

EFFECTS OF LOCOMOTOR TRAINING ON THE PSYCHOSOCIAL ADAPTATION
OF PERSONS WITH INCOMPLETE SPINAL CORD INJURY

By

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A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2004

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by

Elizabeth Marie Hannold

I dedicate this dissertation to my parents, Anne and Dick.
Only through their constant love, support, and self-sacrifice
did this dream become a reality.
I also dedicate it to Rick and Julie.
The spirit, humor, and courage they shared
continue to inspire me every day of my life.

ACKNOWLEDGMENTS

I extend my gratitude to the Department of Veterans Affairs (VA) Office of Academic Affairs (Washington DC) pre-Doctoral Associated Health Rehabilitation Research Fellowship Program, and the Rehabilitation Outcomes Research Center (RORC) of Excellence (Gainesville FL) for funding this study. The RORC is jointly funded by the VA Health Services Research and Development (HSR&D), and Rehabilitation Research and Development (RR&D) divisions. This research was conducted in association with Dr. Andrea Behrman's locomotor training study, which is supported in part by K01HD01348-01 (NICHD) and the VA Brain Rehabilitation Research Center (BRRC) of Excellence (Gainesville FL).

I wish to thank my doctoral advisor, VA Fellowship Preceptor, friend, and kindred spirit, Mary Ellen Young. Having the opportunity to study and work with Mary Ellen has been the highlight of my 4½ years as a doctoral student. Her knowledge, teaching skills and research expertise have been invaluable; and her enthusiasm for her work and compassion for others have been inspiring. I thank Mary Ellen for introducing me to qualitative research, and for her incredible support and guidance throughout my dissertation process. What a joy it was to share this process with someone who loves words as much as I do!

I also wish to thank Maude Rittman who has been an outstanding VA Fellowship Program Director. I will be eternally grateful to Maude for inviting me into the exciting world of VA research, for her constant support throughout my predoctoral fellowship,

and for her continued support now as we look toward building a career within the VA. The feedback and encouragement given to me by Maude and her entire qualitative research group from the Rehabilitation Outcomes Research Center (RORC) of Excellence at the North Florida/South Georgia Veterans Affairs Medical Center have been priceless throughout my fellowship and dissertation process. I also extend my sincere appreciation to Pamela Duncan, RORC Director, for her support throughout my affiliation at the RORC.

This study would not have been possible were it not for Andrea Behrman, who embraced my project and provided me with access to her locomotor training participants. Andrea and her locomotor training team welcomed me into their lab, and provided me with immeasurable support and assistance. It has been an honor to be affiliated with this knowledgeable, dedicated and caring group of people. I thank them for the incredible learning opportunity they provided me, and for their validation of my work.

I would also like to thank the other members of my dissertation committee (Linda Shaw, Robert Glueckauf, and James Stansbury) for their encouragement, guidance, and feedback throughout my time as a doctoral student. Having the opportunity to work and interact with each of them has been a truly rewarding experience and they have contributed to my professional development in ways they will never know.

Lastly, but by no means least, I wish to thank my participants for their time and commitment to this project. It has been a privilege to share their words.

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Abstract of Dissertation Presented to the Graduate School
of the University of Florida in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

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By

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May 2004

Chair: Mary Ellen Young
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Preliminary investigations using Locomotor Training (LT) to promote recovery of walking in persons with incomplete Spinal Cord Injury (iSCI) consistently report improvement in the stepping, gait, and over-ground walking ability of participants. Only one study, however, has alluded to the possible psychosocial impact of LT. To better understand how LT affects the psychosocial adaptation of participants, the objective of our study was to explore the experiences and perceptions of persons with iSCI who participated in 45 sessions of LT. The sample included seven males and one female with iSCI. Four veterans participated. Grounded theory methods were used. Data were obtained from in-depth interviews and treatment-session observations. Audiotaped interviews and field notes were transcribed and then coded using QSR N6[®] software. Codes were then analyzed for themes and patterns to define participants' experiences and perceptions of LT, and the psychosocial impact of the intervention.

Data revealed that the LT therapeutic process promoted empowerment among trainees. Acting as “coach,” “teacher,” and “therapist,” therapists provided support, motivation, and knowledge during training. Therapists engaged trainees as “team members” and involved them in treatment decisions. Data also reflected the physical, cognitive and emotional experiences of trainees. Trainees described LT as physically and cognitively demanding, and perceived cognitive effort to be as challenging as the physical demands of LT. Although the demands of LT sometimes caused frustration for trainees, all trainees highly valued the treatment, and preferred it to conventional gait therapies. Trainees identified functional progress, ambulation knowledge, hope, and the social support of the training team as benefits of LT. Trainees also reported that LT increased self-esteem, confidence, and motivation for recovery. Data suggest some trainees experienced a renewed sense of self due to their increased ability to participate in activities with their families and within their communities. Findings from this study suggest that an empowerment approach to LT may enhance the quality of life and psychosocial adaptation of persons with iSCI (through its potential to enhance recovery of walking, and through cognitive-emotional benefits). Findings may better prepare clinicians to meet the comprehensive needs of LT participants, including the development of empowerment-focused treatment approaches.

CHAPTER 1 INTRODUCTION

Overview of the Research Topic

The Experience of Recovery of Walking after Incomplete Spinal Cord Injury: One Perspective

I didn't know what to think when I took those first few shaky steps in the parallel bars five years ago. It was several days before I trusted them enough to tell anyone. I didn't know what they meant, or if they would stay or get stronger. I didn't know whom I could share these feelings and fears with. Each step meant more hope with no guarantees, enormous expectations with little reality, more distance from my SCI [spinal cord injured] friends, yet no new access to the mainstream. (Holicky, 1995, p. 66)

These poignant words provide a glimpse into one person's experience with recovery of walking after incomplete spinal cord injury. The excerpt appears in an autobiographical article written by Holicky (1995), a man with a C-5 level incomplete spinal cord injury. Through the article, Holicky shares with readers his self-proclaimed emotional roller coaster ride—the ups and downs, uncertainty, hope, and “high anxiety and mixed blessings” experienced after his injury, and throughout his quest to walk again.

Unlike complete spinal cord injuries, where post-injury functional ability may be predicted from the level of spinal cord lesion, persons sustaining incomplete spinal cord injuries maintain the potential for recovery after injury. Although persons with incomplete spinal cord injury typically do experience some return of ambulatory function, the extent of functional gains and time frame for recovery are unpredictable. Given such uncertainty, Holicky (1995) identifies his primary source of anxiety as the

challenging decisions he faced regarding physical therapy treatments. Specifically, deciding what treatments to pursue, and how long to pursue them in order to maximize his recovery of walking were anxiety-ridden decisions for Holicky. For example, Holicky expresses frustration over putting his life on-hold in order to pursue therapy, yet he continues to consult with different physical therapists out of concern that he may not be doing enough to maximize his functional return. In Holicky's case, the uncertain course of recovery associated with his injury led to unrelenting hope for further recovery.

Holicky (1995) goes on to reveal how his feelings of uncertainty and hope led to an ongoing pursuit of therapies aimed at enhancing recovery, and also postponed his emotional adaptation to his spinal cord injury. He relates that his return of function post-injury initially led to denial of his disability; and only when he eventually reached a plateau with his recovery did he experience feelings of anger and depression. In reference to the onset of his psychosocial adaptation process, Holicky claims, "My incompleteness had borrowed several years; now the loan was due" (p. 66). Despite his delay in adaptation, Holicky describes ultimately coming to terms with his functional status and learning to appreciate his functional gains.

Although Holicky's (1995) article appeared 8 years ago, his illustration of the feelings of uncertainty and hope he experienced after his incomplete spinal cord injury, and the psychosocial consequences of such feelings, are perhaps even more relevant today. While regaining the ability to walk after spinal cord injury was previously thought to be impossible, advances in neuroscience research and rehabilitation science have led to a greater understanding of the central nervous system and its potential for neural recovery. Consequently, researchers have focused recent attention on the development of rehabilitation interventions aimed at tapping this potential to promote the recovery of

walking after spinal cord injury. Such efforts are proving successful, as encouraging pilot studies of emerging treatments are resulting in national clinical trial investigations.

Despite such progress, significantly less attention has been devoted to exploring how such treatments may affect the psychosocial adaptation of persons with spinal cord injuries. According to Livneh and Antonak (1997), psychosocial adaptation to disability or chronic illness refers to

An evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence manifested by 1) active participation in social, vocational, and avocational pursuits; 2) successful negotiation of the physical environment; and 3) awareness of remaining strengths and assets as well as existing functional limitations. (p. 8)

In view of the lessons learned from Holicky's experience, the psychosocial impact of treatments to enhance the recovery of walking among persons with incomplete spinal cord injury appears to be an equally compelling and necessary focus of rehabilitation research.

Locomotor Training as an Intervention to Enhance Recovery of Walking after Incomplete Spinal Cord Injury

Of the therapeutic approaches to emerge from recent research efforts, locomotor training has proven one of the most promising. Locomotor training draws on recent knowledge gained about central-nervous-system function to assist individuals with regaining functional walking ability. Although slight variations in locomotor training protocols are evident among researchers and study sites, the crux of the intervention involves providing manual assistance to a participant while he or she steps with

Body-weight support on a treadmill (Behrman & Harkema, 2000). Preliminary studies using locomotor training have consistently reported improvement in the stepping, gait, and overground walking ability of participants with incomplete spinal cord injury

(Behrman & Harkema, 2000; de Leon, Roy & Edgerton, 2001; Dobkin, 1999; Edgerton, et al, 1991; Edgerton, de Leon, et al, 2001; Field-Fote, 2001; Field-Fote & Tepavac, 2002; Harkema, 2001; Protas, et al, 2001; Visintin & Barbeau, 1989).

Despite numerous studies reporting gains in functional ambulation after locomotor training, only one pilot study to date has investigated consumer or participant perspectives regarding the intervention (Nymark et al., 1998). Using data gathered through questionnaires and interviews with 5 locomotor training participants with incomplete spinal cord injury, Nymark et al. found that all participants were positive about the intervention (describing the protocol as physically and emotionally challenging). Findings also suggested the program increased hope and confidence, but cautioned that locomotor training participants should be kept realistic about their treatment expectations.

The findings of Nymark et al. (1998) regarding hope, confidence, and treatment expectations provide the first documented evidence that locomotor training stands to impact participants with incomplete spinal cord injury at both functional *and* psychosocial levels of experience. Although results of the Nymark et al. study are intriguing, at best the study serves as a foundation for further investigation. For example, a review of the methodology and instrumentation used by Nymark et al. reveals a limited focus of inquiry. A substantial portion of the questionnaire used by Nymark et al. was devoted to close-ended questions regarding study protocol issues. Thus, the questionnaire may have failed to elicit and capture empirically and clinically relevant information concerning the full range of participants' locomotor training experiences. Questions not addressed by the Nymark et al. study include those related to the nature and impact of the physical and emotional challenges reported, the emotional impact of unmet expectations,

what the reported increases in hope and confidence meant in the lives of participants, how locomotor training affected the ability of participants to engage in family and community activities, and how it affected the overall quality of life of participants. Additional research is therefore needed to provide an unrestricted, more complete understanding of participants' locomotor training experiences; and of how such experiences affect their psychosocial adaptation to incomplete spinal cord injury.

Exploring How Locomotor Training Affects the Psychosocial Adaptation of Persons with Incomplete Spinal Cord Injury

Over the last several years, certain theoretical models have been recognized for their contribution to understanding how individuals adapt to disability and chronic illness (Kubler-Ross, 1997; Livneh, 2001; Livneh & Antonak, 1997; Trieschmann, 1988; Wright, 1983). Each of these models will be reviewed in Chapter 2. While the evolution of adaptation theory has provided somewhat differing views of psychosocial adaptation to spinal cord injury, one issue not addressed by any of the models cited above is how the introduction of hope for recovery through the use of emerging interventions (like locomotor training) stands to impact psychosocial adaptation to spinal cord injury. As research efforts directed at treatments to promote spinal cord injury recovery and cure continue to expand, the impact of such treatments on psychosocial adaptation theory is a critical area for further investigation.

The potential of locomotor training to affect persons with incomplete spinal cord injury at psychosocial levels of experience becomes even more apparent when comparing the Nymark et al. (1998) findings on hope and treatment expectations with the intense feelings of hope and uncertainty expressed by Holicky (1995). Clearly, participation in any newly emerging, experimental treatment introduces a sense of uncertainty into the

lives of human subjects—to use Holicky’s words, a sense of “hope with no guarantees” (p. 66). Therefore locomotor training may hold unique considerations for persons with incomplete spinal cord injury who may already be coping with feelings of uncertainty associated with their disabilities. The impact of using an uncertain treatment for an uncertain disability and the subsequent effect on one’s psychosocial adaptation to spinal cord injury has yet to be explored. Learning how the uncertainty associated with incomplete spinal cord injury causes participants to respond to the hope offered by locomotor training (whether or not the pursuit of hope via locomotor training occurs at the expense of other life activities; what treatment expectations participants with incomplete spinal cord injury identify, and how they respond if their expectations of locomotor training are not met; and how locomotor training affects the way participants feel about themselves, and how they adapt to their disability) will enable researchers and clinicians to extend their understanding of locomotor training beyond a strictly functional dimension of awareness. To gain a preliminary understanding of these issues, our study explores the experiences and perceptions of persons with incomplete spinal cord injury who participate in locomotor training.

Potential Contribution to Rehabilitation Theory and Practice

Because of limited understanding of the psychosocial impact of locomotor training on persons with incomplete spinal cord injury, our study has relevance for persons with incomplete spinal cord injury, rehabilitation researchers, managers, and clinicians alike. Through exploration of how locomotor training affects the psychosocial adaptation of participants, our study will provide rehabilitation professionals with an opportunity for insight and understanding of the true, personal meaning this treatment holds for persons with incomplete spinal cord injury. Exploring the experiences and

perceptions of participants will help identify the perceived benefits and disadvantages of locomotor training, how locomotor training affects the lives of participants, and how participants respond to discrepancies between locomotor training treatment expectations and actual achievements. This information will better arm rehabilitation professionals to meet the comprehensive needs of locomotor training participants. For example, pending the results of our study, clinicians may choose to alter the intervention or protocol to better meet the needs and goals of participants, broaden the scope of the intervention to include provisions for counseling and/or peer support, or institute/modify participant education programs. Thus, by expanding the locomotor training research focus beyond a strictly physiological/functional domain, our study stands to provide researchers, managers, and clinicians with a necessary and critical perspective for assessing the future of this intervention—that of the personal experiences of participants. Accordingly, the present study has the potential to aid in the development of valid outcome measures for evaluating locomotor training before widespread clinical applications of the intervention.

Procedures Used

The aim of our study is to provide an initial investigation of the effects of locomotor training on the psychosocial adaptation of persons with incomplete spinal cord injury. In keeping with the exploratory nature of the study, grounded theory methods (Glaser & Strauss, 1967) were used for data collection, analysis, and interpretation. Data were collected through in-depth, semi-structured interviews and participant observations with 8 participants, in an ongoing locomotor training study at the University of Florida, Department of Physical Therapy. Data were transcribed into Word® documents, and then coded using the QSR N6® qualitative computer software program. Codes and coded data were analyzed and interpreted using the constant comparative method (Glaser & Strauss,

1967) to identify emerging themes, and patterns and relationships among themes.

Themes and relationships that emerged from the data were used to develop a theoretical framework that was representative of study findings.

Summary

Locomotor training has emerged as a promising intervention to promote the recovery of walking after incomplete spinal cord injury. While preliminary studies have consistently reported improvements in the stepping, gait, and walking ability of locomotor training participants, only one previous study has attempted to investigate the intervention from the perspective of participants (Nymark et al., 1998). Nymark et al. (1998) reported locomotor training was positively received by participants, and increased their hope and confidence; but also cautioned that some participants may hold unrealistic expectations of the treatment. Despite the apparent importance of these findings, they were not thoroughly addressed by Nymark et al., nor were participant experiences and perceptions investigated in depth. These findings (combined with the uncertain course of recovery associated with incomplete spinal cord injury, and the fact that locomotor training is still viewed as an experimental treatment that cannot guarantee positive outcomes) point to the psychosocial implications that the intervention may hold for participants. Understanding how locomotor training affects the psychosocial adaptation of participants with incomplete spinal cord injuries will provide researchers and clinicians with an important perspective for evaluating locomotor training outcomes, and better enable them to meet the comprehensive needs of locomotor training participants.

Statement of the Problem

The primary goal of our study is to answer the research question, “How does participation in locomotor training affect the psychosocial adaptation of persons with

incomplete spinal cord injury?” To adequately answer this question, the following goals and related research questions will be answered:

Goal #1. Describe the experiences and perceptions of persons with incomplete spinal cord injury who participate in a locomotor training study.

- **Question #1.** How do persons with incomplete spinal cord injury describe their locomotor training experiences? What are their psychosocial reactions?
- **Question #2.** What do these experiences suggest about the impact of locomotor training on the lives of persons with incomplete spinal cord injury?
- **Question #3.** How does participation in locomotor training affect the way persons with incomplete spinal cord injury think and feel about their disabilities and themselves?

Goal #2. Use grounded theory methods to develop a conceptual framework showing the effects of locomotor training on the psychosocial adaptation of study participants.

Theoretical Framework

In keeping with the exploratory nature of this study and grounded theory principles (that maintain theory is to be derived inductively from qualitative data) (Glaser & Strauss, 1967), no preconceived theoretical framework was selected to guide this research or interpret research findings. The theoretical framework resulting from our study evolved through an ongoing process of data analysis and interpretation described in Chapter 3 and is described in Chapter 4. Results of our study are presented in Chapters 5 and 6. In Chapter 7, the theoretical framework derived from this study is compared to Trieschmann’s (1988) model of adaptation to spinal cord injury and to the model of psychosocial adaptation to disability and chronic illness described by Livneh (2001).

CHAPTER 2 REVIEW OF THE LITERATURE

Background

Spinal Cord Injury Prevalence and Cost

National figures on the prevalence and cost of spinal cord injury reflect the significant impact this disability has on the United States' health care economy. Recent statistics, for example, estimate approximately 183,000 to 230,000 people in the United States have spinal cord injuries and an additional 11,000 new cases occur each year (National Spinal Cord Injury Statistical Center, 2001). Of those who sustain spinal cord injury, 51.6% have quadriplegia or tetraplegia (injury to a cervical segment of the spinal cord); and 46.3% have paraplegia (injury to the thoracic, lumbar, or sacral regions of the spinal cord). The National Spinal Cord Injury Statistical Center (NSCISC) publication, *Spinal Cord Injury: Facts and Figures at a Glance*, reports that the proportion of persons sustaining incomplete spinal cord injuries is on the rise. Incomplete spinal cord injuries are characterized by preservation of motor or sensory function more than three segments below the level of injury (Go, DeVivo & Richards, 1995). According to the NSCISC, incomplete tetraplegia is the most frequently reported neurologic category since 1990; and recent trends suggest that the number of persons with incomplete paraplegia is also increasing. Go, DeVivo and Richards (1995) attribute the increased numbers of persons with incomplete spinal cord injury to a changing epidemiology of spinal cord injury, due in part to advances in emergency medical services.

Spinal cord injury in the United States results in associated costs estimated to exceed 9.73 billion dollars per year (Berkowitz, O'Leary, Kruse & Harvey, 1998). While individual costs related to spinal cord injury vary depending on level and severity of spinal cord injury and the age of onset, it is estimated that persons with high tetraplegia have approximate annual expenses of \$102,491; while a person with an incomplete spinal cord injury (at any level) may incur costs of \$11,817 per year (NSCISC, 2001). Lifetime expenses associated with spinal cord injury may exceed millions of dollars, even if the injury is acquired later in life. For example, it is estimated that individuals who sustain a spinal cord injury at 50 years of age or older may incur lifetime expenses averaging \$1,286,714 if the injury level is high tetraplegia; and \$353,047 if the injury is incomplete at any level (NSCISC, 2001). Thus, even for the aging population, spinal cord injury results in a significant drain to the United States health care system.

National figures on persons aging with spinal cord injury parallel statistics available on veterans with spinal cord injury. The Department of Veterans Affairs (VA) Allocation Resource Center (ARC), which maintains figures on expenses for VA patient populations, indicates for the fourth quarter of fiscal year 2002, a total of 24,490 Veterans with spinal cord dysfunction resulted in combined costs of \$18,465,460 to the VA (ARC Database, 2003). Such figures provide evidence that spinal cord injury results in sizeable consumption of VA health-care resources. Considering that advances in medicine and technology have resulted in increased life span for persons with spinal cord injury, and the fact that the elderly population is growing, the VA is likely to see growing numbers of aging veterans with spinal cord injury.

Rehabilitation Interventions for Spinal Cord Injury and Locomotor Training

Statistics on the national prevalence and cost of spinal cord injury serve to illustrate the significant economic impact of this disability. However, the mobility limitations and secondary health complications associated with spinal cord injury; the emotional, psychosocial impact of the disability; the resulting restrictions in family and community participation; and the financial demands of living with a spinal cord injury undoubtedly hold greater significance for those individuals having the disability and their families. In an effort to increase functional independence after spinal cord injury (and indirectly, minimize the psychosocial impact and health costs of the disability), spinal cord injury rehabilitation intervention efforts have historically focused on compensatory strategies aimed at maximizing a person's remaining functional capabilities and preventing secondary conditions related to the disability. Throughout the last 2 decades however, rehabilitation research has led to a greater understanding of how the central nervous system functions, and its capacity for recovery. Consequently, the spinal cord injury rehabilitation research paradigm has begun to shift from compensatory interventions toward new approaches aimed at neural recovery. Locomotor training is one such approach receiving considerable attention in the rehabilitation literature, for its demonstrated promise in the treatment of persons with incomplete spinal cord injury.

Locomotor-training interventions used in the rehabilitation of humans are the result of widespread research in the control of locomotion in mammals (Behrman & Harkema, 2000). In its basic form, locomotor training involves providing manual assistance to a participant while he or she steps with body weight support on a treadmill (Behrman & Harkema, 2000). In studies using this procedure, researchers have established that the lumbosacral spinal cord of humans, even when damaged, maintains

the ability to respond to sensory information related to locomotion. Edgerton et al. (1991), pioneering researchers in locomotor training, attribute this phenomenon to the existence of circuits within the spinal cord acting as central pattern generators. These circuits exhibit neural plasticity and are capable of motor learning if properly activated. Edgerton et al. maintain that for activation to occur, specific sensory input associated with performance of a motor task must be provided, followed by repetitive practice of the task. These requirements are fulfilled during locomotor training.

While the specific protocols used in locomotor training programs often vary according to study site and research interests of investigators, all activities integrated into the locomotor training intervention are derived from four guiding principles aimed at optimizing neural recovery. As outlined by Harkema and Behrman (2002), the guiding principles of locomotor training are

- Maximize weight bearing on the legs (e.g., encourage standing whenever possible)
- Optimize sensory input and cues (e.g., try to simulate “normal” walking speeds and movements as much as possible)
- Optimize kinematics for each motor task (e.g., encouraging upright posture and coordinated limb movements)
- Maximize recovery and minimize compensation (e.g., encourage independence versus physical assistance, and use of least restrictive assistive devices).

These principles are followed during step training on the treadmill, during overground walking training, and during community ambulation training (Harkema & Behrman, 2002).

Locomotor training outcomes and the randomized clinical trial study.

Compared to conventional rehabilitation therapies, preliminary studies of locomotor training consistently report improved stepping, gait, and overground walking ability of

participants with incomplete spinal cord injury (Behrman & Harkema, 2000; de Leon, Roy & Edgerton, 2000; Dobkin, 1999, 1999b; Edgerton et al., 1991; Edgerton, de Leon, et al., 2001; Field-Fote, 2000, 2001; Harkema, 2001; Protas et al., 2001; Visintin & Barbeau, 1989). Although published reports of long-term locomotor training outcomes are limited in number, two studies provide preliminary outcome data (Wernig, Nanassy & Müller, 1998; Wirz, Colombo & Dietz, 2001). In follow-up studies conducted 6 months to 6 ½ years after hospital discharge, Wernig, Nanassy, and Müller (1998) compared the locomotor training outcomes of 35 persons with chronic spinal cord injury versus 41 persons with acute spinal cord injury. Wernig et al. found that functional walking improvements gained during locomotor training were maintained in 31 of the 35 chronically injured participants, and in all 41 of the acute participants. Additional functional gains post-training were evident in 3 of the chronic participants, and in 15 of the acute participants; and only 1 chronic participant had reduced function at follow-up. Follow-up studies by Wirz, Colombo, and Dietz (2001) found that former locomotor training participants with incomplete spinal cord injury (who routinely engaged in locomotor activity after training) maintained relatively constant leg extensor EMG activity more than 3 years after training. Conversely, Wirz et al. reported decreased EMG activity in former participants with complete spinal cord injury. While additional longitudinal studies are needed, preliminary findings from the follow-up studies cited provide support that neurophysiological activity and ambulatory gains evidenced by persons with incomplete spinal cord injury during locomotor training are often maintained; and in some cases, continue to improve long after the intervention.

After more than a decade of research, promising results from locomotor training pilot studies with humans led to the funding of a five-site randomized clinical trial study

to test the efficacy and effectiveness of the intervention compared to conventional physical therapy methods (National Institutes of Health, 2003). Results of the clinical trial, which began in 1999 and continues through 2004, will undoubtedly influence the future of locomotor training and the extent to which the intervention is translated into clinical practice. If locomotor training is to gain widespread clinical application however, one important dimension has yet to be considered—the psychosocial impact of the intervention on participants.

Beyond Function: Psychosocial Impact of Locomotor Training and Why It Matters

Despite the growing body of literature on locomotor training and the implementation of a multi-site clinical trial study, rehabilitation research has been largely inattentive to the potential psychosocial impact of the intervention. Although Dobkin (1999) identified participant perceptions about health-related quality of life as a locomotor-training outcome needing further investigation, questions related to the impact of locomotor training on participants' emotional well-being, self-esteem, quality of life, and ability to engage in activities with their families and within their communities have yet to be comprehensively addressed. While a primary goal of studies on new rehabilitation interventions is to assess functional outcomes and effectiveness, the need to consider the domain of the *person* in health care is receiving greater emphasis (World Health Organization, 2002). Consequently, we need an understanding of how locomotor training affects participants beyond physical and functional outcomes; affects participants psychosocially, including their emotional and cognitive reactions to the treatment; and affects family and community participation. Such information will help establish how locomotor training affects the quality of life and motivation for recovery of participants,

and may serve to assist clinicians with developing consumer-centered treatment approaches for the intervention.

Relevant Research

Only one study to date has sought consumer feedback on locomotor training (Nymark et al., 1998). As part of a pilot study, Nymark et al. used a consumer consultant (a former locomotor training participant) to administer a questionnaire and conduct “focused” interviews with 5 participants with incomplete spinal cord injury (on completion of a 12-week locomotor training program). Results of the survey indicated that all participants were positive about the training, and all viewed the protocol to be physically and emotionally challenging and beneficial. Participant comments cited in the article further indicate that the program increased hope and confidence, and that future participants should be kept realistic about their treatment expectations.

While the findings of Nymark et al. (1998) are intriguing, and raise important issues relevant to the psychosocial impact of locomotor training, further investigation of such issues appears warranted. A review of the Participant Feedback Questionnaire used by Nymark et al. indicates that the primary focus of the survey/interview was restricted to feedback on the study protocol, with limited attention given to participants’ psychosocial experiences. Furthermore, most of the questions appearing in the 16 item questionnaire were close-ended, or provided ranked responses with limited opportunity for nonstructured dialog. Such factors suggest that the feedback provided by participants on locomotor training, although informative and interesting, was only minimally tapped.

While Nymark et al. (1998) are the first investigators to allude to the “consumer impact” of locomotor training, quantitative research studies have explored the emotional impact of other emerging therapeutic interventions on persons with spinal cord injury.

Most notably, the psychological impact of functional electrical stimulation (FES) and functional nerve stimulation (FNS) based therapies have been investigated (Agarwal et al., 2003; Baker, Heinemann, Yarkony, & Jaeger, 1989; Bradley, 1994; Guest, Klose, Needham-Shropshire, & Jacobs, 1997; Heinemann, Magiera-Planey, Gimenes, & Geist, 1985). Of these studies, the findings of Bradley (1994) and Guest, Klose, Needham-Shropshire, and Jacobs (1997) appear particularly relevant to studying the psychosocial impact of locomotor training.

Bradley (1994) explored whether participation in an FES exercise program (involving muscle training, bicycle ergometry, biofeedback, conventional physical therapy, and gait training) led to improved affective status for persons with spinal cord injury; and whether unrealistic participant expectations resulted in negative affect. While Bradley found no increase in the positive affective status of participants, she reported increases in depression and hostility within her sample at post-test. Bradley postulated the incongruence between participant expectations and actual experiences as a possible cause of the negative affect; and recommended evaluating the expectations of potential participants before enrollment in similar FES programs.

The findings of Guest, Klose, Needham-Shropshire, and Jacobs (1997) conflict with those of Bradley (1994). Guest et al. investigated the effect of a 32-session training program using the Parastep 1[®] Ambulation system on persons with paraplegia.

Hypothesizing “that standing and walking may have a psychologically more powerful effect than more conventional forms of exercise such as muscle strengthening or bicycle ergometry” (Guest et al., 1997, p. 804), investigators used quantitative measures of self-concept and depression, and brief interviews posttraining, to assess the psychological

impact of the FNS-based intervention. The study found statistically significant increases in self-concept and decreased depression after the ambulation-training program.

Reminiscent of the Bradley study however, Guest et al. also found evidence supporting the influential role of participant expectations throughout treatment. For example, despite the fact limitations of the ambulation system were emphasized with participants before training, Guest et al. reported that 3 of the 15 participants expressed hope for recovery of voluntary leg-muscle function. Although these participants were disappointed with their lack of recovery, they did not evidence increased depression scores.

Although limited to the study of FES and FNS, the work of Bradley (1994) and Guest et al. (1997) provide evidence that emerging interventions aimed at improving ambulation will likely have an emotional impact on persons with spinal cord injury. Questions raised by these researchers regarding the impact of such interventions have on depression and self-concept, and the role of hope and treatment expectations on emotions, are equally applicable to the study of locomotor training. While Nymark et al. (1998) cited in their study results, (a) the need to maintain realistic treatment expectations, and (b) increased hope and confidence among locomotor training participants, these findings were not discussed in depth.

Increased understanding of how locomotor training personally affects participants, their quality of life, and motivation for recovery will serve to influence the future of this intervention; and may provide a foundation for the investigation of psychosocial considerations for other spinal cord injury interventions. Given that the population of persons with incomplete spinal cord injury is growing, locomotor training may be one of the most important interventions to emerge from rehabilitation science. With ongoing advances in rehabilitation medicine and spinal cord injury research, and

the growing recognition of the need to consider the personal domain of health care, it appears that the psychosocial dimension of emerging therapeutic interventions (such as locomotor training) is both relevant and timely. To provide a context for understanding the potential psychosocial impact of locomotor training on persons with incomplete spinal cord injury, an overview of psychosocial adaptation to chronic illness, disability, and spinal cord injury is provided.

Models of Psychosocial Adaptation

A review of the rehabilitation literature reveals that, for more than 60 years, disability scholars and rehabilitation professionals have addressed the topic of psychosocial adaptation to chronic illness and disability (DeLoach & Greer, 1981; Dembo, Leviton & Wright, 1975; Dijkers, Buda Abela, Gens & Gordon, 1995; Frank & Elliot, 1987; Kendall & Buys, 1998; Kubler-Ross, 1997; Livneh, 2001; Livneh & Antonak, 1997; Rolland, 1994; Shontz, 1991; Trieschmann, 1988; Wright, 1983). Included within this body of literature are specific theoretical models that have shaped current understanding of the adaptation process. These models include the work of Wright (1983), Kubler-Ross (1997), Trieschmann (1988), Livneh & Antonak (1997), and Livneh (2001). A brief overview of the aforementioned models will serve to describe the composition of each, demonstrate the evolution of psychosocial adaptation theory through the years, and subsequently, inform the topic of locomotor training effects on the psychosocial adaptation of persons with incomplete spinal cord injury.

One of the earliest and most influential researchers to address the issue of psychosocial adaptation to physical disabilities was Beatrice Wright. Wright's (1983) "cognitive restructuring" model focused almost exclusively on the need of the person

with a disability to change his or her thoughts and values about one's self. She theorized that following a crisis (such as the onset of a disability) a person must make specific value changes in order to accept his or her disability as "nondevaluating." Wright (1983, p. 163) proposed that five value changes occur:

- Enlarging the scope of values or "emotionally appreciating the existence of values in addition to the one(s) lost"
- Subordinating the physique relative to other values
- Containing disability effects
- Transforming comparative states values into asset values
- Acceptance of and adjustment to the physical disability.

The role of the personal cognitive dimension in the adaptation process proposed by Wright has served to influence later adaptation models.

While Wright's (1983) model specifically addressed adaptation to physical disabilities, Kubler-Ross (1997) developed her widely popular theory of loss through her research with terminal cancer patients. Her theory maintains that people pass through five stages when coming to terms with death or loss—denial, anger, bargaining, depression, and acceptance. Kubler-Ross' (1997) model gained popularity among psychologists and counselors, and was soon applied to chronic illnesses other than cancer and to persons with acquired disabilities. For many years, Kubler-Ross' (1997) model was widely applied in rehabilitation settings, and the emotional "reactions" to loss proposed by her theory continue to be evident in current adaptation models.

Trieschmann (1988) was one of the first investigators to specifically address psychosocial adaptation to spinal cord injury. Compared to the value-change model proposed by Wright (1983) and stage model described by Kubler-Ross (1997),

Trieschmann proposed an educational or health care model of spinal cord injury rehabilitation which may be applied to psychosocial adaptation. Within Trieschmann's rehabilitation model, adaptation to spinal cord injury is depicted as a *process* or interactive system in which adaptation (B) is a function of the interplay among psychosocial variables (P), organic/biological variables (O), and environmental variables (E). According to Trieschmann, adaptation is a process of restoring balance among the P, O, and E variables. Trieschmann's educational model of spinal cord injury rehabilitation (as it applies to adaptation) is depicted in Figure 1. According to Trieschmann's spinal cord injury-specific model, psychosocial variables include self-responsibility, will to live, social skills, coping style, locus of control, self-confidence, judgment, problem-solving ability, education, work history, job skills, cultural/ethnic group, gender, creativity, belief system, and philosophical/spiritual outlook. Thus Trieschmann's interpretation of psychosocial variables captures both the psychosocial cognitive/value component of adaptation identified by Wright (1983) and the emotional/coping component proposed by Kubler-Ross (1997). In addition, Trieschmann was the first scholar to recognize the critical dimension of environmental influences in her adaptation model. Following Trieschmann's lead, environmental components were subsequently incorporated into later models of adaptation.

A recent model of psychosocial adaptation was proposed by Livneh and Antonak (1997), and recently revised by Livneh (2001). As cited in Chapter 1, Livneh and Antonak (1997) define psychosocial adaptation as

An evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence manifested by 1) active participation in social, vocational, and avocational pursuits; 2) successful negotiation of the physical environment; and 3) awareness of remaining strengths and assets as well as existing functional limitations. (p. 8)

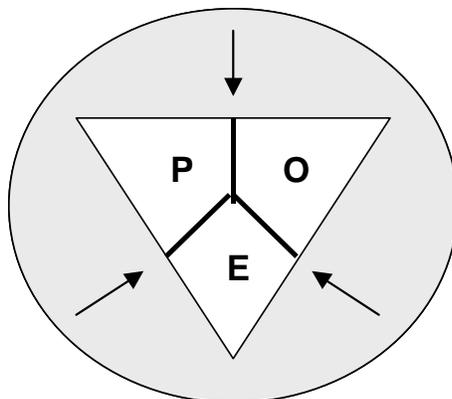


Figure 1. Trieschmann's educational model of spinal cord injury rehabilitation as applied to spinal cord injury adjustment (Spinal cord injuries: Psychological, social and vocational rehabilitation, 1988, p.40)

In contrast to the models of adaptation proposed by Wright (1983), Kubler-Ross (1997), and Trieschmann (1988), Livneh and Antonak suggest people with disabilities and chronic illness experience eight *phases* of psychosocial adaptation—shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgement or acceptance of disability, and adjustment. Livneh and Antonak contend a phase model of adaptation reflects the individual nature of psychosocial adaptation, and accounts for the fact that people may experience two or more overlapping phases simultaneously; may skip phases; or experience certain phases more than once during their lifetime. According to Livneh and Antonak, psychosocial adaptation to disability or chronic illness is an ongoing process that is dependent upon the interaction among disability variables, sociodemographic variables, personality variables, and environmental variables. Thus Livneh and Antonak's model incorporates constructs and variables from the adaptation models proposed by Wright (1983), Kubler-Ross (1997), and Trieschmann (1988).

Compared to Trieschmann's (1988) adaptation model, Livneh and Antonak (1997) identify psychosocial variables as variables associated with the personality attributes of an individual. Livneh and Antonak define psychosocial variables as the use

of coping strategies and defense mechanisms, attributional processes such as locus of control, personal meaning of the condition, attitudes toward health, sickness and deviance, personal values and beliefs, self-concept and ego strength, body image, intellectual ability, acceptance of the disability, premorbid psychosocial adaptation, and experience with similar crises. In the Livneh and Antonak model, such variables are viewed as interdependent with sociodemographic variables and disability/condition related variables. Depicted in Figure 2, Livneh's (2001) revised model of psychosocial adaptation is more comprehensive than his earlier model (Livneh & Antonak, 1997). In it, he includes antecedent variables (triggering events and contextual variables of biological status, psychological status and environmental conditions), process variables (experienced reactions and responses to disability, and contextual influences of condition-related, personality, sociodemographic and environmental variables), and outcome variables (quality of life outcomes in intrapersonal, interpersonal, and extrapersonal functional domains). Through the addition of new components such as triggering factors and outcome variables, and clearly depicted relationships among constructs, Livneh (2001) greatly expanded the scope of his model of psychosocial adaptation.

Compared to his earlier model, in Livneh's (2001) revised conceptual framework for psychosocial adaptation, he defines psychosocial variables much more broadly—as personal and social identities; cognitive, emotional and moral developmental status; family and marital developmental status; and the perceived degree of resultant life threat due to disability. Seemingly in an effort to clarify such variables, Livneh goes on to list the many psychological attributes that have been shown to successfully predict adaptation to disability, including, self-esteem, self-efficacy, locus of control, hardiness

or resiliency, sense of coherence, ego strength, optimism, body image, meaning attributed to the condition, personal attitudes, beliefs, and values, nervousness and emotional arousal, pain tolerance, cognitive ability, use of defense mechanisms, and coping style. Such attributes are largely reflective of those also identified by Wright (1983), Trieschmann (1988) and Livneh and Antonak (1997).

