

THE PSYCHOSOCIAL IMPACT OF LOCOMOTOR TRAINING ON CHILDREN WITH
SEVERE, CHRONIC INCOMPLETE SPINAL CORD INJURIES

By

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To John for reminding me my dreams are important too
To Halle, Neeley, and Ben for teaching me more than I will ever be able to teach you
To Mom for encouraging me to always shoot for the stars.

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The Kids STEP Study at the University of Florida and Brooks Rehabilitation is a research study investigating recovery of walking in children with severe, chronic, incomplete, spinal cord injuries utilizing locomotor training as the primary rehabilitation intervention. This qualitative study examined the psychosocial impact this treatment had on the child participants. This study also examined the impact this intervention had on the family as a whole and on the dynamics associated with the therapy team.

The child, one parent for each child and two therapists were interviewed on four occasions throughout a 16 week program. Each interview was recorded and transcribed for analysis. Information on the child was also gained through observations, parental feedback and interactive play. Additionally, observations of the family and therapy team were recorded. Grounded theory methods were utilized to code, categorize and identify predominant themes.

An emerging substantive theory of adaptation to iSCI formed as a result of this study. This study found that locomotor training provided hope to the children and their families to view rehabilitation as a long-term, ongoing process. Locomotor training and the Kids STEP Study provided families a more realistic perspective of the child's

abilities. At the same time they gave these children and families a renewed sense of hope towards the child's ability to regain function. The therapists believe in the potential for walking recovery: that the brain and spinal cord are malleable and able to renegotiate neurologic pathways for recovery of function. This mentality goes beyond adapting to the functional loss after injury and illuminates the potential for recovery of function, well after initial diagnosis.

With this emerging theory of adaptation to iSCI following participation in locomotor training, this study can begin to set up the building blocks for a child's rehabilitation outcome; physically, emotionally and psychologically. As rehabilitation science progresses newer forms of treatment challenge traditional notions of recovery. There is a need for newer models of adaptation for children with disabilities that reflect that changing dynamic. The current study is a spring board for future research that could lead to a more formal theory of adaptation to pediatric disabilities.

CHAPTER 1 INTRODUCTION

Overview of the Research Topic

“You know if I could walk I would be normal.” (KSS5, age six)

These were the first words I heard from a six-year-old boy I worked with at the Kids STEP Study. The Kids STEP Study (KSS) at the University of Florida and Brooks Rehabilitation is a rehabilitation research program investigating recovery of walking in children with severe, chronic, incomplete spinal cord injuries (iSCI) utilizing locomotor training as the primary rehabilitation intervention. I met KSS5 on his first day of his program. Dressed as a pirate, I was ready to take him on an adventure through the hospital during orientation. I attempted to engage him the first 20 minutes of the orientation, but he only shyly smiled and nodded to all that I had to say. We arrived down at the lab to see the equipment and meet the team. As one of the physical therapists reviewed the program with his parents, I continued to chat with KSS5. On a therapy mat, he leaned toward me and with one finger, motioning me closer. As I leaned in he whispered those first words to me, “You know if I could walk I would be normal.” So much was said in his first words to me—his words showed a sense of inadequacy and dissatisfaction, a hope to be “normal,” and a true desire to walk like everyone else.

Background on SCI

KSS5 is just one of the 259,000 spinal cord injury (SCI) cases in the United States (NSCISC, 2009). The National Spinal Cord Injury Statistical Center (NSCISC) reports that there are an estimated 12,000 new SCI cases reported annually (2009), with at least 10 % of those being pediatric SCIs (Vitale, Goss, Matsumoto, & Roye, 2006). The

NSCISC (2009) further reports an increase in the number incomplete spinal cord injuries (iSCI). An iSCI is defined as an individual having at least some evidence of motor or sensory function below the level of lesion (NSCISC, 2009; Molnar & Alexander, 1999). People with iSCI have a markedly greater potential for post-injury recovery than individuals with complete injuries (NSCISC, 2009; Hannold, 2004).

Traditional Rehabilitation vs. Non-Traditional Rehabilitation

Conventional rehabilitation for patients with iSCI has been based on the level of injury and functional score on the American Spinal Injury Association (ASIA) Impairment Scale (Molnar & Alexander, 1999). The ASIA scale assesses the motor and sensory function of a patient post-SCI. Based on this assessment, a neurologic level is assigned (Molnar & Alexander, 1999). Traditionally, rehabilitation focuses on strengthening the muscles above the level of injury and compensating for the functional loss below the level of injury to achieve maximum functional ability (Behrman & Harkema, 2000; Molnar & Alexander, 1999). Some compensatory strategies include: braces, walkers, manual and power wheelchairs and various orthotic devices based on the extent of injury (Vogel, Mendoza, Schottler, Chlan, & Anderson, 2007; Behrman, Bowden, Nair, 2006; Zidek & Srinivasan, 2003; Behrman & Harkema, 2000; Molnar & Alexander, 1999). A conventional approach towards rehabilitation is based on the assumption that recovery and repair of the spinal cord is not possible and compensation for functional loss is the method of treatment to restore mobility (Behrman et al., 2006; Behrman & Harkema, 2000).

Paradigm Shift

More current research indicates that the nervous system does have the capability to recover and repair itself after injury – the brain and spinal cord are plastic and

malleable and neurons can reorganize themselves after the injury (Harkema, 2008; Behrman et al., 2006; Edgerton, Tillakaratne, Bigbee, de Leon, & Roy, 2004; Barbeau, 2003; Barbeau & Rossignol, 1991). This research indicates that significant gains in recovery of ambulation can be achieved post-iSCI (Behrman, Nair, Bowden, Dauser, Herget, Martin, Phadke, Reier, Senesac, Thompson, & Howland, 2008; Behrman & Harkema, 2000; Dietz, Colombo, Jensen, & Baumgartner, 1995; Stewart, Barbeau, & Gauthier, 1991).

As research continues to progress in the area of functional recovery following iSCI, one of the more promising therapeutic interventions for patients is locomotor training (LT) (Behrman et al., 2008; Prosser, 2007; Hicks, Adams, Ginis, Giangregorio, Latimer, Phillips, & McCartney, 2005; Barbeau, 2003; Barbeau & Fung, 2001; Behrman & Harkema, 2000; Field-Fote, 2000). In these terms, functional recovery at the neuronal level is defined as restoring function in the neural tissue that was damaged or lost after injury (Levin, Kleim, & Wolf, 2009). Levin and colleagues go on to explain recovery of function at the performance level is “restoring the ability to perform a movement in the same manner as it was performed before injury” (p. 4). These definitions of recovery of function rather than compensation to functional loss is a focus in LT. LT is based on the concept of neuroplasticity, the central nervous system’s ability to reorganize itself as a result of activity and experiences (Behrman & Harkema, 2007; Edgerton et al., 2004; Barbeau, 2003). LT essentially promotes walking recovery in an individual with iSCI by providing opportunities for repetition in stepping. LT research began with animal models (Rossignol & Bouyer, 2004; Harkema, 2001; Howland, Bregman, Tessler, & Goldberger, 1995; Barbeau & Rossignol, 1987; Lovely, Gregor, Roy, & Edgerton, 1986)

which then led to many human adult studies (Behrman et al., 2006; Effing, van Meeteren, van Asbeck, & Prevo, 2006; Edgerton et al., 2004; Barbeau, & Fung, 2001; Barbeau, Danakas, & Arsenault, 1993).

Kids STEP Study

There is limited research on LT targeting children with iSCI (Behrman et al., 2008; Prosser, 2007). The University of Florida's KSS is one of the few LT research programs promoting walking recovery among children with severe, chronic iSCI.

The primary aims of the KSS are: to determine if walking can be restored in children with iSCI and little to no leg movement and to identify the neural pathways that permit recovery of walking (KSS, 2008). The KSS promotes walking recovery with body-weight-supported stepping on a treadmill and/or over ground walking. The KSS looked beyond the traditional methods of rehabilitation, trying alternative treatments to determine if walking recovery is an option for children with iSCI.



Figure 1-1 - KSS2 suspended in a body weight supported system while participating in locomotor training with the Kids STEP Study team at the University of Florida (staff photo)

With this ground-breaking shift in the physical rehabilitation of pediatric iSCI patients, there may be a shift in how the patients and families are affected by this therapeutic intervention. The KSS offers an opportunity to investigate the psychosocial as well as physical aspects of walking recovery in children who were once told walking was not an option.

The World Health Organization’s International Classification of Functioning and Health (ICF) provides an ideal framework to demonstrate the need for the current study (WHO, 2001). Figure 1-2 illustrates the interconnectedness between the physical rehabilitation of a patient and the psychosocial factors contributing to the overall rehabilitation process (WHO, 2001; Schneidert, Hurst, Miller, & Ustun, 2003; van der Ploeg, van der Beek, van der Woude, & van Mechlen, 2004; Elfstrom, Ryden, Kreuter, Taft, & Sullivan, 2005).

