner. Each PT had an individual method of developing that relationship and a unique perspective regarding the use of various tools and tactics to facilitate progress. Listening and providing helping relationships whenever possible appeared to be the common ways in which the participants attempted to assist their patients in the psychological and social recovery process. Therefore, the experiences of physical therapists that provide intervention for individuals with SCI can be best understood by looking at the layers that characterize the interaction. The layers begin first with the qualities of spinal cord injury that impact the interaction, then the unique impact that the interaction has on the PT, and finally how the PT contributes to the interaction.

Limitations

There were several limitations inherent in the current study. The participants, while quite diverse, were all Caucasians residing and working in one large city in the Mountain West. Physical therapists of different ethnicities working in different regions of the U.S. and world might have different experiences. The participants in

this study had, on average, over a decade of experience working with individuals with spinal cord injuries. PTs with less experience would surely communicate different perceptions and beliefs. Only four participants were interviewed. While common themes emerged and an attempt was made to reach saturation it is possible that more descriptions, categories, and themes would have emerged with more participants. A further limitation is that this was the first qualitative study conducted by the first author who was an undergraduate student at the time. She clearly and truthfully acknowledges that each facet of the study was 'new' and a more experienced researcher might have come to different conclusions. Establishing trustworthiness is critical in all research. A limitation of this study is that all aspects of credibility and dependability were not integrated into the research protocol. The use of member-checking and reflexivity would have improved the study.

Practical Implications

It was suggested by most of the participants that in order to combat "crashing" post rehabilitation, it would be beneficial to increase the length of the rehabilitation term and incorporate earlier and more comprehensive involvement of the psychology team. The average length of time spent in the rehab unit has decreased from 115 days in 1974 to 39 days in 2004¹. This considerable decline in rehabilitation days allotted, may contribute to the apparent lack of continuity that exists in the treatment of both the physical and emotional response to SCI. Increasing specialty training for physical therapists regarding the psychological response to injury should be considered, especially if the healthcare system prohibits increased rehabilitation time or further involvement of trained psychologists.

Programs that provide helping relationships for SCI patients post hospitalization may help to take some of the responsibility off of the physical therapist to be an emotional confidant as well as a physical caregiver during the rehabilitation process. Providing emotional and physical outlets post rehabilitation, may serve to increase the rate of adaptive recoveries for individuals with SCI.

Treatment of spinal cord injuries requires individualized and comprehensive care. It is imperative that the rehabilitation team functions as a cohesive unit, in which all aspects of injury recovery are monitored and treated, in order to facilitate the individual patient through the dramatic physical and psychological changes that take place post traumatic spinal cord injury.

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