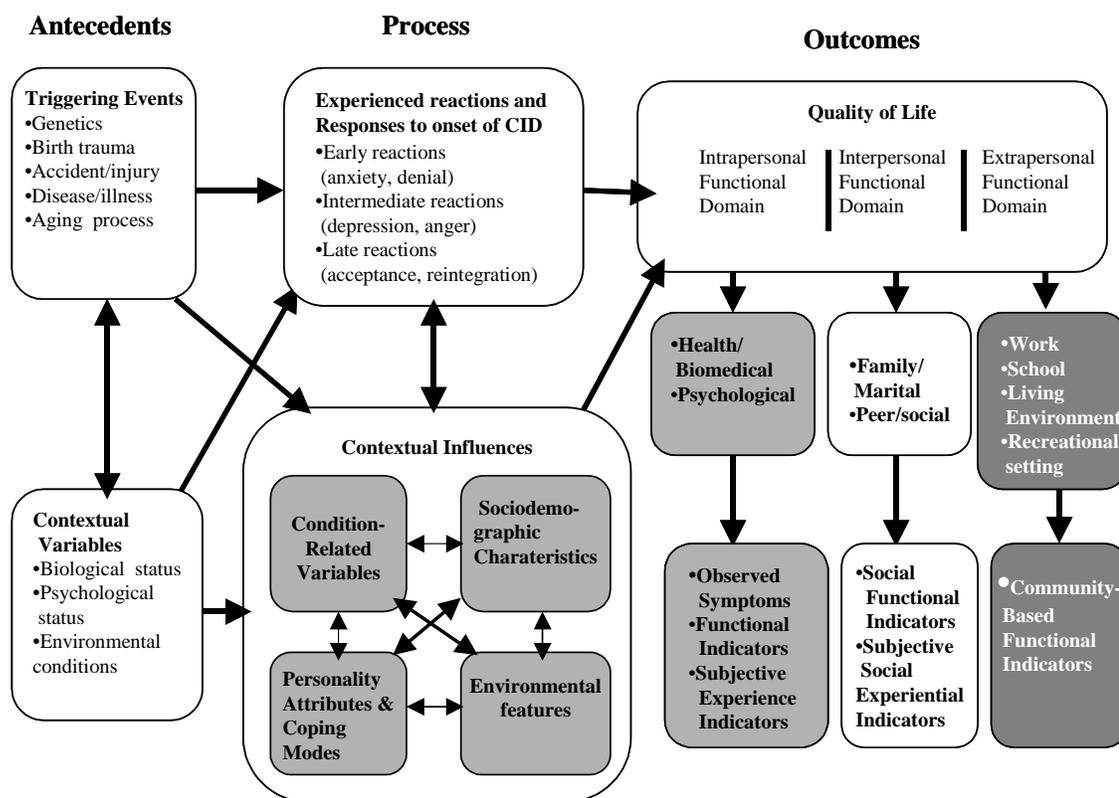


Figure 2. Livneh's (2001) revised model of psychosocial adaptation (Psychosocial adaptation to chronic illness and disability: A conceptual framework, *Rehabilitation Counseling Bulletin*, 44, 2001, p. 155)

According to the Livneh (2001) model, the process of adaptation is characterized by phases of response to the disability, and these phases reflect the psychosocial experiences of the individual. For example, early reactions may be characterized by anxiety and denial, intermediate reactions may be characterized by depression and anger, and later reactions may be characterized by acceptance of disability, and reintegration.

While the theoretical framework is complex, the psychosocial adaptation to disability is an equally complex phenomenon. The Livneh (2001) model represents psychosocial adaptation to disability as an individualized, dynamic, ongoing process that responds to changes and events throughout a person's life after disability.

Psychosocial Adaptation Models and the Prospect of Recovery

One question not addressed by the Livneh (2001) model, nor the other models of psychosocial adaptation previously cited, is how the introduction of hope for recovery through the use of innovative, but experimental, therapeutic interventions affects the adaptation process. The reason for this trend may stem from the fact that disability theorists and researchers have historically conceptualized disability in terms of prognosis and course of progression. For example, Rolland (1994) and Smart (2001) have categorized disabilities and chronic illnesses as constant or static, progressively worsening, or relapsing or episodic.

According to Rolland (1994), constant or static disabilities such as spinal cord injuries, traumatic brain injuries, amputations and single-episode heart attacks are characterized by a sudden onset, followed by stabilization of the condition. Rolland cites various types of cancer as examples of slowly or rapidly progressive illnesses, and defines relapsing or episodic disabilities as having a course that alternates between stable periods where few or no symptoms are apparent, with periods where symptoms are active or exacerbated. Rolland identifies multiple sclerosis and lupus as examples of relapsing or episodic disabilities.

By categorizing disabilities and chronic illnesses as static, progressive or episodic, the prospect of a person's disability significantly *improving* or being *cured* is not considered. Consequently, few psychosocial adaptation theories have previously

reflected how the adaptation process would change if a treatment, such as locomotor training, is introduced late in the process, after the individual has adapted to his or her disability. Given the recent and ever-growing advances in rehabilitation and spinal cord injury research, many of which are focused on curing paralysis, exploring this phenomenon appears highly relevant to the study of rehabilitation outcomes and to psychosocial adaptation theory.

Psychosocial Adaptation to Spinal Cord Injury

In recognition that “the onset of spinal cord injury disrupts a wide range of a person’s life activities and future plans” (Livneh & Antonak, 1997, p. 135), the topic of psychosocial adjustment or adaptation to spinal cord injury has received an abundance of attention in the rehabilitation literature. Within this body of literature, psychosocial adaptation has been addressed a) from a comprehensive perspective, as a process influenced by personal psychosocial variables, variables related to physical functioning and health, and environmental influences (Livneh, 2001; Livneh & Antonak, 1997; Trieschmann, 1980/1988), b) as a personal cognitive-emotional process that involves value change and self-appraisal, and is influenced by personality traits such as coping skills and locus of control (Frank & Elliott, 1987; Galvin & Godfrey, 2001; Wright, 1972/1983), and c) in terms of the myriad of specific issues associated with or affected by spinal cord injury. These issues include depression and psychological adjustment (Frank & Elliott, 1987; Frank, Elliott, Corcoran & Wonderlich, 1987; Fuhrer, Rintala, Hart, Clearman & Young, 1993; Kemp, Krause & Adkins, 1999; Krause, Coker, Charlifue & Whiteneck, 1999; Rintala, Young, Hart & Furher, 1994), suicide (Kewman & Tate, 1998; Kishi & Robinson, 1996), vocational rehabilitation, employment and education (Crewe, 2000; Krause, 1996; Krause & Anson, 1997; Rohe & Krause, 1999;

Yasuda, Wehman, Targett, Cifu & West, 2002; Young, Alfred, Rintala & Hart, 1994), self-esteem (Marini, Rogers, Slate & Vines, 1995), independent living (Adams & Beatty, 1998; DeJong, Branch & Corcoran, 1984; Frieden & Cole, 1985), relationships and sexuality (Ducharme & Gill, 1997; Mona et al., 2000; Sipski, 1997), marriage (Feigin, 1998; Milligan & Neufeldt, 1998; Putzke, Elliott & Richards, 2001), caregiver issues (Elliott, Shewchuk & Richards, 2001; Elliott & Shewchuck, 1998; Kolakowsky-Hayner & Kishore, 1999), and quality of life (Boswell, 1997; Duggan & Dijkers, 1999, 2001; Manns & Chad, 2001). More recent efforts at characterizing the psychosocial adaptation process have focused on describing the personal experiences of persons with spinal cord injuries (Berman & Rose, 1998; Carpenter, 1994; Dijkers, Buda Abela, Gens & Gordon; 1995).

Comprehensive reviews of the spinal cord injury adaptation literature have been conducted by Woodbury (1978), Trieschmann (1988) and Livneh and Antonak (1997). In a chapter dedicated to spinal cord injury adaptation, Livneh and Antonak (1997) conclude that “successful” psychosocial adaptation to spinal cord injury is associated with a younger age at injury, increased time since injury, an internal locus of control, ego resiliency, use of effective coping strategies, and a stable, positive social support network. Of greater concern to the present study are a few selected factors associated with spinal cord injury adaptation that will be briefly addressed. These factors include depression among persons with spinal cord injury, self-image, and community reintegration. These factors were selected because they appear to be particularly relevant to the present study, either in light of the existing literature on recovery of walking, or the likelihood that they may be affected by locomotor training. For example, the previously cited study by Bradley (1994) reported increased depression scores among persons with

incomplete spinal cord injury who participated in FES exercise program, and had “unrealistic” expectations. In addition, through its potential to enhance recovery of walking, it appears locomotor training stands to impact the self-image and community reintegration of persons with incomplete spinal cord injury.

Depression

As already indicated, the topic of depression and spinal cord injury has been widely addressed in the rehabilitation literature (Frank & Elliott, 1987; Frank, Elliott, Corcoran & Wonderlich, 1987; Fuhrer, Rintala, Hart, Clearman & Young, 1993; Kemp, Krause & Adkins, 1999; Krause, Coker, Charlifue & Whiteneck, 1999; Trieschmann, 1980/1988; Rintala, Young, Hart & Furher, 1994). The prevalence of depression among persons with newly acquired spinal cord injuries has also proven to be a point of controversy among some researchers. Likely attributable to the theory of loss proposed by Kubler-Ross (1969/1997), researchers previously relied only on observational reports of behavior to conclude that depression is a common reaction after spinal cord injury (Frank & Elliott, 1987; Trieschmann, 1988). Following her review of the literature on depression and spinal cord injury however, Trieschmann (1988) suggests researcher bias combined with poor research methodology may have led to previous assumptions that depression is a necessary part of the psychosocial adaptation process, especially soon after injury. Instead, Trieschmann suggests feelings of loss or grief and helplessness evidenced by persons with newly acquired spinal cord injuries may have been wrongly labeled as depression. Regarding the prevalence of depression among persons with spinal cord injury, Trieschmann (1988) concludes,

Consequently, we must conclude that spinal cord injury does not necessarily lead to depressive reactions in most people soon after onset and the absence of depression does not imply denial of injury or poor adjustment to disability. Each

study noted the individual differences in emotional response to the disability, which is further evidence for the heterogeneity of the population with spinal cord injury. (p. 79)

While Trieschmann (1988) explored depression primarily from the standpoint of its role in adaptation soon after spinal cord injury, other studies have attempted to determine the prevalence of depression among persons with spinal cord injury after the acute and rehabilitation phases of treatment. For example, Fuhrer, Rintala, Hart, Clearman and Young (1993) conducted a study to determine the prevalence of depressive symptomatology among 100 men and 40 women with spinal cord injury who lived in the community. Using the Center for Epidemiologic Studies Depression Scale, these researchers reported a higher mean score with their sample than within the general population, but found no significant relationship between depression and disability or disability and impairment (Fuhrer, Rintala, Hart, Clearman & Young, 1993). These researchers concluded “depression is associated with restrictions in social role performance that stem from the interactive influences of the environment, disability, and impairment” (Fuhrer, Rintala, Hart, Clearman & Young, 1993, p. 259).

Additional studies have attempted to investigate the relationship between the ethnicity of persons with spinal cord injury and depression. For example, in a study of African Americans, Latinos and Caucasians with spinal cord injuries, Kemp, Krause and Adkins (1999) reported higher depression scores among Latinos than among the African American and Caucasian participants. In another study, Krause, Coker, Charlifue and Whiteneck (1999) explored depression and subjective well-being among American Indians with spinal cord injuries and concluded this group experienced a diminished sense of subjective well-being compared to other ethnic populations with spinal cord

injuries. These findings regarding ethnicity and depression have implications for the assessment, treatment, and service-provision needs of persons with spinal cord injuries.

Self-image

Trieschmann (1988) noted “The altered physical image a person presents to society [after spinal cord injury] can have tremendous impact on the individual’s self-image” (p. 255). Factors that Trieschmann cites as potentially affecting the self-image of persons with spinal cord injury are the use of mobility devices, changes in body appearance such as muscle atrophy and swelling, and the need for products to manage bowel and bladder function such as catheters, legbags, and colostomies. Despite this recognition, Trieschmann acknowledged a lack of literature on the topics of self-image and body image among persons with spinal cord injury. A more recent review of the literature yielded similar findings, suggesting the topics of body image and self-image among persons with spinal cord injury still remain largely untapped areas of investigation. One small qualitative study was found, however, that provides some insight into the self-image and body image of persons with spinal cord injury. In an investigation of body image and physical disability, Taleporos and McCabe (2002) conducted interviews with seven persons with physical disabilities and reported “bodily impairment had a negative influence on the participants’ psychological experiences, feelings and attitudes toward their own bodies” (p. 971). Despite this fact, Taleporos and McCabe also found that their participants grew increasingly accepting of their bodies and disabilities over time.

Community Reintegration

Trieschmann (1988) outlines a number of factors associated with community reintegration. After completing inpatient rehabilitation, and hopefully achieving some

level of functional independence, persons with spinal cord injuries are faced with the task of returning to their lives. Community reintegration involves not only social reintegration, such as adapting to social role changes within the family, establishing or reestablishing relationships with peers, and coping with changes in sexual relationships, but also coping with issues related to health and wellness needs, living arrangements, personal assistance needs, the financial consequences of spinal cord injury, transportation, employment, and recreation and leisure pursuits (Trieschmann, 1988).

Trieschmann (1988) emphasized that successful community reintegration is largely influenced by environmental variables. This fact is reinforced by the results of a study on independent living outcomes conducted by DeJong, Branch, and Corcoran (1984). This study reported that independent living arrangement was predicted by the variables of being married, older age at onset of spinal cord injury, female gender, access to transportation, the need for minimal medical supervision, and few unmet service needs (DeJong, Branch & Corcoran, 1984). This same study also found that variables accounting for variance in productivity outcomes included: the availability of transportation, economic disincentives, educational level, Barthel Index score, the number of vocational rehabilitation services received, and a younger age (DeJong, Branch & Corcoran, 1984).

Undoubtedly, one of the greatest tasks associated with community reintegration is returning to work, or gaining employment. Trieschmann (1988) recognized that there exists an “emphasis on gainful employment as a condition for full citizenship” (p. 196). Given this recognition, it is not surprising that the rehabilitation of persons with spinal cord injuries has largely focused on employment and return to work issues. In fact, a review of the spinal cord injury literature reveals a predominant proportion of the

literature is dedicated to the topic of employment. For example, studies have reported low rates of employment after spinal cord injury (Rohe & Krause, 1999; Young, Alfred, Rintala & Hart, 1994). A recent review of employment research concluded that demographic variables found to influence return to work for persons with spinal cord injury include age at injury onset, chronological age, gender, education, ethnicity, marital status, preinjury work intensity, satisfaction, and psychosocial adjustment to spinal cord injury (Yasuda, Wehman, Targett, Cifu & West, 2002).

Psychosocial Adaptation to Incomplete Spinal Cord Injury

In Chapter 1, an autobiographical article written by Holicky (1995) was introduced as an example of one person's experience with incomplete spinal cord injury. Holicky shared feelings of uncertainty, frustration and unrelenting hope for recovery, and an initial tendency to put other goals on hold in pursuit of recovery of walking. Despite these intriguing issues, a review of the professional literature suggests these apparently unique considerations associated with the psychosocial adaptation to incomplete spinal cord injury have not previously been recognized or explored. While qualitative studies have investigated the experiences of persons with incomplete spinal cord injuries (Berman & Rose, 1998; Carpenter, 1994), themes similar to those raised by Holicky (1995) were not identified. However, it should be noted that each of the studies by Berman and Rose (1998) and Carpenter (1994) were conducted in an effort to gain a greater understanding of spinal cord injury experiences, with a broader goal of enhancing client-centered physical therapy outcomes. Therefore, interview questions may have been more directed at personal experiences as they relate to therapeutic relationships as opposed to individual issues of adjustment. Comparing the experiences of persons with

incomplete versus complete spinal cord injuries is therefore an area for further investigation.

Value of a Qualitative Approach to Investigating the Psychosocial Impact of Locomotor Training

The few existing studies that have attempted to address the emotional impact of interventions aimed at the recovery of walking for persons with spinal cord injury have relied predominately on quantitative methods to collect and analyze data (Bradley, 1994; Guest, Klose, Needham-Shropshire & Jacobs, 1997, Nymark et al., 1998). While these studies provide a foundation for the investigation of the psychosocial impact of locomotor training, much has yet to be learned about the phenomenon under question. A broader approach to inquiry is therefore advisable. Given the documented value of grounded theory methods to obtain descriptions of individual experiences and processes (Glaser & Strauss, 1967; Patton, 1990), it appears the use of qualitative methods would prove to be a more informative approach for investigating the emotional and psychosocial impact of interventions aimed at the recovery of walking.

Literature reviews from the fields of rehabilitation, nursing, and the social sciences indicate qualitative methods have gained merit as a valuable approach to exploring issues related to the psychosocial adaptation of persons with disabilities and chronic illnesses (Becker & Kaufman, 1995; Burton, 2000; Clark, 2000; Dewey, 2000; Doolittle, 1992; Faircloth, Boylstein, Rittman & Young, 2004; Faircloth, Boylstein, Rittman, Young & Gubrium, (In Press); Gubrium, Rittman, Williams, Young, Boylstein & Faircloth, 2003; Kaufman, 1988; Kling, Persson, & Gardulf, 2000; Kosciulek, 1999; Nosek, Howland, Young, Georgiou, 1994; Nosek & Hughes, 2001; Paterson, 2001; Sanders-Dewey, Mullins & Chaney, 2001; Taleporos & McCabe, 2002; Thorne &

Peterson, 2000). Qualitative methods have also proven useful for understanding issues specifically related to the psychosocial adaptation of persons with spinal cord injury (Berman & Rose, 1998; Carpenter, 1994; Duggan & Dijkers, 1999; Duggan & Dijkers, 2001). In addition, Estores (2003) recently advocated the use of qualitative methods as an approach for obtaining consumer perspectives to aid in identifying priorities for rehabilitation-related spinal cord injury research.

The historical use of qualitative inquiry for exploring psychosocial adaptation to disability and disability-related experiences lends further support for the use of such methodologies to investigate the psychosocial impact of emerging rehabilitation interventions aimed at recovery. To date, however, reports of the use of qualitative methods to investigate such interventions remain largely absent from the literature. One exception is the recent, unpublished work of Boylstein, Rittman, Behrman and Davis at the VA Rehabilitation Outcomes Research Center of Excellence (RORC) and VA Brain Rehabilitation Research Center of Excellence (BRRC), both in Gainesville, FL. These researchers have pioneered recent efforts in the use of qualitative methodologies to study the impact of an emerging rehabilitation therapy, Constraint Induced Movement Therapy (CIMT), on Veteran stroke survivors. The grounded theory-based methodology used by Boylstein et al. was developed by Dr. Maude Rittman and the Qualitative Research Group at the VA RORC, and is applicable to other therapies and disability populations. This methodology was therefore used in our study to explore the effects of locomotor training on the psychosocial adaptation of persons with incomplete spinal cord injury. The methods used in the present study are summarized in Chapter 3.

CHAPTER 3 METHODS

Introduction

Study Design

When considering qualitative study design, Lincoln and Guba (1985) identify three determinants for assessing the suitability of research questions to methods, (a) the focus of inquiry, (b) the fit of the inquiry paradigm to the focus, and (c) the ability of the paradigm to substantiate the theory guiding the inquiry. Given the exploratory focus of our study—an investigation of how participation in the newly emerging rehabilitation intervention of locomotor training affects the psychosocial adaptation process of persons with incomplete spinal cord injury, grounded theory methods (Glaser & Strauss, 1967) were used to answer the research questions. According to Glaser and Strauss (1967), grounded theory approaches are useful for answering research questions having an exploratory focus of inquiry. Specifically, such methods are appropriate for research aimed at exploring phenomena about which little is known, especially when the phenomena involves personal experiences and processes (Glaser & Strauss, 1967; Patton, 1990). In keeping with the exploratory focus of our study, a constructivist paradigm of inquiry, one that seeks to “construct” meaning from the subjective realities and meanings of others (Denzin & Lincoln, 2000), was used to guide research activities. The constructivist paradigm, in turn, served to corroborate the grounded theory emerging from the data.

The specific, grounded theory-based methodology used in our study was developed by Dr. Maude Rittman and the Qualitative Research Group at the VA Rehabilitation Outcomes Research Center (RORC) (Gainesville FL) to study patient and caregiver experiences with newly emerging rehabilitation therapies. Although the Qualitative Research Group's current work is in Constraint Induced Movement Therapy (CIMT) for VA patients with stroke, the methodology is applicable to other therapies and disability populations. The methodology was therefore selected for use in our study.

Organization of Chapter

This chapter is organized into four primary sections: participants, instrumentation, procedures, and limitations. The section on participants reviews sampling design, relevance of the sample, inclusion and exclusion criteria for participants, demographics of the sample, and justification of sample size. The second section, instrumentation, summarizes the use of interviews and participant observation for data collection and recording, discusses potential limitations of such methods, and includes my bias statement. The procedures section addresses participant recruitment, consent to participate, data collection and recording, data analysis/interpretation, and efforts to ensure trustworthiness. The final section discusses limitations of the methodology.

Participants

Sampling Design

A convenience sample comprised of 8 individuals was used for our study. Members of the sample included both current and former participants in an ongoing study of locomotor training being conducted at the University of Florida, Department of Physical Therapy. All members of the sample were noncompensated volunteers.

Relevance of Sample

The sample for the study included 8 participants recruited through Dr. Andrea Behrman's NIH-funded, K-01 study, "Activity-Dependent Plasticity After Spinal Cord Injury" (IRB #70-1999), a long-term locomotor training study at the VA Brain Rehabilitation Research Center (BRRC) and the University of Florida Department of Physical Therapy. As current and former enrollees in the locomotor training study, all participants in our study have experience with the phenomena being explored. Two participants newly enrolled in the locomotor training study were recruited for our study prior to beginning treatment. These participants were followed throughout the locomotor training study, and provided prospective data. Six former participants in the locomotor training study were also recruited, and provided retrospective data for our study. All participants completed 45 locomotor training sessions, each with 30 minutes of treadmill training followed by over ground training. Locomotor training sessions took place five times per week, over a 9-week period.

Inclusion and Exclusion Criteria for Participants

For our study, inclusion and exclusion criteria for participants with motor incomplete spinal cord injury reflect those of Dr. Behrman's K-01 project. Inclusion criteria for individuals with spinal cord injury include

- Individuals 18 years or older
- A diagnosis of first time spinal cord injury including etiology from trauma, vascular, or orthopedic pathology at cervical or thoracic levels
- Time since injury of 3 months to 3 years postspinal cord injury
- A spinal cord injury as defined by the American Spinal Injury Association (ASIA) Impairment Scale categories C or D

- A medically stable condition that is asymptomatic for bladder infection, decubiti, osteoporosis, cardiopulmonary disease, pain, or other significant medical complications that would prohibit or interfere with testing of walking function and training or alter compliance with a training protocol
- Documented medical approval from the participant's personal physician verifying the participant's medical status
- The ability to walk independently a minimum of 40 [consecutive] feet with or without an assistive device [and/or contact guard]
- Spending a minimum of 30 minutes [total] per day standing or walking
- Subjects that are on anti-spasticity medication will be asked to maintain their routine dosage throughout the study, whereas subjects that are not on antispasticity medication will be asked to refrain from initiating use of this medication throughout the study
- Ability to give informed consent.

Exclusion criteria for subjects with spinal cord injury include

- Is currently participating in a rehabilitation program or another research protocol that could interfere with or influence the outcome measures of the current study
- Has a history of congenital spinal cord injury (e.g. Chiari malformation, myelomeningocele, intraspinal neoplasm, Frederich's ataxia) or other degenerative spinal disorders (e.g. spinocerebellar degeneration, syringomyelia) that may complicate the treatment and/or evaluation procedures.

Inclusion of Women and Minorities

Inclusion criteria included males and females with incomplete spinal cord injuries, representative of all ethnic groups, enrolled in the locomotor training study or having previously completed locomotor training.

Sample Demographics

Table 1 summarizes the demographics of the sample. Participants represented a range of functional abilities, from a full-time walker (Lynn), to a power wheelchair user who required assistance with activities of daily living (Abe). To protect the identity of study participants, they will be identified and referred to by pseudonyms only.

Table 1. Sample demographics

Participant	Gender	Ethnicity	Age	Level of injury	Date of injury	Date of LT	Veteran status
Abe	M	White	49	C-5, 6	1999	2001	Vet
Ben	M	White	22	T1, C-5-7	1996	1998	non-Vet
Chuck	M	White	44	C-6	1998	2001	Vet
Dan	M	African American	60	C-5	1999	2002	Vet
Ed	M	White	73	C-3, 4, 5	1999	1999	non-Vet
Frank	M	White	62	C-6	2001	2001	non-Vet
Ken	M	White	56	C-5, 6	2002	2003	Vet
Lynn	F	White	46	C-5, 6	2002	2003	non-Vet

Justification of Sample Size

When determining sample size, factors to consider include: the purpose of the study, the goal of the researcher, what depth of data will be useful, and what is feasible given available time and resources (Patton, 1990). For qualitative studies, the goal is to use a sample size that will lead to theoretical saturation or redundancy of data (Patton, 1990). For our study, data were collected from a total of 8 locomotor training participants.

A series of four qualitative interviews were conducted with each of 2 participants currently enrolled in the locomotor training study. Daily training session observations of these individuals were conducted either in vivo or via videotape, until saturation of field note data was reached. Single in-depth interviews and observations of five videotaped training sessions were conducted with 6 former participants. Thus, data was collected through 85 training observations (55 in vivo and 30 videotaped), and a total of 14 interviews—sufficient data to achieve saturation.

While efforts were made to enhance the credibility of results throughout the study, the generalizability of research findings to a larger population is not the intended aim of this project. Rather, the project attempts to provide a preliminary understanding of

the phenomenon under question, the effect of locomotor training on the psychosocial adaptation of training participants, using a sample from a from a specific locomotor training study and grounded theory methods.

Instrumentation

Interviews and the Use of Interview Guides

Semi-structured interviews were used to obtain data on the thoughts and feelings of participants related to all aspects of their locomotor training experience, including how these changes affected their lives outside training. Prospective data was obtained through a series of face-to-face, in-depth interviews with two current locomotor training participants. Interviews were conducted on four occasions—before training began, once during the 4th week of training, once during the 8th week of training, and one month after completion of locomotor training. Retrospective data was obtained through single, in-depth interviews with each of 6 former locomotor training participants. Face-to-face interviews were conducted with 4 former participants, and telephone interviews were conducted with 2 former participants.

Interview guides consisting of open-ended questions were used for all interviews. According to Patton (1990), the use of interview guides facilitates the interviewer's ability to "explore, probe, and ask questions that will elucidate and illuminate that particular subject" (p. 283), and promotes systemic and comprehensive interviewing across participants. Interview guides included questions about the participants' spinal cord injury, its impact on his or her life, experiences related to locomotor training, and changes in activities due to locomotor training. The interview guides therefore served to inform the research questions. While designed to be consistent across participants, the interview guides also allowed for the exploration of each participant's individual

experiences through the use of “personalized” questions. For current locomotor training participants, personalized questions were based upon in vivo observations of training sessions. For each of the former locomotor training participants, personalized questions were based upon observations of five videotaped locomotor training sessions prior to interview. Copies of all interview guides used in the study are included in Appendix A.

Participant Observations and Use of Field Note Collection Sheets

For the two current locomotor training participants, daily observations of training sessions were conducted until saturation of field note data was achieved. The majority of observations were conducted in vivo. When in vivo observation was not possible, a videotape of the training session(s) was observed. For each of the 6 former locomotor training participants, five videotaped training sessions were observed. According to Patton (1990), advantages of the participant observation method include: the ability of the researcher to see things that may escape the conscious awareness of participants, the opportunity for the researcher to learn things participants may be unwilling to discuss during interviews, and the opportunity for researchers to better understand the context within which the phenomenon operates.

During observation sessions, field notes were recorded to document the participant’s observed affect, training activities, interactions with training staff, and interactions with family and significant others. Comments, responses, and significant dialog were recorded. All field notes were recorded using Field Note Collection Sheets, a form I developed to promote consistency in data recording, aid in the organization and storage of field note data, and enhance auditability. Listed on the Field note Collection Sheets are observation dates and dates the data were transcribed and validated. A copy of the Field Note Collection Sheet is included in Appendix A.

Use of QSR N6[®] Qualitative Software

The qualitative software program QSR N6[®] was used to facilitate the systemic analysis of all transcribed data from interviews and field notes. A popular qualitative software program, N6 enables users to browse imported documents/data, electronically code data for later retrieval, develop a coding framework, record memos concerning data, generate reports from data, and prepare data displays. N6 automatically dates and records changes to the coding framework and imported documents/transcripts, and thereby provides an “audit trail” for anyone accessing the data electronically.

While a comprehensive description of how I used N6 as a data analysis tool is reserved for the Procedures section, I now briefly summarize my use of the software. As I reviewed transcripts of interviews and field notes line by line to identify prominent themes, I used N6 to code the data. The coding process enabled me to develop a coding scheme within N6. I then subjected all data to the coding scheme. Through a process of constant comparison (Glaser & Strauss, 1967), I analyzed the emergent themes and associated data to identify relationships among them. The process of constant comparison involves an ongoing, systematic review and comparison of data within and across nodes. As the coding scheme and relationships among themes emerged, I used them to develop a theoretical framework representative of the data.

Limitations of Instrumentation

In reference to methods used by field researchers, Cassell (1980) has stated, “the interaction is the method; the ethnographer is the research instrument” (p. 36).

Qualitative inquiry renders the researcher/observer as the primary instrument of all data collection and interpretation, regardless of what specific methodologies are utilized. Due to the fact the observer is the vehicle by which all methodologies are implemented, the

training and practice of the observer, and observer bias may limit the credibility of results and threaten the trustworthiness of study findings. Given that I was responsible for conducting interviews, participant observations, and data analysis for our study, I summarize my training and practice, and provide an observer bias statement below.

Although my experience as a qualitative researcher per se is limited, my extensive work-related experience with conducting interviews with people with disabilities and recording observations renders me well equipped to collect data through these methods. I have also completed relevant coursework on qualitative methods during my doctoral program and received supervision while completing a qualitative research project as part of course requirements. To further enhance the credibility of my research, I followed member-checking procedures outlined by Miles & Huberman (1994) throughout my study to check for bias. For example, I met with my VA Preceptor on a regular basis to review my data and analyses, and convened a “peer-debriefing” meeting in August to allow my dissertation committee and VA Program Director an opportunity to provide me with feedback on my data.

Personal Bias Statement

I recognize and acknowledge that my own personal biases may influence the work I do in qualitative research, particularly in the field of rehabilitation science. As a person with a congenital disability, I closely identify with the paradigm that disability is largely socially constructed, rather than with a more medicalized model of disability. I actively promote the rights of people with disabilities and the independent living philosophy. I do not believe disability is inherently negative, nor do I view disability as an anomaly needing to be “fixed,” cured, or eliminated. I do however, empathize with and fully support the rights of individuals with disabilities to pursue any rehabilitation

interventions that they feel may improve their physical well-being and increase their quality of life. I also commend the contributions of rehabilitation professionals who assist people with disabilities in pursuing their goals, and maximizing their health and quality of life.

Regarding our study, I understand how my personal disability experience, professional experience and research interests simultaneously served to both enhance and possibly limit my objectivity as a researcher. I feel the fact that I have never walked enhanced my objectivity during the collection and interpretation of data related to participants' physical and cognitive-emotional experiences while relearning to walk. Because walking is a completely foreign process to me, I feel I was able to enter the study with few preconceived expectations regarding what participants may experience. Consequently, I think my own ignorance possibly enabled me to remain more open and receptive to all levels of their experiences. My participants truly became my teachers, and their lessons about the process of walking were fascinating.

My previous professional experience working with persons with incomplete spinal cord injury undoubtedly contributes to a personal bias with respect to our study. I frequently witnessed the uncertainty and hope my consumers with incomplete spinal cord injury experienced following their injuries, and how these feelings affected their service coordination needs and personal goals. For example, it was not uncommon for my consumers to postpone applying for disability-related programs such as personal assistance services or accessible housing in the hopes their functional ability would continue to improve with physical therapy. Such experience, combined with my interest in psychosocial adaptation to disability, peaked my interest regarding how an experimental treatment such as locomotor training may impact participants with

incomplete spinal cord injury on psychosocial levels. While I assumed locomotor training would have psychosocial effects on participants, I tried to use any personal hunches regarding possible outcomes constructively to inform the research questions. For example, based upon my previous experience with consumers postponing goals or plans to pursue therapy, I incorporated into interviews open-ended questions asking participants to identify their personal goals and evaluate how locomotor training affected these goals.

From a cultural perspective, I also recognize that I shared a disability culture and a unique sense of empathy with the participants in my study. While I do not have an incomplete spinal cord injury, my participants and I often conversed about similarities and differences in our disability-related experiences and frustrations during the course of our interviews. For example, I discussed power wheelchairs with Abe, and shared Lynn's frustration about not being able to wear "cute" shoes. While proponents of a more objectivist approach to qualitative methodologies encourage a more distant, impartial approach to data collection and analysis (Charmaz, 2000), I feel the sense of kinship I shared with my participants facilitated communication, and often led me to a deeper understanding and interpretation of their experiences.

Procedures

Protection of Participants and Confidentiality

Our study was approved by the University of Florida Health Science Center Institutional Review Board (IRB-01) and the VA Subcommittee for Investigations (IRB #417-2002, VA #0001) prior to enrollment of participants. Dr. Behrman's locomotor training study was previously approved by the VA Research and Development Committee and the University of Florida Health Science Center Institutional Review

Board (IRB #70-1999). Throughout the project, efforts were taken to protect the identity of participants and ensure confidentiality was maintained with all information and data. On written documentation (including field notes and transcripts) participants were identified by code numbers only. In addition, all audiotapes, computer discs, signed informed consent forms and other written documentation were stored in locked file cabinets in the VA RORC.

Participant Recruitment

Enrollment for our study began in December 2002, and ended in September 2003. Participants for our study were recruited through Dr. Andrea Behrman's NIH-funded, K-01 study, "Activity-Dependent Plasticity After Spinal Cord Injury" (IRB #70-1999), a long-term locomotor training study at the VA Brain Rehabilitation Research Center (BRRC) and the University of Florida Department of Physical Therapy. Dr. Behrman recruits participants through several designated spinal cord injury treatment facilities within the State of Florida Brain and Spinal Cord Injury Program (FBSCIP), including: the Gainesville, FL VAMC, the Tampa, FL VAMC, Shands Hospital and Shands Rehabilitation Hospital in Gainesville, FL and Brooks Rehabilitation Hospital in Jacksonville, FL.

Dr. Behrman was responsible for identifying potential candidates for this project from her pool of former and current locomotor training participants. Dr. Behrman initially contacted all potential candidates in-person or via telephone to describe the study, and ask if they would be interested in participating. If a candidate expressed interest, she would then ask permission for me to meet with him or her in person at the locomotor training lab, or make contact via telephone or email. Upon securing permission, Dr. Behrman provided me with the potential candidate's contact information, or assisted with coordinating a person-to-person meeting.

Consent to Participate

Written informed consent was obtained from all participants, in-person or via mail, prior to beginning the study. All individuals contacted about the study agreed to participate. After receiving notification of a potential candidate from Dr. Behrman, I contacted the candidate in the manner specified. I met current locomotor training participants and former participants living in Gainesville, person-to-person, at the locomotor training lab to discuss the study and informed consent process. I explained the study and reviewed the informed consent form with the candidate, and the candidate was given the opportunity to ask questions. If the candidate chose to participate, he or she was asked to sign and date the informed consent form. After I signed and dated the form, a copy was made and returned to the enrollee for his or her records.

For former participants who lived out-of-town, contact was typically made by telephone. During each call, I introduced myself and told the candidate his or her telephone number was given to me by Dr. Behrman. I then described the study, explained the informed consent process, and asked if he or she might be interested in participating. If the potential candidate expressed interest, I explained an informed consent form would be mailed for his or her review. Candidates were told if, after reviewing the informed consent form, they still wanted to participate in the study, they should sign and date the form and return it to me. Candidates were also encouraged to call me if they had questions regarding the informed consent form.

Every informed consent form mailed to a candidate was accompanied by a brief cover letter, and a self-addressed, stamped return envelope. In the cover letter I thanked the candidate for his or her interest in the study, and asked him or her to review the consent form. A toll-free telephone number was provided so the candidate could contact

me with any questions. The candidate was directed to sign, date and return the consent form to me in the envelope provided if he or she chose to participate in the study.

Candidates were asked to call or email me if they chose not to participate. The letter also informed candidates a copy of the signed and dated informed consent form would be returned to them to keep with their records. Upon receiving the signed, dated consent form from the enrollee, I signed and dated it, and then returned a copy to the enrollee.

Two written informed consent forms were developed for use in this study. One form was developed to obtain consent from current locomotor training participants to be interviewed and observed throughout training. The second written informed consent form was developed to obtain consent from former locomotor training participants to be interviewed. Both forms were approved by the University of Florida Health Science Center Institutional Review Board (IRB-01) and the VA Subcommittee for Investigations prior to use. Prior to implementation of the HIPAA Privacy Rule on April 14, 2003, a separate Authorization form to approve the collection, creation, use or disclosure of participants' protected health information (PHI) was developed and approved by the University of Florida Health Science Center Institutional Review Board (IRB-01) and the VA Subcommittee for Investigations. From April 14, 2003 through August 13, 2003, the HIPAA Authorization form was signed as part of the informed consent process. As mandated by the IRB, prior to the renewal of the study by August 13, 2003, all informed consent forms were revised to include HIPAA language, and the separate HIPAA Authorization form became obsolete. Therefore all participants enrolled in the study from August 14, 2003 through September 9, 2003, when enrollment ended, signed a revised informed consent form with HIPAA language included. Copies of the most recent written informed consent forms that include HIPAA language appear in Appendix B.

Data Collection

According to Patton (1990), “Qualitative methods are particularly oriented toward exploration, discovery, and inductive logic” (p. 44). Given the exploratory nature of the present project, two qualitative methods were used to systematically collect data throughout the study—interviews and participant observations. The use of multiple data-collection methods, or triangulation, serves to enhance the depth of understanding of findings, and provides for richer data (Glesne, 1999). I was responsible for all data collection for our study.

Interview procedures

I typically scheduled interviews directly with participants. On those occasions when interviews had to be coordinated around locomotor training pretesting schedules however, therapists from the University of Florida, Department of Physical Therapy would assist with setting-up interview appointments. As previously indicated, all participants signed a written informed consent form prior to interviews.

With the exception of one interview, all face-to-face interviews were conducted in a meeting room or laboratory at the University of Florida, Department of Physical Therapy. One face-to-face interview was conducted at the office of the former locomotor training participant being interviewed. Telephone interviews were conducted from the VA RORC conference room with two former locomotor training participants. Interview guides consisting of open-ended questions were used for all interviews. Interviews lasted from 30 minutes to 1 hour, and were audio taped.

All audio taped interviews were transcribed into Word ® documents. I transcribed 10 of the 14 interviews conducted. Due to my physical limitations, transcription proved to be a very time-consuming, taxing process. To expedite transcription and data analysis,

I therefore requested during my Peer Debriefing Meeting that I be permitted to obtain assistance for my remaining transcription needs. My dissertation committee approved my request. Consequently, the four remaining interviews were transcribed by master's level physical therapy students to meet graduate program research requirements. I validated all interviews transcribed by the students by listening to the audio taped interview, and correcting the interview transcript as necessary. Once transcribed and validated, all interviews were imported into the QSR N6® software program for coding. After interviews were coded, summary coding reports for each were generated using N6. To enhance readability, reports were converted into Word® documents, and then printed. All printed reports of coded interviews were retained in three-ring binders.

Participant observation procedures

I collected field note data by observing participants during in vivo and videotaped locomotor training sessions. I recorded all observations on Field Note Collection Sheets. For the 2 current locomotor training participants, I initially observed training sessions daily. Although I attempted to conduct all observations in vivo, when in vivo observation was not possible, a videotape of the training session(s) was observed. For each of the 6 former locomotor training participants, I observed five videotaped training sessions prior to conducting the interview.