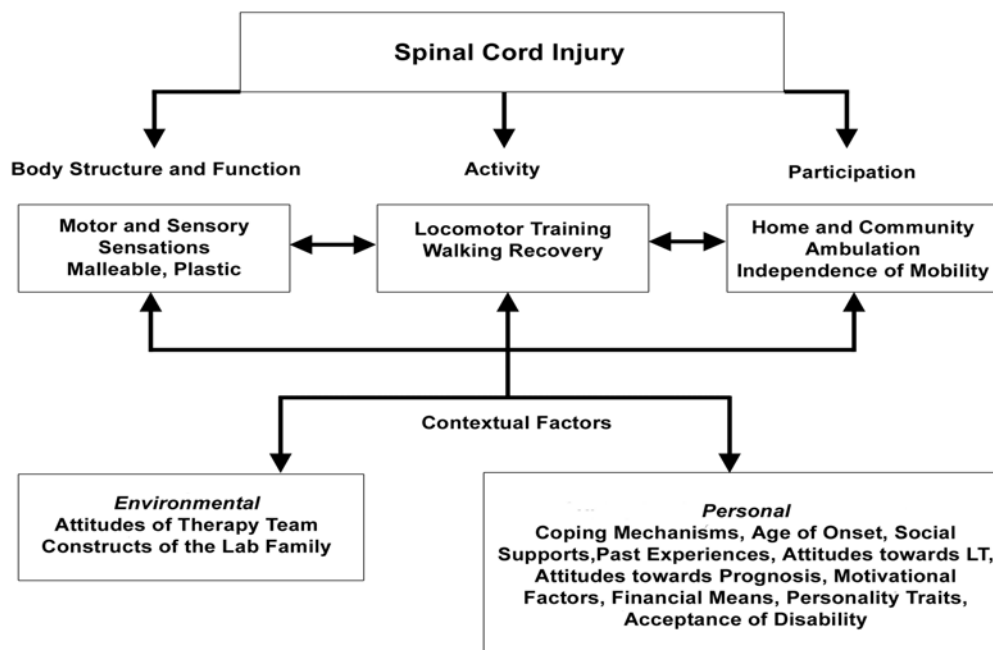


Figure 1-2 - The ICF model as it relates to locomotor training as a therapeutic intervention for patients with severe, chronic, iSCI

Essentially, new therapeutic interventions are changing the concept of recovery for children with severe, chronic, iSCI based on the concept of neuroplasticity. With this shift in the physical rehabilitation of these children, there is likely to be a shift in the psychosocial factors related to the rehabilitation process.

Within the adult population, the physical benefits of LT have been reported at length. The physical benefits include: walking recovery or improved walking (Behrman & Harkema, 2007; Behrman et al., 2005; Hicks et al., 2005; Edgerton et al., 2004; Protas Holmes, Qureshy, Johnson, & Lee, 2001; Harkema, 2001; Behrman & Harkema, 2000; Barbeau et al., 1993; Wernig & Muller, 1992), transition to over ground walking (Behrman et al., 2008; Hicks et al., 2005; Behrman & Harkema, 2000), improved cardiovascular system (Hicks et al., 2005), and muscle strength in lower extremity (Behrman & Harkema, 2007). While the physical benefits are well documented in the literature, literature on the psychosocial benefits is more limited (Hannold, 2004; Nymark, DeForge, Barbeau, Badour, Bercovitch, Thomas, Goudreau, & MacDonald, 1998). Specifically, two studies addressed the psychosocial impact on adults participating in LT as a therapeutic intervention. Nymark and colleagues (1998) investigated the patient's perspective on this form of therapy through a questionnaire and interview process. Patients found the training to be both physically and emotionally challenging, and it increased their hope and confidence (Nymark et al., 1998). However, the Nymark study cautioned that the training could give unrealistic expectations to the participants regarding their walking recovery prognosis (1998).

Qualitative Research on Non-Traditional Rehabilitation

A more recent study (Hannold, 2004) provides a more thorough qualitative analysis of the effects of LT on adult participants. The author found patients had an

increased sense of body awareness, improved self-confidence, and improved quality of life overall. Hannold went beyond providing preliminary findings on the impact of LT on participants and ultimately formed a new theory of adaptation to iSCI after participation in this therapeutic intervention. Within this theory, LT as a therapeutic process impacts the participant through three experiences; physical, emotional, and cognitive. These experiences coupled with the training itself alter the perception the participant has of their iSCI as compared to their perceptions prior to participation (Hannold, 2004). Hannold found that patients actually developed a more realistic perspective of their walking ability after participating in locomotor training.

LT shows great promise for improving all aspects of the lives of individuals with iSCI. Research continues to focus on the physical and psychosocial effects of LT on individuals. Currently, however, there are no reported qualitative studies on the psychosocial impact LT has on non-ambulatory children with iSCI. This present study fills that gap by examining those psychosocial factors impacting the children, the families and the therapy team associated with the KSS.

Specific Aims

The Aim of the Present Study: To Examine the Psychosocial Impact the Concept of Walking Recovery has on Children with Severe, Chronic Incomplete Spinal Cord Injuries Participating in Locomotor Training Research

Research Questions

1. What psychosocial factors face children and parents who participate in locomotor training at the Kids STEP Study?
2. What is the role of the primary caregiver in the rehabilitation process?
3. What is the role of the child in the rehabilitation process?
4. What is the role of the Physical Therapist/Trainer in the rehabilitation process?

5. From the patient's (and families) perspective, what are the perceived benefits of this form of rehabilitation?
6. What impact does this new concept of "walking recovery" have on the child and family participating in the locomotor training rehabilitation research program?

Procedures Used

This qualitative study consisted of in-depth inquiries with the participants of the KSS in order to grasp a better understanding of the psychosocial impact LT has on these children and their families. Specifically, my research involved interviews and observations with each child participating in the LT, interviews with at least one parent of that child and interviews with two of the therapists in the KSS. A convenience sample was utilized as this study recruited participants already participating in the KSS at the University of Florida. These participants were selected because they all have experiences associated with similar phenomena: having participated in or been involved in the walking recovery research of children with an iSCI.

Interviews

Interviews were requested of each participant on four occasions: during the first week of training; approximately midway through the program; during the last week of training; and one month after completion of the LT program. Semi-structured interviews were conducted with each participant and each of these interviews consisted of open-ended questions that followed a pilot-tested, IRB approved interview guide (see appendices A, B and C). These interviews lasted approximately 30 to 60 minutes and were recorded and transcribed for analysis. This researcher conducted all interviews to maintain consistency throughout the research process.

Observations and Field Notes

This study also included observations of the child, the family and the therapy team during LT and outside the lab. Field notes were recorded in a journal during or immediately following the observations.

Observations were made to identify: participants' feelings and attitudes toward the LT, participants' attitudes towards their current life situation, the structure of lab and the atmosphere created by the therapy team, interactions between team members, interactions between the therapy team and the child and family, and any information associated with these particular phenomena.

Participant Recruitment

Before the participants were recruited, this study obtained University of Florida Internal Review Board (IRB-01) approval. Individuals for this study were recruited from the already established KSS. Each person was informed that participation or non-participation in this study would have no impact on his or her participation in the KSS. Once identified, the participants were provided written informed consent forms and these participants were able to discuss the informed consent process with me and an opportunity to ask questions was provided. Adult participants were asked to sign consent and child participants were asked to sign assent to participate. Each participant received a signed copy of his or her consent form.

In order to maintain the confidentiality of these participants, names were removed from all documentation and each participant was coded with a letter/number combination. All data related to each participant was secured. Electronic files were stored on a two-password-protected computer and all paper documents were stored in a locked file cabinet.

Data Analysis

Grounded theory methods were utilized to analyze the interviews and observations of each participant, and to generate new theories of adaptation to iSCI as influenced by this new form of rehabilitation. Grounded theory is an inductive process, the primary goal of which is to generate new theory regarding a particular phenomenon (Patton, 2002; Glaser & Strauss, 1967). Interviews and observations of the children, parents, and therapists were the primary sources for information for this study. From these sources, themes were identified, categorized and coded. A computer tool for sorting this data, NVIVO 8, was utilized to organize the data for analysis. Specifically, NVIVO 8 imports, sorts and analyzes audio files, videos, photos, and word documents. The software further provides graphic displays of project results using models and charts – ideal for qualitative inquiries.

Theoretical Framework

As this is an exploratory study, I used the Glaser and Strauss ground theory (1967) method of qualitative research. As previously mentioned, grounded theory advocates for the generation of theory through the constant comparison of data under study (Glesne, 1998; Glaser & Strauss, 1967). Therefore, this study sought to generate a substantive theory of adaptation to iSCI for children considered non-ambulatory.

This study utilized a model on disability and health to structure and guide the research objectives. The International Classification of Functioning, Disability and Health (ICF) model aided in: generating interview questions; identifying the psychosocial factors that may influence children with disabilities; and providing perspective for the achievement of adaptation to disability.

Personal Perspective

In qualitative research, the researcher's background, experiences and level of involvement in the study all contribute to the overall qualitative inquiry process (Patton, 2002). The very nature of qualitative inquiry is "going into the field" – getting close to the people and circumstances associated with a particular area of interest to capture the essence of the lived experience (Patton, 2002). In doing this, there is a direct interaction between the researcher and the subjects of the study. In order to maintain objectivity/confirmability in qualitative research, it is important for the researcher to be explicit and "as self-aware as possible about personal assumptions, values and biases, (and) affective states" and how they may play a role in the study itself (Miles & Hubberman, 278, 1994).