For both current and former participants, I recorded all data that appeared pertinent to understanding the locomotor training process and participant experiences during this process. This data included documentation of the participant's observed affect, training activities, and comments, responses and significant dialog with training staff and family or significant others. As I reached saturation of data in some areas, I became more selective with data recording. For example, although I initially attempted to

record all training activities, as it became apparent certain activities were routine (e.g., trainers switching places or roles throughout the session) I ceased to record such activities. Participant observations continued until I reached saturation with all field note data. Observations were made of all 45 of 1 current participant's training sessions. Approximately one-half of the second current participant's training sessions were observed.

I transcribed all field notes from participant observations into Word® documents. To ensure the accuracy of my field notes from in vivo observations, I validated all field note data. I re viewed each of the training sessions on videotape, and simultaneously compared it to the corresponding transcribed field notes. I noted all corrections on the transcript, and then edited the transcript to include the revisions. After all field note data were transcribed, and in the case of in vivo observations, validated, transcripts were imported into the N6 software program for coding. Like interview data, after field notes were coded, summary coding reports for each observation session were generated using N6. Reports were converted into Word® documents, and then printed. All printed reports of coded field notes were retained in three-ring binders.

My role as observer/team member. Upon beginning my predoctoral fellowship, Dr. Behrman immediately welcomed me as part of her “locomotor lab team.” I was invited to attend weekly lab meetings and locomotor training sessions for new trainers, and was added to the team's email list to receive all lab/training related correspondence. These opportunities allowed me to establish relationships with team members prior to enrolling participants. I was able to explain my study to them, and describe how I would be conducting my interviews and observations. Several team members also acted as facilitators on my behalf—assisting me with obtaining videotapes of training sessions,

notifying me of changes to the training schedule, and helping to coordinate interviews when necessary. These combined efforts made me feel as though I was a valued, contributing member of the locomotor lab team. Likewise, I sensed the team was also appreciative of my participation. They appeared excited at the prospect of learning about how locomotor training affects participants on a psychosocial level and frequently asked about my findings. I never sensed that team members felt uncomfortable or threatened by my role as observer.

As part of the informed consent process, the two current locomotor training participants were told that I would be observing them during training and recording notes on what I observed. Both participants readily agreed to be observed, and neither appeared hesitant about being watched during training. Once the first, current participant was enrolled however, one of the therapist team members also assigned me a “job” during training sessions. I was given the responsibility of using a stopwatch to track the amount of time participants stepped on the treadmill during each session. This change altered my role from a more passive role as observer, to an active part of the team as observer/timekeeper. According to Patton (1990), such a shift from an “onlooker” to a participant observer often allows for a greater depth of understanding of the experiences under investigation. In addition to recording my observations, I now became responsible for cuing the team on our time status, and counting down the last few seconds before stopping the treadmill. As I quickly became comfortable with my active role, I soon found myself joining in with other team members to “cheer on” the trainees, joke with the trainee and team members, and provide the team with feedback on the trainee’s body position during training.

As locomotor training commenced, team member actions toward me reinforced my feeling that my role as observer/timekeeper was understood and valued. For example, when a trainee commented that her legs felt “tingly” during training, all team members looked toward me in unison—some grinning, some raising their eyebrows, one member even moving her hand in the air to mimic handwriting. These actions served as indicators that team members understood it was my role to capture such information.

Data Analysis/Interpretation Procedures

Qualitative inquiry supports data collection, data analysis, and theory formation as an ongoing, simultaneous endeavor (Denzin & Lincoln, 2000; Glaser & Strauss, 1967; Glesne, 1999; Patton, 1990). Consequently, as I began collecting and transcribing data from interviews and participant observations, I immediately began to code, analyze/interpret the data, and build a coding framework. This evolving framework, in turn, led to the development of a theoretical framework derived from the data. A summary of the iterative process used throughout data analysis/interpretation follows.

Summary of the Iterative Process

Coding and data analysis/interpretation. After verifying transcripts from interviews and field notes, I converted the transcripts from Word® documents into plain text documents, and then imported them into the QSR N6® software program. I labeled each document according to participant code number and data type—interview or observation. I also labeled transcripts of observations by training session/observation number and session date.

N6® enables users to develop a coding “tree” consisting of nodes (Richards, 2002). Nodes are locations where segments of data are assigned codes according to the data’s representative theme or context. The N6® program distinguishes between two

types of nodes—parent nodes and child nodes (Richards, 2002). Parent nodes are used to code primary, broad themes, while child nodes are used to code more specific data falling under the parent nodes.

I began coding after importing my first document into N6. I reviewed all imported documents line by line to identify prominent themes. As I identified a new theme or concept, I would add a “node” to the coding framework and assign it a descriptive code name. I would then select the corresponding text and “code” it accordingly. Using the constant, comparative method described by Glaser and Strauss (1967), I built my coding framework. I would subject each line of every document to the coding framework. If an existing node was representative of the data, I would code it accordingly. If a new node was necessary, I would add it to the framework and then code the data.

Use of the constant, comparative method allowed me to refine my coding framework, ensure codes were representative of the data, and minimize “redundant” coding. By routinely comparing codes and coded data within and across nodes, I also examined data across study participants. When I deemed it appropriate, I would recode data and/or alter the coding framework following such comparisons. Because QSR N6[®] software only enables users to build coding frameworks hierarchically, the constant comparative method of data analysis/interpretation facilitated the identification of more complex relationships and patterns among themes/nodes, including relationships that defined and described participant experiences during locomotor training.

All changes to the coding framework were automatically noted and dated by the N6. I also recorded changes to the framework in a Word[®] document I titled “Tracking Changes to Node Tree.” This document is included in Appendix C.

Memoing. While reflecting on my data throughout the analysis/interpretation process, I often recorded my thoughts through memoing. I would use memos to record ideas that struck me while coding, to describe or propose an emerging relationship among themes, or to remind myself to investigate a piece of information further. Anytime a change was made to a node within the coding framework, the QSR N6[®] program also automatically recorded this change in a node memo. Using N6, I recorded memos for specific nodes and documents. I also copied this information into a Word[®] document I titled “Process Notes.” This document is included Appendix D.

Data reduction. As saturation of data became evident while coding, I began to use data reduction techniques to expedite the coding and data analysis process. Rather than coding data at numerous, child nodes, I would instead code the data at the broader parent nodes preceding the child nodes. For example, once saturation of data was reached regarding the various locomotor training activities that occur during a session, I began coding all data at the broad category of “training activities” rather than coding each of the numerous activities separately. This data reduction technique allowed me to maintain the meaningfulness of the data, while expediting the coding process.

Efforts to Ensure Trustworthiness

Methods of ensuring the trustworthiness or quality of conclusions drawn from qualitative data have been proposed by Guba and Lincoln (1981), Lincoln and Guba (1985), and most recently, by Miles and Huberman (1994). Guba and Lincoln (1981) identify 3 types of criteria for ensuring trustworthiness of qualitative data, 1) Auditability, 2) Credibility, and 3) Fittingness. Auditability as defined by Guba and Lincoln refers to coding data in such a way that an outsider may understand and draw similar conclusions. Credibility is described as structural corroboration or methods to

enhance the internal validity of conclusions. By fittingness, Guba and Lincoln refer to how well conclusions drawn from thick, descriptive data in a specific setting “fit” other contexts.

The criteria proposed by Guba and Lincoln (1981) have been expanded upon by Miles and Huberman (1994), who propose 5 standards for the quality of conclusions derived from qualitative data. These standards include

- Objectivity/ confirmability
- Reliability/ dependability/ auditability
- Internal validity/ credibility/ authenticity
- External validity/ transferability/ fittingness
- Utilization/ application/ action orientation.

Each of the standards identified by Miles and Huberman will be briefly described, and then discussed in terms of the procedures used for our study.

Objectivity/Confirmability

Miles and Huberman (1994) define the standard of objectivity/ confirmability as “neutrality and reasonable freedom from unacknowledged bias” (p. 278). The authors further relate this standard also captures the external reliability or replicability of the study. Miles and Huberman identify the queries listed below for evaluating how well this standard is met by a qualitative study. The queries are summarized in terms of our study.

Explicit description of methods and procedures, including techniques used for data collection, analysis/ interpretation and display. An attempt has been made in this chapter to thoroughly describe all methods and procedures used in our study. To further describe the data analysis/ interpretation process, I recorded personal reflections and decisions about my data by creating memos using the N6® program and by making notations in a document I titled “Process Notes.” I documented decisions and thought processes regarding changes to my coding framework in a document I titled “Tracking

Changes to Node Tree.” These documents are included in Appendix D and Appendix C, respectively.

Existence of an “audit trail” to record methods and procedures, and availability of data for reanalysis by others. The QSR N6[®] software program automatically records the date and time any document is imported into the program or altered due to coding, editing or appending. The program also records all changes to each node within the coding framework according to date and time. The changes may include cutting and moving nodes to new locations in the framework, coding new data at the node or changing the title of a node. Notations generated automatically by the N6 program to record changes to my project are retrievable by accessing the program stored on the hard drive of my laptop computer, or the computer discs used to save my project files.

Regarding written documentation, as already described, I recorded and dated notations in documents titled “Process Notes” and “Tracking Changes to Node Tree” to provide justification for my decisions related to data analyses/interpretation or changes to the coding framework. I also used N6 to generate node summary reports throughout the coding and data analysis process. Reports were generated monthly, or following significant changes to the framework resulting from data analysis. As such, node summary reports serve to document the evolution of the entire coding framework. To facilitate data access and retrievability by others, all written documentation related to our study are maintained in three-ring binders. These documents include node summary reports, coding summary reports for interviews and field notes, untranscribed field notes, “Process Notes” and “Tracking Changes to Node Tree.”

Researcher is explicit about personal biases and assumptions. I have included in this chapter a personal bias statement in which I attempt to expound my beliefs, values and potential biases with respect to our study.

Reliability/Dependability/Auditability

Miles and Huberman (1994) describe the standard of reliability/ dependability/ auditability as “whether the process of the study is consistent, reasonably stable over time and across researchers and methods” (p. 278). This standard reflects whether the study has been conducted with “reasonable care” (Miles & Huberman, 1994). Queries proposed by Miles and Huberman to assess this standard are summarized relative to our study.

Research questions are clear and the study design is congruent with them.

Research questions were clearly defined in Chapter 1. The selection of a grounded theory approach for data collection and analyses/interpretation was consistent with the exploratory nature of this study.

Researcher’s role and status within the site is explicitly described. My role and status within the locomotor training team is described in the present chapter.

Findings show meaningful parallelism across data sources. A review of Chapters 4 through 6 does reveal parallel findings across study participants.

Provisions for “checks” on coding and data quality. To enhance the rigor of the study, the project Preceptor met with the VA predoctoral fellow on a monthly basis to review data, coding and the data analyses/interpretation processes. In addition, a *Peer Debriefing Meeting* was held in August 2003 to review and reflect upon all data analyzed to date. The meeting was attended by the Fellow, Preceptor, VA Program Director, and dissertation committee members. During the meeting, I summarized my current status

with transcription, coding and data analyses. I also introduced my theoretical framework, and allowed attendees to review my coding framework and coded data. Attendees felt that data had been coded appropriately and concluded that my theoretical framework was representative of the data. Attendees also recommended that my dissertation focus upon the process components of the framework.

Internal Validity/Credibility/Authenticity

Miles and Huberman (1994) describe the standard of internal validity/ credibility/ authenticity as the “truth value” (p. 278) of the study. This standard is used to determine if findings make sense and if they are credible to informants and readers (Miles & Huberman, 1994). Queries used by Miles and Huberman to assess this standard include the following issues.

Descriptive data are context rich and meaningful or “thick.” Regular “peer debriefing” meetings were held with the study preceptor to ensure the adequacy of data and the integrity of the analyses/interpretation processes.

The account is comprehensive, “makes sense” and facilitates a “vicarious presence” for readers. Efforts were made to provide a thorough, meaningful account for readers. The study Preceptor also reviewed drafts of dissertation chapters.

Triangulation produced converging conclusions. As is evident in Chapters 5 and 6, interviews and participant observations did lead to convergence of study results.

Data are well linked to the emerging theory and concepts are systematically related. Figures and tables were used to illustrate relationships among concepts and emerging theories.

External Validity/Transferability/Fittingness

According to Miles and Huberman (1994), the standard of external validity/ transferability/ fittingness refers to the ability to transfer or fit study conclusions to other contexts. Miles and Huberman relate that the ability to “generalize” conclusions from the sample to a population is “less helpful for qualitative studies” (p. 279), but that “generalization” of conclusions may be considered for analytic or theory-connected purposes or for case-to-case transfer. Miles and Huberman identify the following queries for use in assessing this standard.

Characteristics of the sample, settings, processes and outcomes are adequately described to permit comparisons with other samples and across different settings. Efforts have been made to provide thorough descriptions of all aspects of the study throughout this dissertation.

Limitations of the study are discussed and the scope and boundaries of reasonable generalization are defined. Limitations of our study are discussed in the present chapter and reiterated in Chapter 7.

Findings are congruent with, connected to, or confirmatory of prior theory. In Chapter 7, findings from our study are compared to those of similar studies.

The transferable theory from the study is made explicit and recommendations are made for further investigation. In Chapter 4, the theoretical framework that emerged from the study is thoroughly described and recommendations for future research are provided in Chapter 7.

Utilization/Application/Action orientation

Miles and Huberman (1994) define the standard of utilization/ application/ action orientation as “knowing what the study does for its participants” (p. 280). This standard

is used to determine the extent to which findings may be used to influence program or policy changes (Miles & Huberman, 1994). Queries used by Miles and Huberman to assess this standard include the following issues.

Study findings are intellectually and physically accessible to potential users.

As previously indicated, data from the study are maintained on the hard drive of my personal computer and on computer discs. Hard copies of field notes and node summary reports are maintained in ring binders. To ensure the accessibility of study findings, efforts have been made to disseminate results. To date, presentations have been conducted at 3 poster sessions. In addition, the publication of study findings in scholarly journals is planned for the near future.

Various levels of usable knowledge are offered. In Chapter 7, the implications of study findings are discussed in terms of clinical application and future research.

Study Limitations

Limitations of our study relate to the use of a convenience sample of participants. For example, the fact that data were collected from participants enrolled at only one locomotor training site limits the transferability of study findings to other sites—particularly those findings related to the empowering effects of the therapeutic process. Further research is needed to determine if the trainee-focused, empowerment-driven approaches adopted by therapists associated with Dr. Behrman's locomotor training study are unique to this particular site, or if therapists at other locomotor training sites use similar approaches.

Further limiting the transferability of study findings is the fact that the sample was not representative of the general population on the basis of gender and ethnicity. Predominantly comprised of white males, the sample may have produced data that is not

representative of the experiences of females, or of persons from other ethnic backgrounds. Consequently, additional research is needed to gain an understanding of the experiences and perceptions of women and of ethnically diverse participants enrolled at other locomotor training sites.

A final limitation of my study stems from the fact that enrollees in Dr. Behrman's study were self-selected, voluntary participants. As evidenced by their willingness to commit to a time-demanding study that required trainees to participate in training sessions Mondays through Fridays over a 9-week period, participants appeared to be highly motivated, optimistic and hopeful about their potential for recovery of walking. Consequently, these individuals may have achieved a higher level of psychosocial adjustment and been prone to success before the locomotor training study than the "average" participant. Additional studies of the experiences and perceptions of nonvoluntary locomotor training participants are therefore needed.

CHAPTER 4 INTRODUCTION TO THE THEORETICAL FRAMEWORK

Overview

Data analysis and interpretation using the constant comparative method (Glaser & Strauss, 1967) yielded a coding framework of more than 500 nodes representative of locomotor training and participant experiences of the treatment. Relationships and themes to emerge from the coded data were used to develop the theoretical framework presented in Figure 3. Three categories of variables, *Input*, *Process*, and *Outcome* variables, are used to classify the six components of the theoretical framework. Labeled A through F for ease of reference, these components include (A) Therapist Variables, (B) Trainee Variables, (C) the Trainee's Psychosocial Adaptation to Incomplete Spinal Cord Injury (incomplete spinal cord injury), (D) the Locomotor Training Therapeutic Process, (E) Trainee Experiences (Physical, Cognitive and Emotional) Resulting from the Therapeutic Process, and (F) Locomotor Training Outcomes.

Therapist variables (A) and trainee variables (B) are classified as input variables since they determine the processes that occur during locomotor training. As the focus of our study, the variable of psychosocial adaptation to incomplete spinal cord injury (C) is featured in the framework. Psychosocial adaptation is interpreted as both a specific trainee variable and a locomotor training outcome variable. Due to the fact psychosocial adaptation may be viewed as either a "state of being" or a recurring cognitive-emotional process, it may be discussed in terms of input, process and/or outcome variables. This

component is therefore depicted as a gray, double-headed arrow extending across the input, process and outcome categories.

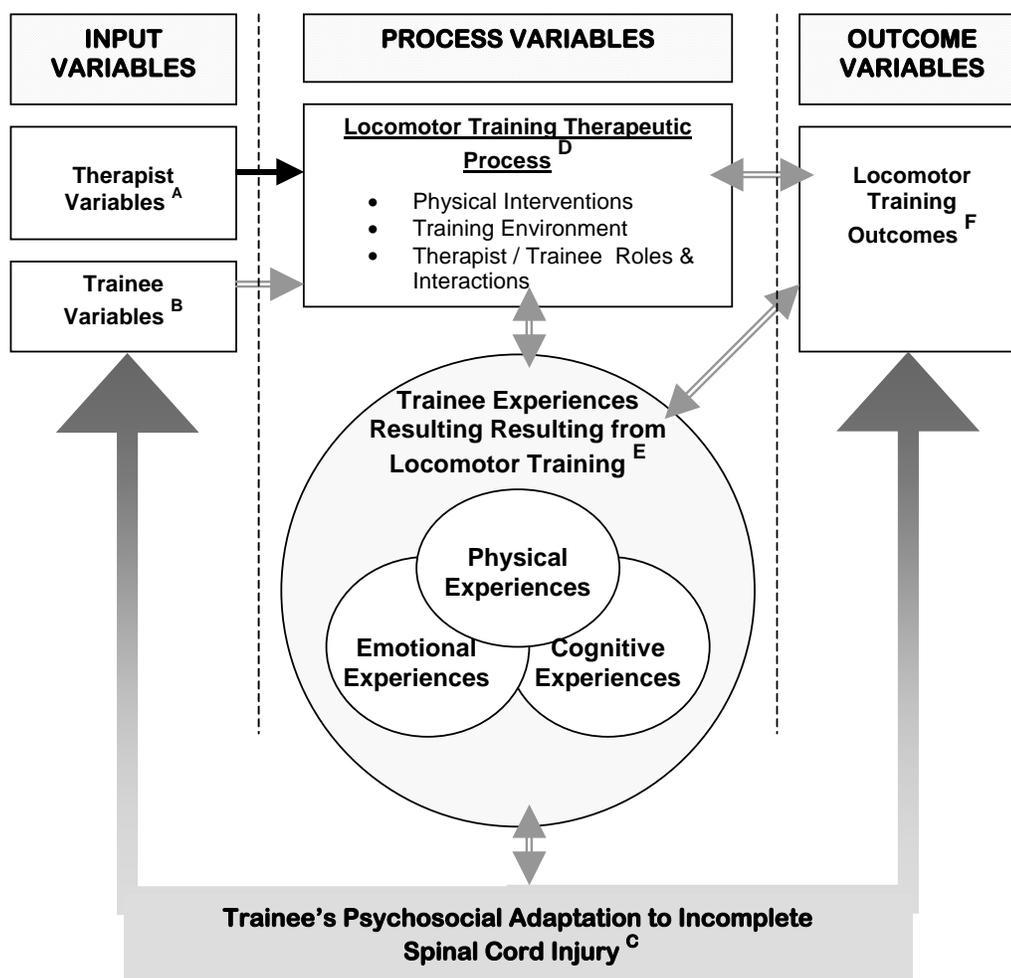


Figure 3. Effects of locomotor training on the psychosocial adaptation of persons with incomplete spinal cord injury. A) Therapist variables. B) Trainee variables. C) Trainee's psychosocial adaptation to incomplete spinal cord injury. D) Locomotor training therapeutic process. E) Trainee experiences resulting from the therapeutic process. F) Locomotor training outcomes.

Three processes to emerge from the data are the locomotor training therapeutic process (D), trainee experiences resulting from the therapeutic process (E), and the trainee's psychosocial adaptation to incomplete spinal cord injury (C). As process variables, these components interact with each other and influence locomotor training outcomes. Due to the predominant number and intriguing nature of process related

themes to emerge from the study, the locomotor training therapeutic process and trainee experiences are the focus of study results. Both processes are interpreted in terms of their impact upon trainees' psychosocial adaptation to incomplete spinal cord injury.

Logically, locomotor training outcomes (F) are classified as outcome variables. As the context for interpreting study findings, the trainee's psychosocial adaptation to incomplete spinal cord injury (C) is also classified as an outcome variable. Prior to the presentation of study results, a description of each component of the theoretical framework follows.

Therapist Variables

For our study, therapist variables are defined as the collective personal and professional characteristics of each therapist who provides locomotor training in the treatment setting. These variables include the personality of the therapist, his or her professional values, how he or she engages the trainee, his or her choice of treatment approach or protocol, level of skill with implementing the treatment, and the type of training environment he or she fosters. Several examples of therapist variables were evident during observations. For example, while I was collecting data for the two current trainees, Ken and Lynn, the "therapist component" of the locomotor training team was comprised of the Principal Investigator, physical therapists from research-oriented clinical settings, physical therapists who were full-time doctoral students, and occasionally, student volunteers from a Master's level physical therapy program. The Principal Investigator is a seasoned researcher who is well known for her work with locomotor training. While one clinical physical therapist did have experience implementing locomotor training, the majority of the training team had been recently trained in the intervention prior to Ken's enrollment. I had the opportunity to observe

some of the training sessions for team members and repeatedly heard the Principal Investigator tell the team that trainees should be the sole focus of their attention during training sessions—just as if they were working as the trainees’ “personal trainers.” In an effort to make each session a “positive experience” for trainees, team members were subsequently asked to minimize their personal conversations and interactions, and to identify their roles prior to a trainee’s arrival to minimize confusion and expedite training activities. Thus, although therapists initially had differing levels of experience with implementing locomotor training, the Principal Investigator set the stage for the manner in which trainees were to be engaged during training sessions—a reflection of her professional values. As will be discussed in Chapters Five and Six, many other therapist variables became apparent as they engaged trainees throughout the locomotor training therapeutic process, including their senses of humor and ability to teach and motivate trainees. A bold, right arrow is used to represent the contribution of therapist variables to the locomotor training therapeutic process.

Trainee Variables

Trainee variables are defined as the combined individual characteristics each trainee brings to the treatment setting as a participant in the locomotor training therapeutic process. These variables include the trainee’s physical, cognitive and emotional status, personality traits, social-environmental influences, cultural perspective, and life history prior to treatment. The trainee’s functional status following incomplete spinal cord injury, family support, treatment expectations, and psychosocial adaptation to incomplete spinal cord injury are examples of trainee variables that were found to influence the processes and outcomes of locomotor training in our study. A gray, lined right arrow is used to represent the contribution of trainee variables to the locomotor

training therapeutic process. Within the theoretical framework, gray, lined arrows are used to denote all relationships influenced by and affecting the trainee. Table 2, which provides brief background descriptions of trainees who participated in our study, captures some of each trainee's individual variables.

Trainee's Psychosocial Adaptation to Incomplete Spinal Cord Injury

As previously indicated, the trainee's psychosocial adaptation to incomplete spinal cord injury is interpreted as both a trainee variable and an outcome variable. For study purposes, *psychosocial adaptation* is operationally defined according to the following definition proposed by Livneh and Antonak (1997):

An evolving, dynamic, general process through which the individual gradually approaches an optimal state of person-environment congruence manifested by 1) active participation in social, vocational, and avocational pursuits; 2) successful negotiation of the physical environment; and 3) awareness of remaining strengths and assets as well as existing functional limitations. (p. 8)

Although Livneh and Antonak define the concept of psychosocial adaptation as a process, within our study it is also recognized to be a temporary "state" or "level." It is assumed trainees will be at some level of adaptation at a given point in time prior to beginning the locomotor training study and after completing the study. Within the theoretical framework, the trainee's psychosocial adaptation to incomplete spinal cord injury is represented by a gray, shaded, double-headed arrow. The arrow extends from the trainee variables box, through the process variables category, to the locomotor training outcome variables box. The arrow represents the mutual effect the two components of trainee's psychosocial adaptation and locomotor training outcomes have upon each other.

Table 2. Background descriptions of trainees

Trainee	Background description
Abe	Abe is a 49-year old Veteran. He is single and resides with a family member. Abe has not worked since acquiring his injury. Abe does not drive, and requires some assistance with his activities of daily living. Abe uses a power wheelchair for mobility, but practices walking at home using a platform walker.
Ben	Ben is 22 years old. He is single and employed. Ben drives and is independent with his activities of daily living. He uses a manual wheelchair and crutches for mobility. Ben enjoys participating in wheelchair sports.
Chuck	Chuck is a 44-year old Veteran. He is married and has children. At the time of his interview, Chuck was in his last semester at a local community college. He has not worked following his injury. Chuck drives and is independent with his activities of daily living. He uses a power wheelchair for mobility, but walks at home three to six times a day using a platform walker.
Dan	Dan is a 60-year old Veteran. He shares a home with his fiancée, who assists him with his minimal personal assistance needs. Dan has not worked following his injury. He is unable to drive. At the time of his interview, Dan was using a walker as his primary mobility device. He stated he only uses his power wheelchair for traveling long-distances. Dan describes himself as active and enjoys participating in a variety of social activities, including, shopping at flea markets.
Ed	Ed is 73-years old. He is married and retired. Ed's wife provides him with the "80%" assistance he requires with his personal needs. At the time of his interview, Ed was using a manual wheelchair for mobility. In the past year, Ed has experienced physical setbacks due to complications resulting from his spinal cord injury. Consequently, Ed feels he has physically regressed since completing the locomotor training study.
Frank	Frank is 62-years old. He is married and is the father of adult children. Following rehabilitation, Frank returned to his job. He is able to drive and is independent with his activities of daily living. At the time of his interview, Frank was walking full-time with the assistance of a single cane. A physically active person prior to injury, Frank now does aerobic workouts, rides a stationary bicycle, and swims whenever he can.
Ken	Ken is a 56-year old Veteran. He is married and has grown children. Following rehabilitation, Ken returned to his job. Ken is independent with his activities of daily living. At the time of Ken's final interview, he was walking with a cane, and was preparing to begin driving again.

Table 2. Continued

Trainee	Background description
Lynn	Lynn is 46 years old. She is married and has a grown child. Lynn was involved with charity work prior to her injury, but has not worked since her injury. Lynn is independent with her activities of daily living and is able to drive. At the time of her final interview, Lynn was occasionally using a cane and AFO brace while walking.

A gray, lined, double-headed arrow also extends from the trainee experiences component to the psychosocial adaptation component. This arrow signifies the reciprocal relationship between these two process components. Due to the fact the locomotor training therapeutic process impacts trainee experiences, an “indirect” relationship also exists between the locomotor training therapeutic process and the trainee’s psychosocial adaptation process.

Locomotor Training Therapeutic Process

The concept of *therapeutic process* has been defined as “all the meaningful activity that mediates [therapeutic] procedure and [therapeutic] outcomes” (Csordas & Kleinman, 1996, p. 8). Csordas and Kleinman (1996) define therapeutic procedures as “the organized application of techniques with some goal in mind” (p. 8), and describe therapeutic outcomes as evidence of how recipients of such techniques characterize their satisfaction with treatment, and changes in symptoms and/or function upon completion of the therapeutic process. In an attempt to explicate the meaning of therapeutic process, Csordas and Kleinman identify four ways in which the concept of therapeutic process has been construed: “1) the course of a treatment event, 2) a sequence of experiential or intrapsychic phenomena, 3) the course of an illness episode, and 4) social and ideological control exercised through healing practice” (p. 8). According to Csordas and Kleinman, the course of treatment may include the phases of physical interventions received by the

patient, and/or the interactions and relationships between treatment providers and recipients. The experiential process includes emotional response to treatment, insight, and somatic processes, while the course of illness determines decision-making processes regarding diagnosis and treatment (Csordas & Kleinman, 1996). Finally, social and ideological control refer to the way in which treatment and healing convey social and political issues (Csordas & Kleinman, 1996).

Within the context of our study, the locomotor training therapeutic process is operationally defined as the interactive process among 1) the physical interventions used during the treatment, 2) the roles of the therapists and trainees and their resulting interpersonal interactions, and 3) the training environment created through these activities and interactions. While these three components are captured by the dimensions described by Csordas and Kleinman (1996), their relationships are represented somewhat differently within the theoretical framework. For example, although the definition of therapeutic process proposed by Csordas and Kleinman excludes treatment procedures from the process, the interventions used during locomotor training were interpreted as an integral part of the therapeutic process. Accordingly, these interventions were included in the diagrammatic representation of the locomotor training therapeutic process. This discrepancy in interpretation may stem from the way Csordas and Kleinman conceptualize treatment by making clear distinctions between the roles of treatment “providers” versus treatment “recipients.” Characteristic of a medical model of treatment, providers are characterized as being responsible for treatment decisions, procedures and goals, while recipients are viewed as passive beneficiaries of the treatment process. As will be demonstrated in Chapter Five, such a conceptualization contradicts results of our study, which found trainees contributing to the therapeutic process by taking an active role in implementing treatment decisions and procedures.

To provide the reader with a context for understanding the locomotor training process, a description of the physical environment where locomotor training occurred and an overview of locomotor training procedures are provided. This information is adapted from field notes recorded during participant observations.

Description of the treatment setting

At the time of data collection, the laboratory used for locomotor training was modest in size, and often quite crowded with objects and people. Against the left wall was a sink, storage cabinets, a computer station with a chair, and filing cabinets. The right wall held a mounted rack used for hanging the harnesses needed for the locomotor training. Several harnesses hung from the rack. They appeared as life preserver-like support devices; each boasting straps and metal rings used to hook the trainee to the Body Weight Support (BWS) machine. A large exercise mat was positioned below the rack, against the right wall. To the left of the mat were filing cabinets, and to the right was a large TV/VCR rack, a storage rack and a desk with a computer. A videocassette recorder was mounted on a stand near the exercise mat, just a short way in and to the right of the doorway.

The treadmill machine stood centered against the wall opposite the doorway, and near the only window. An ordinary treadmill, the machine was mounted into a rectangular wooden platform approximately 18 to 24 inches high. The front of the treadmill faced the right wall. From each of the four corners of the platform rose a perpendicular wooden brace or pole. The poles were approximately four feet high, and were used when needed for attaching bungee cords to trainee harnesses, or portable railings to the sides of the treadmill. The right side of the treadmill served as the "entrance," and was flanked by a portable, wooden staircase that led up to the platform. A

full-length mirror stood on the platform, across from the stairs, and facing the trainee's left side. It was centered on the treadmill. A second mirror was secured in the front of the treadmill/BWS machine to face the trainee. Both mirrors enabled the trainee and therapists to monitor stepping and positioning. At the front of the treadmill was a speed control panel, on and off switches, and a heart-rate monitor.

The Body Weight Support (BWS) machine was positioned at the front of the treadmill. The machine was comprised of a large metal frame. The main part of the frame extended vertically, from the platform upward to the ceiling. A knob controlling the weight suspension system was positioned about one-quarter of the way up this section of the machine. Branching off from the main frame were sections that angled toward the left, closer to the center of the treadmill. Passing through these branches was one large cable cord that centered above the treadmill and extended downward from the ceiling. Attached to the cable was a triangular "trapeze" bar that held a sturdy metal ring at either end. These rings were used to attach the shoulder straps of the trainee's harness. The trapeze bar would rise upward as the body weight support was increased, and lower as the body weight was decreased. A second, stationary cable extended downward from the ceiling. Independent from the body weight suspension system, it appeared somewhat thinner than the cable holding the trapeze, and had loop-like projections along its length. The cable was a safety device that would prevent the trainee from falling should he or she stumble, or should a mechanical failure occur with the weight suspension system. Prior to every session, a loop from the cable was hooked to each of the two trapeze loops. When in use, the body weight suspension system would emit a "Puhhhh" sound every so often, resembling a mechanical sounding "exhale." A portable treadmill speed control unit was positioned outside the platform, near the BWS machine control.

Positioned at the front, left side of the treadmill was an almost life-sized cardboard cutout of the television character, “Xena The Warrior Princess.” A conversation with the Principal Investigator revealed that one of the first participants in the locomotor training study had given all therapists nicknames based upon his perceptions of them. He labeled the Principal Investigator “Xena” due to the warrior-like demeanor she presented during training—always encouraging trainees to push ahead, overcome obstacles and not let anything get in the way of their progress and goals. Subsequently, a team member found the Xena figure at the local shopping mall, and she has been a permanent fixture in the lab ever since. Xena serves as a fun conversation piece in the lab, especially when new trainees arrive. Therapists add to the fun by occasionally dressing Xena with sunglasses and T-shirts, and making Xena references during training. At a deeper level, Xena appears to serve as a symbolic source of motivation for trainees—watching over them as they step on the treadmill and reminding them that nothing is impossible.

Overview of treatment procedures

The basic protocol of the locomotor study involved trainees stepping with body weight support on a treadmill, followed by “over ground” training off the treadmill with no body weight support (Figures 4 & 5). The study’s Principal Investigator described the treadmill and body weight support system as a “permissive, controlled” environment that allows trainees to safely attempt ambulation-related tasks they would otherwise be unable to perform in their usual environments. After being assisted with donning a harness, the trainee would be assisted with ascending the treadmill platform. Once on the treadmill, the trainee would be hooked to the body weight support system by the straps of his or her harness.

A typical treadmill training session usually involved several “bouts” or rounds of stepping, each lasting two or more minutes. Due to the intensity of training, trainees were typically given short rest periods, as needed, between rounds. Throughout each session, therapists alternated roles as “leg trainers,” “hip trainers,” machine control operators, data recorders, and observers. Leg trainers sat in specially adapted seats, one on each the left and right side of the treadmill. While facing the trainee, each of the two leg trainers would provide hands-on assistance with flexing and extending the trainee’s legs as needed to achieve ambulation. The hip trainer would stand behind the trainee, straddling the treadmill, and position his/her hands on the trainee’s hips and/or back as necessary to assist with achieving hip flexion and extension. The hip trainer also assisted the trainee with maintaining an upright, aligned posture while stepping. For those trainees who evidenced difficulty maintaining an upright posture, a “trunk trainer” was sometimes used to stand in front of the trainee and support his or her shoulders while stepping. As trainees became more independent with stepping, assistance from leg, hip and trunk trainers was reduced, and sometimes, completely eliminated.



Figure 4. Training on the treadmill with body weight support and manual trainers



Figure 5. Overground training

Machine control operators positioned themselves at the right side of the treadmill, and were responsible for stopping and starting the treadmill, changing the speed controls, and changing settings on the body weight support machine. For each session, a data recorder was responsible for entering data on the maximum treadmill speeds, the time spent stepping, and the body weight support setting. Typically, one trainer served as an observer during any given training “bout.” He or she would sit within good viewing distance of the trainee, monitor the trainee’s body position and stepping, and observe leg and hip trainer techniques. The primary purpose of the observer was to provide the team with feedback, including any corrections that may be necessary to optimize stepping and positioning.

Upon completion of treadmill training, over ground training ensued. Over ground training enabled trainees to translate the skills and principles they had practiced on the treadmill to “normal” conditions. Over ground training consisted of trainees walking with varied levels of assistance in indoor and outdoor environments. The specific approaches used during treadmill and over ground training were adapted to the individual needs of each trainee.

Due to the fact that locomotor training requires the combined efforts of several therapists working together in a variety of capacities, the ability of individual therapists to draw upon their individual styles and skill levels and negotiate their differences to form a cohesive, effective team, appears critical for successful locomotor training outcomes and positive treatment experiences for trainees.

Trainee Experiences Resulting from the Therapeutic Process

For the purposes of our study, the component of trainee experiences is viewed as the collective physical, cognitive, and emotional experiences and responses of the trainee resulting from the locomotor training therapeutic process. As will be discussed in depth in Chapter Six, trainees' physical experiences included a lack of control over their bodies and physical sensations resulting from locomotor training. Trainees described the cognitive demand associated with training and reported emotions such as frustration, excitement and hope. The interdependent relationship among the three dimensions of experience is represented in the theoretical framework by three overlapping circles. Gray, lined double-headed arrows depict reciprocal relationships among trainee experiences and the components of the locomotor training therapeutic process, trainee's psychosocial adaptation to incomplete spinal cord injury and locomotor training outcomes. The final variable of the theoretical framework, locomotor training outcomes, will now be addressed.

Locomotor Training Outcomes

Therapeutic outcomes have been defined as "the disposition of participants at a designated end point of the therapeutic process, with respect to both their expressed (high or low) satisfaction and to change (positive or negative) in symptoms, pathology, or functioning" (Csordas & Kleinman, 1996, p. 9). Within our study, locomotor training

outcomes are synonymous with therapeutic outcomes, and are defined as the range of physical, cognitive and emotional results attributable to participation in the locomotor training study. Outcomes include, (a) changes in the physical appearance and function of the body, (b) changes in functional ambulation, (c) changes in the trainee's cognitive-emotional status affecting variables such as self-esteem, confidence, motivation and hope, (d) changes in the trainee's ability to participate in activities within the home, workplace or community, and (e) changes in the trainee's psychosocial adaptation to incomplete spinal cord injury.

Due to the fact trainees began to report changes or results during the course of locomotor training, and these results often reciprocally impacted the therapeutic process and trainee experiences, locomotor training outcomes are not restricted to interpretation as "end-products" of the treatment. This view differs from the Csordas and Kleinman (1996) definition of therapeutic outcomes. In addition, the broader definition of outcomes adopted in our study extends beyond the more typical focus of rehabilitation interventions and research on strictly *functional* outcomes. The theoretical framework depicts the locomotor training outcomes component as having reciprocal relationships with the components of locomotor training therapeutic process, trainee experiences resulting from the therapeutic process, and trainee variables. Relationships with the locomotor training therapeutic process and trainee experiences are both denoted by gray, lined, double-headed arrows. The large, gray-shaded, double-headed arrow representing the trainee's psychosocial adaptation to incomplete spinal cord injury extends between locomotor training outcomes and trainee variables. The arrow is used not only to identify psychosocial adaptation as both an outcome and a trainee variable, but also to depict the reciprocal relationship between the two variables.

Summary

The theoretical framework to emerge from our study is reflective of the World Health Organization's (2001) *International Classification of Functioning, Disability and Health* (ICF). The ICF system classifies the health characteristics of individuals "within the context of their individual life situations and environmental impacts" (WHO, 2001, p. 242). ICF organizes health-related information into two parts or categories (a) functioning and disability, and (b) contextual factors (WHO, 2001). Each part is further divided into two components. The World Health Organization (2001) uses the category of "Functioning and Disability" to encompass the components of Body Functions and Structures, and Activities and Participation. The components of Environmental Factors and Personal Factors comprise the category of "Contextual Factors" (WHO, 2001). Within the ICF framework, the component of body functions and structures is used to classify physical changes occurring as a result of injury or disease, while activities and participation is used to classify basic tasks or complex activities associated with all areas of life (WHO, 2001). A model depicting the ICF conceptual framework is replicated in Figure 6.

As an intervention aimed at enhancing the recovery of walking, locomotor training stands to impact the body structures and functions, and activities and participation of persons with incomplete spinal cord injury. Similar to the ICF system, the framework resulting from our study captures personal variables of both the trainee and therapist. Environmental factors that impact trainees are considered to be included in the trainee's variables and the impact of the locomotor training environment upon the trainee and his or her treatment outcomes is also depicted in the framework. In its illustration of the relationships among (a) the locomotor training therapeutic process, (b)

the trainees' physical, cognitive and emotional experiences of the treatment, (c) the resulting impact on psychosocial adaptation and (d) on treatment outcomes that include changes in activity participation and psychosocial adaptation, the framework to emerge from the data provides a comprehensive picture of recovery that is not restricted to functional changes alone. Such a concept is very reflective of the ICF system. Chapters Five and Six will focus on the two process variables to emerge from the theoretical framework. Chapter Five will describe the locomotor training therapeutic process and Chapter Six will describe the trainees' physical, cognitive and emotional experiences of locomotor training.

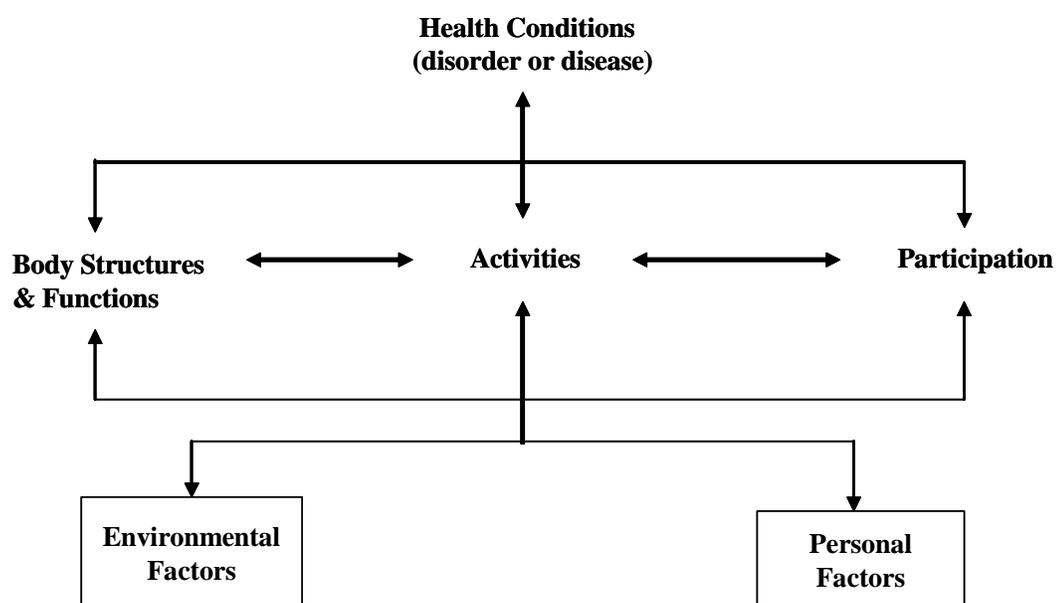


Figure 6. Model of functioning and disability (WHO, 2001, p. 18)

CHAPTER 5
THE ROLE AND MEANING OF EMPOWERMENT IN THE LOCOMOTOR
TRAINING THERAPEUTIC PROCESS

Introduction

Almost immediately upon beginning my participant observations, I was struck by the manner in which the theme of *empowerment* resonated throughout the locomotor training laboratory. Given my background in independent living and disability advocacy, I was all too familiar with service provision approaches aimed at promoting empowerment among people with disabilities. My professional life focused on promoting consumer independence, on educating consumers in areas of need to enable them to make informed choices and take control of their lives, on encouraging them to actively make decisions, including decisions related to goal planning and services, and supporting consumer decisions to take risks in their pursuit of quality of life. What I did not anticipate prior to data collection was the extent to which I would witness these same approaches being implemented in the locomotor training laboratory. Instead, I was heartened to find therapists engaging trainees, not as “patients,” but as “team members.” I observed therapists encouraging trainees to take active roles during their locomotor training sessions—to make decisions regarding training activities and treatment goals. I observed therapists educating trainees about ambulation principles and body mechanics in a manner that would enable them to understand specific movements or tasks they must perform to improve their walking ability. I observed therapists creating a supportive, fun training environment where the trainee was the focus of attention, and where boundaries

were not placed on potential treatment outcomes. My discussions with trainees regarding their locomotor training experiences, and observations of their responses to the training approaches adopted by the therapists served to confirm my initial instincts: I was witnessing empowerment.

Empowerment defined. The concept of empowerment has its roots in the civil rights and consumer movements of the 1960s. For persons with disabilities, this era ultimately led to two movements that both embodied and popularized the concept of empowerment: the deinstitutionalization of persons with psychiatric disabilities and the advent of the independent living movement (DeJong, 1979, 1983; Dickerson, 1998). Consistent with a shift in treatment paradigms as described by DeJong (1979, 1983), from a medical model of rehabilitation service provision to a one that is more consumer focused, empowerment became touted as a preferred approach for the delivery of disability-related and rehabilitation services by the 1990s (Banja, 1990; Emener, 1993; Houser, Hampton & Carriker, 2000).

Despite growing support for the concept of empowerment within rehabilitation contexts, a review of the rehabilitation literature reveals limited attempts to define and describe empowerment as it applies within the distinct disciplines of rehabilitation. Although the fields of rehabilitation counseling (Bolton & Brookings, 1996; Houser, Hampton & Carriker, 2000; Kosciulek, 1999), rehabilitation psychology (O'Hara & Harrell, 1991; Webb & Glueckauf, 1994; Zimmerman & Warschausky, 1998), and occupational therapy (Chenq, Rodger, Polatjko, 2002; Pizzi, 1992; Townsend, 1992) have made initial, albeit limited, efforts to explore empowerment from theoretical, empirical, and service provision perspectives, the literature indicates the disciplines of physical therapy and speech therapy have been less inclined to do so (Frost, 2001). This

discrepancy may stem from the fact rehabilitation counselors, rehabilitation psychologists and occupational therapists maintain (a) a holistic treatment focus aimed at enhancing the overall role participation and psychosocial adjustment of people with disabilities, and (b) an understanding of the personal and social/environmental factors that may dissuade participation and adjustment. Consequently, these disciplines may have more readily recognized empowerment as both an approach to rehabilitation service provision and a desired outcome of such services. The fact that the disciplines of physical therapy and speech therapy have been late to address the topic of empowerment is somewhat unexpected considering the concept of *patient* empowerment has more recently been applied to models of medical service delivery, and has emerged as a prevalent theme in the nursing and health care services literature (Barker, 2002; Brennan & Safran, 2003; Falk-Rafael, 2002; Houston & Cowley, 2002; Loft, McWilliams & Ward-Griffin, 2003; Powers, 2003; Roberts, 1998; Ryder & Wiltshire, 2001; Salmon & Hall, 2003).

Given the range of disciplines to address empowerment, many definitions of the concept have been proposed. For example, Houser, Hampton and Carriker (2000) present several definitions of the term “empowerment” relevant to the field of rehabilitation counseling. They include definitions by Fawcett et al. (1994), who define empowerment as “the process of gaining some control over events, outcomes, and resources of importance to an individual or group” (p. 472), and Guitierrez (1990) who describes empowerment as “a process of increasing interpersonal, or political power so individuals can take action to improve their life situations” (p. 149). In her discussion of empowerment as it relates to persons with psychiatric disabilities, Dickerson (1998) describes the concept as being comprised of three attributes, “self-determination, social

engagement, and a sense of personal competence” (p. 255). Dickerson suggests ways in which traditional therapies may promote consumer/patient empowerment, including, sensitivity to the stigma and disenfranchisement associated with disability, emphasizing the strengths and abilities of consumers, and involving consumers in the planning and delivery of disability-related services.

Like the previous definitions, the themes of control and active participation are also reflected in the work of Falk-Rafael (2002) and Zimmerman and Warschausky (1998). In a study exploring how public health nurses conceptualize empowerment, the findings of Falk-Rafael (2002) yielded an empowerment model of “evolving consciousness” characterized by “increasing awareness, knowledge, and skill interacted with the clients’ active participation to move toward actualizing potential” (p. 1). In an article entitled *Empowerment Theory for Rehabilitation Research*, Zimmerman and Warschausky (1998) present the term “psychological empowerment (PE)” — a concept originally introduced by Zimmerman (1990). Psychological empowerment is defined as “empowerment at the individual level of analysis” (Zimmerman & Warschausky, 1998, p. 4). The concept encompasses motivation to control, knowledge and skills needed to influence one’s environment, and active participation (Zimmerman, 1995).

As is evident by the definitions cited above, the term empowerment refers to the process of gaining power. Aleksziuk (1996) labels the result of this process as a *sense of personal power*. A sense of personal power is defined as “the perception by the individual that he or she has the ability to take effective action” (Aleksiuk, 1996, p. 35). Synonymous with self-efficacy and a sense of competence, a sense of personal power leads to psychological well being by generating feelings of serenity, self-esteem, inner strength, self-confidence, and immunity to stress (Aleksiuk, 1996). The remainder of this

chapter will summarize findings that characterize the locomotor training therapeutic process as a process of empowerment, and describe how the sense of personal power resulting from this process impacted the psychosocial adaptation of trainees.

Findings

Themes to emerge from our study provide evidence of how the locomotor training therapeutic process promoted trainee empowerment, and what meaning this approach held for trainees. As illustrated in the theoretical framework summarized in Chapter 4, and reproduced in Figure 7, the locomotor training therapeutic process constitutes the physical interventions implemented by therapists during training sessions, the training environment, and the roles and ensuing interactions between therapists and trainees.

Themes to emerge from the locomotor training therapeutic process include

- “Coach,” “Teacher” and “Therapist”: Therapist roles that foster empowerment.
- Power through equality: The trainee as “Team Member.”
- Power through knowledge: Trainee perceptions.

Each of these themes is described and discussed in terms of trainee experiences and meaning.

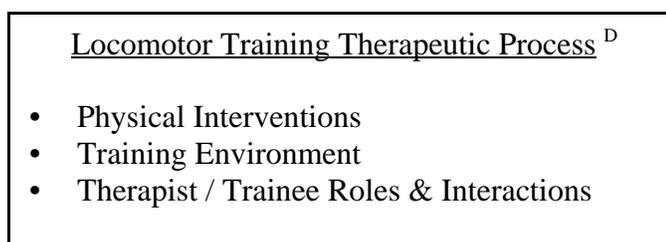


Figure 7. Locomotor Training Therapeutic Process

Meaning. Finally, how the process and increased sense of personal power resulting from locomotor training impacted the psychosocial adaptation of trainees is summarized.

“Coach,” “Teacher,” and “Therapist”: Therapist Roles That Foster Empowerment

Participant observations revealed therapists alternated among three roles during locomotor training sessions—the role of “Coach,” the role of “Teacher,” and the role of “Therapist.” Data suggest each of the roles adopted by therapists contributed to the creation of an empowering environment in a different, but equally valuable manner. A description of the 3 roles, and how each contributed to the empowerment of trainees will follow. First, however, a commentary on the use of the terms “therapist” and “trainee” is necessary. When asked to describe their roles during locomotor training, the therapists did in fact, describe themselves as “therapists.” Their selection of the term “therapist” to describe their role reflects a traditional rehabilitation or medical orientation to treatment. It should also be noted however, that therapists typically referred to locomotor training participants as “trainees” rather than “patients.” Use of this terminology in reference to study participants conflicts with a traditional rehabilitation model of treatment, and instead, is suggestive of an education-focused orientation to rehabilitation, such as the model proposed by Trieschmann (1988) that was described in Chapter 2. Data reveal that the locomotor training therapeutic process was in fact, directed at educating and empowering trainees. The use of “therapist/trainee” terminology in the locomotor training environment therefore implies that, while therapists may view themselves as using the same range of activities as they do in more traditional rehabilitation settings, in this particular experimental setting, they recognize the value of adopting a more educational, trainee-centered approach to treatment. The manner in which therapists implemented an educational, empowerment-driven treatment by assuming multiple roles will now be addressed.

The therapist as “coach.” During locomotor training sessions, therapists frequently assumed the role of “coach.” By engaging in behaviors characteristic of coaching an athletic team, namely, the use of “team talk,” hand gestures, and “motivational talk,” therapists promoted a sense of team spirit, unity and social support within the training environment, and served as motivating forces during sessions. Although the locomotor training study’s Principal Investigator typically assumed the role of “head coach” or “leader,” other therapists were also given leadership duties within the training laboratory. They frequently acted as session leaders or “assistant coaches,” particularly when the Principal Investigator was not present.

The use of “team talk” or team references was initiated by the Principal Investigator, who collectively referred to everyone involved with the locomotor training study, including trainees, as “our team.” Other therapists involved with the study soon adopted the same terminology, and soon, the use of phrases such as “Way to go, team!” and “Good work, team!” were frequently heard during training sessions. Team talk promoted a sense of unity and camaraderie among members, and recognition that all members were valuable contributors to the locomotor training process.

In addition to team references, the Principal Investigator’s attempt to promote team spirit through the use of hand gestures was evident early in the study. For the Principal Investigator in particular, gestures appeared to be an important and meaningful form of communication with the team members. For example, prior to Ken’s arrival on his first day of locomotor training, the principal investigator gave the training team a brief “pep talk,” outlining their goals and objectives for the session. She began the talk by initiating a hand-over-hand “huddle” with the members present. Following Ken’s session, the principal investigator “high-fived” all team members for a very successful first

session. Based upon these examples, it appears both the “huddle” and the “high-five” were used to motivate therapists and establish a sense of unity among team members.

While the Principal Investigator frequently used gestures with other therapists early in the semester, when many of them were new to the team and developing their locomotor training skills, the use of gestures was also extended to trainees as they were enrolled in the locomotor training study. The principal investigator frequently initiated “high-fives” with trainees throughout sessions as a way of recognizing their effort and performance. As with therapist members, high-five gestures also appeared to be used as a symbol of unity or membership with trainees, and also as a way to congratulate them on a “job well done.”

Another way in which therapists assumed the role of coach was through the use of “motivational talk” with the team. Motivational talk included words of encouragement to the trainee and team, cheering, acknowledging progress, and providing the team with feedback on the locomotor training sessions. It was not uncommon, for example, to hear team members begin to chant a trainee’s name as he or she neared the end of a stepping round. Trainees were also encouraged by frequent exclamations of verbal praise such as “Excellent!” or “You look great!” when they demonstrated good stepping and posture during training. Motivational talk was also used to encourage the team as a whole, as evidenced by the following statement made by a therapist during a session with Ken:

"Nice, everybody. Sounds great. Looks great. It is great!"

By assuming the role of “coach,” therapists promoted a sense of team spirit within the locomotor training environment. The feelings of unity, social support, enthusiasm, and encouragement created through the use of team talk, gestures and motivational talk helped to build an empowering environment for trainees. The coaching

approach adopted by therapists in the locomotor training study was clearly more reminiscent of approaches used by athletic coaches or personal trainers than those typically used by physical therapists in the rehabilitation of persons with spinal cord injury. Perhaps therein lies its value. The typical therapist-patient relationship established in a rehabilitation treatment setting is consistent with a medical model of rehabilitation, whereby the therapist assumes the role of treatment provider and the patient is the recipient of treatment. In the “coach–team member” relationship established in the locomotor training study however, the trainee is not treated as a patient, but instead, is actively engaged and “cheered on” as a valued member of the team. In the *Handbook of Sport Psychology*, Vealey (2001) relates confidence among athletes is generated through (a) being part of a social support network that results from team-building activities, and (b) being associated with coaches who adopt an autonomous coaching style that promotes athletes’ perceptions of control through the use of instructional feedback and reinforcement. These same elements were evident throughout the locomotor training therapeutic process. Vealey therefore provides support for the assertion that therapists, by establishing a coach-team member relationship during locomotor training, likewise stood to enhance to the confidence, positive self-esteem and sense of personal power of trainees.

The therapist as “teacher.” A primary role of therapists was that of “teacher.” As teachers, therapists provided trainees with the knowledge and skills necessary to optimize their walking ability. The teaching process involved drawing trainee attention to their current walking style and compensatory habits, while simultaneously educating them on the characteristics of “good” walking. Providing the framework for all teaching

efforts were the four principles of locomotor training described by Harkema and Behrman (2002). These principles include

- Maximize weight bearing on the legs
- Optimize sensory input and cues
- Optimize kinematics for each motor task
- Maximize recovery and minimize compensation.

On the basis of these principles, therapists provided trainees with ambulation skills and techniques required to improve their stepping, gait, and walking ability.

A significant focus of the observed teaching efforts was directed at increasing trainees' awareness of their body positions and movements at any given time. Due to functional limitations and proprioceptive deficits resulting from their spinal cord injuries, trainees had developed compensatory strategies for walking prior to beginning locomotor training. Because these strategies were typically counterproductive to locomotor training principles, therapists attempted to extinguish them by pointing them out to trainees, and then actively teaching trainees how to position and move their bodies in a manner that would promote spinal cord recovery, and maximize their walking ability. For example, the need to maintain an upright, aligned posture while stepping on the treadmill and over ground was constantly reinforced with trainees. Consequently, therapists frequently used body positioning cues such as "head up," "shoulders back," "hips forward," "tighten your buttocks under you," "relax your arms," and "swing your arms" to teach and remind trainees about proper body position during training. The effectiveness of this teaching approach is evident in the following exchange that occurred between a therapist and Ken, just prior to beginning an over ground training session:

Therapist: What three things do you have to remember?

Ken: Head up, shoulders back, rear end in!

Therapists also used cues to teach trainees how to correct or improve their stepping. Stepping cues included directions about step length, leg and/or foot movement, the rhythm or timing of steps, stepping speed, stepping force or intensity, and shifting weight from side to side while stepping. For example, during a training session with Lynn, the therapist cued her to "kick it out" in reference to her left leg's tendency to rotate medially. In this instance, the stepping cue was used to teach Lynn how to alter her stepping pattern in an attempt to "override" her compensatory tendency.

For all participants in our study, establishing a consistent rhythm while stepping on the treadmill proved challenging. Consequently, therapists provided trainees with rhythmic, verbal cues by which they could match their own stepping rhythm. In a session with Ken, for example, the therapist used rhythm cues to teach him when to extend his leg during the stepping cycle; stating, "Help me kick it out now. . . now . . . now. . . ." Similarly, a videotaped training session with Abe revealed a therapist using rhythm cues to teach him when to shift his weight from side to side by chanting, "Right leg . . . right . . . left . . . right . . . left. . . ."

In addition to cueing trainees about body position and stepping, therapists also provided trainees with more in-depth instruction on body mechanics and ambulation principles. During Ken's first week of training, for example, therapists used a combination of physical demonstrations and verbal explanations as they began to teach him about his maladaptive, compensatory movements and how to correct them. During his first session, a therapist positioned her hands on Ken's leg and hip to demonstrate how he should not lift his right leg and hip while swinging the leg forward. She proceeded to instruct him to not try to lift the leg, but simply "give it" to her while

stepping. Two days later, a different therapist instructed Ken how to alter the way he lifts his leg, from hiking or lifting it at the hip, to kicking it outward:

Therapist: What I want you to do is help me out. Try to kick your (right) leg out straight before your foot hits—can you see that?

Ken: Yeah.

During Ken's fourth training session, the body mechanics instruction continued when a therapist told him he was working "too hard" with his right leg. In reference to Ken's tendency to hike his right hip upward when trying to bring his leg forward, she told him to think of his leg like a pendulum and simply "let it drop" and swing forward. In this example, the therapist enabled Ken to visualize the task at hand by using a metaphor to teach him about body mechanics.

Another area in which therapists reinforced an aligned posture and proper body mechanics was in the use of mobility devices. Although teaching patients or consumers how to use mobility devices is a common duty among physical therapists, within the context of the locomotor training setting, the instruction focused on introducing locomotor training principles to the task to optimize sensory input. When mobility devices were necessary, therapists taught trainees how to use the device in a manner that promoted an upright posture. For example, during an overground training session with Ken, a therapist showed him how to use the walker differently to obtain a more natural posture by holding it out further in front of him and not bending his shoulders forward while he walked.

To maximize the possible benefits of locomotor training, therapists also acted in the role of teachers by assigning trainees "homework." Therapists often encouraged trainees to practice ambulation-related skills or tasks at home, or for those individuals

who experienced muscle stiffness, to implement a home stretching program. For example, therapists suggested to Ken that he stretch his right leg at home by bending his right knee and resting it on a chair while standing and keeping his left leg straight. Lynn, on the other hand, was shown exercises she could do at home to increase her ankle flexibility.

Chally (1992) stated that the process of *empowerment through teaching* occurs when teaching is “characterized by caring, commitment, creativity, interaction, and a recognition of the humanity of both teacher and students” (p. 117). In their roles as teachers, therapists in the locomotor training study embodied each of these characteristics while simultaneously providing trainees with skills and knowledge related to principles of locomotor training, ambulation, and body mechanics. As previously indicated, therapists’ references to locomotor training study participants as “trainees” versus “patients” suggest they valued and actively promoted an education-oriented treatment approach throughout the study. While in the medical model of service delivery, “patient” education has long been recognized to fall within the range of responsibilities of health care providers such as physicians, nurses, and therapists, the literature reveals few studies or theoretical articles have actually equated these educational efforts to those of “teachers” (Calman, 1986; Grannis, 1981; Reichard, 1996; Spoltore & O’Brien, 1995; Wellard, Turner & Bethune, 1998). One study that did acknowledge the teaching role of physical therapists was conducted by Grannis (1981), who attempted to compare how elderly patients and physical therapists rate the “ideal physical therapist” on the basis of four roles—therapist, teacher, worker or person. While results of the study suggest both therapists and patients rated the role of therapist as most descriptive, patients rated the role of teacher higher than physical therapists did. As will be discussed later in the

chapter, these results reflect the findings of our study that found locomotor training participants highly valued the knowledge they gained from therapists. Based upon the Grannis study findings, perhaps the physical therapy profession has yet to fully appreciate the extent to which therapists are valued as teachers by their patients, and their subsequent potential to empower patients through this role.

The therapist as “therapist.” In their roles as “therapists,” therapists applied their professional knowledge and expertise in the locomotor training laboratory as they would in a typical rehabilitation setting. They assessed and evaluated trainees, made treatment decisions, provided treatment, and problem solved regarding treatment strategies. Data from our study suggest trainees highly valued and respected the expertise of therapists acting in their professional roles as “therapists” during locomotor training. For example, they were frequently heard “consulting” with therapists by asking for information or advice regarding their functional status and treatment. It appears plausible the respect, confidence and trust trainees held for their therapists, and their ability to interact with such “experts” while participating in locomotor training, enhanced the trainees’ personal sense of power.

In addition to conducting initial functional assessments with trainees, therapists closely evaluated the status of trainees during locomotor training sessions in an effort to prevent any treatment-related complications. For instance, when a therapist noticed a trainee’s legs appeared red as he stood on the treadmill one day, he immediately consulted with the Principal Investigator and another therapist. Together they concluded the redness was due to poor circulation, not from irritation caused by the trainers' hands. On another occasion, when a therapist noted a trainee's arms looked blue as he stood on the treadmill platform, she had him raise his arms in the air, and then asked another

therapist to check and see if the harness was up too high under his arms. The therapist checked, and reported the harness was indeed positioned too highly under the trainee's arms. In both circumstances, therapists ensured the safety and well being of trainees through their professional vigilance.

In addition to assessing and evaluating trainees, therapists were also responsible for making treatment decisions and establishing guidelines for treatment in response to trainee progress or complications. However, as will be discussed in the next section, this responsibility was shared with trainees. Data suggest therapists took a more active role in making decisions to ensure the safety and well being of trainees. For example, following one trainee's complaint of soreness, the Principal Investigator suggested in order to minimize soreness temporarily, they do a lighter workout on Tuesdays and Thursdays, and "push harder" on Mondays, Wednesdays, and Fridays; adding the team could reevaluate that plan at a later time. Conversely, decisions regarding treadmill speed, level of body weight support, and duration of stepping rounds were often shared between therapists and trainees, particularly as the training progressed and trainees developed an understanding of the locomotor training process.

Throughout the locomotor training therapeutic process, therapists implemented their locomotor training skills, in addition to the more typical range of skills used by physical therapists in a rehabilitation setting. For example, when Ken arrived for a training session one day, therapists initiated a new stretching routine with him. After asking him to lie down on the mat and roll onto his stomach, a therapist lifted Ken's lower legs upward, off the mat, while explaining to him the team had watched his videotaped session and felt his muscles were not flexing as easily due to the amount of

time he spent in a sitting position. The implementation of such stretching routines is typical of the role of a therapist in a rehabilitation setting.

As is evident in the previous example, whereby a stretching program was instituted in response to Ken's muscle stiffness, data from our study suggest therapists frequently had to act in a problem-solving capacity during the locomotor training therapeutic process, a duty also consistent with the role of therapist. The creativity and persistence required of therapists when problem solving during locomotor training was well described by Chuck. During Chuck's interview, he was asked to clarify an observation from one of his videotaped locomotor training sessions. In the video, a therapist appeared to be doing something with Chuck's foot. Chuck summarized the attempts of therapists to maintain a grip on his foot while stepping on the treadmill as follows.

Chuck: To help them [therapists] lift it [the foot] up and get it. . . (demonstrates by moving hand) And they had tried to keep my toes from draggin . . . 'cause when they'd [toes] catch the treadmill, it would kick this spasticity in. . . . They [therapists] ace bandaged themselves to my shoe . . . they Velcro-ed (smiling and rolling his eyes) . . . themselves to my shoe . . . they, they . . . uh, athletic taped themselves to my shoe.

Chuck's account is one of many examples of how therapists used their knowledge, skills and creativity to effectively meet the problem solving demands of the locomotor training therapeutic process.

Summary. Acting in multiple roles as coach, teacher, and therapist throughout the locomotor training therapeutic process, therapists fostered an empowering environment for trainees. As coaches, therapists motivated trainees by providing them with a sense of team spirit, unity and support. As teachers, they provided trainees with knowledge and skills regarding locomotor and ambulation principles, and body

mechanics to enable them to optimize their walking ability. As therapists, therapists implemented their professional knowledge and skills as they would in the typical rehabilitation setting, to ensure the safety and well being of trainees while working to maximize treatment outcomes.

Power Through Equality: The Trainee as “Team Member”

The extent to which therapists engaged trainees as “team members” was readily evident during observations of locomotor training sessions. Trainees were not relegated to passive “patient” roles, but instead were treated as valuable, contributing members of the locomotor training team. Therapists encouraged trainees to actively make decisions during training sessions and to provide feedback to the team. Trainees were also kept actively informed by therapists, who provided them with explanations regarding training related activities, and notified them about what would occur during training. By interacting with trainees as fellow team members, therapists empowered trainees by promoting a sense of equality. During his interview, Frank expressed the personal meaning he derived from being engaged as a team member.

Frank: One of the things about the uh . . . project that I was especially impressed with was the degree to which the staff (3-second pause) engaged me as a uh . . . coinvestigator. And that was really very uh . . . powerful. I really felt like we were all working together on a common project.

For Frank, his involvement with the locomotor training therapeutic process was an emotionally “powerful” experience characterized by a sense of mutual striving toward a common goal. Frank’s selection of the term “coinvestigator” to describe his role, as opposed to study participant, suggests the sense of equality he experienced by being involved as a contributing team member. By engaging him in this manner, therapists not only demonstrated their combined support and commitment to Frank’s recovery, but also

reinforced for him the belief that he had the power and ability to equally influence his own recovery process.

One way in which therapists engaged trainees as team members was by promoting their active decision making throughout the locomotor training therapeutic process. Trainees were encouraged to make decisions related to the training routine such as how long to step on the treadmill during a single bout or an entire session, when to begin or stop individual stepping bouts within a session, and the length of breaks or rest periods between bouts. As trainees learned the locomotor training principles, became familiar with the training process and routine, and began to build their endurance while stepping, they were often encouraged to take on more responsibility by deciding what the treadmill speed setting should be, and how the body weight support should be altered.

In addition to decisions related to training routines, trainees were also encouraged to make decisions regarding treatment goals, and goals for each session. For example, the Principal Investigator routinely involved trainees in treatment goal planning sessions. During these sessions, she would seek trainee input on his or her perceived progress to date, and then ask him or her to identify and help prioritize remaining training goals based upon continued areas of need.

Trainees were also involved with deciding upon goals for individual training sessions. For example, when Ken arrived for one of his training sessions, the following dialog transpired:

Therapist: What's the goal for today, my friend?

Ken: To go as long as I can.

Later in the same session, Ken informed the team he would like to step on the treadmill for 25 minutes total that day. Prior to the start of a stepping round, he told one of the

therapists he wanted to continue stepping until he reached his goal of 25 minutes, but if his steps began to “lose quality,” he wanted to stop the round and then begin again. In obvious displays of approval of Ken’s decisions and directive approach, the therapist smiled and responded, “The boss has spoken” while the Principal Investigator cheered and clapped her hands.

In addition to making treatment related decisions, trainees were also encouraged to make decisions related to their ambulation needs. For example, as a trainee stood on the treadmill during one training session, a therapist asked, “Can you find . . . find a good balance point there? You look like you're fallin' back. What do you need to do?” In so doing, the therapist drew the trainee’s attention to his body position, and then charged him with deciding how to correct the problem. By encouraging independent decision-making and problem solving during locomotor training, therapists likely increase the probability that trainees will continue to implement these same skills both within and outside the locomotor training environment. In fact, data suggest trainees did initiate decision making/problem solving strategies as they progressed through locomotor training. During one of Lynn’s training sessions, for example, she asked the therapist who was serving as a leg trainer if she noticed anything “different” during the bout she had just completed, and then explained, “I was trying to push off from my toes instead of just bending the knee.” In this instance, Lynn made the decision to apply her understanding of body mechanics to devise a different strategy for moving her leg. Lynn’s problem solving approach was subsequently reinforced by the Principal Investigator who commented, “That's a nice idea.”

Another method by which therapists engaged trainees as team members was by encouraging them to provide feedback to the team. As is evidenced by the following example, this feedback included corrective feedback to therapists on their technique:

Therapist (serving in the role of hip/trunk trainer): Give me any feedback. I'm not on the trunk too often.

Ken: You weren't pushing down as much. I felt like I was being lifted, and I can see myself too. I kept going to the left.

At times, trainees also provided feedback to the team when they perceived their body positioning or body movements were not optimal while they were stepping on the treadmill. For example,

Ken: I feel like I'm really goin' to the left.

Therapist: Alright, when you say really goin' . . .

Ken: Well I mean, really leaning to the left. When I look in the mirror, I'm not straight up and down."

In conversations such as the one cited above, where the team ultimately concluded the trainee's harness needed to be adjusted, trainee feedback often led to successful problem solving between the trainee and therapists. The ability of trainees to influence the locomotor training therapeutic process through their feedback undoubtedly promoted their sense of personal power.

In addition to offering corrective feedback, trainees often provided the team with feedback on their physical status during training. While therapists frequently checked on the status of trainees by asking how they felt, or if they needed a break or a drink of water, some trainees began to offer such feedback unsolicited. For example, near the end of one of Ken's sessions, he informed the team, "The first five minutes are harder than the last five minutes. My legs are startin' to get tingly now so I know they're fatiguing."

In apparent recognition that, out of concern for him and in the interest of locomotor training, the team would want to know what he was feeling and experiencing, Ken volunteered this feedback. Trainees' recognition of their ability to teach fellow team members through their experiences is yet another example of how involvement as "team members" may have empowered them. The seeming sense of altruism trainees obtained from being involved as team members during locomotor training will be further addressed in the upcoming section on the psychosocial impact of team membership. A final approach by which therapists engaged trainees as team members was keeping them informed about what would occur throughout the locomotor training process. Rather than relegating trainees to passive treatment-recipient roles, therapists routinely notified them of impending changes in training activities or if a new activity would be introduced. In the following example, a therapist informs a trainee, in detail, of a new training task—arm swinging:

Therapist (standing on the treadmill, behind the trainee): Abe, on this next walk I'm gonna hand you . . . well actually, I'm gonna hand you something right now, in your left hand. (extending the end of a pole toward him) Can you grab that? (A few seconds later) Abe, in your right hand, I've got another one of those. Okay, Abe what these are gonna do is, I'm gonna actually do this (begins to alternately push and pull the other ends of the poles to facilitate arm swinging) while you're walking.

By notifying trainees about what to expect during training sessions, therapists not only minimized trainee anxiety about treatment, they simultaneously enhanced their sense of involvement with the treatment process. Using this approach, trainees were empowered through both a sense of involvement with their treatment and an increased awareness of what to expect from the treatment process.

Trainee perceptions of involvement as "team members." Therapists engaged trainees as team members by encouraging them to actively make decisions during

sessions, encouraging their feedback, and keeping them informed of what was to occur during training. Such approaches promoted a sense of personal power among trainees, and it was observed most trainees adopted active, directive approaches in their team member roles. To better understand the perceptions of those trainees who adopted such roles, they were asked during interviews to identify what caused their active, directive approach. Chuck provided the following response:

Chuck: Probably my 21 years in the military (Smiles). . . . If I'm uncomfortable . . . ya know if I'm in a position I'm uncomfortable with, pretty much I'll say "I need to move". . . "I need to get more weight on this leg" or . . . I'll let 'em know I need to be adjusted. I'm not gonna sit there and be quiet and shy about that (Chuckles).

Through his answer, Chuck related his assertive, “take charge” tendencies have been evident since his days in the military, and consequently, he felt comfortable expressing his needs during locomotor training. While therapists engaging Chuck as a team member did not “cause” his directive behavior, the empowering environment they created enabled him to use this personality strength, to be the assertive person he naturally is, to further the therapeutic process. Ben, on the other hand, cited a completely different reason for his directive approach:

Ben: It was somethin' I did. I mean (pause) I'm doin' the therapy for free. I mean, they don't have to be there helpin' me out . . . so, ya . . . I mean, if I can help out . . . some way, I'm gonna help out. Because... it means a lot that they're helping me out.

From Ben’s viewpoint, taking an active, directive role during training sessions was a way to “return the favor” to therapists. In appreciation for the team’s assistance, Ben construed his active participation as a team member to be a sign of gratitude or a way to give back to his team.

Trainees were also asked how participating as active team members affected their progress and/or locomotor training experience. Again using examples provided by Chuck and Ben, we learn the value of active participation during treatment as perceived by these trainees:

Chuck: HUUUH (exhaling) . . . (repeats question softly to himself, then pauses)
 Uhhhh . . . made me feel good about myself I guess, some. Uhhh, it felt positive.
 Uhhh . . . there was no negativity there at all. Uhhh. . . I wanna be as much of an active member to whatever I'm doin . . . even though I'm a kinda confined to the chair right now, I still wanna partake in as much as possible.

Ben: Uh it just . . . I mean when you're . . . it's kinda like (pause) when you're involved in somethin'? The more involved you are, the more a part of it you become? I mean if you're . . . if I was . . . it's an active . . . type theory . . . therapy instead of a passive . . . like you're... sittin' there and you're gettin' stretched, you're gettin' massaged . . . but you're not involved. You know when you take an active role in therapy . . . it means more . . . to you. You get more out of it, it means more to them because . . . it show that you're . . . it shows them that you're interested in what you're doin'. And . . . in the end, it works out better.

For Chuck, whose activity was restricted due to physical limitations and subsequent need of a power wheelchair for mobility, the prospect of being “active” in any manner possible was welcome. He described his involvement as an active team member as a positive experience that enhanced his self-esteem. Like Chuck, Ben also found value in being an active team member. Whereas Chuck enjoyed the opportunity to simply take an active part in something, Ben valued the sense of involvement he experienced through his activity. Ben distinguishes between conventional forms of physical therapy, which he views as “passive,” and locomotor training, which he describes as active, and relates he felt he benefited more from locomotor training because he was able to take an active role in the treatment.

The psychosocial impact of equality through team membership. As was evident throughout this section, the manner in which therapists engaged trainees as team

members served to empower them. By being encouraged to make decisions throughout training, to provide the team with feedback, and being informed about the locomotor training process, trainees perceived they were equal partners in the treatment process. As suggested by the data, having “equal status” as team members and the subsequent ability to actively contribute to the therapeutic process promoted senses of personal power, community, and positive self-esteem among trainees.

In addition to the psychosocial benefits listed, the theme of *altruism* emerged as another valued benefit of participating in the locomotor training therapeutic process. Altruism has been defined as “ a specific form of motivation for one organism, usually human, benefiting another” (Batson, Ahmad, Lishner & Tsang, 2002, p. 485). The recently cited example of Ben taking an active role during locomotor training as an expression of gratitude for team members’ efforts to promote his recovery is one illustration of altruism. While, in this case, Ben’s altruistic motive was to “return a favor” to team members, the data supports he and other trainees viewed their participation in the locomotor training study as a means to advance the understanding of the intervention, and ultimately, help other people with incomplete spinal cord injury. For example, during his interview, Ben identified the following benefit of participating in locomotor training:

Ben: . . . ya know they're . . . it, it means a lot, ya know, and it meant a lot to me to participate in it because . . . first . . . for example, it . . . it helped me out? But . . . it's gonna benefit somebody else better . . . because . . . me participating, ya know, they learned something from me participating, so it's . . . gonna help somebody out long . . . down the long run . . . I get satisfaction out of the fact that it's gonna help somebody out in the long run, so . . .

Like Ben, who drew meaning and satisfaction from the fact team members learned from him and would use this knowledge to help others, Ken also understood his potential to educate team members through his locomotor training experiences. During Ken’s first of

four interviews, for example, he stated he was, “lookin’ forward to helpin’.” After beginning locomotor training, Ken told the team he and his wife thought they were doing him “a lot of good,” and he hoped he was “helpin’ you all some too.” Ken’s stated desire to “help” the locomotor training team, even before he began training, suggests altruism may have been a motivating factor in his decision to participate in the locomotor training study.

As in our study, previous investigations have found altruism to be a motivating factor for individuals who participate in research studies (Fry & Dwyer, 2001; Vandenburg, 2001), and in voluntarism (Unger, 1991). Thus for noncompensated, voluntary research participants, like the trainees in the locomotor training study, altruistic motives may be especially common. It has been recognized that “People need to feel they are needed” (Yalom, 1985, p. 14). Through his work with group psychotherapy patients, Yalom (1985) learned of the therapeutic and psychosocial benefits of altruism. He reported his patients increased their self-esteem not only from the reciprocal giving and receiving of support, but “also from the intrinsic act of giving” (Yalom, 1985, p. 14). Interpreting Yalom’s theory within the context of the locomotor training study, it appears the study not only benefited trainees through the reciprocal acts of giving and receiving that occurred between the trainee and members of the locomotor training team, but also by providing trainees with an altruistic outlet. The locomotor training study afforded trainees the opportunity to use their spinal cord injury experience in a positive way to educate and impact others, and in so doing, provided them with a sense of purpose and power, and enhanced their self-esteem. The trainees’ desire to help other persons with spinal cord injury, like themselves, is supported by the altruism literature, which labels the motivation to benefit a particular group of people as *collectivism*. Collectivism has

been recognized as a particular type of altruistic motivation that may result from group identity (Batson, Ahmad, Lishner & Tsang, 2002).

Power Through Knowledge: Trainee Perceptions

As previously indicated, data from participant observations revealed therapists held the potential to empower trainees by sharing ambulation-related knowledge in their roles as “teachers.” The impact this knowledge had upon locomotor training participants was evident from data gathered through trainee interviews. In fact, the value of the knowledge gained through the locomotor training therapeutic process was a consistent theme described by trainees.