Qualitative Stance

My personal, qualitative perspective is that of Constructionism. Social Constructionism emphasizes the hold culture has on us as individuals and in turn culture affects the way we see and feel things (Patton, 2002). Essentially, each individual's culture gives him or her a unique view of the world. I agree that reality is socially constructed and that we are all influenced by the world we live in. In this study, each person has a different set of experiences and perceptions, each resulting in a different view of the study itself. Through the Social Constructive perspective, it is beneficial to capture each of the different views of a common experience. This perspective informs my methodological choices including; in-depth interviews, case studies, life history and narratives. No one individual's perceptions are valued higher than another; rather, it is the combination of these various "realities" that provide a wealth of information to my study. In this study, I see each child, parent, and therapist

as providing a wealth of information, each offering a different set of characteristics and a unique perspective on the rehabilitation experiences. Each of these individuals has provided a valuable set of data that in turn provides a more detailed look at rehabilitation research that focuses on walking recovery among children with iSCI. Examining these varying sets of I hoped I could provide both breadth and depth to the understanding of the same lived experience.

Role as Rehabilitation Counseling Intern

One method of collecting information on those lived experiences is through observation (Patton, 2002). Patton explains participant observation permits the evaluation researcher to understand a program or treatment to an extent not entirely possible using only insights of others obtained through interviews (22-23).

As part of this study, I became involved as a Rehabilitation Counseling Intern with the KSS. My role in the KSS was: to assist the project coordinator in material development for the program, to be a liaison with the families prior to and during their four month stay in Gainesville, to develop and facilitate the orientation for each incoming child and to assist with any additional needs the child or family might have during their stay. As a participant observer in the KSS, I was able to understand more clearly the experiences of the LT for the child, the parents and the therapists. This also allowed me not only to form a relationship with the child and the family, but also to build a rapport with the therapy team and participate in the training itself.

Personal Perspective

As a qualitative researcher, I feel it is important to provide some detail as to my own life experiences and how my personal perspective may have shaped and molded this study. I am not only a researcher, but also the mother of three children. Two of my

children have primary immune deficiency and have chronic medical issues. In addition, one of the two was born with a rare chromosome deletion that also presents her with learning difficulties and social biases from others. It is as a parent of children with disabilities that I came to be enrolled in a Ph.D. program in Rehabilitation Sciences. As a mother who has seen her children struggle and suffer, I want there to be additional purpose and positive outcomes to arise from my family's own experiences. I have found purpose in working with children with disabilities and their families. Because of my own personal experience, I tend to appreciate and connect with these families in a unique way. In turn, I believe many of the family members too have connected to and opened up to me more fully than they otherwise might have with another researcher without this parental perspective.

Potential Contribution to Rehabilitation Theory and Practice

The Hannold (2004) study was the first research that documented extensive findings on the patient's perspective of the impact LT had on adults with iSCIs. No research to date has examined the psychosocial impact this intervention has on non-ambulatory children. Walking recovery research targeting children with severe, chronic iSCI provides a new dynamic to rehabilitation for those children and their families who were once told the child would never walk again. The idea of "hope" in a form of rehabilitation that was not previously possible for these children opens a whole new world of influences impacting their attitudes and behaviors toward their disability and the rehabilitation process.

Through the combination of studying the child, the family and the therapy team, this study provides further insight into the dynamic rehabilitation of children once considered non-ambulatory. The goal of this study is to more closely examine walking

recovery research on non-ambulatory children in order to move toward providing the best rehabilitation experience for these children and their families.

The findings of this research could help rehabilitation professionals to better serve their patients with LT as a form of rehabilitation. This study also looked at the role each individual plays in this rehabilitation process and the perceived benefits and/or limitations of the training program. Further, the impact on the future hopes and aspirations of all those involved has been examined to again give an overall picture of the rehabilitation experience for the participants and their families.

CHAPTER 2 LITERATURE REVIEW

Background on Spinal Cord Injuries

The purpose of this study is to determine the psychosocial impact “walking recovery” research has on the child participants and their families participating in the Kids STEP Study. This chapter will review the relevant literature that provided the background for this research.

Pediatric Spinal Cord Injuries

The NSCISC reports approximately 259,000 individuals in the United States are living with SCIs (2009). Each year there are an estimated 12,000 newly reported SCI cases in the United States (NSCISC, 2009). Of the newly reported cases, approximately, 1,455 are children (Vitale et al., 2006). That is more than 10% of the total SCI population being admitted to U.S. hospitals each year for treatment are under the age of 18 (Vitale et al., 2006).

Of those 1,455 newly-reported pediatric patients, twice as many boys with SCI are reported than girls (DeVivo & Vogel, 2004; Vitale et al., 2006). For children aged 5 and younger, however, there is an equal number of girls and boys acquiring SCI (DiVivo & Vogel, 2004). The male population’s injuries increase with age.

Table 2-1 (DiVivo & Vogel, 2004) highlights the various etiologies for SCIs based on age and gender. Motor vehicle accidents are the primary cause of SCIs across all the age spans, yet the percentage of cases decreases as age increases. Of those children reported to have acquired their injuries in a motor vehicle accident, approximately 67% were not wearing seatbelts (Vitale et al., 2006). Vitale and colleagues (2006) further explain the percentage of injuries caused by violence and

sports peaks in adolescence, while the percentage of injuries caused by medical surgical complications is greatest in the youngest of children (aged 5 and younger).

Table 2-1. Characteristics of each age group
Age (years)

	0-5	6-12	13-15	16-21	22+
Male %	50.7	58.2	69.2	83.1	80.5
Etiology (%)					
Motor vehicle	65.2	51.7	40.7	49.1	44.3
Violence	8.7	21.6	18.9	21.6	15.8
Sports	0.2	10.6	28.2	18.3	7.6
Falls	6.5	6.5	7.9	8.1	24.1
Medical Surgical Complications	11.6	4.9	2.8	0.6	3.1
Other	7.7	4.7	1.5	2.2	5.1

Injury Level (%)					
C1-C4	11.7	15.8	18.1	15.7	20.7
C5-C8	20.2	18.2	36.1	35.9	33.2
T1-S5	66.3	64.2	43.9	46.9	44.7
Normal	1.7	1.7	1.9	1.5	1.4

Injury Extent (%)					
Complete	67.9	62.1	54.9	56.3	47.3
Incomplete	30.4	36.2	43.2	42.2	51.3
Normal	1.7	1.7	1.9	1.5	1.4

(DeVivo & Vogel, 2004)

The NSCISC reports that the incidence of incomplete spinal cord injuries (iSCI) is on the rise (2009). A SCI is classified as incomplete when there is evidence of any motor or sensory function more than three segments below the level of injury (NSCISC, 2009). Among children, about two-thirds of cases are reported as complete injuries in the youngest age category (67.9%) and more incomplete injuries are reported as age rises (DeVivo & Vogel, 2004). In addition, cervical injuries are more common in younger children and younger children have greater incidence of spinal cord injury

without radiographic abnormality (SCIWORA) (Osenbach & Arnold, 1991; DeVivo & Vogel, 2004).

Life Expectancy

As science and medicine improve, the life expectancy for individuals with SCIs continues to rise (NSCISC, 2009). The NSCISC defines life expectancy as “the average remaining years of life for an individual” (2009). However, an individual’s life expectancy varies based on the level of injury and age at the time of injury (NSCISC, 2009). Table 2-2 provides a summary of a recent study that determined the life expectancy post SCI across age spans (Shavelle, DeVivo, Paculdo, Vogel, & Strauss, 2007).

Table 2-2. Life expectancy for males who are 2 or more years post-injury, with nonviolent etiology

Age (y)	General Population	C5 A	C5 A	Paraplegia BC	Paraplegia BC
		Injured age <16 y	Injured age > 16 y	Injured age <16 y	Injured age > 16 y
5	70.1	42.2	--	50.8	--
10	65.2	38.6	--	46.7	--
20	55.5	30.8	34.2	38.2	41.7
30	46.2	23.5	26.5	30.2	33.3
50	28.2	11.9	13.9	16.4	18.8
70	13.1	4.2	5.1	6.4	7.8

(Shavelle et al., S52, 2007)

If individuals survive the first couple years post-injury, their life expectancy improves, yet it is substantially lower than for those individuals without SCIs (Shavelle et al., 2007). Shavelle and colleagues found that children injured at a young age had

lower life expectancies than those who were injured later in life. The study further found that secondary health complications affecting a young growing body seem to impact the long-term health of children with SCI. Children with SCIs present a unique set of characteristics that their adult counterparts may not present, including: scoliosis (as a result of skeletal immaturity), pulmonary complications resulting from scoliosis, hip dislocations or issues related to organ development as children's bodies have not met physical maturity (Shavelle et al., 2007; Vogel, Hickey, Klaas, & Anderson, 2004). These child-specific medical issues may play a role in the life expectancy of these children.