Both current and former locomotor training participants discussed how the acquisition of knowledge related to locomotor and ambulation principles, and body mechanics enabled them to appreciate the complex processes involved with walking, and enhanced their walking ability. Trainees commonly described a general sense of unawareness of walking and locomotor training prior to beginning the intervention. For example, during his interview, Dan stated, “First of all, I’ll be frank with you, I didn’t even . . . know the different stages that your body go through for you to walk.” Trainees indicated this lack of walking awareness stemmed from the fact walking had been an “automatic” process for them prior to injury. As described by Abe, “You just, you just never really think about it [walking] till you . . . have the accident.” This same sentiment was described by Frank. When discussing how therapists showed him the action his leg should be taking and how his foot should strike the ground, Frank emphasized, “Because none of that is automatic.”

Data suggest the loss of walking as an automatic experience combined with the increased understanding of ambulation principles gained through locomotor training led

trainees to a greater appreciation of the complexities involved with ambulation or walking. As described by Abe:

Locomotor training makes you realize . . . that walking's not just a . . . just . . . easy (laughs). . . . There's a lot involved in walking. . . . Different muscles, whatever. . . . You know standing straight up, not leanin' over and . . . balance is important . . .

Like Abe, other trainees commonly shared during interviews the lessons they learned about walking through locomotor training. In the following excerpt from Dan's interview, he explains how the knowledge he gained through locomotor training enabled him to correct one of his compensatory strategies, watching his feet while walking, and relearn how to walk:

Dan: And for a long time I always had to keep my eyes down to help me move. Through that training program, it . . . they . . . I use to walk with my body leanin' forward . . . and they always told me (smiling) you look like you're skiing! 'Cause every time I walk I wouldn't fall. . . . I'm workin' on a technique . . . and so . . . Goin' through that training program I learned how to place my feet back, how to . . . learned how to shift my weight . . . I learned quite a bit . . . lots from it.

The enthusiasm with which trainees discussed the knowledge gained through locomotor training rivaled their descriptions of functional gains due to the intervention, suggesting both outcomes were equally valued. For example, in reference to locomotor training, Frank stated, "And I thought that was a God-send (3-second pause) because it really did uh . . . teach . . . reeducate me as to how to move and how to walk." Like Dan, Frank told how locomotor training provided him with feedback regarding his compensatory strategies, stating he thought he was "walking good" until he began the locomotor training study. Frank explained he was shuffling and dragging his feet, and said of therapists, "They really helped to . . . educate me as to how to walk . . . increase my strength, capacity or what not." While Frank stated he considered the conventional physical therapy he received during his acute phase of rehabilitation important because it

helped him move again, he characterized the locomotor training study as teaching him *how* to walk.

While data provided by Dan and Frank imply the knowledge they gained about ambulation was a highly valued benefit of the locomotor training therapeutic process and a critical determinant of their successful outcomes, Abe's description of his perceived impact of ambulation knowledge suggests how such knowledge led to a personal sense of power.

Abe: You know, like I said, I . . . I learned a little bit more about what's involved . . . in ambulation, and it gave me a little more insight on it so you know how . . . you know what to work on. . . . You can work on it even harder. . . . 'Cause you're a little more knowledgeable on it.

Abe's indication that the knowledge he gained through locomotor training allowed him to work "even harder" toward his recovery illustrates the sense of personal power he gained through locomotor training. In Abe's case, knowledge of ambulation not only *enabled* him to pursue his recovery of walking independently, following completion of the locomotor training study, it *motivated* him to do so.

Abe: Well it gives ya, it gave me a little more drive. . . . You know, I know what's involved now. . . . And I know what, what areas to work on . . .

As will be discussed in Chapter 6, Abe admitted his functional outcomes did not meet his initial treatment expectations. For Abe, who did not achieve independent walking as he had hoped, the knowledge gained through locomotor training was identified as the outcome he valued the most. He claimed, "But I didn't . . . even though it wasn't, I still did . . . ya know it still taught me a lot. And I'm still working on what I . . . on what I did learn." Although Abe began to allude to his unmet expectations in this statement, he quickly pointed out how much he learned from locomotor training, and how he continues to use this knowledge. For Abe, the knowledge he gained about ambulation appeared

particularly meaningful. Not only did it motivate and empower him to independently practice walking on a daily basis, in a broader sense, it empowered him to pursue his stated hope of someday achieving a full recovery from his spinal cord injury.

The French philosopher Foucault has written extensively on the relationship between knowledge and power (Foucault, 1972, 1980; Turner, 1995), recognizing the relationship between knowledge and power to be so integrated, in fact, he coined the term “knowledge/power” to represent the unity of the concepts (Turner, 1995). In our study, participants commonly expressed the value of the knowledge they gained through locomotor training. While Aleksasuk (1996) maintains the acquisition of knowledge leads to a sense of personal power, he claims it is the process of putting knowledge into use that generates a sense of competence. Aleksasuk’s assertion was supported by findings of our study. Trainees’ dialogs reveal how the knowledge they gained through the locomotor training therapeutic process empowered and motivated them to impact their own recovery. Specifically, knowledge of ambulation and locomotor principles

- Facilitated trainees’ progress
- Enabled trainees to translate and practice their developing ambulation skills in home and community environments.
- Provided trainees with a framework by which they could self-monitor their ongoing progress and recovery.

Trainees actively applied their ambulation-related knowledge and (as will be discussed in Chapter 6) often reported increased confidence as a result of their knowledge and functional progress.

Summary

“Empowerment” was a predominant theme to emerge from data related to the locomotor training therapeutic process. Although the influence of trainee characteristics

on the therapeutic process should not go unrecognized, in our study, the contributions of therapists proved to be tangible determinants of the empowerment process. In addition to implementing the locomotor training intervention, therapists created an environment of empowerment through their interactions with trainees. While locomotor training as a *physical* intervention held the potential to empower trainees through ambulation recovery and resulting increases in functional independence, data suggest themes related to the locomotor training environment shaped by interactions between the therapists and trainees promoted trainee empowerment through cognitive-emotional levels of experience.

By acting in multiple roles as coach, teacher, and therapist, therapists empowered trainees through motivation, social support, knowledge, and access to their professional skills and clinical expertise. By actively engaging trainees as fellow team members, therapists empowered them through a sense of equality and involvement with the therapeutic process. The ability to advance the understanding of locomotor training through their experiences also provided trainees with an altruistic outlet that may have further enhanced their self-esteem. Trainees' perspectives indicated the value of the ambulation-related knowledge they gained, and how the knowledge shared by therapists empowered and motivated them to apply their skills independently in home and community environments. Collectively, the actions of therapists improved the trainees' sense of personal power, competency, confidence and self-esteem. Such variables are critical determinants of an individual's psychological well being, including his or her psychosocial adaptation to disability.

The themes of interactions that occurred between therapists and trainees during the locomotor training therapeutic process reflect an earlier investigation of caregiver

empowerment. In a study exploring strategies used by occupational therapists to engage family caregivers of elderly home health services recipients in the therapeutic process, Clark, Corcoran, and Gitlin (1995) identified four types of occupational therapist-caregiver interactions: caring, partnering, informing, and directing. Study authors suggest the use of such strategies promoted caregiver empowerment. While the specific approaches used by therapists in our study to promote empowerment were very different from those in the Clark et al. study, the general themes of caring, partnering, informing, and directing were clearly evident as described throughout the present chapter. Although the focus of the Clark et al. investigation was caregivers versus therapy recipients, their findings lend support to our study.

Empowerment themes emerging from the locomotor training therapeutic process are also representative of the dimensions of psychological empowerment identified by Zimmerman and Warschausky (1998). These dimensions include

- A sense of personal control
- Active participation with others to achieve goals
- A critical awareness of factors that may enhance or deter goal achievement.

Trainee perceptions of personal control, for example, were enhanced not only by increased mastery over ambulation-related tasks, but also by therapists engaging trainees as “equal” team members who were able to exercise control over their training, and eventually, community environments. Participating with other team members (namely, therapists) to achieve ambulation goals, was facilitated by the team spirit and environment of support fostered by therapists. Lastly, the knowledge therapists shared with trainees regarding principles of locomotion and body mechanics resulted in a “critical awareness” of factors hindering or enhancing trainee efforts to control functional ambulation. Given such examples, the cognitive-emotional dimensions of empowerment

described in our study may be more appropriately termed *psychological empowerment*. Psychological empowerment appears to have been a particularly important outcome for locomotor training participants, including those participants whose functional gains may have been limited or less than expected.

Throughout this chapter, numerous examples of data have been provided in an effort to elucidate the role and meaning of empowerment in the locomotor training therapeutic process. Consequently, our study provides a preliminary understanding of how a consumer-centered, empowerment-driven treatment approach enhanced the experiences and outcomes of participants of one locomotor training study. From a broader perspective, the following definition proposed by Banja (1990) captures the true meaning of empowerment as applied to the field of rehabilitation. Banja states,

The notion of empowerment transcends the connotations of “maximal restoration of function” since achieving such functional restoration does not necessarily imply its appreciation or utilization. To empower in rehabilitation, however, is to energize and catalyze a rehabilitation consumer’s capacity for life as well as to maximally enable him or her to ambulate, communicate, process information, and so on. (p. 615)

The manner in which therapists in our study succeeded in *energizing and catalyzing* trainees’ *capacity for life* is evident in the following chapter—“Horizons Of Meaning: The Physical, Cognitive And Emotional Experiences Of Locomotor Training.”

CHAPTER 6
HORIZONS OF MEANING: THE PHYSICAL, COGNITIVE AND EMOTIONAL
EXPERIENCES OF LOCOMOTOR TRAINING

Introduction

While published studies of locomotor training have focused almost exclusively on the physical and functional dimensions of the intervention, themes to emerge from our study revealed the cognitive-emotional experiences of locomotor training participants were equally prevalent and compelling. As depicted by the theoretical framework summarized in Chapter 4, and reproduced in Figure 8, trainees' descriptions of their locomotor training experiences characterized an interdependent relationship among the physical, cognitive, and emotional levels of experience. These collective experiences of locomotor training are the focus of the present chapter.

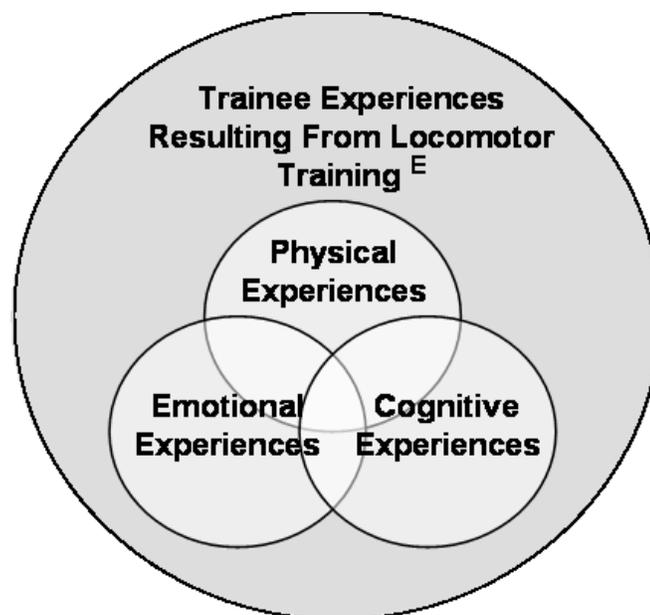


Figure 8. Trainee experiences resulting from the locomotor training therapeutic process

Locomotor training experiences were revealed through the “horizons of meaning” shared by trainees. According to Gubrium (1993), horizons of meaning are “drawn by the patterns of narrative linkages each [individual] makes with experiences” (p. 9).

Gubrium’s (1993) description is adapted from the work of Goffman (1986), who defined the term “horizon” in the following definition.

By an ‘information state’ I mean the knowledge an individual has of why events have happened as they have, what the current forces are, what the properties and intents are, and what the outcome is likely to be. In brief, each character at each moment is accorded an orientation, a temporal perspective, a ‘horizon.’ (Goffman, 1986, p. 134)

Using the conceptualizations of Gubrium and Goffman, statements made by trainees during locomotor training sessions and interviews are their narrative linkages to their disability and locomotor training experiences. Through these linkages, trainees’ reveal their knowledge, perceptions and interpretations of training-related events at a given point in time. The horizons of meaning concept is used to provide a framework for presenting and interpreting trainees’ individual experiences of the locomotor training therapeutic process.

Horizons of Meaning

Loss of Body Control Leads to Loss of Sense of Self: The Spinal Cord Injury Experience

To gain an understanding of trainees’ individual spinal cord injury experiences, they were asked during interviews to describe the ways in which their spinal cord injuries had affected their lives. Despite individual variations in levels of functional ability, one fundamental theme proved quite consistent. Trainees routinely described loss of function and control over their bodies and a resulting decrease or change in their role participation. Data analyses suggest these changes ultimately led to a lost or decreased sense of self among trainees.

Loss of body control was a theme commonly heard when trainees described the impact of their spinal cord injuries. For example, during his first interview, Ken alluded to his frustration over his body's lost capabilities and loss of control. According to Ken,

nothing has been as difficult as, as, as . . . knowing you can do something, or knowing that your body can do things . . . and you're not able to do it. . . . When ya know your mind says to (in a demanding tone of voice) "do it!", but then get that message to where it needs to be (smiles and shrugs shoulders).

Ken attributed his loss of control to a mind-body disconnection—describing his mind's inability to deliver messages through to his body.

While Ken's reference to loss of body control occurred prior to beginning locomotor training, Chuck described body control as a persistent issue he must cope with posttreatment. In the following interview excerpt, Chuck expresses continued frustration over his inability to gain control of his left leg, even after ongoing physical therapy and locomotor training. Chuck states,

the same frustrations I probably still have—gettin' more control of this left leg . . . And even the therapists were frustrated with the left leg. . . . Even the therapists who work with me now are frustrated with this left leg. (frustration evident in his voice). . . . And the family too. I mean my wife . . . helps me stretch out a lot . . . and it's always this damn left leg. Ya know, so . . . that's probably the only frustration (pause) that I . . . wasn't able to leave here . . . a totally independent walker . . . ya know . . . and . . . the left leg was probably the only frustration . . . and that was un . . . it's still uncontrollable. . . . Ya know? So that . . . that's probably the frustrating part—that ya can't control it.

Chuck described his inability to control his left leg as his primary source of frustration and even appeared to blame his leg for limiting his progress during locomotor training. The loss of sense-of-self trainees experienced due to loss of body control and function was readily evident from retrospective and prospective interview data. When Frank described the impact of his injury during his retrospective interview, for example, he recounted his previous athletic ability and enjoyment of physical activity prior to injury.

He then added, “For one thing I used to be a pretty strong man (5-second pause) I . . . don't do or can't do much . . . is gone too, now.” Despite the fact Frank is independent with his activities of daily living and has returned to work, his words and silence powerfully related his sense of loss over the man he once was. Within the context of his interview, it was clear from Frank’s statement he attributed this loss to his decreases in function, physical endurance, and ability to participate in physically demanding activities.

Compared to Frank, Ken frequently discussed his injury in terms of its impact upon his ability to fulfill his roles as “worker” and “family man.” During his first of four interviews for example, Ken explained, “Perception wise? You know, I just . . . I feel bad because . . . uh, in our family we all pitch in and do things . . . and I’m not able to participate. That’s hard . . . It really is very hard.” For Ken, whose sense of self was closely tied to his roles as husband, father, and head of household, his sense of disconnectedness, sadness and disappointment over his perceived decreased ability to contribute to his family activities was especially evident.

While narratives provided by Frank and Ken directly related a loss of sense of self due to decreased body control and function, and reduced role participation, Lynn described how the rehabilitation experience resulting from her limitations contributed to her decreased sense of self. She explained,

Your self-image does change. I think also . . . you know, the nine months I've been . . . I've been . . . Uh . . . Uh . . . a body a . . . prodded, poked, pulled. So you loose . . . you know, you just become that. . . . After awhile you loose a sense of it being you.

For Lynn, her sense of self was diminished while in the role of patient. She described the objectification of her body while in treatment and consequently, felt she became nothing

more than a body. By being reduced to “a body,” Lynn lost her sense of self as a “whole” person. Lynn went on to further describe how her injury has altered her own perceptions of her feminine role and how she is gradually regaining her sense of self. Lynn said,

It's . . . it's . . . you know, I can't wear my shoes anymore and I can't wear my clothes anymore. That sort of thing. But . . . (pause) So yeah. There's a change there. But I think that's . . . I think that's all in my head. I don't think it's in no one else's head. Really. But yeah. I'd say it took me about 7 months before I even felt to put some earrings on again or paint my nails or do anything. And so now I'm beginning to at least enjoy those things again.

The loss of body control and associated changes in sense of self described by trainees serve as prime examples of the cognitive-emotional impact of the physical limitations resulting from their spinal cord injuries. The experiences of loss of body control and decreased sense of self following injury and in some cases, persisting following locomotor training, further serve as indicators by which the psychosocial impact of locomotor training may be evaluated. By understanding what was “lost” following injury, we may be better able to appreciate trainees' perceptions of what was gained through their locomotor training experiences.

The Quest for Body Control: Trainee Experiences Resulting From Locomotor Training

The field of rehabilitation has historically regarded “the body” from physiological and functional perspectives—as an object to be healed or restored. Conversely, the social sciences have interpreted the body within a broader, social context—viewing it as a conduit for fulfilling social roles (Turner, 1995; Seymour, 1998). Through her work with persons with spinal cord injuries, Seymour (1998) provides a sociological interpretation of the body that is particularly relevant to our study. Seymour explored the processes by which persons with spinal cord injuries “remade” their injured bodies. Acknowledging that the body is inseparable from “the self,” Seymour's use of the phrase “remaking the

body” is synonymous with “reconstruction of self.” Although Seymour recognizes that formal rehabilitation is an intrinsic part of remaking the body, she cautions that such a medicalized approach aimed at restoring the body to “normal” function bestows the resulting bodily changes “with the labels and expectations of the rehabilitation industry” (Seymour, 1998, p. xiv). Offering an alternative and less restrictive view of rehabilitation, Seymour instead suggests the processes involved in remaking the body are the daily activities and social routines in which everyone participates and through which we define who we are—our “embodied selves” (Seymour, 1998). According to Seymour, “The body has become highly reconstructable. We can be other than that which we are” (Seymour, 1998, p. 7).

Applying the conceptualization used by Seymour (1998) to our study, locomotor training represented a mechanism for trainees to regain control and “remake” their bodies. Given trainees’ loss of body control and function, locomotor training offered them the potential to recover some level of control over their functional ambulation skills and subsequently, affect their ability to participate in the social roles and routines through which they define themselves. Themes to emerge from interviews and observations provide insight into trainees’ experiences during this quest for control. These experiences included “first-time on the treadmill” experiences, a decreased sense of proprioception that often led to uncertainty during training, and a struggle to regain control due to involuntary movements and spasms. Occasionally, trainees perceived therapist interventions as contributing to their struggle for control. Together, decreased proprioception and the need to struggle for control often resulted in frustration for trainees. In addition, trainees experienced a variety of body sensations during locomotor

training and described locomotor training as physically and cognitively demanding, but well worth the effort. Each of these themes will now be described.

First-time on the treadmill experiences: Elimination or magnification of disability

In an effort to ascertain trainee reactions to using machines and people to facilitate their walking, trainees were asked during interviews to describe their first-time on the treadmill. Data analyses revealed a continuum of responses. Trainees at one end of the continuum described the experience as temporarily eliminating their disability. For these trainees, seeing themselves in the mirror standing upright and “walking” was a normalizing experience. For trainees at the opposite end of the continuum, the experience served to magnify their disabilities and limitations. For example, Ben’s description of his first-time on the treadmill characterizes his experience as quite positive. Ben recalled,

(exhaling) Huuuh . . . (long pause) Yeah uh it was pretty interesting you know. . . . I got really tired of course. . . . My endurance wasn't very good, but it was . . . it was kinda neat because it's . . . you know you're not . . . holdin' on to anything . . . 'cause you're in a harness an' . . . it's . . . the closest I been to . . . you know, walkin' like . . . before my accident.

According to Ben, the sense of freedom he gained using the harness was reminiscent of walking before his injury. For Ben, and other trainees like him, who associated being on the treadmill with “walking like before,” their first-time on the treadmill was an emotionally powerful experience that temporarily eliminated their disability and allowed them see themselves as they use to be.

Contrary to Ben’s experience, Abe provided the following description of his first-time on the treadmill. Abe said,

Uhh (pause) Well . . . goin' up those steps . . . tryin' to go up those steps. Two or three steps to get up there an' . . . gettin' strapped into the harness. (pause) Getting up there and finding out that my uh balance isn't all that good. My balance is just not all that good. And uh (pause) you know you think that, you think that you're

gonna be able to move your legs . . . you know you can move your legs but . . . you're not movin' 'em right. You gotta' have somebody guide 'em.

For Abe, who had more disability-related functional limitations than Ben, the process of first ascending the stairs to get to the treadmill and then attempting to step on the treadmill clearly served to emphasize the extent of his limitations and his need for assistance. Consequently, Abe did not perceive himself as “walking like before.” Instead, Abe’s first-time on the treadmill experience served to magnify his disability and signal what he would have to overcome in order to reach his goal of walking again.

While Ben and Abe differed in their level of spinal cord injury and subsequent functional abilities, data did not suggest a distinct relationship between functional ability and first-time on the treadmill experiences. For example, Chuck, who used a power wheelchair for mobility like Abe, said he felt like he was “walking again” when on the treadmill. Perhaps personality traits such as attributional style play a stronger role in influencing trainees’ perceptions of their first-time on the treadmill.

Decreased proprioception leads to uncertainty

As a result of their spinal cord injuries, the ability of trainees’ to receive sensory input was limited. While the extent of sensory limitations varied among trainees, the decreased sensory feedback they experienced resulted in decreased proprioception, or the ability to accurately perceive their body position and movement. Trainees frequently referred to decreased proprioception as impacting their ability to achieve good quality stepping and posture while on the treadmill and walking over ground. For example, when discussing the challenges of locomotor training, Dan described how his decreased sense of proprioception affected the process. He stated,

. . . it's . . . believe it or not - it gets hard. You see by only havin' about from my waist down I only have maybe 50 percent of my . . . my, my feeling back. So

when you place you . . . you . . . your foot out in front of the other one, you really don't even know where it's at.

For Dan and other trainees, their decreased sense of proprioception rendered locomotor training challenging and, at times, difficult and frustrating.

The impact of decreased proprioception was often evident when observing locomotor training sessions. For example, during Ken's first training session, Ken was asked by the therapist if he understood what he (the therapist) meant when saying "relax your left leg, keep your heel on the ground longer." Ken indicated he understood, but could not feel if he had made the change. Similarly, in videotaped training sessions, Abe was frequently observed asking for feedback about his body's position while stepping on the treadmill. For example, during one session, Abe, who had difficulty holding his trunk upright, asked, "I feel like I'm leanin' forward, am I?" In Abe's case, the uncertainty he experienced due to decreased proprioception led to an apparent discrepancy in how he perceived his performance on the treadmill versus how therapists viewed his performance. Training sessions showed Abe frequently making negative comments and appearing frustrated over his performance, while therapists reassured him it "wasn't that bad." When asked about this apparent discrepancy during his interview, Abe commented, "Well I think the feedback I'm getting' up in my head from down below is not (pause) I'm not really perceivin' the way it really is."

The examples of Dan, Ken and Abe reveal the challenges decreased proprioception often presented to trainees during locomotor training. The decreased ability of trainees to perceive their own body position and movement often led to a sense of uncertainty and frustration when attempting to implement changes as directed by

therapists. Decreased proprioception also made it more difficult for trainees to self-assess their progress when stepping on the treadmill or during over ground training.

The struggle for control

Just as trainees had identified their loss of body control and function as affecting their lives postinjury, this same theme emerged during descriptions of their locomotor training experiences. Trainees' descriptions of their experiences were often characterized by "body control talk" that illustrated the struggle to regain control of their bodies. Body control talk included trainees' references to their spinal cord injury-related functional limitations, symptoms and consequences, and how these factors impacted locomotor training.

For some trainees, it appeared their loss of body control and function was, at least initially, magnified as they tried to meet the functional demands of locomotor training. In the following example, Frank discusses his frustration with trying to gain control of his left leg during locomotor training. He explains,

Uh . . . (3-second pause) They . . . one of the things, one aspect of it was, that was one of the areas that I felt most frustrated in. . . . That uh . . . the left leg really uh (3-second pause) lagged behind . . . the right, in terms of like being able to incorporate what it was suppose to do. And I . . . it was very hard to, to release that spasm and to uh . . . to shift weight . . . And so I think that it . . . that uh, the left leg (4-second pause) was a source of frustration for me and I got agitated sometimes . . . with some of the staff. But even the newer ones, when I would say something to them . . . they'd incorporate it.

For Frank, trying to regain control of his left leg was especially difficult and frustrating due to involuntary muscle spasms. Possibly due to these involuntary movements, Frank spoke of his leg as if it had a will of its own—referring to its ability "to incorporate what it is suppose to do." For some trainees, like Frank, who experienced spasms or increased tone due to their spinal cord injuries, the action of stepping on the

treadmill often triggered increases in the number and/or intensity of spasms.

Consequently, therapists would attempt to address the issue by altering their technique as leg trainers, adjusting the body weight support setting, or varying the treadmill speed in search of an optimum speed at which spasms would be minimized. Thus in Frank's case, trying to gain control of his leg became a joint effort between him and the therapists.

Frank's stated frustration with the staff and their subsequent incorporation of his feedback, suggest his aggravation may have been due to the need to *negotiate* for control of his leg. Rather than controlling his leg independently as he did prior to injury, Frank's locomotor training experience, at times, represented a three-way struggle for control—Frank versus Frank's leg versus staff. This same theme was articulated again in Frank's interview, when he described working with new or less experienced therapists.

Frank explained,

But when uh they'd have some of the kids that had not had as much experience? . . . would be working on it they would just be concentrating on what they were supposed to be doing . . . not what I was doing. They would kinda . . . they would be just a little bit out of sync . . . with natural pacing and they'd . . . be more looking at, are we getting the leg straight . . . in terms of kicking out. And uh . . . and they'd kind of take over that function. And I was working real hard to try to get it. And it was like they were over riding . . . my control.

Themes emerging from Frank's interview were largely representative of other trainees' experiences when describing their struggle to gain control of their bodies during locomotor training. Similar to Frank, Abe also had to contend with involuntary movements and muscle spasms, and consequently, depicted a struggle for control between him and his body. Through the use of metaphors, for example, Abe described the intensity with which he experienced involuntary muscle spasms. He stated, "It was like a (pause) it's, it was, it's just a sudden thing, like a . . . like a . . . "pow!" You know like a firecracker it, it would just . . . launch your foot." Abe's sense of his foot being

launched by some outside force serves to emphasize the magnitude with which trainees often perceived a lack of control of their bodies and why the process of regaining control represented a struggle. During one of his early training sessions, for example, Abe repeatedly experienced muscle spasms in his leg. Sounding upset and somewhat bewildered, he finally asked, “Just a second, what's goin' on here? What's goin' on?” Like Frank, Abe’s struggle for control during locomotor training was often a frustrating experience.

Body sensations represent recovery

In addition to decreased proprioception and a struggle to gain control of their bodies, trainees also described various body sensations due to locomotor training. After hearing trainees refer to body sensations during observations of training sessions, they were subsequently asked during interviews to describe any sensations they experienced. While only Ed identified the burning sensations he experienced due to locomotor training as pain, other trainees labeled the sensations they experienced as discomfort, soreness, tingling or burning. Interestingly, data reveal these negative-sounding experiences were typically perceived as positive signs of recovery by trainees. It appears the paralysis and/or sensory limitations secondary to spinal cord injury caused trainees to perceive any sensations resulting from locomotor training as “good” sensations—even those that under normal circumstances may be viewed as negative.

When asked about body sensations during his interview, for example, Frank provided the following response.

Now that you mention it, there were a couple of times that I felt like there was an electrical current in some nerves but particularly in the front of my shin and up into my knee. It would be progressive, almost if you flicked the switch on some lights or one of those little radios. You can see it going and you can feel it move up, and it would move in rhythms. . . .And that was fascinating to me, I think I

mentioned to you before. . . . But that eventually stopped. . . . The only time I ever experienced discomfort there would be the muscles would cramp, like a Charlie horse. And that can be very discomfoting—it's still not exactly pain, but it is painful.

Frank described two types of sensations. He characterized the tingling sensations he experienced as “electrical” in nature and was noticeably intrigued by the sensation. Frank's comparison of the sensation to electricity provides an insightful and appropriate metaphor for the neural recovery process. As indicated in Chapter Two, this process has been described in the neurorehabilitation literature as the “recharging” of circuits within the spine that act as central pattern generators (Edgerton et al., 1991). Consequently, although the electrical sensations only lasted temporarily, it appears Frank construed them positively because they represented neural recovery. Likewise, although Frank described feeling discomfort due to muscle cramps resulting from locomotor training, he did not linger over this experience during his interview or depict it as particularly negative. Perhaps Frank also perceived muscle cramps as a sign of recovery.

While Frank described feeling electrical sensations and discomfort due to muscle cramps, Chuck and Ken described feeling burning and soreness due to locomotor training itself. In the following excerpt from Chuck's interview, he associates his thighs “burning” during locomotor training as an indicator of a successful “work out.” He states,

Well I know when ya . . . I know when my muscles were fatigued, and . . . I use to lift weights a lot . . . And uhhh . . . and I know . . . you get a good muscle burn when you work out real hard . . . So I can tell when my thighs were burning . . . that they got a good work out.

Just as Chuck experienced burning sensations during locomotor training similar to what he use to feel when lifting weights prior to his injury, Ken associated the soreness he experienced due to locomotor training with intense physical exercise. For example, upon arriving for training one afternoon, a therapist asked Ken how he felt after walking

on the treadmill for a longer period of time the previous day. The following dialog ensued.

Ken: Sore this mornin'. Really. Well like I . . . ya know that kind of sore ya get when you haven't worked out in a long time? That kind of sore.

Therapist: It's a good kind of sore then?

Ken: Oh yeah! It was one I had to put every effort into gettin' outta bed this mornin'!

For Chuck and Ken, the burning and soreness they experienced due to locomotor training were reminiscent of feelings they experienced during strenuous exercise prior to injury. For them and other trainees, the ability to once again engage in a physical activity at a level of intensity strong enough to cause some level of discomfort appeared to be both a physically and emotionally gratifying experience. Just as the discomfort associated with strenuous exercise is interpreted as a sign the exercise was effective, trainees perceived the soreness, aching, cramping, and burning they experienced during and after locomotor training as signs the treatment was “working” to increase their strength, mobility and endurance. Thus the adage “no pain, no gain” appears representative of trainees’ cognitive-emotional responses to the body sensations they experienced during locomotor training.

Physically and cognitively demanding, but well worth the effort

Data from our study expose the scope of the combined physical and cognitive requirements of locomotor training. In an effort to enhance trainees’ functional ambulation skills, locomotor training typically required trainees to simultaneously (a) attempt to move their bodies as independently as possible in spite of their decreased control and proprioception, and the occurrence of involuntary movements, muscle spasms and body sensations, (b) implement these ambulation-related tasks at varying

walking speeds and levels of body weight support, (c) listen to and implement the directions and verbal cues given to them by therapists, and (d) attempt to independently remember and apply ambulation principles throughout training sessions. Given these requirements, it is not surprising that trainees consistently described locomotor training as both physically and cognitively demanding, and that they often described these demands in terms of the fatigue they experienced. Although data suggest trainees often became overwhelmed and frustrated by the combined physical and cognitive demands of locomotor training, data also revealed that all trainees highly valued the treatment and perceived the associated demands to be well worth the effort required of them.

Physical demand and fatigue. The physical demands of locomotor training were readily apparent during observations of training sessions. The effort trainees put forth during locomotor training was not only evident in their strained facial expressions, heavy breathing, perspiration and thirst, but also in the “grunts,” groans, and sighs often heard from them during sessions. In order to gain an understanding of how trainees perceived the physical demands of the intervention, they were subsequently asked during interviews to talk about the physical demands or amount of energy required of them during locomotor training.

All trainees described locomotor training as tiring. Chuck however, described the fatigue he experienced during locomotor training as severe enough to temporarily inhibit his ability to transfer independently. Chuck related,

It, it [locomotor training] was quite exhausting, 'cause it was five days a week, basically. . . . And . . . week 3 was the worst! Uh . . . 'cause I'm able to transfer pretty good in and outta my chair [wheelchair] . . . and gettin' into my van seat and stuff like that. Week 3 I was so exhausted (pause) they had to help me . . . get from my chair . . . to my van seat. . . . And when I'd get to the hotel room I would just kinda' full-fall into the bed. I just didn't have the strength to transfer. We actually had to decrease how much time they had me up there [on the treadmill]

. . . the remainder of that week. And in the middle of week 4, I got my strength back.

The fact that Chuck could recall with such clarity the impact of the fatigue he experienced two years ago suggests the physical demands of the intervention were a memorable part of his locomotor training experience. While other trainees did not experience fatigue to the same extent as Chuck, most described feeling tired at the end of the day or feeling the need to sleep or rest. For instance, when discussing how the physical demands of locomotor training affected him, Abe said, “Oh yeah it made me tired. I, I slept real good.” Frank, on the other hand, described how the fatigue he experienced would build if he were not able to rest after his training sessions. Frank explained,

Uh, depending on whether or not I could take a nap. . . .Usually, fairly soon after I got home I would lie down for a few minutes and take a nap and sleep pretty soundly. And then I was fine, but if I didn't do that I would be tired. If I didn't do that . . . then it would carry over.

Trainees further described the physical demands of locomotor training as relatively consistent throughout the 9-week duration of the study. When asked how the physical demands of locomotor training changed over the course of his participation for example, Chuck responded, “First couple weeks, I probably was tired (pauses while thinking) three to four hours . . . afterwards. Annnnd . . . I'd say after week four . . . an hour . . . two. I was buildin' my endurance.” Chuck indicated as he progressed through locomotor training and built his endurance, he experienced less fatigue following training sessions. Although Chuck did not describe the physical demands of the intervention as lessening, he implied he had to expend less energy to meet those demands. Lynn also described the consistent physical demand of locomotor training. During her third

interview, Lynn stated, “It actually . . . yeah I think . . . I think . . . I do have more endurance now.” However, Lynn further explained,

If we were doing what we were doing at the beginning [of the study] then it would be easier. But, because we’re not . . . you’re moving on the whole time. . . . You’re pushing the boundaries all the time. It . . . it just is tiring really. . . . But, mostly I’d leave [training] feeling tired. . . . Walking back to the car, it’s . . . it’s a challenge.

Similar to Chuck, although Lynn felt her endurance had improved, she continued to experience fatigue. Lynn attributed her fatigue to the fact that therapists would constantly establish new, more challenging treatment goals in response to the progress she evidenced throughout the study.

Despite the fact trainees consistently described locomotor training as tiring, exhausting and energy depleting, data suggest trainees often perceived these experiences positively and felt the potential benefits they stood to gain through locomotor training were well worth the physical effort involved. For example, Ben described the physical demands of locomotor training in the following manner.

I mean it's, it's . . . physically demanding, but in, in a good way. . . . I was worn out a little bit . . . but it felt good. It's the kinda . . . kinda tired that . . . feels good. When you know . . . you feel like you've accomplished somethin'.

Just as trainees had interpreted sensations such as aching, soreness and burning as positive locomotor training experiences, Ben perceived the tiredness resulting from the physical demand of locomotor training as a “good” experience because it represented a sense of physical accomplishment. Similar to Ben, Dan also viewed the physical demands of locomotor training as positive. When discussing the effort required of him during locomotor training for example, Dan stated,

Oh man! It requires lots of energy . . . but see it requires lots of it. And I think that was . . . the reason why I'm where I'm at now. Is because it required lots of me and I had to give a lot. . . . And in order for me to give lots, of course, I gained.

Dan's description indicates he attributes the physical demands of locomotor training as responsible for his positive outcomes. Dan's words illustrate his perception that he had to "rise to the challenge" presented by locomotor training. Through the "giving" of his energy and physical effort to successfully meet this challenge, Dan feels he was able to reap the benefits of his efforts.

Cognitive demand and fatigue. Like the physical demands of locomotor training, the cognitive demands of the intervention were also evident during observations of training sessions. The looks of intense concentration apparent on trainees' faces while stepping on the treadmill and over ground served as one indicator of the cognitive demand of locomotor training. Comments made by trainees during training sessions provided further evidence of the cognitive demand associated with the intervention. For example, during one of Ken's training sessions, a therapist noticed Ken was barely swinging his right arm while stepping on the treadmill. The therapist subsequently asked Ken about his observation in the following dialog.

Therapist: So Ken, are you concerned with hittin' her [the leg trainer positioned at Ken's right leg] in the head with your right arm?

Ken: No, _____. Too many things to concentrate on—nothin' [related to stepping] comes natural anymore.

In Ken's reply, he explains that walking is no longer a "natural" process for him and consequently, suggests he forgot to swing his arm because he was concentrating on other aspects of stepping. In order to gain an understanding of how trainees perceived the cognitive demands of the intervention, they were subsequently asked during interviews to talk about the cognitive effort or amount of concentration required of them during locomotor training.

Data suggest some of the primary factors contributing to the cognitive demand of locomotor training included (a) trainees' decreased sense of proprioception, (b) as described in Chapter 5, their perceived loss of walking as an automatic process and subsequent need to "think about" the mechanics of walking postinjury, and (c) verbal cues and directions given by therapists. Trainees' narratives revealed the process of trying to contend with these factors while simultaneously relearning how to walk on the treadmill and over ground required significant concentration. In the following excerpt from an interview with Ken, he reiterated his loss of walking as an automatic process and explains how "thinking" now plays a critical role in his ability to walk.

And to think . . . ya know, that I guess . . . the hardest thing that (pause) is . . . when you've walked before (3 second pause) you have to think so much about it. Ya know, and now I'm having to . . . I'm having . . . I mean I can, I can . . . cheat and raise my leg up, and, and move some of this leg forward but . . . when I really stop and think about that like that . . . my, my ankle up, put my toe up, and then try to bring my leg forward . . . and, and when I do that . . . it really works. . . . But then if I try to hurry up and I forget to think . . . and then it goes to . . . I have to go back to cheating and stuff, so.

Likewise, Frank also described the need to concentrate while walking. He stated, "I have very little, you know, solar plexus. And uh, I can make the muscles work . . . but I definitely need to concentrate."

Data also suggest the need for trainees to assimilate and then apply the numerous verbal cues and directions given to them by therapists while stepping on the treadmill or over ground further added to the perceived cognitive demand of locomotor training. During observations of training sessions, trainees sometimes appeared frustrated when trying to execute a series of verbal cues, or commented in reference to the concentration required to implement the directions. For example, during one training session while Ken was stepping on the treadmill, he commented he had "lost" the rhythm when stepping.

When a therapist subsequently inquired about what had caused the disruption, Ken answered, "I was havin' to think about too many things." This same theme emerged again during Frank's interview. When describing the cognitive demand during locomotor training, Frank said, "It was uh . . . really difficult (clears throat) for me to concentrate on all those things people were telling me about."

An example of how proprioceptive limitations, the need to concentrate while stepping, and the need to process therapists' verbal cues may collectively impact trainees as they relearn to walk during locomotor training is provided by Lynn. When asked during her third interview to describe how her need to concentrate during locomotor training has changed, Lynn provided the following answer.

I think it's getting a little easier. What I still find is that . . . I was trying to work it out with the guys [therapists] yesterday . . . the cue that they give me to bend my left leg to start the swing process . . . they give it to me, to what seems to me, too early. So that my . . . my . . . I am lifting it too late at the back. And they want me to lift it earlier. But I . . . I've come to realize that I think what's happening is that . . . there is a lag between my brain telling it move and it moving. For me to get it to move at the right time, I've actually got to tell it to move . . . earlier . . . so it seems . . . it looks more symmetrical. But it feels more asymmetrical because of that. . . . So it . . . that requires still a little concentration. I have to keep thinking "bend it," "bend it," "bend it" . . . sooner than I would, normally.