Cost of Spinal Cord Injuries

The immediate and long-term medical care for individuals with SCI can be costly. It has been estimated that the total annual aggregate costs for patients with SCI is \$9.7 billion for adults and children combined (French, Sabharwal, Nelson, Palacios, & Gavin-Dreschnack, 2007). The cost of care for each individual will vary according to the severity of the injury and individual needs of the patient. French and colleagues (2007) estimated the cost of the first year after injury could range from \$218,504 to \$741,425, with reoccurring annual costs ranging from \$27,568 to \$132,807. These staggering expenses place a significant burden on the U.S. health care system (French et al., 2007). Lifetime expenses associated with a SCI for one individual can be millions of dollars, even when that injury occurs late in the life (French et al., 2007; Hannold, 2004). Table 3 breaks down some of those expenses associated with living with a SCI, based on level of injury. A child who acquired his or her SCI at the age of five could have a lifetime (if lived to the age of 47) health care expense total of over \$2.6 million. This is based on a first year cost of \$300,000 and 46 years of estimated costs of \$50,000

annually. The cost for treatment and care of children with spinal cord injuries over their lifetime can be staggering and research on providing the best possible care is warranted in order to lower those expenses and improve the overall quality of life for those individuals.

Table 2-3. The NSCISC lifetime expenses based on level of injury

Severity of Injury	Average Yearly Expenses (in 2008 dollars)		Estimated Lifetime Costs by Age at Injury (discounted at 2%)	
	<u>First Year</u>	<u>Each Subsequent Year</u>	<u>25 years old</u>	<u>50 years old</u>
High Tetraplegia (C1-C4)	\$801,161	\$143,507	\$3,160,137	\$1,860,390
Low Tetraplegia (C5-C8)	\$517,356	\$58,783	\$1,786,836	\$1,131,560
Paraplegia	\$292,740	\$29,789	\$1,055,869	\$720,169
Incomplete Motor Functional at Any Level	\$236,109	\$16,547	\$704,344	\$510,452

(NSCISC, 2009)

Physical Issues Associated with Spinal Cord Issues

As part of the rehabilitation process, children and their families begin to learn how to deal with the secondary medical conditions associated with SCI (Vogel et al., 2004; Molnar & Alexander, 1999). One significant issue impacting SCI patients is neurogenic bladder, the loss of the sensation for fullness and the loss of the ability to initiate urination and completely empty the bladder (Vogel et al., 2004; Vogel & Anderson, 2003; Zidek & Srinivasan, 2003; Molnar & Alexander, 1999). As a result of this issue, children and families learn clean intermittent catheterization (CIC) which offers regular bladder emptying that reduces urinary tract infection and renal complications (Vogel et al., 2004; Vogel & Anderson, 2003). Children can be taught self catheterization beginning as early as 5 to 7 years old, under the supervision of an adult (Vogel et al.,

2004). This is a primary concern for children of all ages, as continence is a social norm and essential for positive self-esteem (Vogel, et.al, 2004).

Vogel and colleagues (2004) further discuss the embarrassment associated with the odor, the sound of rustling undergarments, and the teasing from peers. Establishing proper bladder and bowel control can be one of the most important components for children to move on to independence and build self-confidence (Vogel, et al, 2004; Vogel and Anderson, 2003).

One of the most serious secondary complications associated with SCI is autonomic dysreflexia (AD), often seen in patients with T6 or higher lesions (Khastgir, Drake, & Abrams, 2007; Vogel et al., 2004; Vogel & Anderson, 2003; Zidek & Srinivasan, 2003; Molnar & Alexander, 1999). Essentially, AD is the over activity of the autonomic nervous system, leading to increased blood pressure (Vogel et al., 2004; Zidek & Srinivansan, 2003). AD can be life threatening and can lead to seizure, stroke, or even death (Khastgir et al., 2007). Younger children have more limited cognitive and verbal communication abilities; therefore, symptoms of AD can be difficult to identify and treat (Vogel & Anderson, 2003). Parents, teachers and all those that work with the child must know the causes, symptoms and treatment of AD (Vogel & Anderson, 2003).

The literature indicates children with SCI are at risk for the same secondary medical conditions as those individuals with adult onset; however, approach to treatment of those conditions can be different (Shavelle et al., 2007; Vogel et al., 2004; Vogel & Anderson, 2003; Molnar & Alexander, 1999). Children also face complications unique to their immature bodies (Shavelle et al., 2007). One unique complication that affects the majority of children who have acquired their SCI prior to skeletal maturity

(approximately 11-13 years of age) is scoliosis, or curvature of the spine (Shavelle et al., 2007; Zidek & Srinivansan, 2003). Approximately two-thirds of the children with scoliosis at a young age have severe cases that will require surgery (Shavelle et al., 2007; Zidek & Srinivansan, 2003; Dearolf, Betz, Vogel, Levin, Clancy, & Steel, 1990). Another characteristic of pediatric SCI patients can be pulmonary issues, as children may have more restrictive lung disease as a result of scoliosis (Shavelle et al., 2007, Vogel et al., 2004). These children can be at greater risk for respiratory infections and recurrent infections can affect their lung development as their bodies grow and mature throughout their lifespan (Shavelle et al., 2007).

Another complication unique to pediatric SCI is hip dislocation, especially for children initially injured under the age of ten (Shavelle et al., 2007; Vogel et al., 2004; Vogel & Anderson, 2003). Shavelle and colleagues noted that hip dislocation can result in uneven sitting that may increase the occurrence of pressure ulcers among these children with SCI. Shavelle and colleagues (2007) further indicated there may be unknown effects of a SCI on young children that are not yet evident in the literature. These could include metabolic effects or issues related to organ development (kidneys or lungs that may have infections that limit growth).

In sum, a child's immature system can present a number of challenging complications when facing a SCI. These complications, if not treated properly, can lead to long-term health risks and expenses. Continued research into these unique medical complications associated with pediatric SCI is critical. Further, researching techniques to better treat and rehabilitate children with SCI is imperative.

As mentioned previously, children with SCI face a number of medical issues, including but not limited to: neurogenic bladder and bowel, pressure ulcers, autonomic dysreflexia, spasticity, pulmonary issues, orthopedic complications, autonomic dysreflexia, and deep venous thrombosis (Shavelle et al., 2007; Vogel et al., 2004; Vogel & Anderson, 2003; Zidek & Srinivansan, 2003; Molnar & Alexander, 1999). Care for these medical issues is important to address with the child and his or her family. With the numerous medical concerns children with iSCI face, it is important to consider the dramatic developmental changes that occur during childhood and the need to educate families regarding these medical issues (Vogel et. al, 2004).

Children with SCI may represent a small percentage of all reported injuries, but these significant cases often require extensive medical treatment and long-term rehabilitation care. As the literature demonstrates (Shavelle et al., 2007, Vitale et al., 2006; Surkin, Gilbert & Harkey, 2000; Rice & Mackenzie, 1989), care for these children can place a significant financial burden on the families and on the U.S. health care system as a whole (French et al., 2007). Therefore, it is important to understand the unique physical, emotional, intellectual, psychological and social issues unique to children with SCI to better address and care for these children over their lifetimes.

Psychosocial Issues of Children with Spinal Cord Injuries

Children with SCI face a number of psychosocial issues that influence the recovery and adaptation to their injury (King, Currie, Bartlett, Gilpin, Willoughby, Tucker, Strachan, & Baxter, 2007; Oladeji, Johnston, Smith, Mulcahey, Betz, & Lauer, 2007; Vogel et al., 2006; Lund, Nordlund, Nygard, Lexell, & Bernspang, 2005; Russell, 2005; Gorski, Slifer, Townsend, Kelly-Suttka, & Amari, 2004; Elfstrom, Ryden, Kreuter, Taft & Sullivan, 2004; & Anderson, 2003, Molnar & Alexander, 1999). Those psychosocial

factors associated with children with SCI are very different than from those faced by their adult counterparts (Vogel et al., 2006; Russell, 2005).

Developmental stage

Children often respond to their injury based on their developmental stage at the time of injury, and their response will change as they grow and develop (Russell, 2005). In working with children with SCI, it is important to assess the developmental stage of the child at the time of onset. It is also important to continue to assess the child's developmental stage as he or she grows and incorporate developmental needs into the therapy goals and daily life activities (Vogel et al., 2006; Russell, 2005; Vogel et al., 2004).

Family influence

In addition to the child's reaction to injury, the entire family experiences life changes with the onset of this disability (King et al., 2007; Russell, 2005; Vogel et al., 2004). The entire family is often traumatized by the child's SCI and it is important for the rehabilitation team to deal with each family member's needs, as they impact the child (King et al. 2007; Russell, 2005). The literature also emphasized that the child's and his or her family's ability to cope during the initial trauma after injury can influence and/or predict how the child and family deal with the child's rehabilitation and adjustment to life after diagnosis (Elfstrom et al., 2004; Steiner, Ryser, Huber, Uebelhart, Aeschlimann, & Stucki, 2002). Russell takes into account the need to assess a family's level of functioning prior to the accident, as this tends to be reflexive of how the child and family cope post-injury (2005).

Attitudes, behaviors and experiences

When working with children with SCI, it is important to consider the child's attitudes, behaviors, motivations, and abilities, along with those of the family, as they will impact the rehabilitation outcomes (King et al., 2007). Other factors contributing to a child's recovery and adjustment after an SCI include: child characteristics (personality/temperament, competence, motivation, problem-solving skills, attitude) (Oladeji et al., 2007; Gorski et al., 2005; Lund et al., 2005); family dynamics (family environment, family adjustment/acceptance of disability, family resources) (Gorski et al., 2005; Lund et al., 2005); ability to handle stress (i.e., coping strategies) (Gorski et al., 2005; Elfstrom et al., 2005) and access to social supports (Gorski et al., 2005; Lund et al., 2005).

Vogel and colleagues (2004) name a few additional psychosocial factors that must be considered in working with children with SCI. These factors include the child's: medical status; developmental and cognitive levels; social/emotional issues; family status; school situation; financial information; medical equipment needs; transportation needs and recreation interests (Vogel et al., 2004).

Navigating the world of disabilities can be quite challenging for any person, and even more challenging for children. Better understanding of these psychosocial influences can help children meet their rehabilitation goals (Vogel et al., 2004). The overall goal for all children and adolescents with a SCI is to return to a sense of "normalcy," or an active lifestyle at home, at school, at play and within the community (Vogel et al., 2004).

In order to return to a new form of "normalcy," children must become active in the rehabilitation process. Once a child's health is stabilized post-SCI, he or she is

transferred to acute rehabilitation. The overall goal of rehabilitation is to help the child and family learn to care for a body that now functions differently, and help the child reintegrate into his or her family, school and community (NSCISC, 2009).

Traditional Rehabilitation

Physical Rehabilitation after Spinal Cord Injury

Traditional rehabilitation after SCI is primarily based on the individual's ASIA Impairment Score (Molnar & Alexander, 1999). The ASIA scale assesses the motor and sensory function of a patient post-SCI and a neurologic level is assigned to the individual based on this assessment (Molnar & Alexander, 1999).

ASIA IMPAIRMENT SCALE

A = Complete: No motor or sensory function is preserved in the sacral segments S4-S5.

B = Incomplete: Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.

C = Incomplete: Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3.

D = Incomplete: Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.

E = Normal: Motor and sensory function is normal.

Figure 2-1. ASIA Impairment Scale

Traditionally, rehabilitation focuses on strengthening the muscles above the level of injury and compensating for the functional loss below the level of injury to achieve maximum rehabilitation outcome (Behrman & Harkema, 2000; Molnar & Alexander, 1999). In considering mobility, conventional strategies used to compensate for functional loss include, but are not limited to: bracing, walkers, manual and power wheelchairs and various orthotic devices (Vogel et. al., 2007; Behrman et.al., 2006; Zidek & Srinivasan, 2003; Behrman & Harkema, 2000; Molnar & Alexander, 1999). In

addition, behavioral strategies are taught to adjust to the change in the body's abilities (Behrman & Harkema, 2000). Traditional rehabilitation is based on the assumption that recovery and repair of the spinal cord is not possible after injury, therefore rehabilitation focuses on the compensation for functional loss rather than the recovery of ability or function (Behrman et. al., 2006; Behrman and Harkema, 2000).

Acute rehabilitation works to maintain independence of the child's body after injury, including management of: bowel and bladder care; skin care to prevent pressure ulcers, pulmonary care and muscle and joint care (NSCISC, 2009). The NSCISC (2009) goes on to indicate the focus of rehabilitation is to help the child and family "adapt to and re-learn" those activities required for re-integration into school and community. This concept of adapting and re-learning highlights the concept of compensation to functional loss as it relates to patients' ability to participate in daily activities with modifications and assistance (Behrman & Harkema, 2000; Molner & Alexander, 1999).

Traditional therapy focuses on making the child as independent as possible post-injury. This includes learning tasks such as: rolling over in bed, chair to bed transfer, floor to chair transfer and other daily tasks that utilize muscles above the level of lesion to compensate for lower extremity loss (Behrman & Harkema, 2007; Molnar & Alexander, 1999). Traditional therapy also utilizes gait training after an iSCI – this includes the use of tilt tables, parallel bars, braces and other assistive devices to achieve an upright standing position and compensate for lower extremity paralysis (Behrman & Harkema, 2007).

Figure 2-2 depicts traditional rehabilitation as it relates to the World Health Organization's (WHO) framework for classifying health and disability: the International Classification of Functioning, Disability and Health (ICF). This model shows the interconnectedness between the hardwired injury to the spinal cord (body structure), the therapeutic intervention of traditional rehabilitation (activity), and the rehabilitation outcome (participation). This model also displays a strong link between these three factors and the psychosocial factors (contextual factors) associated with the individual, the family and the rehabilitation team (WHO, 2007; WHO, 2001).

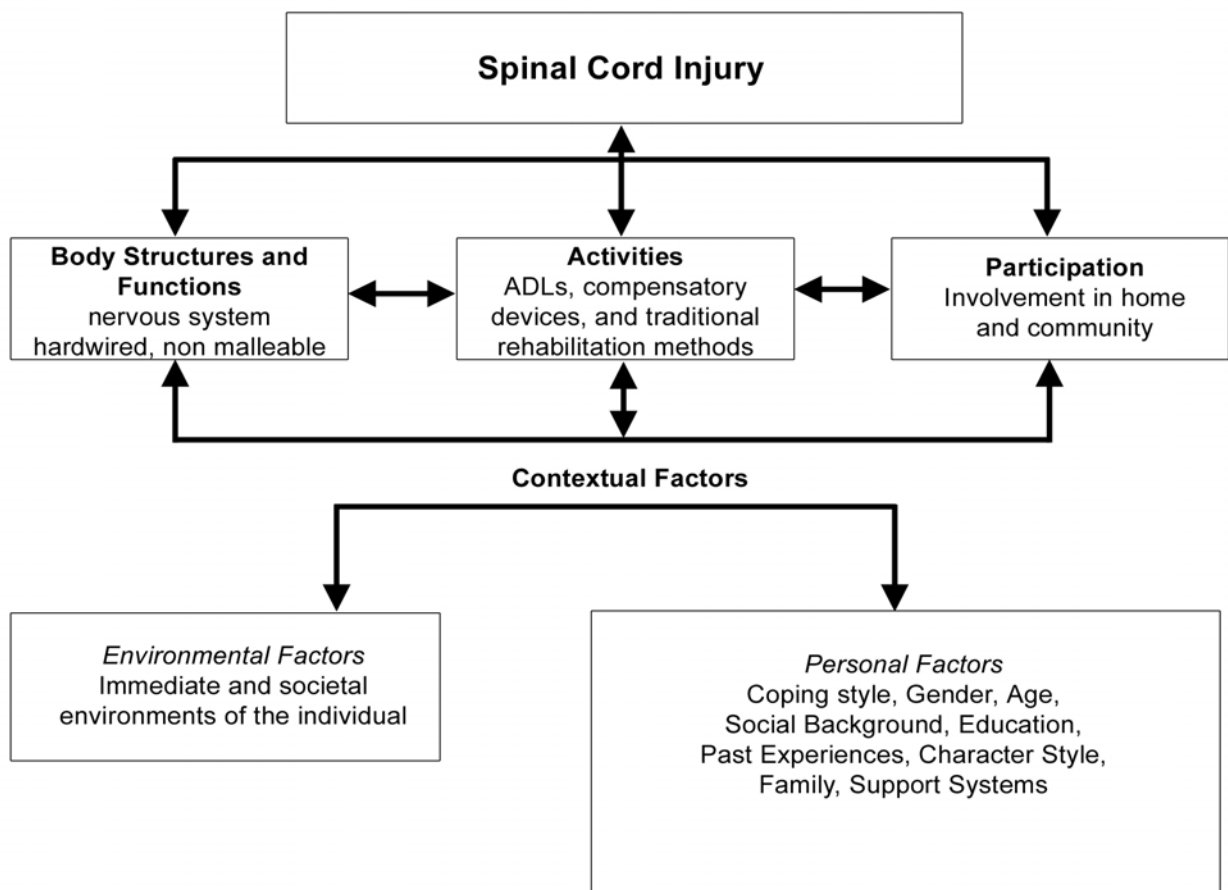


Figure 2-2. The Interconnectedness of the ICF model as it relates to traditional rehabilitation

This biopsychosocial model not only accounts for an individual's structural and functional disability, but also accounts for the complex interaction between the individual and his or her environment (WHO, 2001). One of the benefits of the ICF model is this interrelation of contextual factors with a person's health state: essentially each individual's view of his or her health/disability is unique, based on his or her own life experiences (Schneidert et al., 2003; WHO, 2001). The ICF model shifts the focus of disability from the cause of an illness or injury to:

'life', i.e., how people live with their health conditions and how these can be improved to achieve a productive, fulfilling life. The ICF takes into account the social aspects of disability and provides a mechanism to document the impact of the social and physical environment on a person's functioning. (WHO, 2001)

Within the ICF model, there are "environmental factors" and "personal factors" of the model and these contextual factors have a direct impact on the child's rehabilitation outcomes (WHO, 2001; Schneider et al., 2003; van der Ploeg et al., 2004). These contextual factors include the physical, psychological, social and attitudinal factors associated with the individual child (WHO, 2001). Within this framework, each individual's experiences with his or her disability are uniquely different from how others may respond to the same disability. This can have a dramatic impact on the rehabilitation process. Each person is going to bring in his or her own unique set of traits, attitudes, and behaviors that will in turn affect his overall performance.