Through her description, Lynn reveals the rather complex cognitive process involved with relearning how to move her left leg through the swing phase of walking. First, she identified a discrepancy in timing between the verbal cue given to her by therapists and what felt "right" to her. Next, through problem solving with the therapists, Lynn reasoned what she perceived to be a timing discrepancy when moving her leg was likely due to her leg's inability to quickly receive her brain's message to move. Finally, Lynn concluded the therapists' cue of when to swing her leg was appropriate and determined she can approximate the correct movement by "telling" her leg to move

earlier than feels normal. Although Lynn indicates the amount of concentration needed to move her left leg has improved, the fact that she must focus to actively and repetitively move her leg in a timing pattern that she perceives as unnatural and asymmetrical yields some indication of the cognitive demand associated with locomotor training tasks.

Given the complexity of tasks involved with locomotor training and the level of concentration necessary to complete them, it is not surprising most trainees described the cognitive demands associated with locomotor training to be just as challenging as the physical demands of the intervention. In Frank's case however, he characterized the cognitive demands of locomotor training to be *more* challenging than the physical demands. When asked to compare the physical demands of locomotor training with the cognitive demands, Frank explained,

Oh, I think the cognitive demand is much more of a task. Yeah. Uh . . . there's . . . the physical effort is significant. But uh . . . the cognitive part for me is much more taxing, the level of concentration. And it can be fatiguing.

Although trainees indicated the cognitive demand associated with locomotor training lessened as they progressed through the study and gained better control over functional ambulation, they indicated that walking postlocomotor training continues to require some amount of concentration. Thus even after locomotor training, walking is still not perceived as the "automatic" process it was prior to injury. In the following example, Frank describes that even though his walking has greatly improved, the process still requires concentration. Using a scenario of walking in a public area, Frank says,

. . . I could probably walk reasonably well and . . . it's conceivable to me that if nobody knew me and what had happened, and I was walking at a reasonable amount of pace, uh . . . it wouldn't appear to them . . . I had a difficulty. . . . But I wouldn't be able to talk . . . at the same time, or to look out and see somebody wave to me. The concentration's got to be there. It 's gotten . . . a little better, and I think it continues to build a little . . . but uh . . . especially if I'm fatigued or cold . . . or distracted . . . uh, I can't do it.

Similar to Frank, Lynn described during her fourth interview how walking continues to require concentration.

I've . . . I think that what I've noticed is that sometimes when I . . . when I start thinking about what I'm doing I find that there is muscles that are firing without me consciously saying . . . "Turn it on, turn it on." . . . Um, so I think in that sense it's a more . . . it's getting a little more automatic. . . . Um, but in order to get the gait you know, how everybody wants it . . . still requires a little more concentration.

Although Lynn indicates walking is becoming a more automatic process for her, she claims she still needs to concentrate when trying to approximate a "normal" walking gait.

Locomotor training is worth the effort. Despite the physical and cognitive demands of locomotor training, data revealed that given the opportunity, all trainees would continue to participate in the intervention. For example, when asked during his interview what, if anything, he would change about his locomotor training experience, Chuck replied, "Yeah. Instead of make it 9 weeks? Make it like 52 weeks!" Like Chuck, Lynn also indicated she would continue to participate in the study. When asked during her final interview how she felt about herself since completing the locomotor training study, Lynn said, "I just wish it [the study] was longer. Wish it would start all over again." Similar to Chuck and Lynn, Ben also expressed his desire to continue locomotor training. He, however, provided considerable detail about how he would alter his current lifestyle in order to participate in locomotor training for a longer period of time. Ben explained,

But now, if I had the chance to do it [locomotor training] again? Like, I have a job . . . I'd probably . . . I'd probably quit my job and move down here and . . . get a . . . part-time job or whatever . . . just to pay some bills, to do it again . . . if I could . . . if I do, do that I could do it for awhile . . . instead of just a month, but I could do it longer? I'd definitely make the sacrifice because . . . you know, there's always a job out there. . . . And . . . I'd probably just come down and go to school and . . . work part-time (almost inaudible) and do that.

From Ben's viewpoint, even giving up his job appears to be a reasonable and acceptable sacrifice given the potential benefits he stands to receive from additional locomotor training.

Summary

Trainees described a number of experiences associated with their quest for control through locomotor training. These experiences included first-time on the treadmill experiences, a decreased sense of proprioception that resulted in a sense of uncertainty, the struggle to regain control due to involuntary movements and muscle spasms, and body sensations. Trainees further characterized locomotor training as physically and cognitively demanding. Although trainees often experienced frustration in their quest for control, data suggest all trainees highly valued locomotor training, perceived it to be well worth the effort involved, and would continue to participate in the intervention if afforded the opportunity. In an effort to elucidate the reasons why trainees found locomotor training to be so valuable and appealing, the following section examines the benefits of locomotor training as perceived by trainees.

Benefits of Locomotor Training: Trainee Perceptions

To better understand how trainees drew meaning from their collective physical, cognitive and emotional experiences of locomotor training, they were asked during interviews to identify what they have personally gained from locomotor training, what physical and emotional benefits of the intervention they perceived, what benefits of locomotor training they valued the most, and what they enjoyed about participating in the locomotor training study. Data analyses subsequently revealed several themes and relationships representative of trainees' perceived benefits of locomotor training. These benefits are displayed in Figure 9.

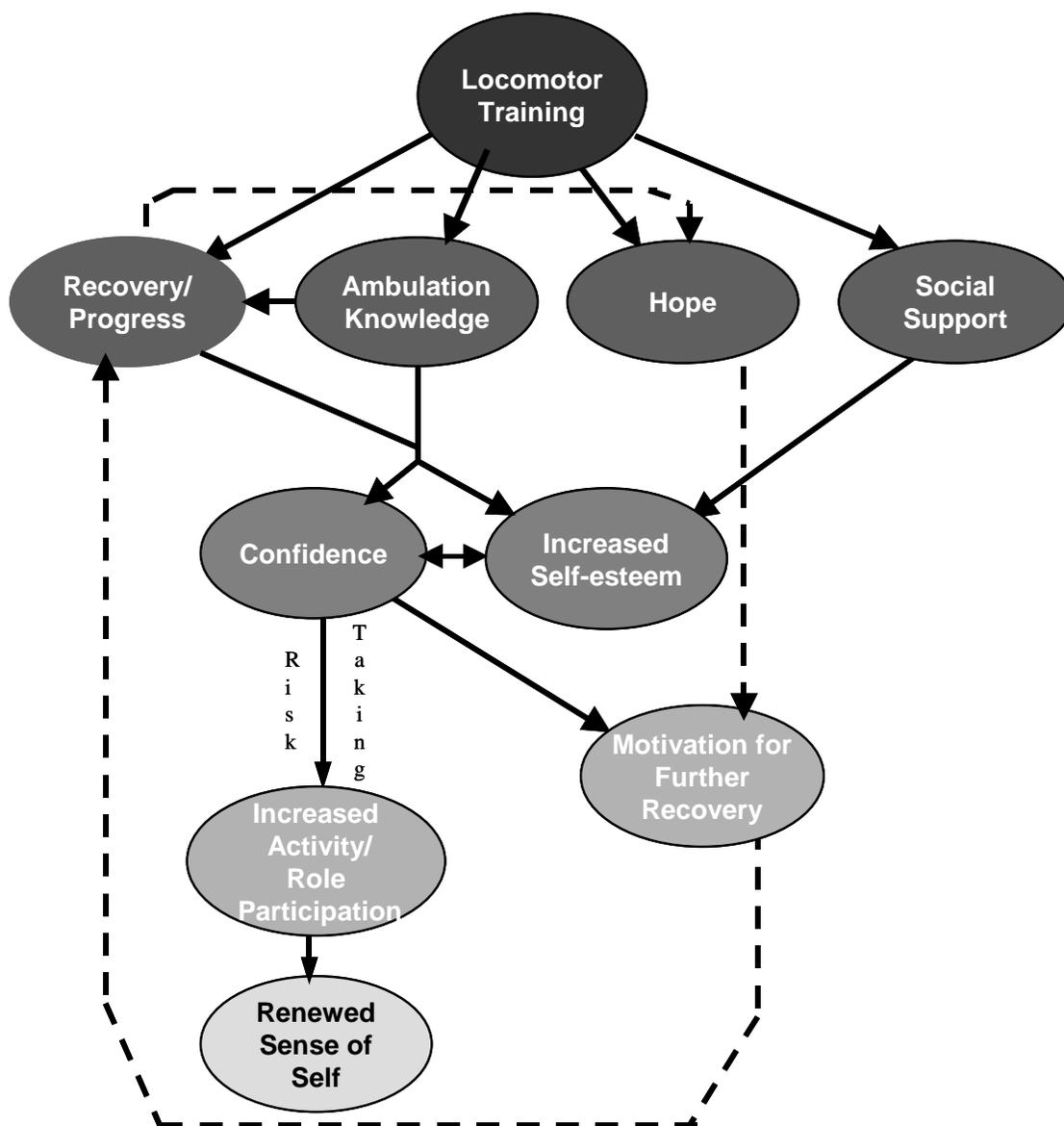


Figure 9. Benefits of locomotor training as described by trainees with incomplete spinal cord injury

Benefits of locomotor training identified as highly valued by trainees include (a) the functional recovery and/or progress they achieved as evidenced by improvements in their gait and mobility, body control, balance, endurance, and strength, (b) the knowledge they gained about ambulation, (c) the sense of hope for further recovery they gained through the study, and (d) the perceived social support they received from the therapists

and/or locomotor training team. Data analyses and interpretation suggest these benefits or variables interrelate and subsequently, influence additional variables perceived as benefits of treatment. These variables include confidence, increased self-esteem, activity and role participation, motivation for further recovery, and a renewed sense-of-self. The perceived benefits of locomotor training are the focus of the remainder of this chapter.

Power Through Progress and Recovery: Trainees' Response to Functional Gains

In Chapter 5, the locomotor training therapeutic process was described from an empowerment perspective. The chapter provided examples of how the roles adopted by therapists and the manner in which they engaged trainees created an environment that promoted trainee empowerment. The theme of empowerment was equally evident through trainees' descriptions of the perceived benefits of locomotor training. These findings suggest that the therapists' treatment approaches did, in fact, enhance the sense of personal power of trainees.

As previously discussed, locomotor training was a mechanism for trainees to regain control of their bodies and enhance their functional ambulation. From an empowerment perspective, Aleksuk (1996) describes control of the body as "our most important form of control" (p. 108), and asserts the more control a person has over his or her body, the greater his or her sense of personal power will be. It therefore appears locomotor training is an intervention that stands to directly impact the sense of personal power of participants with incomplete spinal cord injury. During interviews and observations, trainees did, in fact, frequently describe how the locomotor training therapeutic process resulted in functional gains in ambulation-related activities and activities of daily living. Narratives shared during our study provide evidence that

trainees' feelings of personal power and competence were enhanced as they experienced progress and recovery during locomotor training.

Progress and recovery. As depicted in Figure 9, progress and recovery resulting from locomotor training was perceived as a highly valued benefit of treatment. Data reveal that as trainees evidenced progress through increased control of their bodies and improved mobility, they experienced an increased sense of personal power. For example, Dan described how his balance and endurance improved while using the Body Weight Support (BWS) system. Reflecting on his locomotor training, Dan said,

And I remember after the first couple weeks they start lowerin' it [body weight support] and lowerin' it and lowerin' it. Until I would have but, wasn't no time til they got it down to where I . . . really didn't have anything to hold me up. I could hold my own body weight up.

While Dan did not specify feelings of power resulting from his progress, the obvious pride and enthusiasm with which he described his ability to support his body weight independently served as sufficient evidence of his increased sense of mastery and personal power.

Confidence, self-esteem, and motivation for recovery. As represented in Figure 9, progress and recovery, together with ambulation knowledge, led to increased confidence and self-esteem among trainees. Trainees frequently cited increased confidence as an outcome of locomotor training and used the term "confidence" interchangeably, to denote both "self-confidence" and "confident when walking." For example, when discussing what he gained from locomotor training, Frank stated, "Oh yeah, I think I am much more confident and capable of uh . . . independent mobility. So, I do go to the store and feel confident navigating curbs and stairs." As indicated in Chapter 5, such feelings of self-confidence reflect a sense of personal power (Aleksiuk, 1996).

Furthermore, as was evidenced by Abe in an example appearing in Chapter 5, increased confidence served to motivate trainees for further recovery.

Like confidence, trainees also identified increased self-esteem when describing benefits gained from locomotor training. For example, Frank cited, “a feeling of pride, a sense of accomplishment, and increased self-esteem” as emotional benefits of the treatment. Similarly, Ben explained, “like, ya know, it makes you feel . . . you know you feel a little better about yourself because . . . you can do a little more?” For Ben, it appears his increase in self-esteem was directly related to his functional progress and recovery—his ability to “do a little more.” As depicted in Figure 9, data suggest a reciprocal relationship existed between the variables of confidence and self-esteem.

Risk-taking, increased activity and role participation, and renewed sense of self. Data further revealed that the increased confidence trainees experienced due to their progress and recovery frequently led them to increased risk-taking behavior. Empowered by their improved ambulation skills and knowledge of ambulation, trainees felt confident enough to attempt to perform increasingly complex functional tasks. For instance, when discussing how locomotor training affected his activities, Ben explained,

Like, for example . . . like before the . . . like now, if I go to a set of stairs? And, you know, I’m in my chair [manual wheelchair]? I’ll just grab onto the rail and walk up the stairs and drag my chair with this hand (raising his hand). Before [locomotor training] . . . I, I probably wouldn’t have tried that.

According to Ben, locomotor training led him to try a challenging activity he otherwise would not have tried—a clear illustration of how the confidence resulting from functional progress may enhance trainees’ ability to participate in a greater variety of activities (Figure 9).

Ken provides additional examples of how increased confidence leads to risk-taking and subsequent increases in activities and role participation. For example, on

Ken's fifth day of training, while therapists were assisting him with putting on his harness before training, the following dialog ensued between Ken and his wife.

Wife: "Did you tell them [therapists] what you did last night?"

Ken: (to the therapists) "I went up the stairs and slept in my bed for the first time in four months."

Thus after only four locomotor training sessions, Ken felt confident enough to attempt to walk up a staircase independently.

The staircase incident was just the first of many risks for Ken. In fact, it was a rather common occurrence for Ken to arrive for training sessions and share with the team his "landmarks" of activity participation that often reflected his ever-increasing risk-taking. Such landmarks included the performance of now challenging activities that he performed routinely prior to his injury, for example, walking across the uneven surface of his backyard to get to his barn, or trying new activities—such as the day he arrived for training using only a cane for support. Table 3 summarizes Ken's progress by depicting his perceived benefits of locomotor training and corresponding changes in activities throughout his nine weeks in the locomotor training study. The data displayed in Table 3 serve to further illustrate how the increased range of activities Ken was able to perform resulted in greater participation in his social roles. For example, Ken's increased ability to share in routine household tasks with his wife enabled him to carry out his role as husband as he did prior to his injury. Data suggest the substantial functional gains Ken was able to achieve through locomotor training, and the rather dramatic increases in activities and role participation he experienced, resulted in a *renewed sense of self* for Ken (Figure 9). As Ken told the locomotor training team in reference to his progress, "You gave me my life back." Thus in Ken's perception, locomotor training enabled him to return to the person he was prior to his spinal cord injury.

Table 3. Power through progress: Ken's reported benefits of locomotor training and activity changes at weeks 4, 8, and 1 month posttraining

	Week 4	Week 8	1 Month Posttraining
Perceived Benefits of Training	<ul style="list-style-type: none"> - Easier to control trunk - Better stability and balance - Increased leg strength and endurance 	<ul style="list-style-type: none"> - Walking over ground is easier. "I don't have to go as fast, and it's not as tiring for some reason." - Better balance and strength - Increased endurance when standing. "I don't have to sit down as frequently." - Less "scared" about moving around; more confidence. Less concentration required. - "I'm more productive." - "Less numbness." 	<ul style="list-style-type: none"> - More ankle and knee flexibility - Less swelling in leg - More endurance; standing longer - "It's given me more freedom and independence. - "Physically, I've gained more mobility. Emotionally, the friendships and support I've gained have been outstanding.
Reported Changes in Activities	<ul style="list-style-type: none"> - "Walk more on my own; walk with less assistance" - "Able to stay up longer." - Able to climb stairs to sleep in his own bed. - "Haven't used wheelchair at home in 2 weeks" 	<ul style="list-style-type: none"> - "I've gone to the crutches [from a walker], and now I'm starting to use the cane. I'm able to do some without the cane as well." - "I'm able to do a lot more in the house . . . Just you know, routine things. Help load the dishwasher, help unload the dishwasher. It's a lot more comfortable doing it." - "Carrying things is so much easier now." - Able to bend over and pick things up. 	<ul style="list-style-type: none"> - "I've been moving around a lot more . . . I've been a lot more independent." - Able to do more things in the house; "routine things" like set up for supper. - Rarely using power wheelchair at work. - No longer requires family or others to spot activities; standing, getting up from chair, going up or down stairs. - Easier to get in and out of places in the community.

Power Through Knowledge

The exchange of ambulation-related knowledge between the therapist and trainee emerged as a predominant component of the locomotor training therapeutic process. Consequently, the theme of power through knowledge was introduced and comprehensively described in Chapter 5. Due to the fact however, that ambulation knowledge was consistently identified by trainees as one of the benefits of locomotor training, the topic is briefly revisited at this time.

The knowledge of locomotor training principles and body mechanics therapists shared with trainees provided them with a critical understanding of ambulation that would serve to both facilitate and further their progress (Figure 9). Knowledge therefore empowered trainees in their quest for body control and increased mobility, and enabled them to continue to pursue recovery independently after the study ended. Data suggest all trainees highly valued the knowledge component of locomotor training. When asked to identify what aspect of locomotor training he valued the most, for example, Abe identified the knowledge he gained about ambulation. Abe then elaborated upon his answer by saying,

Well, I uh, just that . . . it, it gives you the kno . . . it's, it . . . you can't pursue anything unless you know . . . know what you're doin'. . . Like I said, you know, you just never really think about what's involved . . . in walking . . . until you can't.

As was evident by Abe's explanation, he perceived that knowledge of ambulation was the key to his pursuit of ongoing recovery, even after his participation in the locomotor training study had ended. As already indicated, data analyses suggest functional progress plus ambulation knowledge jointly empowered trainees and subsequently, enhanced their confidence, self-esteem and motivation for recovery.

Power Through Hope and the Impact of Treatment Expectations

Hope was a recurrent theme to emerge from the data. Defined as “A positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed determination) and (b) pathways (ways to meet goals)” (Snyder, Irving, & Anderson, 1991, p. 287), hope was evidenced by all trainees throughout the locomotor training study. During interviews, for example, trainees typically expressed hope when recounting their spinal cord injury experiences that occurred prior to the locomotor training study. Data suggest locomotor training represented hope for trainees due to its potential to aid in their recovery of body control and mobility, and as trainees began to evidence functional progress due to locomotor training, their sense of hope was reinforced. While some trainees identified hope for further recovery as a benefit of locomotor training they valued the most, one trainee described the need to *reconcile* hope. Finally, data also provided evidence of one trainee’s disability readaptation process in response to unfilled hope or unmet treatment expectations. In order to gain a better understanding of hope as a perceived benefit of locomotor training, each of the previously cited hope-related themes will now be addressed.

Hope prior to locomotor training. Data reveal that trainees had feelings of hope prior to their enrollment in the locomotor training study. For example, trainees often expressed hope for recovery when sharing details about the history of their spinal cord injuries. In the following excerpt from Abe’s interview, for example, he indicated how his hope for recovery has evolved since the time of his injury. Abe said,

You know you just have all sort . . . when you first get hurt . . . I had all sorts of asp . . . asp . . . ya know . . . ideas about what was gonna happen. But as times goes by (pause) you still . . . I still think they're gonna happen but . . . it's just gonna take longer.

Annd, tried to work on my arms and stuff but . . . my triceps just . . . they just haven't made it back yet . . . I say yet (emphasizing the word 'yet') . . .

Abe's explanation indicates that although he had high aspirations or hope for recovery shortly after acquiring his spinal cord injury, his hope has now been moderated. As is demonstrated by his emphasis on the word "yet," Abe still believes that recovery will occur—it will just take longer than originally anticipated.

Similar to Abe, Ken also expressed hope in relation to his spinal cord injury. During Ken's first interview, which took place before he began locomotor training, he provided the following summary of his functional progress and recovery to date. Ken explained,

difficult . . . it's been difficult for me, but . . . I seen, I've seen how much (pause) I've come. Ya know . . . and how far I've come from, from day one. Uh, to not being able to move, not being able to feel. And then very quickly thereafterward is when I started having some sensation. And then after, after the operation I started having some movement. And always I think I've pretty much already said, arm movement. But uh, leg movement came, little by little. And, ya know, first time I (pause) the first time they tried to get me up to stand, uh . . . physical therapist said, "this is not gonna to work." Ya know, I'm not gonna be able to stand. Well, soon I was standing, and I was uh . . . standing by myself . . .

Through Ken's description of his progress, the theme of hope becomes apparent. Ken enthusiastically detailed steady recovery and functional progress since acquiring his spinal cord injury—even proving one of his therapists wrong by gaining the ability to stand independently. For Ken, his rapid progress to date suggested more recovery would ensue. His progress led hope for further recovery. The theme of progress leading to hope is also evident by Ken's statement, "It's just a matter of time. It's [his leg] already beginning to respond quite a bit more. It's a small amount. (smiling and joking) Tomorrow, tomorrow, tomorrow!" Thus for Ken, his progress led him to hope that improved walking is an imminent possibility.

Locomotor training as hope. Although trainees displayed hope prior to the study, data suggest locomotor training presented them with “new” hope. The previously cited definition of hope proposed by Snyder, Irving, and Anderson (1991) serves to clarify the association between hope and locomotor training. As a new method for trainees to fulfill their determination to enhance their ability to walk, locomotor training contributed to their existing state of hope for recovery. In an effort to better understand trainees’ hopes, goals, and expectations related to locomotor training, they were asked during interviews what they hoped to accomplish through the intervention. Trainee responses served as their expressions of hope relative to locomotor training. Table 4 displays trainees’ expressions of hope for locomotor training, together with their corresponding activities of daily living (ADL) status prior to and after locomotor training.

Progress and recovery leads to hope, motivation for further recovery, and additional progress. Just as Ken’s progress led to hope prior to beginning the locomotor training study, data reveal the functional gains and recovery achieved by trainees during locomotor training led them to a greater sense of hope for recovery. Data analyses additionally suggest that the increases in hope and confidence resulting from progress enhanced the trainees’ motivation for further recovery, which in turn, led them to engage in additional efforts aimed at progress and recovery. Examples used earlier in the chapter to characterize trainees’ perceptions of locomotor training being “worth the effort” also reflect the relationships among progress, hope, confidence and motivation for recovery. Specifically, given what they had achieved through locomotor training—progress and confidence, all trainees experienced increased hope and motivation for recovery, and therefore expressed they would have continued to participate in the intervention if

Table 4. Summary of trainees' ADL status and expressions of hope

Trainee	ADL status (prestudy)	Expressions of hope– “What did/do you hope to accomplish through locomotor training?”	ADL status (poststudy)
Abe	<ul style="list-style-type: none"> - Able to walk with platform walker - Power wheelchair user - Independent with grooming - Unable to dress/undress - Unable to drive 	<p>“Well gee, ya know... ya always have dreams of walkin’ again. So that was . . . that was the dream. Ya know you . . . before you get to the program you’re thinkin’, well this is all I need to . . . I’m gonna be over the hump and I’ll be walkin’ again.”</p>	<ul style="list-style-type: none"> - Able to walk greater distances using platform walker - Power wheelchair user - Independent with grooming - Unable to dress/undress - Unable to drive
Ben	<ul style="list-style-type: none"> - Manual wheelchair user - Able to walk with crutches - Independent with self-care - Able to drive 	<p>“I wanted to . . . you know, mainly . . . my right leg is my main problem. You know, spasm wise. Just, you know... get that one under control...”</p>	<ul style="list-style-type: none"> - Primarily uses crutches - Uses manual wheelchair for efficiency
Chuck	<ul style="list-style-type: none"> - Able to walk with platform walker - Power wheelchair user - Independent with self-care - Able to drive 	<p>“Uh . . . just that it would make me a little bit... more physically stronger... uh maybe a little bit closer to becomin’ a . . . walking person again . . . independent walking.”</p>	<ul style="list-style-type: none"> - Able to walk with crutches - At interview, was using power wheelchair and platform walker
Dan	<ul style="list-style-type: none"> - Able to walk using walker - Manual wheelchair user - Requires assistance with bathing, grooming, dressing and transfers - Unable to drive 	<p>“Well I was hoping to gain... I gained everything I hoped to gain. I was hoping I could gain, where I could. . . have the strength I use to learn to walk say, a straight distance. But I can walk a long distance, now I can walk probably half a mile with my walker.”</p>	<ul style="list-style-type: none"> - Primarily uses walker for mobility

Table 4. Continued

Trainee	ADL status (prestudy)	Expressions of hope– “What did/do you hope to accomplish through locomotor training?”	ADL status (poststudy)
Ed	<ul style="list-style-type: none"> - Manual wheelchair user - Able to use walker with assistance - Requires “80%” assistance with personal care - Unable to drive 	<p>“Well I, I thought that uh . . . I would uh... you know uh... get a little more . . . mobile on my legs.”</p>	<ul style="list-style-type: none"> - Able to walk a greater distance using walker
Frank	<ul style="list-style-type: none"> - Able to walk using a walker or two canes - Independent with self-care - Unable to drive 	<p>“Really, I was excited about the possibility of uh . . . getting my proprioception center jump-started. Uh . . . and that I think was uh, one of the . . . most exciting goals, for both the staff and... uh, the other function that uh . . . I was really told . . . that I was really invested in . . . was uh to see how much the treadmill training could help with my balance with walking.”</p>	<ul style="list-style-type: none"> - Able to walk using a cane - Able to drive
Ken	<ul style="list-style-type: none"> - Uses power wheelchair at work - Walks with walker- Independent with self-care - Unable to drive 	<p>“I hope at the end of nine weeks I'm walkin' much better than I'm walkin' now, so. That's where I want to be, ya know.”</p>	<ul style="list-style-type: none"> - Able to walk using a cane - More independent at home and in the community - Able to drive
Lynn	<ul style="list-style-type: none"> - Able to walk using cane and orthosis - Independent with self-care - Able to drive 	<p>“I'd like to be able to get rid of the orthosis.”</p>	<ul style="list-style-type: none"> - Walks using cane and orthosis, but has more normal gait and greater speed and endurance

provided the opportunity. The cyclical relationship among the variables of progress, hope, and motivation is depicted in Figure 9. Arrows with dashed lines are used to denote the relationships among the variables.

Hope as a benefit valued the most. While locomotor training represented hope to trainees before they began the study, data suggest trainees' perceptions were only reinforced by the training experience. Irrelevant of the amount of functional return or progress trainees gained through the study, trainees all indicated locomotor training reinforced their hope for further recovery. Some trainees cited hope for further recovery as one of the benefits of locomotor training they valued the most. When identifying hope as a valued treatment benefit, Ed, for example, stated,

you know it [locomotor training] gives you hope. Hope, that you may progress.” Similarly, when Chuck identified locomotor training as a benefit he valued the most, he said, “The thing . . . I tell ya. . . . the emotion . . . that there. Uhh . . . instilling some belief in me that . . . I'm gonna become an independent walker again. . . . A big . . . big, big bag a hope.

The healing power of hope has been widely recognized in the professional literature (Elliott & Kurylo, 2000; Elliott, Witty, Herrick, & Hoffman, 1991; Kubler-Ross, 1997; Snyder, 1995, 1998; Snyder, Irving, & Anderson, 1991). Given the high value trainees placed on the hope they derived from locomotor training, it is likely that this sense of hope contributed to their psychological well being after their spinal cord injuries and provided them with a sense of personal power. This assertion is supported by current literature on hope and acquired disabilities. For example, Snyder (1998) claims that hope enables people with acquired disabilities to maintain both a positive self-image and a future outlook. In a case study of a young woman with an acquired disability, Elliott and Kurylo (2000) report that hope provided meaning and a sense of direction to the woman, and served to guide the coping activities of her family. In addition to these

personal benefits of hope, Snyder (1995) also recognizes several advantages to maintaining high levels of hope. He claims people with high hope have more goals, have more success with achieving them, are happier and experience less stress, and recover better from illness and injury. Given the numerous benefits of hope, it appears the hope derived from locomotor training is as powerful a benefit as trainees perceived it to be.

Reconciling hope. Despite the beneficial value of hope, Frank discussed his personal need to "reconcile hope." Frank explained that his wife still continues to encourage him "to do more"—to pursue any treatments or activities that may further enhance his recovery. Although Frank stated that he maintains hope for further recovery, he expressed he does not want to expend his energy in nonproductive ways. Frank explained that he prefers to put his energy into making the most of every day and living life the best he can, given his current functional status. Consequently, Frank said he and his wife have to *reconcile* or negotiate their differences regarding hope for further recovery versus living life as is. Interestingly, Frank did indicate he would participate in additional locomotor training sessions if given the opportunity, and when asked what he would change about his locomotor training experience, Frank said he thought that regular follow-up sessions would have been very beneficial.

Psychosocial impact of unmet expectations: Abe's experience. Reminiscent of previously cited studies by Nymark et al. (1998), Bradley (1994) and Guest, Klose, Needham-Shropshire, and Jacobs (1997), unmet treatment expectations were also evident in our study. As depicted in Table 4, Abe expressed high hopes for locomotor training—"dreaming" it would enable him to walk again. Data analyses of Abe's interview revealed that Abe experienced a number of cognitive-emotional reactions as he began training, and subsequently began to realize he may not leave the locomotor

training study as an independent walker. Themes to emerge from Abe's narratives suggest that his unmet treatment expectations triggered a cognitive-emotional process by which he had to "readapt" or come to terms with the reality of his spinal cord injury and modify his treatment expectations. Abe's adaptation process to his unmet expectations is shown in Figure 10.

Following a discrepancy between his expectations and his performance during locomotor training, Abe experienced frustration. Next, Abe alluded to a cognitive shift or change in perspective in which he acknowledged the reality of his spinal cord injury and the fact that his expectations for a full recovery may have been too high. Data suggest Abe's ability to then focus on what he was gaining through locomotor training served to motivate him for further recovery, including continuing to practice walking after he completed the study. Abe's ongoing recovery led him to the realization that his progress may be slow and served to reinforce his hope for further recovery. In Abe's case, the acknowledgment that his recovery will be a slow process appeared to moderate his hope for recovery. Abe's "moderated" sense of hope led him to adopt a new perspective of living life one day at a time, working hard, and hoping for the best in the future. Finally, this new perspective also served to enhance Abe's motivation for recovery.

In spite of Abe's unmet treatment expectations and ensuing psychosocial adaptation process, he expressed that he valued his locomotor training experience and felt the process made him "emotionally stronger." As already indicated, studies have cautioned that emerging interventions aimed at enhancing function after spinal cord injury may lead to unrealistic expectations among participants (Nymark et al., 1998; Bradley, 1994; Guest, Klose, Needham-Shropshire, & Jacobs, 1997), and that interventions such as counseling may therefore be advisable during participation in such interventions (Bradley, 1994). While educational efforts and provisions for enhancing

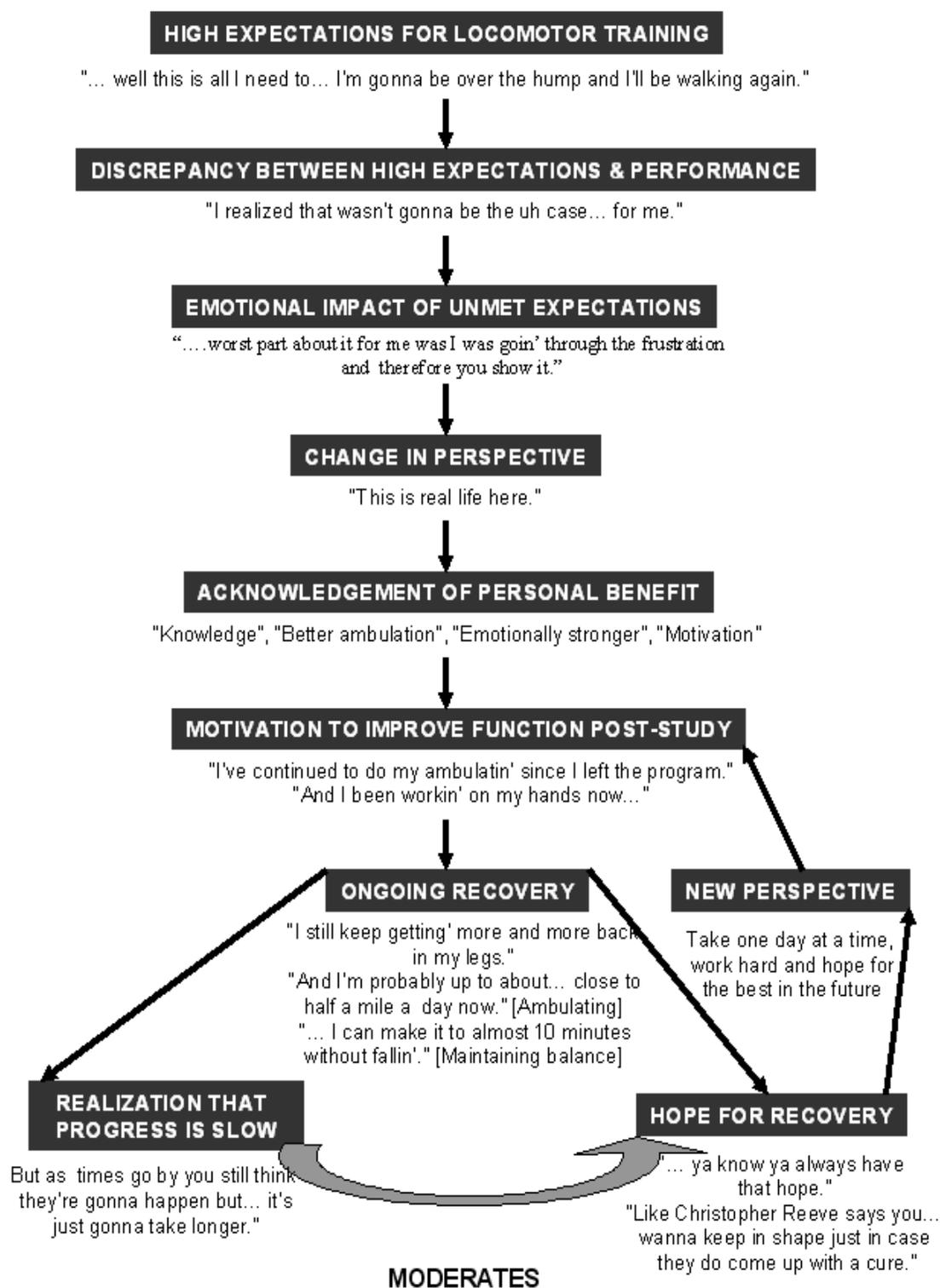


Figure 10. Abe's adaptation to unmet expectations during locomotor training

emotional support would likely benefit trainees, Abe's experience serves as an example of how a trainee may successfully cope with unmet treatment expectations and still draw positive meaning from locomotor training.

Abe's experience also raises the question of how clinicians should address the topic of treatment expectations with patients/consumers. The importance of addressing patient/consumer treatment expectations has gained growing recognition in the medical and rehabilitation literature (Lysack, Zafonte, Neufeld, & Dijkers, 2001; Mondloch, Cole, & Frank, 2001; Staniszewska, 1999; Shaw, McMahon, Chan, & Hannold, in press). For example, Mondloch, Cole, and Frank (2001) examined the evidence for a relationship between patients' expectations for recovery and their health outcomes, and concluded that there exists a need for clinicians to clarify patients' expectations and to promote appropriate recovery expectations among patients. Staniszewska (1999) reported that patients' treatment and recovery expectations influence their health-related quality of life. Staniszewska also discussed the development of scales to measure patient expectations, and raised questions about the impact of unmet expectations on health-related quality of life. The need to address patient expectations was further supported by Lysack, Zafonte, Neufeld, and Dijkers (2001). These investigators compared patient and occupational therapists' expectations of patients' self-care independence with patients' actual self-care performance, and found patients' expectations exceeded those of their therapists. While each of the studies cited supports the need to address patients' treatment and recovery expectations, specific recommendations for *how* to address expectations are not provided. The topic of how to bring divergent therapist and consumer expectations into alignment has however, been discussed in the professional counseling literature. For example, in a study targeted at developing a training program to align rehabilitation counselor and

consumer expectations, Shaw, McMahon, Chan, and Hannold (in press) report the use of a conflict resolution model to enhance the ability of rehabilitation counselors to assist consumers achieve greater congruence in their expectations about the counseling relationship and rehabilitation services. Similar approaches may prove equally useful for addressing expectations of emerging interventions like locomotor training.

Power Through Social Support

A final theme to emerge regarding the perceived benefits of locomotor training was the value of social support as evidenced by the therapists and team members. When asked what they valued and enjoyed about locomotor training, trainees routinely referred to their interactions with the training team. For example, Lynn cited “the people” as the component of training she enjoyed the most. Likewise, Ed identified “the company” as the aspect of treatment he found most enjoyable. When reflecting upon the benefits of his locomotor training experience during his fourth interview, Ed stated, “Emotionally, the friendships and support I’ve gained have been outstanding.”

Data provided some indication of what therapist characteristics trainees perceived as valuable. Lynn, for example, described the training team as, “Very nonjudgmental. . . .Um, you know, they’re always encouraging me. They didn’t seem to make me feel as though you know . . . done something wrong . . . or whatever. Um, yeah, they’re very kind. They’re a great bunch. They’re very relaxed . . .” While Lynn valued the unconditional acceptance and encouragement offered by team members, Ben identified the altruism demonstrated by team members and their dedication to spinal cord injury recovery as characteristics he valued. Ben said,

And um . . . just the fact that people were volunteerin' their time . . . to help me out, meant a lot. I mean it, you know . . . it means a lot when somebody volunteers their time. Uhh . . . the reaso . . . I mean, 'course they have grants to do

it . . . But still they're . . . they're puttin' forth their time, ya know, for somethin' they believe in and . . .

In addition to these characteristics, data suggest all trainees enjoyed the therapists' senses of humor, and the fun and enjoyable training atmosphere they created. Observations of training sessions yielded numerous examples of humorous exchanges and laughter among team members. During interviews, trainees were subsequently asked how humor impacted their training experiences. Ben provided the following response when asked about humor during training sessions,

It was just fun, you know. Interactin' with the therapists and stuff . . . was a lot of fun. Because they all had really good attitudes an' a . . . it was just fun to . . . come and cut up with 'em . . . while we were workin'.

Likewise, Ed explained, “ You know because uh . . . there was a lot of people around, you know, and uh, yeah we had . . . I had a lot of fun you know, so, it really made a difference. It's a good thing.”

Data also revealed that trainees perceived humor as relieving the intensity associated with locomotor training. For example, Abe said, “It, it makes everything smoother. You . . . it makes you relax. You feel a little bit more comfortable in, in the situation.” Similarly, when discussing humor, Frank reported, “Oh, it really made it uh . . . a lot lighter. It was a way of interacting that . . . you know it is hard work, for all of the folks assisting” Given trainee responses, it appears trainees not only appreciated therapists' humor for the sense of fun it created, but also perceived that the humor demonstrated during training sessions had a purpose—to relieve the intensity associated with a treatment that is both physically and cognitively demanding.