Psychosocial Factors Associated with Traditional Rehabilitation

The literature highlights the influence psychosocial factors (contextual factors as depicted in the ICF model) has on the child with iSCI and their rehabilitation outcomes. In fact, the rehabilitation outcomes for the child are impacted not only by his or her own interaction with the rehabilitation experience, but is also impacted by his or her family's

attitudes and expectations towards the process (King et al., 2007; Goldstein, Cohn & Coster, 2004; Simeonsson et al., 2003). King and colleagues (2007) emphasized the importance of taking time to get to know the family and the family's attitude toward the child's rehabilitation as the rehabilitation team develops the child's outcome goals. King's study found that experienced therapists had a greater appreciation for the psychosocial impact a child's disability can have on the entire family, noting families have many external factors associated with the disability, and the whole child must be considered to elicit a greater level participation in the rehabilitation process (2007).

Another psychosocial issue to consider in pediatric rehabilitation post-SCI is the child's inability or limited ability to express information regarding his or her own experience, whether because of his or her age, ability to articulate his or her experience or level of cognitive function (Simeonsson et al., 2003). Professionals must often rely more heavily on interviews and observations with the parent or caregiver (Simeonsson et al., 2003).

In considering rehabilitation, the child's participation level is directly impacted by what he or she feels is important to him or her and what his or her family depicts as important to the child (King et al., 2007). In order to increase the participation level, or rehabilitation outcome of a child with the disability, it is important to practice tasks that are meaningful to child and family (King et al, 2007; Goldstein et al, 2004). The literature also emphasizes the need to consider the environmental context of the child when adopting interventions to elicit participation in rehabilitation (King, 2007; Lawlor, Mihaylov, Welsh, Jarvis, & Colver., 2006; Gorski et al., 2005; Russell, 2005; Goldstein et al., 2004; Simeonsson et al., 2003; Majnemer & Limperopoulos, 2002).

Rehabilitation provides an opportunity for a child to change and an opportunity for a child to increase his or her level of activity and participation. A few key catalysts for that change are: 1) supporting the child and family's therapy goals (King et al., 2007; Lawlor et al., 2006; Goldstein et al., 2004); 2) acknowledging the expertise the family has on providing for the child (King et al., 2007; Goldstein et al., 2004; Majnemer & Limperopoulos, 2002); 3) engaging the child in the therapy – “encourage clients to ‘buy into’ interventions by maximizing their sense of involvement, meaningfulness, and control” (King et al., 234, 2007; Goldstein et al., 2004); 4) working on short-term client-centered goals (King et al., 2007, Majnemer & Limperopoulos, 2002); 5) assessing attitudinal issues related to child's disability and motivation for therapy (Goldstein et al., 2004; Lawlor et al., 2006) and 6) providing the child with an experienced therapy staff in a child-friendly environment (King et al., 2007).

These psychosocial influences can play a role in how an individual adapts to his or her disability (Livneh & Antonak, 1997). Consideration of these psychosocial factors can influence the child's psychosocial adaptation to injury (Theofanidis, 2007; Summers et al., 1989).

Psychosocial Adaptation to Disability in the Adult Population

For this study's purpose, psychosocial adaptation is operational defined 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. (Livneh & Antonak, 8, 1997)

Livneh and Antonak (1997) do not distinguish between the psychosocial adaptation to SCI of the adult and pediatric populations. Rather their research is focused on the adult population. Regardless, their theory of psychosocial adaptation is

one of the leading models within disability sciences (Bishop, 2005; Hannold, 2004, Livneh & Antonak, 1997).

Each individual's response to disability is varied based on several factors associated with their particular circumstances (Smart, 2001). These factors include: time of onset (congenital or acquired); type of onset (acute or insidious); functions impaired; severity of disability (mild, moderate, or severe); visibility of disability; degree, if any, of disfigurement; degree of stigma; course of disability (stable, progressive, episodic); prognosis of disability; and treatment of disability (Smart, 2001).

An individual's reaction to his life situation can lead him through several phases of adaptation in order to achieve adjustment to his disability. Livneh and Antonak (1997) have identified these phases as: shock (psychic numbness); anxiety (confused thinking, over activity); denial (selective attention to facts); depression (mourning of loss); internalized anger (guilt, attribution); externalized hostility (passive-aggressive); acknowledgement (cognitive reorganization); and adjustment (affective and sociobehavioral). These phases are nonexclusive, nonsequential and overlapping (Livneh & Antonak, 1997).

More specifically, as described by Livneh and Antonak (1997) shock is the initial reaction to the sudden onset of a physical injury or psychological trauma. Another phase, anxiety is a "panic stricken reaction" to the diagnosis of a disability that often includes confused thinking, cognitive flooding and mindless overactivity. Individuals with a disability may also experience denial. Denial is classified as a defensive mobilization against a difficult and painful situation (i.e. psychological retreat).

One phase people with disabilities often struggle with is depression. Depression is considered a typical reaction to the initial diagnosis and is often prevalent throughout different aspects of chronic illnesses. Anger is also a phase most people with disabilities experience at some point. Anger can be either internalized or externalized. Internalized anger is often associated with guilt or self-blame as it relates to the injury or illness. Externalized hostility is considered a retaliation against their limitations whether that be geared towards a person, object or environment associated with the diagnosis. Acknowledgement of the disability comes at different points in time for everyone. This is the first sign the person has begun to cognitively recognize the permanency of their disability. Finally, adjustment is considered the final phase of adaptation in which the individual understands his functional limitations and has: reestablished self-worth, discovered potential, considered social and vocational goals; and successfully overcome obstacles associated with their condition. An individual can be in one or more phase at one point in time and it is not necessary to go through each phase to achieve successful adaptation to disability (Livneh & Antonak, 1997).

Coping with disability is the way in which one deals with what life has given him (Livneh & Antonak, 1997; Summers et al., 1989). The literature has identified two primary methods of coping: adaptive (positive, flexible, reality-based) and maladaptive (negative, rigid, emotion-focused) (Livneh & Antonak, 1997; Zeitlin, 1980; Haan, 1977). Appropriate coping strategies have been identified as a key factor in the successful adjustment to a physical disability (Elfstrom et al., 2005; Lazarus & Folkman, 1984).

Psychosocial Adaptation for Adults with SCI

Effective coping strategies are some factors associated with positive adaptation to spinal cord injuries (Livneh & Antonak, 1997). Other factors associated with positive

adaptation to SCI include: younger age, increased time since injury, internal locus of control, and stable and positive social support (Livneh & Antonak, 1997). Depression is one of the more difficult phases of adaptation for adults with SCI. However the nature and severity of this phase has not been fully researched and is often overestimated by rehabilitation staff (Livneh & Antonak, 1997; Cushman & Dijkers, 1990). Adaptation to adult SCI as represented by Livneh and Antonak are measured by 1) degree of life satisfaction, 2) vocational or avocational productivity, 3) prevention of medical complications, 4) use of activities of daily living skills, 5) coping styles, 6) degree of disability acceptance and 7) degree of emotional stress.

An individual's personality attributes (i.e. self-concept, optimism, motivation) and situational conditions (i.e. socioeconomic status, financial resources and social supports) are key predictors of adaptation outcomes (Livneh & Antonak, 1997; Summers et al., 1989).

Psychosocial Adaptation to Pediatric Spinal Cord Injury

While the literature does not identify a leading theory for psychosocial adaptation for children with disabilities, it does identify a number of factors to take into account. In considering a child's ability to adapt to a spinal cord injury in general, it is important to account for the family's ability to cope and adjust to that disability, as the two are strongly linked (King et al., 2007; Elfstrom, 2004, Steiner et al, 2002). The child's ability to face their disability is influenced by various family dynamics: family environment; social support; family adjustment/acceptance of disability; and family resources (Gorski et al., 2005; Lund et al., 2005).

A child's adjustment and progress in rehabilitation is strongly impacted by his family's strengths, weaknesses and emotional reactions (Ziolko, 1991; Power & Dell

Orto, 1980). The parent's perception of the severity of the child's disability may also affect their ability to fully accept and adapt to the injury (Ziolko, 1991; Whaley & Wong, 1982). Acceptance of a child's disability is influenced by the parent's ability to understand the child's limitations and appreciate the child's abilities (Ziolko, 1991; Naidoo, 1984).

The parents, during the stage of adjustment, are able to actively carry out programs to benefit the child. They eventually become adapted to the problem and the family routine may return to normal. The well-adjusted parent is able to understand realistic limitations that the disability places on the child and to treat the child as nearly normal as possible. (Ziolko, 31, 1991)

This assumes parents are willing to adapt to the "problem." This process of adaptation is based on the concept of traditional rehabilitation, one in which the functions impaired are finite and unable to improve after a set period of time, typically a year (Burns & Ditunno, 2001; Ditunno, Cohen and Hauuk, 2000). Again, the final phase of adaptation is one in which the individual understands this permanent functional limitation (Livneh & Antonak, 1997). More current research challenges this concept of permanency.