Data suggest the support and encouragement offered by the locomotor training team served to enhance the self-esteem of participants (Figure 9). Aleksasuk (1996) has

recognized that the personal connections established through social relationships serve to empower individuals by providing them with emotional support and positive regard, and enhancing their self-esteem. In addition, social support has been linked with biological-based benefits, such as physiological or hormonal changes, particularly during times of stress (Taylor, Dickerson, & Cousins Klein, 2002). Similarly, the healing power of humor and laughter has also been recognized in the literature (Balick & Lee, 2003; Basmajian, 1998; Cousins, 1976; Rosner, 2002; Spero, 1999). Attempts have even been made to specifically explore (a) the effects of humor in rehabilitation settings (Basmajian, 1998; Kennedy & Marsh, 1993) and (b) the psychological impact of humor upon persons with spinal cord injury (Schmitt, 1990). Given the documented evidence on the healing power of hope, social support and humor, it could be said trainees gained a sense of personal power through their involvement with the “healing environment” created during locomotor training.

Summary

Perceived benefits of locomotor training as identified by participants with incomplete spinal cord injury include (a) the functional recovery and/or progress they achieved as evidenced by improvements in their gait and mobility, body control, balance, endurance, and strength, (b) the knowledge they gained about ambulation, (c) the sense of hope for further recovery they gained through the study, and (d) the perceived social support they received from the therapists and/or locomotor training team. Data analyses revealed these variables combined to increase trainees’ confidence, self-esteem, activity and role participation, motivation for further recovery, and ultimately, led to a renewed sense-of-self among some trainees.

Data from our study also provided evidence of two intriguing processes. The first was one trainee's cognitive-emotional adaptation response to unfulfilled hope or expectations during locomotor training. Although the trainee experienced disappointment and frustration, he was able to accept his remaining functional limitations by focusing on what he gained through locomotor training and maintain hope for further recovery by acknowledging that his recovery will be slower than he originally anticipated. The second process revealed that functional gains and progress led trainees to increased confidence and a greater sense hope for recovery, which in turn, enhanced their motivation and led them to engage in additional activities aimed at progress and recovery.

Just as in Chapter 5, where the locomotor training therapeutic process was described in terms of its potential to empower trainees, data analysis and interpretation revealed that the perceived benefits of locomotor training (as identified by trainees during our study) resulted in an increased sense of personal power among trainees. Trainees gained power through progress, power through knowledge, and power through a healing environment characterized by hope, social support, and laughter. Such findings suggest that, in this particular study, the locomotor training experience met the criteria for empowerment proposed by Banja (1990) and truly succeeded in *energizing and catalyzing* trainees' *capacity for life*.

CHAPTER 7 SUMMARY AND CONCLUSIONS

Introduction

Our study employed grounded theory methods to explore the experiences and perceptions of persons with incomplete spinal cord injury who participated in 9 weeks of locomotor training—an emerging intervention aimed at enhancing recovery of walking. Interviews and observations were conducted with six former and two current participants in an ongoing locomotor training study at the University of Florida, Department of Physical Therapy. Data analysis and interpretation revealed numerous themes representative of the locomotor training therapeutic process and the physical, cognitive, and emotional experiences of participants. These themes were used to develop a theoretical framework that reflects the effects of locomotor training on the psychosocial adaptation of persons with incomplete spinal cord injury.

This chapter serves to summarize study findings and discuss the possible implications for clinical practice and future research. First, the theoretical model to emerge from the data will be briefly compared to models of psychosocial adaptation proposed by Trieschmann (1988) and Livneh (2001). Next, findings related to the locomotor training therapeutic process and the physical, cognitive, and emotional experiences of locomotor training will be summarized. The limitations of the study and efforts to ensure trustworthiness will then once again be reviewed. The implications that study findings may hold for (a) persons with incomplete spinal cord injuries, (b) clinical

application and (c) rehabilitation policy will be discussed. Finally, recommendations for future research will be proposed.

Comparison of Models

The theoretical framework that emerged through data analysis depicts how the locomotor training therapeutic process stands to impact the psychosocial adaptation of persons with incomplete spinal cord injury. Unlike the models of psychosocial adaptation developed by Trieschmann (1988) and Livneh (2001), the theoretical framework derived from our study specifically delineates the potential for a therapeutic intervention such as locomotor training to affect the psychosocial adaptation process. The prospect of a therapeutic intervention (like locomotor training) affecting the adaptation process is not directly captured by either the Trieschmann or the Livneh models.

As illustrated in Chapter 2, the model of adaptation to spinal cord injury proposed by Trieschmann (1988) is very general, reflecting an ongoing, interactive process among psychosocial, organic, and environmental variables. If findings from our study were applied to Trieschmann's model, locomotor training could be viewed as an intervention that would impact the organic and psychosocial variables of participants. Through its potential to improve functional ambulation among persons with incomplete spinal cord injury, locomotor training could be interpreted as directly affecting the organic variables of participants. Furthermore, as demonstrated by our study, the potential for locomotor training to affect psychosocial variables such as confidence, and self-esteem, suggests the intervention could also be interpreted as having impact at the personal, psychosocial dimension of Trieschmann's model. Despite the ability to conceptualize the potential for locomotor training to affect participants at organic and psychosocial variables, the complex relationships between the locomotor training therapeutic process and the

resulting physical, cognitive, and emotional experiences of trainees as evidenced in our study would be lost if the general Trieschmann model of adaptation were used to interpret study findings.

Also described in Chapter 2, the Livneh (2001) model of psychosocial adaptation is more elaborate and comprehensive than the Trieschmann model. It too, however, fails to recognize the role that therapeutic interventions aimed at recovery may have upon the adaptation process. As applied to the Livneh model, the locomotor training therapeutic process could conceivably be categorized as a “triggering event” that initiates a psychosocial adaptation process. Currently, however, Livneh restricts his definition of triggering events to those associated with the cause of disability. Events that stand to alter the impact of disability after onset are not recognized by Livneh’s model.

Compared to the models of psychosocial adaptation proposed by Trieschmann (1988) and Livneh (2001), the theoretical framework to emerge from our study illustrates a relationship between the therapeutic intervention of locomotor training and the psychosocial adaptation process. Data from our study, together with the resulting theoretical framework, therefore contribute to the existing bodies of knowledge on both psychosocial adaptation to incomplete spinal cord injury and locomotor training. While additional research will be needed to fully understand the impact of locomotor training and other emerging interventions on psychosocial adaptation to disability, the theoretical framework developed through this study reflects preliminary evidence that the locomotor training therapeutic process and the resulting physical, cognitive, and emotional experiences of trainees with incomplete spinal cord injury did affect the trainees’ overall psychosocial adaptation process. The manner in which the trainees’ psychosocial

adaptation to incomplete spinal cord injury was affected is outlined next, in the summary of findings.

Summary of Findings

Findings Regarding the Locomotor Training Therapeutic Process

Themes to emerge from our study characterized the locomotor training therapeutic process as a process of empowerment. While the current neurorehabilitation literature supports the potential of locomotor training to enhance ambulation recovery and increased mobility among persons with incomplete spinal cord injury, themes to emerge from the data indicate that the therapists involved with the locomotor training study promoted trainee empowerment through physical interventions aimed at recovery, and also through cognitive-emotional levels of experience. Specifically, the manner in which therapists engaged trainees, and the environment therapists created, jointly promoted trainee empowerment. Data revealed the potential to “psychologically empower” trainees was fostered by the actions of therapists performing in multiple roles as “coach,” “teacher,” and “therapist” throughout the locomotor training therapeutic process, and through the ability of therapists to engage trainees as active team members.

In their roles as “coaches,” therapists served as motivating forces for trainees by providing them with a sense of team spirit, unity and support. In their roles as “teachers,” therapists provided trainees with knowledge and skills related to locomotor and ambulation principles, and body mechanics that would enable them to optimize their walking ability and pursue their recovery independently. Data suggest the knowledge trainees gained through locomotor training greatly enhanced their confidence and sense of personal power. Consequently, trainees frequently cited the knowledge they gained about ambulation as a highly valued outcome of locomotor training. In their roles as

“therapists,” therapists implemented their professional knowledge and skills as they would in a typical rehabilitation setting, to ensure the safety and well being of trainees while working to maximize locomotor training outcomes.

In addition to the activities performed by therapists in their multiple roles as “coach,” “teacher” and “therapist,” data further revealed that therapists promoted a sense of “power through equality” among trainees by engaging them as team members and actively involving them in the therapeutic process. Trainees were involved with identifying treatment goals and were encouraged to take responsibility for treatment-related decisions during training sessions. Trainees were also encouraged to provide the training team with feedback. This feedback included corrective feedback on therapy techniques and personal feedback related to trainees’ physical status and body position during training sessions. Therapists also engaged trainees as team members by keeping them informed about what training-related activities would occur throughout the locomotor training process. Data suggest the ability of trainees to be actively involved in the therapeutic process and to take part in their own recovery provided them with altruistic benefits and enhanced their self-esteem and sense of personal power.

In conclusion, therapists in our study promoted empowerment among trainees through their actions in the roles of “coach,” “teacher” and “therapist,” by engaging them as “equals” or active team members, and by providing them with ambulation knowledge. Therapists’ actions provided trainees with a sense of unity and support, and enhanced their knowledge, confidence, self-esteem and sense of personal power. While such psychosocial variables stand to positively influence the psychological adjustment and well being of any individual, data suggest that in our study, such variables also positively influenced the trainees’ psychosocial adaptation to incomplete spinal cord injury. Given

that trainees in our study identified factors such as improved mobility, strength and endurance, social support, knowledge, hope and increased confidence and self-esteem as benefits of locomotor training, it may be concluded that the empowerment-focused treatment approach adopted by therapists succeeded in lessening the perceived negative impact of trainees' incomplete spinal cord injuries, enhanced the trainees' overall sense of well-being, and consequently, better armed them to cope with their remaining functional limitations.

Findings Regarding the Physical, Cognitive and Emotional Experiences of Locomotor Training

While investigations of locomotor training as an intervention to enhance the recovery of walking among persons with incomplete spinal cord injury have focused on the functional outcomes of the intervention, results from our study revealed that the locomotor training therapeutic process resulted in equally powerful cognitive-emotional experiences for trainees. Trainees evidenced and described cognitive-emotional responses in conjunction with their physical experiences of locomotor training, and identified cognitive-emotional benefits of the treatment. Data analysis and interpretation suggest that, together with the functional gains resulting from locomotor training, the cognitive-emotional benefits of treatment served to empower trainees and enhance their psychosocial adaptation to incomplete spinal cord injury.

The collective physical, cognitive, and emotional experiences of trainees were evident throughout the locomotor training therapeutic process. For example, all trainees described the loss of control over their bodies following spinal cord injury and a subsequent loss of their senses of self. Subsequently, locomotor training represented a means for trainees to regain control of their bodies and their ability to walk. Trainees

described several experiences associated with their quest for control through locomotor training. These experiences included first-time on the treadmill experiences, a decreased sense of proprioception that resulted in a sense of uncertainty when stepping, the struggle to regain control due to involuntary movements and muscle spasms, and body sensations. As a result of these experiences, trainees described locomotor training as physically and cognitively demanding. While trainees often experienced frustration due to the physical and cognitive demands of locomotor training; data revealed all trainees highly valued locomotor training, perceived it to be well worth the effort involved, and would continue to participate in the intervention if afforded the opportunity.

The cognitive-emotional impact of locomotor training was further evident in trainees' descriptions of the benefits of treatment. The benefits of locomotor training as perceived and identified by participants with incomplete spinal cord injury included

- Functional recovery and/or progress trainees achieved as evidenced by improvements in their gait and mobility, body control, balance, endurance, and strength
- Knowledge trainees gained about ambulation
- The sense of hope for further recovery trainees gained through the study
- The perceived social support trainees received from the therapists and/or the locomotor training team.

Data analyses revealed these variables combined to increase trainees' confidence, self-esteem, activity and role participation, motivation for further recovery, and ultimately, led to a renewed sense-of-self among some trainees. Data analyses also revealed that together, the variables or benefits of locomotor training identified by trainees served to empower trainees and enhance their overall psychosocial adaptation to their incomplete spinal cord injuries. Data analyses suggest that the empowerment-

focused locomotor training therapeutic process, as evident in our study, facilitated trainees' psychosocial adaptation process by lessening the functional impact and mobility restrictions associated with incomplete spinal cord injury; improving trainees' ability to navigate the environment and engage in activities within their homes and communities; and by promoting psychosocial variables associated with psychological well-being such as confidence, self-esteem, hope, and a sense of personal power or competence.

Data from our study also provided evidence of two intriguing cognitive-emotional processes experienced by trainees. For example, 1 trainee evidenced a cognitive-emotional adaptation response to his unfulfilled hope or expectations during locomotor training. Although the trainee experienced disappointment and frustration as part of this process, data analyses revealed he was able to accept his remaining functional limitations by focusing on what he gained through locomotor training and maintain hope for further recovery by acknowledging that his recovery will be slower than he originally anticipated. The second cognitive-emotionally driven process to emerge from the study revealed that functional gains and progress led trainees to increased confidence and a greater sense hope for recovery, which in turn, enhanced their motivation and led them to engage in additional activities aimed at progress and recovery.

Results from our study both corroborate and contradict reports appearing in the relevant literature. For example, our study supports the findings of Nymark et al. (1998), who reported that locomotor training participants found the intervention to be physically and emotionally challenging, and felt it increased hope and confidence but may lead to unrealistic treatment expectations. However, findings from our study provided a much deeper understanding of the factors that led to these results and of the personal meaning trainees drew from such experiences. As previously described, our study also yielded

numerous other findings related to the cognitive-emotional experiences and perceptions of locomotor training participants.

Unlike the autobiographical account of Holicky (1995) that was discussed in Chapter 1, trainees did not appear to experience significant frustration related to the uncertainty associated with their incomplete spinal cord injuries. When discussing the impact of their spinal cord injuries for example, trainees did not raise the issue of uncertainty nor was the theme of uncertainty evident from interview or observational data. Furthermore, unlike Holicky, trainees did not describe putting their lives on hold in their pursuit of recovery through locomotor training. Although Lynn came to the United States for the sole purpose of therapy following her injury, she stated that she was prepared to devote one year to therapy “and then life goes on as is.” Likewise, some trainees participated in locomotor training while working and others participated while pursuing their education. Data suggest that for those trainees who were not employed or pursuing their education, participating in the locomotor training study was perceived as a valuable activity and a welcome opportunity for spending their time.

While the study by Bradley (1994) cited in Chapter 2 reported increases in depression and hostility following participation in an FES exercise program, such feelings were not overtly identified or insinuated by trainees who completed the locomotor training study. Although sadness and frustration were evident when some trainees discussed the impact of their spinal cord injuries, and Abe did identify frustration as part of the adaptation process he described in response to his unmet treatment expectations, trainees reported no depression and evidenced no hostility in response to locomotor training.

Study Limitations

As identified in Chapter 3, the primary limitations of our study stem from the use of a convenience sample of participants. Specifically, the fact that data was collected from voluntary participants enrolled at only one locomotor training site limits the transferability of study findings. Although the ability to generalize findings from a sample to a population is not the aim of our study, or of qualitative research in general, additional research is needed to permit the comparison of experiences of voluntary and nonvoluntary locomotor training participants enrolled at other training sites. In addition to this limitation, the fact that the sample of participants was not representative of the general population also restricts the transferability of study findings. Due to the fact the sample was predominantly comprised of white males, the data collected may not be representative of the experiences of females, or of persons from other ethnic backgrounds. Once again, additional studies using more diverse samples are needed to gain a better understanding of how locomotor training affects the experiences and perceptions of women, and of persons from varied ethnic backgrounds.

Efforts to Ensure Trustworthiness

Also as discussed in Chapter 3, efforts were undertaken to ensure the trustworthiness or quality of conclusions drawn from our study. Each of the five standards proposed by Miles and Huberman (1994) to assess the quality of conclusions derived from qualitative data were addressed. Queries that were relevant to our study and subsequently used to assess these standards will once again be briefly summarized.

Objectivity/Confirmability

- Explicit descriptions of methods and procedures, including techniques used for data collection and analysis/ interpretation, were provided.

- An “audit trail” exists to record methods and procedures, and data is available for reanalysis by others.
- The researcher was explicit about personal biases and assumptions.

Reliability/Dependability/Auditability

- Research questions are clear and the study design is congruent with them.
- The researcher’s role and status within the site is explicitly described.
- Findings show meaningful parallelism across data sources.
- Provisions exist for “checks” on coding and data quality.

Internal Validity/Credibility/Authenticity

- Descriptive data are context rich and meaningful or “thick.”
- The account is comprehensive, “makes sense” and facilitates a “vicarious presence” for readers
- Triangulation produced converging conclusions.
- Data are well linked to the emerging theory and concepts are systematically related.

External Validity/Transferability/Fittingness

- Characteristics of the sample, settings, processes and outcomes are adequately described to permit comparisons with other samples and across different settings.
- Limitations of the study are discussed and the scope and boundaries of reasonable generalization are defined.
- Findings are congruent with, connected to, or confirmatory of prior theory.
- The transferable theory from the study is made explicit and recommendations are made for further investigation.

Utilization/Application/Action orientation

- Study findings are intellectually and physically accessible to potential users.
- Various levels of usable knowledge are offered.

Study Implications

Implications for Persons with Incomplete Spinal Cord Injury

Results from our study hold important physical therapy treatment implications for persons with incomplete spinal cord injury. While results from the national clinical trial study will largely determine the future of locomotor training and the extent to which the intervention becomes utilized in clinical settings, findings from our study serve as testimony to the personal value and meaning this intervention holds for participants. Although preliminary studies of locomotor training have reported increased mobility due to the intervention, findings from our study reveal that locomotor training provided via an empowerment approach may also enhance the ability of trainees to engage in activities within their homes and communities due to perceived increases in balance, strength and endurance, and may promote positive psychosocial variables such as confidence, self-esteem, motivation, hope and a sense of personal power. Given these benefits, it appears locomotor training provided via an empowerment-focused approach enhanced the psychosocial adaptation and overall quality of life of the persons with incomplete spinal cord injury enrolled in our study.

Furthermore, as described in Chapters 5 and 6, all trainees interviewed for this study highly valued their experiences with the locomotor training study, enthusiastically touted numerous benefits of the treatment, and indicated they would embrace the opportunity for continued participation in locomotor training. These factors, combined with the fact that all trainees preferred locomotor training to conventional gait therapies, suggest locomotor training may be perceived by persons with incomplete spinal cord injury as one of the most advantageous treatments to emerge from rehabilitation science in recent years. Given the documented benefits of locomotor training, the challenge

facing persons with incomplete spinal cord injury lies in their access to the treatment. Until locomotor training surpasses its status as an experimental treatment and becomes more widely available to the general public, persons with incomplete spinal cord injury will have limited access to the treatment and the benefits it provides. If locomotor training does become more widely applied in clinical practice, the issue of whether or not medical insurance will cover the costs of the “newly emerging” treatment is another factor that will have to be considered by policymakers and potential candidates.

Implications for Clinical Application and Practice

Findings from the present suggest three primary implications for the clinical application of locomotor training. First, the empowerment-focused treatment strategies implemented by therapists in our study exemplify the value of consumer-centered treatment approaches. Data reveal that trainees responded favorably to being actively engaged in all aspects of the locomotor training therapeutic process and that such involvement enhanced the functional and cognitive-emotional outcomes of the intervention. Such findings may be used to educate and train physical therapists to better meet the comprehensive needs of locomotor training participants. Findings may also be used to train physical therapists in the development of similar consumer-centered, empowerment-driven treatment approaches for locomotor training and other therapeutic interventions aimed at neural recovery.

The second implication for clinical practice pertains to the educational needs of locomotor training participants. All trainees in our study indicated they knew very little about locomotor training prior to beginning actual training sessions. Efforts to enhance participants’ awareness and understanding of locomotor training are therefore recommended. A specific recommendation is use data from our study to develop an

educational training manual to supplement participants' understanding of locomotor training. Themes that emerged from our study suggest such a manual should address topics such as

- The goals and purposes of locomotor training
- Principles of locomotor training and ambulation
- The limitations of the intervention
- The respective roles of the therapist and participant in the locomotor training therapeutic process
- Examples of the physical, cognitive and emotional experiences locomotor training participants have previously described.

The third implication for clinical practice pertains to the need to address treatment expectations with locomotor training participants, and to make provisions for the emotional support needs of participants whose treatment expectations are not fulfilled. As discussed in Chapter 2, findings by Nymark et al. (1998), Guest, Klose, Needham-Shropshire, and Jacobs (1997) and Bradley (1994) all alluded to the need to address the treatment expectations of participants whether they are involved with interventions aimed at promoting recovery of mobility, or exercise programs aimed at enhancing limb movement, strengthening and conditioning. Similarly, as described in Chapter 6, our study also provided an example of 1 trainee's psychosocial response to unmet treatment expectations. Given the likelihood that some participants will experience sadness, frustration or distress if their expectations of locomotor training are not fulfilled, clinicians should be prepared to respond to such issues. One recommendation is to encourage clinicians to engage locomotor training participants in ongoing, open dialogs about their treatment expectations and satisfaction with treatment progress and outcomes. A second recommendation is for clinicians to mobilize peer support provisions for locomotor training participants. For example, former locomotor training participants

may be willing to meet with prospective or current participants to answer questions about locomotor training and to share experiences or discuss issues of concern.

Implications for Rehabilitation Policy

While results from the national clinical trial study of locomotor training will influence the extent to which the intervention is applied in physical therapy clinical practice, findings from our study and future studies that may address the psychosocial impact of locomotor training may also influence rehabilitation policy pertaining to the future of locomotor training. For example, robotic assisted devices such as the Lokomat[®] are now becoming available for use with locomotor training. While such devices stand to decrease the number of trainers needed to facilitate stepping on the treadmill, findings from our study provide evidence that the ability of therapists to interact with trainees in the roles of coach, teacher and therapist were critical to the locomotor training therapeutic process and the empowerment of trainees. Furthermore, the social support provided by therapists was identified by trainees as a highly valued benefit of treatment. These findings suggest that the replacement of therapists by a robotic device may jeopardize a critical dimension of treatment. Consequently, if robotic assisted devices grow in popularity, clinicians may have to develop treatment approaches that allow for regular periods of therapist/trainee interaction, or intermittent “task specific” interactions targeted at coaching or teaching.

Recommendations for Future Research

Research Regarding Locomotor Training

Results from our study were derived from a convenience sample of 8 participants with incomplete spinal cord injury from one locomotor training study site. Although an in-depth understanding of the experiences and perceptions of these participants was

obtained, as already indicated, the sample was primarily comprised of white males and was therefore not representative of the general population. Additional studies of the experiences and perceptions of participants with incomplete spinal cord injury should therefore be conducted at other locomotor training sites. Studies conducted at additional locomotor training sites may allow for a more diverse sample of participants and therefore permit the comparison of data across gender and ethnicity. Replicating our study at other sites would also allow for comparisons of the locomotor training therapeutic process, and any ensuing similarities or differences in participants' experiences and treatment outcomes.

Studies that investigate the impact of therapist and trainee variables (as defined in Chapter 4) on the locomotor training therapeutic process and treatment outcomes are also recommended. Findings related to the influence of therapist variables on treatment approaches and outcomes may have implications for evidence-based practice. Likewise, understanding how individual differences among locomotor training participants influence treatment and outcomes may lead to the development of trainee-centered treatment approaches.

Future research efforts should also investigate the experiences and perceptions of locomotor training participants with disabilities other than incomplete spinal cord injury. For example, given study findings from our study regarding the prevalence and intensity of the cognitive-emotional experiences associated with locomotor training, studies should be initiated to explore how participants with stroke, multiple sclerosis, and traumatic brain injury experience and respond to the cognitive demands of treatment. Findings from such studies may be used to determine if and how locomotor training treatment approaches need to be altered to meet the individual needs of participants.

Research Regarding Physical Therapy Practice

Our study also has implications for future research related to physical therapy practice. For example, Jensen, Gwyer, Shepard, and Hack (2000) interviewed physical therapists in an effort to define dimensions of expert practice in physical therapy. The following four dimensions of expert practice were identified:

1) a dynamic, multidimensional knowledge base that is patient-centered and evolves through therapist reflection, 2) a clinical reasoning process that is embedded in a collaborative, problem solving venture with the patient, 3) a central focus on movement assessment linked to patient function, and 4) consistent virtues seen in caring and commitment to patients. (Jensen, Gwyer, Shepard & Hack, 2000, p. 28)

Although these dimensions are representative of therapists acting in their “therapist” role during the locomotor training therapeutic process, they do not capture the teaching or coaching/motivating/support efforts of therapists as evident in our study. Perhaps like the Grannis (1981) study cited in Chapter 5, the physical therapists sampled by Jensen et al. (2000) did not recognize the value of the teaching role of physical therapists as perceived by patients/consumers. Given results of our study which indicate therapists promoted empowerment among trainees by supplementing their professional therapists’ roles with the more nontraditional roles of “coach” and “teacher,” further research is needed to identify characteristics of therapists who adopt such consumer-centered treatment approaches and determine how these characteristics fit current definitions of expert practice in physical therapy. Based upon trainees’ positive perceptions of the empowerment focused, consumer-centered treatment approach adopted in the locomotor training study, future studies of physical therapy expert practice may be well advised to seek out and incorporate patient/consumer input into definitions of expert practice.

APPENDIX A
FIELD NOTES COLLECTION SHEET AND INTERVIEW GUIDES

Elizabeth M. Hannold

IRB# 417-2002, VA# 0001

Live Observations _____

Videotape Observations _____

Participant #:

Session #:

Date Observed:

Videotape #:

Date Recorded:

Fieldnotes transcribed as of:

Validated as of:

People present during training session:

Indicators of participant affect (facial expressions, comments, interactions, etc...):

New occurrences / observations, or occurrences unique to session:

Session summary / timeline and noteworthy dialog, comments, and interactions

Participant Interview #1 (Before Training)

1. Could you tell me about your spinal cord injury? How has your life changed since your injury?
2. What things have been the most problematic for you since your injury?
3. How do these problems/issues affect you on a daily basis?
4. What accommodations have you had to make for your disability (home, travel, etc...)?
5. How have you been feeling physically since your injury?
6. How do you feel about yourself since your injury?
7. What activities have changed for you since your injury (job, recreation, self-care, etc...)?
8. How do you think your disability has changed the way others see you?
9. What are your personal goals for the year? What about next year?
10. What do you know about locomotor training? What are your concerns? Any expectations?
11. Describe your first experience of being up on the treadmill.
12. What do you hope to accomplish through locomotor training? What is the most important change you hope to accomplish?

Guide for “Ken”—Interview #2 (Week 4 of training)

1. Describe for me what your first day of locomotor training was like (being on the treadmill, having the team assist you, etc...)
2. What aspects of locomotor training have been the easiest for you? What aspects have you found to be the most difficult?
3. What changes have you noticed since beginning the therapy? What are you able to do now that you weren't able to do before starting locomotor training? So far, what changes have been most important to you?
4. How have you been feeling physically since beginning the study? What pain and/or soreness have you experienced? How long do/did the effects last? Do/did you do anything special to treat or cope with the effects?
5. Talk about your energy expenditure during locomotor training. How does it affect you? How long do the effects last? Do you do anything special to treat or cope with the effects?
6. What can you tell me about the amount of concentration locomotor training requires of you? How would you compare it to the physical demands of the training – as difficult, more, less?
7. How has your participation in the locomotor study affected your family members?
8. How has your participation in the locomotor study affected the way you feel about yourself?
9. What other aspects of your life are changing due to the training? Does your life seem easier or more difficult?
10. Describe your emotions since beginning the study.
11. What things about locomotor training are different from what you expected?
12. So far, what have you gained from locomotor training?

Guide for “Lynn”—Interview #2 (Week 4 of training)

1. Describe for me what your first day of locomotor training was like (being on the treadmill, having the team assist you, etc...)
2. What aspects of locomotor training have been the easiest for you? What aspects have you found to be the most difficult or frustrating? What was it like when the team covered up the mirror?
3. What changes have you noticed since beginning the therapy? What are you able to do now that you weren't able to do before starting locomotor training? So far, what changes have been most important to you?
4. How have you been feeling physically since beginning the study? What pain and/or soreness have you experienced? How long do/did the effects last? Do/did you do anything special to treat or cope with the effects?
5. Talk about your energy expenditure during locomotor training. How does it affect you? How long do the effects last? Do you do anything special to treat or cope with the effects?
6. What can you tell me about the amount of concentration locomotor training requires of you? How would you compare it to the physical demands of the training – as difficult, more, less?
7. How has your participation in the locomotor study affected your family members?
8. How has your participation in the locomotor study affected the way you feel about yourself?
9. What other aspects of your life are changing due to the training? Does your life seem easier or more difficult?
10. Describe your emotions since beginning the study.
11. What things about locomotor training are different from what you expected?
12. So far, what have you gained from locomotor training?

Guide for “Ken”—Interview #3 (Week 8 of training)

1. How has your locomotor training changed since we last talked? What aspects of locomotor training have been the easiest for you now? What aspects do you currently find to be the most difficult?
2. What changes have you noticed since our last interview? What are you able to do now that you weren't able to do then? What changes have been most important to you during this time period? How have these changes altered your life?
3. What aspects of locomotor training are most important to you now?
4. How have you been feeling physically since our last interview? What pain and/or soreness due to training have you experienced? How long do/did the effects last? Do/did you do anything special to treat or cope with the effects?
5. How has your understanding of locomotor training changed since our last interview?
6. How has your energy expenditure changed during your past month of locomotor training. How does it continue to affect you? How long do the effects last? Do you do anything special to treat or cope with the effects?
7. How has the amount of concentration required of you during locomotor training changed? How would you compare it to the physical demands of the training now—as difficult, more, or less?
8. How has your participation in the locomotor study affected your family members since our last interview?
9. How has your participation in the locomotor study affected the way you feel about yourself in the last month?
10. Describe your emotions during the past month.
11. How have your accomplishments in locomotor training matched your expectations for the study?
12. What have you gained from locomotor training during the past month?
13. Next week is your last week in the study. Describe your thoughts and feelings as it comes to an end.
14. How will you continue to carry over what you have learned and accomplished through locomotor training into your daily life?

Guide for “Lynn”—Interview #3 (Week 8 of training)

1. How has your locomotor training changed since we last talked? What aspects of locomotor training have been the easiest for you now? What aspects do you currently find to be the most difficult?
2. What changes have you noticed since our last interview? What are you able to do now that you weren't able to do then? What changes have been most important to you during this time period? How have these changes altered your life?
3. What aspects of locomotor training are most important to you now?
4. How have you been feeling physically since our last interview? What pain and/or soreness due to training have you experienced? How long do/did the effects last? Do/did you do anything special to treat or cope with the effects?
5. How has your understanding of locomotor training changed since our last interview?
6. How has your energy expenditure changed during your past month of locomotor training. How does it continue to affect you? How long do the effects last? Do you do anything special to treat or cope with the effects?
7. How has the amount of concentration required of you during locomotor training changed? How would you compare it to the physical demands of the training now—as difficult, more, or less?
8. How has your participation in the locomotor study affected your family members since our last interview?
9. How has your participation in the locomotor study affected the way you feel about yourself in the last month?
10. Describe your emotions during the past month.
11. How have your accomplishments in locomotor training matched your expectations for the study?
12. What have you gained from locomotor training during the past month?
13. Next week is your last week in the study. Describe your thoughts and feelings as it comes to an end.
14. How will you continue to carry over what you have learned and accomplished through locomotor training into your daily life?
15. What do you hope to accomplish by the time of our next interview – 5 or so weeks from now?

Guide for “Ken”—Interview #4 (One month post-training)

1. What have you been doing since our last interview? How have your activities changed since the locomotor training study ended?
2. How have you been feeling physically since our last interview? What pain and/or soreness do you experience now that the study has ended? How long do the effects last? Do you do anything special to treat or cope with the effects?
3. Describe your energy expenditure / fatigue since completing the study. How long do the effects last? Do you do anything special to treat or cope with the effects?
4. Describe the amount of concentration required of you now while walking independently. How would you compare it to the level of concentration required of you during locomotor training – while on the treadmill and practicing over ground?
5. How do you feel about yourself since completing the study? How do you think others see you?
6. What did you gain from locomotor training? How has your life changed due to locomotor training? How have your activities changed? What physical changes have you noticed? What changes do you value the most?
7. How did your participation in the locomotor study affect your family life?
8. What did you value the most about participating in the study?
9. What did you enjoy the most about participating in the study?
10. How, if at all, did humor in the lab affect your locomotor training experience?
11. How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
12. What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
13. How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

Guide for “Lynn”—Interview #4 (One month post-training)

1. What have you been doing since our last interview? How have your activities changed since the locomotor training study ended?
2. How have you been feeling physically since our last interview? What pain and/or soreness do you experience now that the study has ended? How long do the effects last? Do you do anything special to treat or cope with the effects?
3. Describe your energy expenditure / fatigue since completing the study. How long do the effects last? Do you do anything special to treat or cope with the effects?
4. Describe the amount of concentration required of you now while walking independently. How would you compare it to the level of concentration required of you during locomotor training – while on the treadmill and practicing over ground?
5. How do you feel about yourself since completing the study? How do you think others see you?
6. What did you gain from locomotor training? How has your life changed due to locomotor training? How have your activities changed? What physical changes have you noticed? What changes do you value the most?
7. How did your participation in the locomotor study affect your family life?
8. What did you value the most about participating in the study?
9. What did you enjoy the most about participating in the study?
10. How, if at all, did humor in the lab affect your locomotor training experience?
11. How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
12. What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
13. How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

“Abe’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
- Before the locomotor training study, in what ways did the SCI affect you/your life the most?
- How does the SCI continue to affect your life now?
- Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
- What do you remember the most about your first time up on the treadmill?
- In some of your videos, you made comments about your stepping, like “it doesn’t seem good”. Even when the trainers made comments about your progress, or said “It’s not that bad”, you made replies like, “doesn’t seem that way to me.” What were you using as your reference point during the study; what were you comparing your stepping to?
- You appeared to be working so hard physically in your videos. Talk to me about the energy expenditure required of you during the study. How did it affect you? How long did the effects last?
- One thing that struck me while watching the videos was that there seems to be a lot of concentration or mental “work” also required of you. For example, the therapists do a lot of directing - like, “shoulders back”, “hips forward”, “keep your heel down longer”, etc... What was that like for you? How would you compare it to the physical demands of the training – as difficult, more, less?
- In your videos, you provided great descriptions of your body sensations during the training – things like “firecrackers under (your) feet,” “springloaded.” Could you tell me more about the body sensations you experienced during the study – both while on the treadmill and at home? Did you experience any pain?
- In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
- The videos showed very little of your over-ground training. What can you tell me about your over-ground experiences?
- What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.

- Incomplete SCI is associated with a lot of uncertainty, and so are experimental therapies like locomotor training. How has the uncertainty of both having an iSCI AND participating in locomotor training affected your life? Would you say locomotor training has enabled you to pursue various goals, or caused you to put some goals on hold. Why?
- What did you gain physically from locomotor training? What about emotional gains or benefits? What specific gains do you value the most?
- What did you enjoy about participating in the study? What things would you change or do differently if you could do it over?
- How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
- What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
- How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

“Ben’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
- In what ways has the SCI affected your life the most? Your family’s life?
- Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
- What do you remember the most about your first time up on the treadmill?
- What can you tell me about the energy expenditure required of you during the study? How did it affect you? How long did the effects last? Did you do anything special to treat or cope with the effects?
- When watching your videos, it seemed as though you were really aware when your position or stepping didn’t feel right. You then did a great job of giving the team feedback on what seemed wrong or if something needed to be done differently. How did you know it wasn’t right? What were you comparing it to?
- I also noticed that you were very involved with your training sessions from the very beginning. For example, in addition to giving the team feedback, you also worked the speed control and monitored the time, etc... What caused you to adopt that approach? How do you think it affected your progress and/or training experience?
- Some people who have done locomotor training describe feeling “sensations” during or after training – things like tingly, or sparks in their legs or firecrackers under their feet. Did you experience any sensations during the study – either while on the treadmill or at home? Describe. What about pain?
- In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
- I also heard music playing during some of your sessions. Whose idea was it to play music? How did it affect your training?
- What can you tell me about your over-ground training experiences?
- What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.
- Incomplete SCI is associated with a lot of uncertainty, and so are experimental therapies like locomotor training. How has the uncertainty of both having an iSCI AND participating in locomotor training affected your life? Would you say

locomotor training has enabled you to pursue your goals, or caused you to put some goals on hold. Why?

- How did locomotor training help you? What did you gain physically from locomotor training? How have your activities changed? What about emotional gains or benefits? What specific gains do you value the most?
- How did locomotor training affect the way you feel about yourself? What about the way others see you?
- How did locomotor training affect your goals or plans for the future?
- What did you enjoy about participating in the study? What was difficult about participating the study? What things would you change or do differently if you could do it over?
- How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
- What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
- How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

“Chuck’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
- In what ways has the SCI affected your life the most? Your family’s life?
- Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
- What do you remember the most about your first time up on the treadmill?
- In a couple of your early videos, it looked like the therapists were taping your shoes, or wrapping tape around their hand and your shoe? What was that about?
- In some of your videos, you were experiencing pain in your knees and left ankle. What can you tell me about that? How was it treated? What kind of pain, if any, do you continue to experience?
- What can you tell me about the energy expenditure required of you during the study. How did it affect you? How long did the effects last? Did you do anything special to treat or cope with the effects?
- When watching your videos, I was very impressed with the way you seemed to “take charge” of your sessions from the very beginning. For example, you directed the team when and how you needed to be repositioned, you knew how to work the controls, directed what you wanted to do next in the session, etc... What caused you to adopt that approach? How do you think it affected your progress and/or training experience?
- Some people who have done locomotor training describe feeling “sensations” during or after training – things like tingly, or sparks in their legs or firecrackers under their feet. Did you experience any sensations other than pain during the study – either while on the treadmill or at home? Describe.
- In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
- What can you tell me about your over-ground training experiences?
- What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.
- Incomplete SCI is associated with a lot of uncertainty, and so are experimental therapies like locomotor training. How has the uncertainty of both having an iSCI

AND participating in locomotor training affected your life? Would you say locomotor training has enabled you to pursue your goals, or caused you to put some goals on hold. Why?

- How did locomotor training help you? What did you gain physically from locomotor training? How have your activities changed? What about emotional gains or benefits? What specific gains do you value the most?
- How did locomotor training affect the way you feel about yourself? What about the way others see you?
- How did locomotor training affect your goals or plans for the future?
- What did you enjoy about participating in the study? What was difficult about participating the study? What things would you change or do differently if you could do it over?
- How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
- What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
- How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

“Dan’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
 - In what ways has the SCI affected your life the most (ADLs, work, etc...)? Your family’s life?
3. Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
 4. What do you remember the most about your first time up on the treadmill? What was it like being on the treadmill, having the team assist you, etc...?
 5. What parts of locomotor training were the easiest for you? What aspects were the most difficult?
 6. What can you tell me about the energy required of you during the study? How did it affect you? How long did the effects last? Did you do anything special to treat or cope with the effects?
 7. In one of your early videos, where they were testing you, I noticed they were taking your heart rate frequently and you appeared to be perspiring quite a bit. What types of physical changes or problems did you notice during locomotor training? What pain or soreness did you experience? How long did the effects last? What did you do to treat or cope with the effects?
 8. Some people who have done locomotor training describe feeling “sensations” during or after training – things like tingly, or sparks in their legs or firecrackers under their feet. Did you experience any sensations other than pain during the study – either while on the treadmill or at home? Describe.
 9. What can you tell me about the amount of concentration locomotor training required of you? How would you compare it to the physical demands of the training – as difficult, more, less?
 10. In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
 11. What can you tell me about your over-ground training experiences?
 12. What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.