Non-Traditional Rehabilitation Research

Recent research indicates that the brain and spinal cord have the capability to recover and repair itself after injury – the nervous system is plastic and malleable and neurons can reorganize themselves after the injury (Harkema, 2008; Behrman et al., 2006; Edgerton, Tillakaratne, Bigbee, de Leon, & Roy, 2004; Barbeau, 2003; Barbeau & Rossignol, 1991). This research indicates that significant gains in recovery of ambulation can be achieved post-iSCI (Behrman, Nair, Bowden, Dauser, Herget, Martin, Phadke, Reier, Senesac, Thompson, & Howland, 2008; Behrman & Harkema, 2000; Dietz, Colombo, Jensen, & Baumgartner, 1995; Stewart, Barbeau, & Gauthier,

1991). More recent research challenges the methods utilized in traditional rehabilitation of children with iSCIs.

More specifically, this novel research in the area of rehabilitation post-iSCI has become grounded on the idea of neuroplasticity of the central nervous system (Levin et al., 2009; Harkema, 2008; Behrman & Harkema, 2007, Edgerton et al., 2004; Barbeau, 2003; Harkema, 2001; Barbeau, & Rossignol, 1991). Neuroplasticity is the central nervous system's ability to reorganize itself by forming new neural connections throughout life (Behrman & Harkema, 2007; Edgerton et al., 2004; Barbeau, 2003). Neuroplasticity allows neurons in the brain and spinal cord to compensate for injury or disease and adjust to loss in response to changes in behavioral, sensory and cognitive experiences (Kleim & Jones, 2008). Kleim and Jones (2008) go on to explain neural plasticity is the "mechanism by which the brain encodes experience and learns new behaviors" (S225). It is this neuroplasticity that offers a greater potential for sensory and motor function recovery after iSCI (Edgerton et al., 2004). Rehabilitation research now focuses beyond initial recovery and compensation of adapting to iSCI – it has now begun to test the potential for regeneration and recovery of function years beyond the date of initial injury (Behrman & Harkema, 2007; Edgerton et al, 2004; Harkema, 2001).

Research scientists continue to look for new treatments for iSCI and hope for even a cure. Much of the current rehabilitation research on iSCI patients is based on activity being beneficial for individuals with central nervous system injury (Behrman & Harkema, 2007, Dromerick, Lum, & Hidler, 2006). This concept of activity in rehabilitation is readily acceptable, yet as previously mentioned, most rehabilitation is focused on

compensation not restoration of function (Dromerick et al., 2006; Behrman & Harkema, 2007).

Activity-based therapy (ABT) refers to therapeutic interventions that provide “activation of the neuromuscular system below the level of lesion with the goal of retraining the nervous system to recover a specific motor task” (Behrman & Harkema, 2007, p. 185). ABT is driven by repetitive practice of a specific task to essentially reorganize the nervous system which can lead to improvement or recovery of function (Behrman & Harkema, 2007; Dromerick et al., 2006; Finch & Barbeau, 1985).

Locomotor training, first proposed by Finch and Barbeau (1985), is the most prominent activity-based therapy intervention for patients with iSCI which focuses on the neuroplasticity of the nervous system (Behrman & Harkema, 2007; Behrman et al., 2005; Behrman & Harkema, 2000, Barbeau et al., 1993).

Locomotor Training

Locomotor training (LT) is an activity-based therapy that utilizes a treadmill as the environment to simulate stepping patterns with individuals suspended in a body weight support system and “this physiologically based strategy is believed to trigger and enhance intrinsic plasticity of the spinal cord central pattern generators for locomotion (SPGL)” (Behrman et al., 2008, p.2). Four main principles that guide LT are based on recreating the natural experience of walking through repetition. These principles are: 1) to maximize load bearing by the lower extremities; 2) to optimize sensory cues for walking; 3) to optimize the kinematics (i.e., trunk and extremities) for each motor task; and 4) to maximize recovery strategies and minimize compensation strategies (Behrman & Harkema, 2007). These principles are founded in animal research.

Animal Model

Locomotor training is based on the cat animal models that demonstrated the recovery of hindlimb stepping after complete spinal transaction (Harkema, 2001; Barbeau & Rossignol, 1987; Lovely et al., 1986). In this research, the cat's forequarters are placed on a stationary platform and the hind limbs are placed on a treadmill. The animal is then trained to walk at different speed and bear more weight on its hind limbs (Rossignol & Bouyer, 2004). Rossignol and colleagues report the cats that were transected at T13 all recovered the ability to walk after LT (Rossignol & Bouyer, 2004; Barbeau & Rossignol, 1987). It has been reported that LT was more successful in younger animals, as they show greater locomotor recovery (Howland et al., 1995). The cat model suggests neural pathways are capable of forming a locomotor pattern on their own after injury (Rossignol & Bouyer, 2004).

Locomotor Training as a Therapeutic Intervention in Humans

This form of rehabilitation was first reported by Barbeau and colleagues (1987 & 1993), continues to be adapted by physical therapists in the field of walking recovery research among the adult, human population (Behrman et al., 2006; Barbeau, 2003; Harkema, 2001; Behrman & Harkema, 2000; Dietz et al., 1995; Stewart et al., 1991).

As previously mentioned LT utilizes a treadmill as the environment to simulate stepping patterns that mimics a natural walking gait. Patients are often suspended over a treadmill in a body weight supported harness with overhead support (Harkema, 2001; Behrman & Harkema, 2000; Dietz et al., 1998; Wernig et al., 1992; Stewart et al., 1991). The body weight support system provides a means by which one can offer balance control, manually assist trunk and leg movements during weight bearing stepping and standing bouts on the treadmill (Harkema, 2001). Body weight supported locomotor

training provides the ideal setting to simulate natural ambulation while providing sensory input (Harkema, 2001; Barbeau & Fung, 2001; Behrman Harkema, 2000). Essentially, LT provides an input response to initiate movement from the foot up, rather than input from the brain down. Current research presents evidence that demonstrates the central nervous system is “malleable and can learn,” after a spinal cord injury (Behrman et al., 2006; Barbeau & Fung, 2001; Harkema, 2001). LT is presenting potential opportunities for walking recovery in patients who were expected to accept their disability as permanent and static.

Figure 2-3 highlights this shift in the rehabilitation of individuals with iSCI as it relates to LT as a treatment for potential walking recovery.

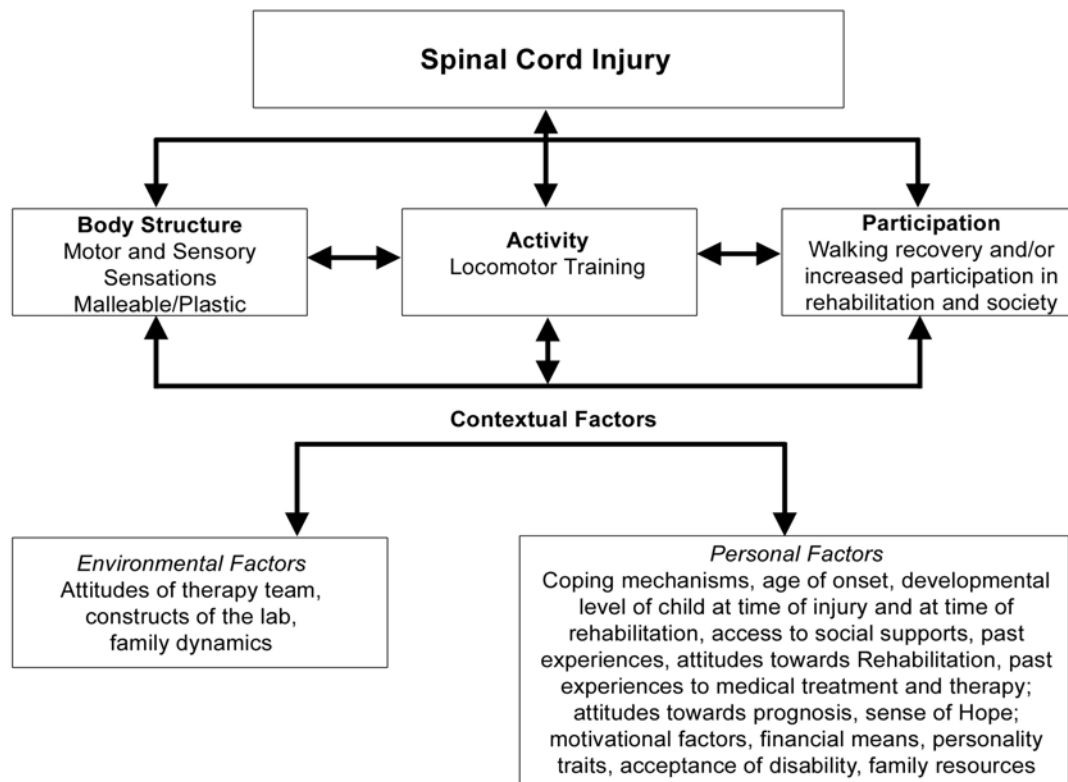


Figure 2-3. The ICF model as it relates to locomotor training: A shift in rehabilitation focus

This ICF model shows a change from its comparison to traditional rehabilitation as it relates to the body structure and function. Recent research indicates there is a potential for the body structure/function to repair itself after injury. With this change in the brain and spinal cord's ability to reorganize itself, the approach to rehabilitation has begun to shift towards recovery of function as it relates to treatment. This opens the door to newer therapeutic interventions that tap into that plasticity. Within Figure 2-3, note the activity or intervention as it relates to the ICF model is LT. The literature shows both physical and psychosocial benefits of this therapeutic intervention.