13. Incomplete SCI is associated with a lot of uncertainty, and so are experimental therapies like locomotor training. How has the uncertainty of both having an iSCI AND participating in locomotor training affected your life? Would you say locomotor training has enabled you to pursue your goals, or caused you to put some goals on hold. Why?
14. How did locomotor training help you? What did you gain physically from locomotor training? How have your activities changed? What about emotional gains or benefits? What specific gains do you value the most?
15. How did locomotor training affect the way you feel about yourself? What about the way others see you?
16. How did locomotor training affect your goals or plans for the future?
17. What did you enjoy about participating in the study? What things would you change or do differently if you could do it over?
18. What things about locomotor training were different from what you expected? How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied,” how would you rate your satisfaction with what you accomplished during the study?
19. What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
20. How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

“Ed’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
- In what ways has the SCI affected your life the most? Your family’s life?
- Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
- What do you remember the most about your first time up on the treadmill?
- In your videos, it looked like you had lots of spasms during training. How did the spasms affect your locomotor training?
- What can you tell me about the amount of energy it took you to do the study? How did it affect you? How long did the effects last? Did you do anything special to treat or cope with the effects?
- Some people who have done locomotor training describe feeling “sensations” during or after training – things like tingly, or sparks in their legs or firecrackers under their feet. Did you experience any sensations other than pain during the study – either while on the treadmill or at home? Describe.
- In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
- What can you tell me about your over-ground training experiences?
- What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.
- Would you say locomotor training has enabled you to pursue your goals, or caused you to put some goals on hold. Why?
- How did locomotor training help you? What did you gain physically from locomotor training? How have your activities changed? What about emotional gains or benefits? What specific gains do you value the most?
- How did locomotor training affect the way you feel about yourself? What about the way others see you?
- How did locomotor training affect your goals or plans for the future?

- What did you enjoy about participating in the study? What was difficult about participating the study? What things would you change or do differently if you could do it over?
- How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
- What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
- How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

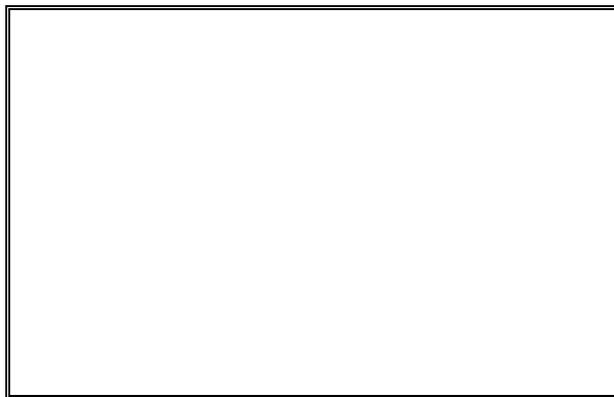
“Frank’s” Interview Guide

- I’d like to start by asking you to give me some background on your spinal cord injury.
- In what ways has the SCI affected your life the most? Your family’s life?
- Before you started the study, what did you know about locomotor training? What did you hope to accomplish through the study?
- What do you remember the most about your first time up on the treadmill?
- In a couple of your videos, it looked like you were having spasms in your left leg while you were training? How did the spasms affect your training?
- I also noticed in the videotapes that the trainers did a lot of teaching and demonstrating about how your body moved and how it was suppose to move. How did this information affect your training?
- What can you tell me about the energy expenditure required of you during the study. How did it affect you? How long did the effects last? Did you do anything special to treat or cope with the effects?
- Some people who have done locomotor training describe feeling “sensations” during or after training – things like tingly, or sparks in their legs or firecrackers under their feet. Did you experience any sensations other than pain during the study – either while on the treadmill or at home? Describe.
- In addition to all your hard work, there also appeared to be some fun during the sessions – laughing, a little teasing and joking. From what you remember, did humor seem to affect your experience at all, and if so, how?
- What can you tell me about your over-ground training experiences?
- What emotions do you remember experiencing during the study - for example, happiness, excitement, hope, fear, frustration, anxiety, sadness, anger, etc...? Please explain.
- How did locomotor training help you? What did you gain physically from locomotor training? How have your activities changed? What about emotional gains or benefits? What specific gains do you value the most?
- How did locomotor training affect the way you feel about yourself? What about the way others see you?
- How did locomotor training affect your goals or plans for the future?

- What did you enjoy about participating in the study? What was difficult about participating the study? What things would you change or do differently if you could do it over?
- How did locomotor training meet, or fail to meet, your expectations? On a scale of 1 to 10, where 1 is “not at all satisfied” and 10 is “completely satisfied”, how would you rate your satisfaction with what you accomplished during the study?
- What would you tell someone with an iSCI who is considering enrolling in a locomotor training study or program?
- How does locomotor training compare to the gait training you received during your in-patient rehabilitation?

APPENDIX B
INFORMED CONSENT FORMS
IRB # _____

*Informed Consent to Participate in Research
and Authorization for Collection, Use, and
Disclosure of Protected Health Information*



You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your protected health information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary.

1. Name of Participant ("Study Subject")

2. Title of Research Study

Effects of Locomotor Training on the Psychosocial Adaptation of Persons with Incomplete Spinal Cord Injury **Consent to Interview and Observe Therapy**

3. Principal Investigator and Telephone Number(s)

If you have any questions or problems related to this study, please contact the Principal Investigator, Lisa Hannold, at (352) 376-1611 ext.6843, or (352) 271-0987.

4. Source of Funding or Other Material Support

This study is funded by the Department of Veterans' Affairs (VA) Pre-Doctoral Associated Health Rehabilitation Research Fellowship Program.

5. What is the purpose of this research study?

You have been asked to take part in this study because you have been selected to participate in an ongoing study of locomotor training at the University of Florida, Department of Physical Therapy. Locomotor training is a new therapy developed to improve the walking ability and walking speed of people with incomplete spinal cord injuries. Little is known however, about how locomotor training affects the way participants think and feel about themselves and their spinal cord injury, and how it affects their lives. The purpose of this add-on project is to describe how locomotor training participants, and the people they have significant relationships with (spouse, partner, or adult child), experience locomotor training. The goal is to help us understand how locomotor training affects the thoughts, feelings, and activities of participants and their spouse, partner, or adult child.

6. What will be done if you take part in this research study?

If you agree to participate in this add-on study, your locomotor training will not change in any way. You will receive the usual locomotor training therapy for people with incomplete spinal cord injuries. The only difference is that the Principal Investigator will observe your therapy, and will interview you four times.

While observing your locomotor training, the Principal Investigator will take notes on what occurs.

The Principal Investigator will interview you: 1) before you begin treatment, 2) once during the fourth week of treatment, 3) once during the eighth week of treatment, and 4) during your one-month follow-up visit after completion of locomotor training. Interviews will last about 45 minutes to 1 hour and will be tape-recorded. After the interviews, the content of the audiotapes will be typed into written documents or transcripts for data analysis. During the interviews, the Principal Investigator will ask you to talk about your experience with locomotor training, how you think and feel about the treatment, how it affects the way you think about yourself and your spinal cord injury, how things change or remain the same for you, and how you understand what is happening with the treatment.

If you decide to participate in this study, the Principal Investigator is also interested

in conducting a single interview with a person you have a significant relationship with – for example, a spouse, partner, or adult child. This person will be asked questions similar to your interview questions. The interview will last 45 minutes to 1 hour, and be tape-recorded. The interview will preferably take place at or around the time of your one-month follow-up visit after completion of locomotor training. If you do not have a significant relationship, you are still eligible to participate in this study and your locomotor training will not be affected in any way. If you do have a significant relationship with a spouse, partner, or adult child, the decision to ask this person to participate is entirely yours. You are still eligible to participate in this study whether or not you decide to ask this person to be interviewed, and your locomotor training will not be affected. If you decide to ask your spouse, partner or adult child to participate in this study, he or she is free to refuse, and a refusal would not affect your eligibility for this study or your locomotor training. If he or she agrees to be interviewed, please contact the Principal Investigator at the number on the front page of this form.

7. What are the possible discomforts and risks?

A possible discomfort you may experience is having someone observing you while you are in your locomotor training sessions. Another discomfort may be that you get tired during the interviews. If this happens, you will be given a break to rest. If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

Throughout the study, the researchers will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

8a. What are the possible benefits to you?

Participating in this study may not benefit you directly. However, sometimes people do benefit from having someone listen to them talk about their experiences.

8b. What are the possible benefits to others?

Information gained from this study may help us provide better rehabilitation therapies, like locomotor training, and related support services for others.

9. If you choose to take part in this research study, will it cost you anything?

No

10. Will you receive compensation for taking part in this research study?

No

11. What if you are injured because of the study?

If you experience an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be provided without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other compensation is offered.

12. What other options or treatments are available if you do not want to be in this study?

The option to taking part in this study is to continue with your present therapy/locomotor training. If you do not want to take part in this study, tell the Principal Investigator and do not sign this Informed Consent Form. Participation in this study is entirely voluntary. You are free to refuse to be in the study, and your refusal will not influence current or future health care you receive at this institution, including your involvement with the locomotor training study.

13a. Can you withdraw from this research study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty, and you will not lose any benefits you are entitled to. Your involvement with the locomotor training study will continue.

If you decide to withdraw your consent to participate in this research study for any reason, you should contact Lisa Hannold at (352) 376-1611 ext.6843, or (352) 271-0987.

If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

13b. If you withdraw, can information about you still be used and/or collected?

If you decide to withdraw from the study, you will not be required to participate in any further interviews. Information already collected from you during interviews will not be used in the study.

13c. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons: 1) you are withdrawn from the locomotor study, or 2) you are consistently unable to keep interview appointments and do not reschedule with the Principal Investigator.

14. How will your privacy and the confidentiality of your protected health information be protected?

To ensure the information you provide remains confidential, you will be assigned a code number. The code number, not your name or initials, will be used to identify you in observation or field notes, interview transcripts, audiotapes, and computer discs used to store transcripts. All audiotapes, interview transcripts, observation notes and computer discs will remain in the locked file cabinet at the VA RORC for use with manuscript preparation.

Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If you participate in this research, your protected health information will be collected, used, and disclosed under the terms specified in sections 15 – 24 below.

15. If you agree to participate in this research study, what protected health information about you may be collected, used and disclosed to others?

To determine your eligibility for the study and as part of your participation in the study, your protected health information that is obtained from you, from review of your past, current or future health records, from procedures such as physical examinations, x-rays, blood or urine tests or other procedures, from your response to any study treatments you receive, from your study visits and phone calls, and any other study related health information, may be collected, used and disclosed to others. More specifically, the following information may be collected, used, and disclosed to others:

Information gathered through interview questions and/or locomotor training

observations. Specifically, references to the impact of spinal cord injury and locomotor training may be collected, used, and disclosed to others. For example:

- Medical information related to the spinal cord injury (level of injury, medical or functional complications, medications, and effect on activities of daily living)
- Medical information related to history of rehabilitation therapies or treatment, including locomotor training (perceptions about therapy and therapy outcomes)
- Information related to psychological adjustment to spinal cord injury and locomotor training – including, diagnosis and treatment of a mental health condition (emotional reactions, self-esteem and body image, and impact on activities)

16. For what study-related purposes will your protected health information be collected, used and disclosed to others?

Your protected health information may be collected, used and disclosed to others to find out your eligibility for, to carry out, and to evaluate the results of the research study. More specifically, your protected health information may be collected, used and disclosed for the following study-related purpose(s):

The purpose of this study is to describe how persons with incomplete spinal cord injury, and the people they have significant relationships with (spouse, partner, or adult child), experience locomotor training. The goal is to help us understand how locomotor training affects the thoughts, feelings, and activities of participants and their spouse, partner, or adult child.

17. Who will be authorized to collect, use and disclose to others your protected health information?

Your protected health information may be collected, used, and disclosed to others by

- a. the study principal investigator, Elizabeth M. Hannold, and her staff
- b. other professionals at the University of Florida or Shands Hospital
- c. the University of Florida Institutional Review Board
- d. other professionals at the Malcolm Randall VA Medical Center (Gainesville)
- e. the VA Subcommittee for Clinical Investigation (SCI) and the VA Research and Development Committee (R&D)

18. Once collected or used, who may your protected health information be disclosed to?

Your protected health information may be given to:

- the study sponsor (*VA Office of Academic Affiliations*)
- United States and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections
- Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and Federal, State and local health departments
- Malcolm Randall VA Medical center (Gainesville)

19. If you agree to participate in this research, how long will your protected health information be collected, used and disclosed?

Forever, or until your permission to use this information is withdrawn.

20. Why are you being asked to authorize the collection, use and disclosure to others of your protected health information?

Under a new Federal Law, researchers cannot collect, use or disclose any of your protected health information for research unless you allow them to by signing this consent and authorization.

21. Are you required to sign this consent and authorization and allow the researchers to collect, use and disclose (give) to others of your protected health information?

No, and your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. *However, you cannot participate in this research unless you allow the collection, use and disclosure of your protected health information by signing this consent/authorization.*

22. Can you review or copy your protected health information collected, used or disclosed under this authorization?

You have the right to review and copy your protected health information. However, you will not be allowed to do so until after the study is finished.

23. Is there a risk that your protected health information could be given to others beyond your authorization?

Yes. There is a risk that information received by authorized persons could be given to others beyond your authorization and not covered by the law.

24. Can you revoke (cancel) your authorization for collection, use and disclosure of your protected health information?

Yes. You can revoke your authorization at any time before, during or after your participation in the research. If you revoke, no new information will be collected about you. However, information that was already collected may be still be used and disclosed to others if the researchers have relied on it to complete and protect the validity of the research. You can revoke by giving a written request with your signature on it to the Principal Investigator.

25. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

26. Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how the participant's protected health information will be collected used and disclosed:

Signature of Person Obtaining Consent and Authorization

Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your protected health information will be collected, used and disclosed. You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. You hereby authorize the collection, use and disclosure of your protected health information as described in sections 14-24 above. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting and Authorizing

Date

IRB# _____

***Informed Consent to Participate in Research
and Authorization for Collection, Use, and
Disclosure of Protected Health Information***



You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your protected health information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary.

1. Name of Participant ("Study Subject")

2. Title of Research Study

Effects of Locomotor Training on the Psychosocial Adaptation of Persons with Incomplete Spinal Cord Injury **Former Participant Consent to be Interviewed**

3. Principal Investigator and Telephone Number(s)

If you have any questions or problems related to this study, please contact the Principal Investigator, Lisa Hannold, at (352) 376-1611 ext.6843, or (352) 271-0987.

4. Source of Funding or Other Material Support

This study is funded by the Department of Veterans' Affairs (VA) Pre-Doctoral Associated Health Rehabilitation Research Fellowship Program.

5. What is the purpose of this research study?

You have been asked to take part in this study because you have previously participated in an ongoing study of locomotor training at the University of Florida, Department of Physical Therapy, and consented to allow videotapes of your locomotor training sessions to be used for research purposes. Locomotor training is a new therapy developed to improve the walking ability and walking speed of people with incomplete spinal cord injuries. Little is known however, about how locomotor training affects the way participants think and feel about themselves and their spinal cord injury, and how it affects their lives. The purpose of this add-on project is to describe how locomotor training participants, and the people they have significant relationships with (spouse, partner, or adult child), experience locomotor training. The goal is to help us understand how locomotor training affects the thoughts, feelings, and activities of participants and their spouse, partner, or adult child.

6. What will be done if you take part in this research study?

If you agree to participate in this add-on study, you will be interviewed by the Principal Investigator. Your relationship with the locomotor training program and the researchers involved with the study will not change in any way. During the interview, the Principal Investigator will seek your feedback on a number of questions related to locomotor training. Before the interview takes place, the Principal Investigator will develop some of the interview questions by watching videotapes of your training sessions. You may, for example, be asked to talk about your personal experiences with locomotor training, including, how you thought and felt about the treatment, how it affected you physically, how it affected the way you thought about yourself and your spinal cord injury, how your life changed or remained the same, and what you valued most and least about the training. The interview will be conducted in-person or over the telephone, and will last about 1-1.5 hours. The interview will be tape-recorded. After the interview, the content of the audiotape will be typed into a written document or transcript for data analysis.

7. What are the possible discomforts and risks?

A possible discomfort you may experience may be that you get tired during the interview. If this happens, you will be given a break to rest. If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

Throughout the study, the researchers will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

8a. What are the possible benefits to you?

Participating in this study may not benefit you directly. However, sometimes people do benefit from having someone listen to them talk about their experiences.

8b. What are the possible benefits to others?

Information gained from this study may help us provide better rehabilitation therapies, like locomotor training, and related support services for others.

9. If you choose to take part in this research study, will it cost you anything?

No

10. Will you receive compensation for taking part in this research study?

No

11. What if you are injured because of the study?

If you experience an injury that is directly caused by this study, only professional consultative care that you receive at the University of Florida Health Science Center will be provided without charge. However, hospital expenses will have to be paid by you or your insurance provider. No other compensation is offered.

12. What other options or treatments are available if you do not want to be in this study?

The option to taking part in this study is to continue with your present therapy/locomotor training. If you do not want to take part in this study, tell the Principal Investigator and do not sign this Informed Consent Form. Participation in this study is entirely voluntary. You are free to refuse to be in the study, and your refusal will not influence current or future health care you receive at this institution, including your involvement with the locomotor training study.

13a. Can you withdraw from this research study?

You are free to withdraw your consent and to stop participating in this research study at any time. If you do withdraw your consent, there will be no penalty, and you will not lose any benefits you are entitled to. Your involvement with the locomotor training study will continue.

If you decide to withdraw your consent to participate in this research study for any reason, you should contact Lisa Hannold at (352) 376-1611 ext.6843, or (352) 271-0987.

If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

13b. If you withdraw, can information about you still be used and/or collected?

If you decide to withdraw from the study, you will not be required to participate any further. Information already collected from you during interviews will not be used in the study.

13c. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reason:
1) You are consistently unable to keep your interview appointment and do not reschedule with the Principal Investigator.

14. How will your privacy and the confidentiality of your protected health information be protected?

To ensure the information you provide remains confidential, you will be assigned a code number. The code number, not your name or initials, will be used to identify you in the interview transcript, observation notes, audiotape, and computer disc used to store the transcript. All audiotapes, interview transcripts, observation notes and computer discs will remain in the locked file cabinet at the VA RORC for use with manuscript preparation.

Authorized persons from the University of Florida, the hospital or clinic (if any) involved in this research, and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of them to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

If you participate in this research, your protected health information will be collected, used, and disclosed under the terms specified in sections 15 – 24 below.

15. If you agree to participate in this research study, what protected health information about you may be collected, used and disclosed to others?

To determine your eligibility for the study and as part of your participation in the study, your protected health information that is obtained from you, from review of your past, current or future health records, from procedures such as physical examinations, x-rays, blood or urine tests or other procedures, from your response to any study treatments you receive, from your study visits and phone calls, and any other study related health information, may be collected, used and disclosed to others. More specifically, the following information may be collected, used, and disclosed to others:

Information gathered through interview questions and/or locomotor training observations. Specifically, references to the impact of spinal cord injury and locomotor training may be collected, used, and disclosed to others. For example:

- Medical information related to the spinal cord injury (level of injury, medical or functional complications, medications, and effect on activities of daily living)
- Medical information related to history of rehabilitation therapies or treatment, including locomotor training (perceptions about therapy and therapy outcomes)
- Information related to psychological adjustment to spinal cord injury and locomotor training – including, diagnosis and treatment of a mental health condition (emotional reactions, self-esteem and body image, and impact on activities)

16. For what study-related purposes will your protected health information be collected, used and disclosed to others?

Your protected health information may be collected, used and disclosed to others to find out your eligibility for, to carry out, and to evaluate the results of the research study. More specifically, your protected health information may be collected, used and disclosed for the following study-related purpose(s):

The purpose of this study is to describe how persons with incomplete spinal cord injury, and the people they have significant relationships with (spouse, partner, or adult child), experience locomotor training. The goal is to help us understand how locomotor training affects the thoughts, feelings, and activities of participants and their spouse, partner, or adult child.

17. Who will be authorized to collect, use and disclose to others your protected health information?

Your protected health information may be collected, used, and disclosed to others by

- j. the study principal investigator, Elizabeth M. Hannold, and her staff
- k. other professionals at the University of Florida or Shands Hospital
- l. the University of Florida Institutional Review Board
- m. other professionals at the Malcolm Randall VA Medical Center (Gainesville)
- n. the VA Subcommittee for Clinical Investigation (SCI) and the VA Research and Development Committee (R&D)

18. Once collected or used, who may your protected health information be disclosed to?

Your protected health information may be given to:

- the study sponsor (*VA Office of Academic Affiliations*)
- United States and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections
- Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and Federal, State and local health departments
- Malcolm Randall VA Medical center (Gainesville)

19. If you agree to participate in this research, how long will your protected health information be collected, used and disclosed?

Forever, or until your permission to use this information is withdrawn.

20. Why are you being asked to authorize the collection, use and disclosure to others of your protected health information?

Under a new Federal Law, researchers cannot collect, use or disclose any of your protected health information for research unless you allow them to by signing this consent and authorization.

21. Are you required to sign this consent and authorization and allow the researchers to collect, use and disclose (give) to others of your protected health information?

No, and your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. *However, you cannot participate in this research unless you allow the collection, use and disclosure of your protected health information by signing this consent/authorization.*

22. Can you review or copy your protected health information collected, used or disclosed under this authorization?

You have the right to review and copy your protected health information. However, you will not be allowed to do so until after the study is finished.

23. Is there a risk that your protected health information could be given to others beyond your authorization?

Yes. There is a risk that information received by authorized persons could be given to others beyond your authorization and not covered by the law.

24. Can you revoke (cancel) your authorization for collection, use and disclosure of your protected health information?

Yes. You can revoke your authorization at any time before, during or after your participation in the research. If you revoke, no new information will be collected about you. However, information that was already collected may be still be used and disclosed to others if the researchers have relied on it to complete and protect the validity of the research. You can revoke by giving a written request with your signature on it to the Principal Investigator.

25. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

26. Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how the participant's protected health information will be collected used and disclosed:

Signature of Person Obtaining Consent and Authorization

Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your protected health information will be collected, used and disclosed. You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. You hereby authorize the collection, use and disclosure of your protected health information as described in sections 14-24 above. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting and Authorizing

Date

APPENDIX C TRACKING OF CHANGES TO NODE TREE

05/20/03

Nodes under “training session routine” were grouped into 7 nodes to categorize activity themes and facilitate coding.

The node “Humor” was sub-categorized into 4 nodes to 1) identify who initiated the humor and see if any patterns emerge, and 2) specifically identify the perceived impact of humor on training.

The theme “Empowerment” was added under “Locomotor Lab Environment/Atmosphere Descriptors,”

05/23/03

To eliminate redundancy, the node “Positive reinforcement”, listed under “Corrective feedback”, was deleted and its data re-coded at the node named Positive Feedback. The theme “Positive feedback” was then re-named Positive Reinforcement.

Node 24134 broadened to include visual descriptors.

Node 24134 immediately changed – deleted the word “visual” when text reflected an auditory cue.

Node 121, “Therapy Principles” moved to 311, under Therapist role/Teacher/Therapy principles.

The majority of codes developed for the Holicky article were deleted – all fell under psychosocial adaptation. To date, none of my data supported those themes.

05/27/03

To minimize redundancy, the node “Empower Participants” was moved from therapist roles to the node titled “Empowerment” under the environment node. The node was then renamed, “Therapist activity that promotes trainee empowerment”. The node appears to fit better in this broader category. LOG: 11:30 am, 5/27/03. : Cut from node (2 3 3) .

Also moved to the “Empowerment” category was the node “Empower team members.” This node was renamed “Therapist activity that empowers team members.” LOG: 11:46 am, 5/27/03. : Cut from node (2 3 6) .

Under “Progress and Recovery Indicators”, 3 new categories were defined: 1) Physical indicators during training, 2) Participation landmarks described by trainee, and 3) Using less restrictive adaptive aids. All nodes previously listed under the category were then cut and pasted under “Physical Indicators.” *Posture* - LOG: 12:06 pm, 5/27/03. : Cut from node (2 1 3 2 1). *BWS setting tolerated* - LOG: 12:07 pm, 5/27/03. : Cut from node (2 1 3 2 2). *Treadmill speed tolerated* - LOG: 12:07 pm, 5/27/03. : Cut from node (2 1 3 2 3). *Stepping ability* - LOG: 12:07 pm, 5/27/03. : Cut from node (2 1 3 2 4). *Leg extension* - LOG: 11:48 am, 1/13/03. : Cut from node (2 2 4 2 4 2 1) AND LOG: 12:07 pm, 5/27/03. : Cut from node (2 1 3 2 5). *Leg flexion* - LOG: 11:48 am, 1/13/03. : Cut from node (2 2 4 2 4 2 2) AND LOG: 12:08 pm, 5/27/03. : Cut from node (2 1 3 2 6). *Hip extension* - LOG: 12:08 pm, 5/27/03. : Cut from node (2 1 3 2 7). *Hip flexion* - LOG: 12:08 pm, 5/27/03. : Cut from node (2 1 3 2 8).

05/29/03

Deleted node entitled “Observed” and renamed “Affect” as “Observed affect”.

Reorganized and renamed codes under Emotional, Physical & Cognitive headings to help refine concepts.

06/02/03

Categorized themes identified under “Identified Outcomes/Benefits of LT Training” – several new nodes specified.

06/03/03

Renamed node (2345) “Directing team how to improve task” TO “Directing team what to do” to reflect a broader concept.

Deleted node (2222310) “Teaching trainee how to correct stepping” and recoded data under node (2312), “Teacher of trainees and staff/ body mechanics” to minimize redundancy.

Copied Node (23262), “Stepping cues” to Node (23111), “Therapy principles/promote proper timing of steps.” Better organization. LOG: 3:21 pm, 6/3/03. : Copy of subtree (2 3 2 6 2). Later, deleted Node 23262.

Cut Node (222239) “Promote trainee body position awareness” and attached to Node (23112) “Promote aligned position.” LOG: 10:08 pm, 6/3/03. : Cut from node (2 2 2 2 3 9). Then, cut Node (23261), “Body position cues” and attached to Node (231121), “Promoting trainee’s body position awareness.” LOG: 10:12 pm, 6/3/03. : Cut from node (2 3 2 6 1). Node (2326), “Cuing trainees” was replaced by Node (23263) “Breathing cues” after all other cuing data was moved.

Under Node (21321), “Physical indicators during training,” the Node (2132141) “Endurance indicators” was added along with children “Total time stepping” and “Distance walked.”

06/05/03

Under Node (21121), “Physical demands of locomotor training”, added Node (211214), “Impact on how trainee feels.” Cut and pasted Node (21124), “Discomfort indicators,” under the new node – now Node (2112141) [LOG: 2:36 pm, 6/5/03. : Cut from node (21124)], and also added the new Node (2112142), “Feels okay.”

Added Node (22254310), “Physically “Guarding” trainee for safety” under Node (222543), “Trainer activities.”

07/12/03

Added node (2352), “Identifying a discrepancy in stepping or its cause.”

Added node (2311116), “Leg position or movement” under “Stepping cues.”

07/16/03

Added node (22254225), “March in place” under “Standing breaks”.

08/03/03

Renamed and defined node (222237), “Relating progress” to “Progress talk.”

Added node (2132144), “Walking at higher speeds” under “Progress or recovery indicators”/”Stepping ability.”

Added node (21311315), “Contractures” under “Talk about secondary issues.”

Added node (231311), “Practice opportunities” under “Corrective feedback.”

Added node (2132145), “Amount of assistance required” under “Progress or recovery indicators”/”Stepping ability.” Nodes for “Leg extension”, “Leg flexion”, “Hip extension” and “Hip flexion” were then cut and pasted under this node.

Added nodes (22254241), “Moving parallel bars” and (22254242), “Loftstrand crutches” under “Overground training.”

08/10/03

Added node (110), “Personal history” as a depository for personal information that does not fit in any other categories.

Added node (213112117), “Increased sense of community/support” under SCI impact on life.

Added node (213112118), “Learning to accept assistance” under SCI impact on life.

Added node (213112119), “What has been most problematic” under SCI impact on life.

Added node (2131121191), “Re-learning ADL skills” under “What has been most problematic?”

Added node (21311316), “Numbness” under “Talk about secondary issues.”

Added node (21311210), “Assistive devices used” under “ADL function.”

Cut and pasted node (21311214), “Ability to drive” to (21311214) under “On trainee’s community participation.” LOG: 9:17 pm, 8/10/03. : Cut from node (2 1 3 1 1 2 1 4) .

Added node (21311317), “Fatigue,” under “Talk about secondary issues.”

Added node (213114), “Treatment talk” under “SCI impact & experience/on trainee.”

Added node (21311318), “Blood clots” under “Talk about secondary issues.”

Added node (21212), “I’m not doing enough” under “Hope for recovery.”

Added node (213112135), “Cane” under “Mobility devices used.”

Deleted node (211141), “Self-esteem” - redundant.

08/12/03

Renamed node (21113), “Response to progress” to “Response to LT progress.” Compared coding from this node, with node (2132), “Progress and Recovery Indicators,” and determined I was seeing two types of data – data that reflected response to progress as a result of LT, and trainee descriptions of recovery or progress independent of LT. To capture the latter, I identified a new node, “Progress talk” (21323) under node (2132), “Progress and Recovery Indicators.” Then cut and pasted node (213231), “Participation landmarks described by trainee” under it. LOG: 1:17 pm, 8/12/03. : Cut from node (2 1 3 2 2) .

Retitled node (21114) from “Walking on treadmill affects sense of self” to “First time on the treadmill experiences” and deleted nodes beneath – body image, and positive & negative experiences. Decided a broader context was more useful for discussing this data.

Cut node (2131113), “Family and support indicators” and pasted under node (2131), “iSCI Impact and experience” – now node (21315). Location is more indicative of the fact that such indicators are not identified as such by participant. LOG: 5:08 pm, 8/12/03. : Cut from node (2 1 3 1 1 1 3) .

Added node (21311213), “Rehabilitation or treatment is a priority” under node (2131121), “Personal Perceptions.”

Added node (21213), “Goals for the year” under “Hope for recovery.”

Cut node (21136), “Comparing oneself to others” and pasted under node (2131114), “Coping talk.” New address is (21311142). After reviewing content, the data appeared more consistent with coping strategies, than a direct LT experience. LOG: 7:44 pm, 8/12/03. : Cut from node (2 1 1 3 6) .

Added node (2131121321), “Training needs” under “Crutches.”

Added node (2131121110), “A New awareness” under “iSCI impact on life”.

09/17/03

Added node (2163), “Role Participation” under “Carry over to home/community environment” to reflect how training impacts participation.

Changed definition of node (21321411), “Total time stepping” to read “... session/bout.” Longer bouts also reflect progression and increased endurance.

11/03/03 (Coding K03 Interview)

Added node (125), “2 years” under “Time since injury.”

Added node (165), “Bicycle accident” under “Cause of SCI.

Added node (2111611), “Due to inexperienced trainers” under “Frustration.”

Added node (21214), “Reconciling hope” under “Hope for recovery” to capture this negotiation process as described by K03.

Added node (21311319), “Feeling cold” under “Talk about secondary issues.”

Added node (21563), “Add follow-up sessions” under “What would you change.”

Added node (215311), “Increased Awareness of Walking” under “Knowledge of ambulation/locomotor principles.”

11/04/03 (While coding K04 Interview)

Changed name of node (215311), “Increased Awareness of Walking” to “Analyzing others walking” and moved it to location (211341). When the theme emerged again and I compared data, it was evident that analyzing the way others walked was used as a learning tool. Added node (21134), “Processing walking” under node “Cognitive/perceptual experiences.” Then cut and pasted nodes (211341) – “Analyzing others walking” [LOG: 2:52 pm, 11/4/03. : Cut from node (2 1 5 3 1 1) . LOG: 2:59 pm, 11/4/03. : Cut from node (2 1 1 3 3).] and (211342) – “Use of walking memory” [LOG: 2:59 pm, 11/4/03. : Cut from node (2 1 1 3 5) .] under it.

Added node (21573) “Over ground training” under “What did you find the most difficult?”

11/12/03

Added node (22255) “Cancellations or Absences” under “Activity”.

12/20/03

Added node (21574) “Transportation” under “What did you find the most difficult?”

APPENDIX D PROCESS NOTES

02/12/03 - Reflection on data

In lines 832-845, K02 jokes about his function dilemma - poor trunk and good legs. He compares himself to a peer - male, also 49, with C5 injury who has good trunk control but nothing in his legs - irony. Do other trainees compare themselves to peers? What's the purpose - "you have x and I have y"? Does it help identify/clarify personal strengths and serve to reinforce self-esteem?

02/11/03 - Reflection on data

K02 appeared concerned about the impact of his frustration on the PT team.

K02's comments re: hope sounds like an adaptation process occurred when his expectations were not fulfilled. EX High expectations re: hope for recovery (walking again)..> discrepancy between expectations and performance (limited progress)..> emotional impact of unmet expectations (frustration)..> change in perspective (this is "real life")..> acknowledgement of personal benefit (knowledge, better ambulation, motivation, emotionally stronger)..> continues walking / training at home ..> slow, ongoing recovery promotes more hope (getting more return in legs)..>BUT hope is mediated by realization that progress is slow ..> NEW PERSPECTIVE (take one day at a time and work hard every day to keep in shape in case a cure for SCI is discovered).

02/10/03

For K02, over-ground training was the hardest part of the sessions.

02/08/03 - Reflection on Data

K02 identifies primary impact of SCI has been on finances and inability to find help.

K02 has established a routine to practice walking at home every day. Do other participants do the same thing?

02/07/03 - Reflection on Data

K02 frequently uses and emphasizes the word "yet" when discussing his functional status - an indicator that he still maintains a strong sense of hope for recovery. He believes he will continue to improve, but acknowledges the process is slow.

When discussing his accomplishments and expectations regarding the study, K02 shares that he referred someone to the study. He later talks about a man from the Tampa VA who he believes is coming into the study - he seems excited about it. It's as if K02 is trying to convey his faith in the treatment (i.e. wants to get others involved) even though it did not help him become a functional walker.

Unlike some other participants, when K02 describes his first time on the treadmill, he does not express joy or excitement about being upright and "looking" like he is walking. Instead, he expresses disappointment and frustration about the realization that his balance is poor, he couldn't move his legs correctly, and that others needed to guide his legs. Thus, the first time on the treadmill was not a "normalizing" experience for K02, but rather served to magnify the impact of his disability. K02 does however, express gratitude for the available help.

When asked about the apparent discrepancy between the therapists' observations and his perceptions regarding his performance, K02 attributes it to a "perceptual" problem - "Well I think the feedback I'm getting' up in my head from down below is not (pause) I'm not really perceivin' the way it really is." Is this due to sensory input limitations? I previously thought it may be due to using a reference point of how he use to walk, but when asked what he was comparing his walking to, K02 said he tried to visualize it in his head. However, he then said "Annd (pause) 'course it's ha... it's very difficult. But uh (pause) it just felt like my left side was... I was havin' to work harder on my left side" - which sounds like a sensory-related answer. K02 also confirmed that his walking was different from what it use to be. Perhaps the discrepancy is due to both sensory deficits and a normal walking frame of reference.

03/02/03

Draw diagram comparing K02 and #3, maybe K01 - regarding walking memory, normal walking refence point, proprioceptive differences, discrepancy and outcomes of discrepancy.

NO DATE

Explore the context of humor and when it occurs. For example, to alleviate frustration? Or does unintentional teasing or quips distract from valid issues or questions being raised by the trainee?

05/20/03

Diagram the theme of empowerment; showing relationships among transfer of knowledge between therapist/team and trainee, empowering actions by therapist, etc...

05/30/03 Reflection on data

When discussing going to school, K01 relates even though he's near graduation, he feels he won't be happy doing computer work. Although he would take a computer job if offered, he

says "At this point in my life, the next thing I do I wanna make sure I'm happy doin' it."
Has SCI caused him to reassess his priorities?

05/30/03 Memo for node (21522) /Increased confidence

Confidence refers to self-confidence and "ambulation" confidence. Not exclusively an emotional benefit, data suggests it results from increased knowledge of ambulation (cognitive) and perceived increase in strength. DIAGRAM

05/31/03 Reflection on data; K01 Interview

When asked about emotions experienced during training, K01 discusses his ongoing frustration with his inability to control his left leg. He appears to blame his leg for preventing him with being an "independent walker" at the end of training. It does appear K01 had unmet expectations re: treatment outcomes, but a full-blown adaptation response, as evidenced by K02, is not clearly evident. Why? 1) Maybe K01's expectations weren't as high as K02's. K02 says outright he was hoping for a cure. K01 mentions increased strength and "getting closer to becoming an independent walker" as goals, or 2) Maybe K01 is less inclined to share the full range of hopes, emotions, and disappointments he really experienced, so I am getting a limited picture of his true experience.

K01 is experiencing ongoing frustration over his leg, pain, and uncertainty with how he will feel day to day.

K01 describes his life as "on hold" since the injury regardless of locomotor training. He says locomotor training "... really hasn't changed anything... Ya know, everything's still kinda the same." << COMPARE TO HOLICKY ARTICLE >>

K01 says training gave him confidence that walking is around the corner... more hope for recovery. Just "doesn't know how long the corner is." << COMPARE TO K02'S RESPONSE >>

06/02/03 Memo for Node (21521 – A sense of altruism)

See what literature on volunteer research subjects has to say about altruism.

06/03/02

Compare node 21122 /Sensory & Proprioceptive experiences with Node (2333) " How did task feel?"

08/12/03

Under node (2121) Hope for Recovery, child nodes "Motivation to improve function" and "Recovery promotes more hope" appear to be common themes to all trainees; a recurring, cyclical relationship.

11/03/03

(Document memo) K03 mentions how his right leg "lags behind" and is not able to incorporate what it is suppose to do – as if legs have a mind of their own. Check for similar data.

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BIOGRAPHICAL SKETCH

Elizabeth “Lisa” M. Hannold, M.S., is a candidate in the rehabilitation science doctoral program the University of Florida College of Public Health and Health Professions (Gainesville, FL). Ms. Hannold received a Master of Science degree in community counseling/counseling psychology from Gannon University (Erie PA) in 1996. A recipient of a 2002-2003 Department of Veterans Affairs (VA) Pre-Doctoral Associated Health Rehabilitation Research Fellowship, Ms. Hannold completed her dissertation study at the Rehabilitation Outcome Research Center (RORC) at the North Florida/South Georgia Veterans Affairs Medical Center (Gainesville, FL). Accomplishments during Ms. Hannold’s doctoral student career include a 2001 Graduate Student Teaching Award from the University of Florida Office of Research and Graduate Studies, presenting at a national life-care planning conference in 2002, and receiving the 2003 John Muthard Research Award from the University of Florida College of Health Professions, Department of Rehabilitation Counseling. Ms. Hannold holds memberships in several professional organizations, and has had articles published in *Paraplegia News* magazine and the *Journal of Applied Rehabilitation Counseling*. As a former independent living center program manager, Ms. Hannold has 12 years of experience meeting the peer support, independent living skills, and rehabilitation-to-community transition needs of consumers with physical disabilities. As a person with a severe neuromuscular disability who has been both a consumer and provider of disability-related services, Ms. Hannold maintains a unique understanding of the rehabilitation and independent living needs of persons with

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