Adult LT – Physical Benefits

Research has provided strong evidence of the physical benefits of LT for adults with iSCI – those individuals with iSCI regain a higher level of locomotor function than those in conventional therapy (Behrman & Harkema, 2007; Behrman et al., 2005; Hicks et al., 2005; Edgerton et al., 2004; Protas et al, 2001; Harkema, 2001; Behrman & Harkema, 2000; Barbeau et al., 1993; Wernig & Mueller, 1992). Additional physical benefits include improved gait speed during locomotor training, and some patients transmitted this to over ground walking or improved on their over ground walking ability (Behrman & Harkema, 2000; Hicks et al., 2005). Other studies found similar benefits, as Protas and colleagues (2001) found gait speed and gait endurance tripled during training and patients walked faster, farther and more efficiently as a result of this form of rehabilitation. Another benefit of LT is the fact that it induces neuromuscular activation below the level of lesion (Behrman & Harkema, 2007). Behrman and Harkema (2007) identify additional benefits as: strengthening muscles below the level of the lesion; improved ability to stand and/step; improved endurance; improved ability to negotiate obstacles; and increased community ambulation. Another study found benefits beyond

walking recovery including: significant changes in muscle morphology; improved cardiovascular strength; increased muscle fiber areas; improved blood lipid profile and increased glucose tolerance (Hicks et al., 2005).

Such benefits may reduce the incidence of secondary complications such as pressure sores, heart disease and diabetes in people with iSCI, and therefore may decrease the cost associated with recovery after iSCI. LT has also led to improvements in emotional and psychological wellbeing (Hicks et al., 2005; Hannold, 2004; Nymark et al., 1998). These health benefits are crucial to helping people living with paralysis lead healthier lives.

Adult LT- Psychosocial Benefits

The psychological, social and emotional impact this new form of rehabilitation has on individuals participating in the LT has not been a focus of research until recently. In 2005, Hicks and colleagues researched 14 individuals with SCI participating in LT and found an improvement in “subjective well-being” including increases in overall life satisfaction and satisfaction with physical function regardless of any change in functional mobility as a result of the study (p. 297). These results indicate LT provides improvements beyond physical function, but, also has the potential to improve the quality of life for these individuals.

Nymark and colleagues' (1998) reported adult participants in LT found this treatment to be physically and emotionally challenging, and it also led to unrealistic expectations for recovery. A conflicting study on an adult LT program reported participants felt more educated on the impact of LT had on their body (Hannold, 2004). Hannold goes on to explain these participants felt more control over their body, empowering them regardless of the amount of recovery of function. This insight into the

effects LT has on the individual participating in this intervention has the potential for altering the participants' overall adaptation to his or her disability.

Psychosocial Adaptation to iSCI as it relates to Locomotor Training in the Adult Population

Hannold's study took an in-depth look at the effects LT has on the psychosocial adaptation of adults with iSCI (2004). Hannold interviewed six individuals, four of whom had already completed the training and two of whom were currently participating in the training. She conducted a total of 14 interviews with the participant and his or her caregiver. In addition, she conducted several observations of the LT either in person or by video footage (2004). As a result of this study, Hannold found that the LT as a therapeutic process was a process of empowerment for participants and trainers alike.

Therapists who conducted the LT:

promoted empowerment among trainees through their actions in the roles of 'coach,' 'teacher' and 'therapist,' by engaging them (the participants) 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. (Hannold, 2004, p. 177)

Hannold indicates that this positive atmosphere had the potential for positively influencing the psychosocial adaptation to iSCI. Participants in this study identified a number of benefits as a result of the trainers' actions: improved mobility, strength and endurance, social support, knowledge, hope and increased confidence. These results indicate therapists' actions can have a direct impact on the psychosocial adaptation to iSCI. In addition, participants identified benefits of the LT intervention as: 1) functional recovery and/or progress achieved (gait, mobility, body control, balance); 2) knowledge gained about ambulation; 3) sense of hope for further recovery; and 4) perceived social support received from the therapy team. These perceived empowering benefits play a

role in the participant's psychosocial adaptation to his or her injury. Participation in the LT program provided participants with a realistic perspective of recovery with the potential for further recovery as science progresses (Hannold, 2004).

Overall, LT has the potential to improve quality of life for individuals with iSCI (Hannold, 2004). Hannold challenged the Livneh and Antonak's model of adaptation as LT is based on the premise that the participant's injury is not permanent but has the potential for change. This changes the participant's acceptance and psychosocial adaptation to injury. Hannold's study is the first to challenge adaptation to an iSCI after participation in LT (2004). Currently, the literature only addresses the psychosocial impact LT has on the adult population. LT of pediatric iSCI patients is just emerging.

Pediatric Locomotor Training – Kittens Revisited

The literature provides limited studies on pediatric participation in LT. Yet, the literature noted in animal research, it was the younger cats that displayed better locomotor recovery after spinalization (Howland et al., 1995). It is only recently that

research has begun to focus on young human iSCI patients. The animal models indicate there may be more to learn from the neuroplasticity of younger patients (Howland et al., 1995; Behrman et al., 2008).

Within the pediatric population, the literature reports primarily on children with cerebral palsy and with Down syndrome who have participated in LT with partial body weight support (Day, Fox,



Figure 2-4. KSS1/K19 participating in body-weight supported locomotor training (photo by staff photographer)

Lowe, Swales, & Behrman, 2004; Cherng, Liu, Lau, & Hong, 2007; Ulrich, Ulrich, Angulao-Kinzler, & Yun, 2001; Schnidl, et al., 2000). The Day (2004) case study examined a nine-year-old boy diagnosed with spastic tetraplegic cerebral palsy that was unable to support his body weight and had never experienced walking. After participation in LT, the child was able to walk over ground in short distances utilizing a rolling walker and minimal assistance (Day et al., 2004). Other studies found marked improvement in ambulation for children with cerebral palsy and Down syndrome (Cherng et al., 2007; Ulrich et al., 2001; Schnidl et al., 2000).

More limited rehabilitation research is focused on increasing ambulation among pediatric patients with iSCI, using LT (Behrman et al., 2008; Prosser, 2007). Behrman and colleagues (2008) indicate that the current literature does not discuss the difference in the neuroplasticity of the young central nervous system as compared to the adult counterpart, and the implications this may have on rehabilitation strategies.

A recent study by Behrman and colleagues (2008) utilized LT as the method of rehabilitation with a non-ambulatory 4 ½ year old boy with a severe, chronic iSCI. This study found that after 76 sessions of body weight supported LT; the child recovered a reciprocal stepping pattern during walking. In addition, the child's primary means of ambulation both at home and in the community changed from upper-extremity crawling and/or wheelchair propulsion to walking independently with a walker and some wheelchair use (Behrman et al., 2008). This is the first study that reports the recovery of full-time community ambulation with a rolling walker in a child with a severe, chronic, incomplete SCI (Behrman et al., 2008). In addition, this study reports the child was able to later attend kindergarten using a walker full-time. The results of Behrman and

colleagues' study are physically remarkable for this child. Further, the psychosocial impact on this child and his family can be deemed outstanding based on the physician's initial prognosis for the child.

Studies focused on children with iSCI participating in LT is just emerging in the literature (Behrman et al, 2008; Prosser, 2007), with each study showing extraordinary physical gains in the child receiving the treatment. These studies also suggest the importance of further research on LT for children with iSCI. Currently, Behrman and colleagues at the University of Florida and Brooks Rehabilitation have developed the Kids STEP Study, a research rehabilitation program that is offering LT to children with severe, chronic, iSCI.

Kids STEP Study

The Kids STEP Study at the University of Florida and Brooks Rehabilitation is currently investigating recovery of walking in children with chronic, severe, iSCI. The study is funded by the Craig H. Neilsen Foundation, an organization dedicated to spinal cord injury research and recovery. The KSS aims to investigate: 1) the use of locomotor training for restoring ambulation in children with chronic, severe iSCI, and 2) the neural substrates underlying walking function, specifically the descending systems from supraspinal motor areas below the cortex (midbrain and/or medulla).

Eligibility criteria for the KSS include: 1) pre-adolescent children, age 3-13 years old; 2) diagnosed with an incomplete SCI of the cervical or thoracic spinal cord; who are 3) unable to walk or have impaired walking for more than one year (Kids STEP Study, 2008). This study utilizes LT as an activity-based therapy to promote plasticity and recovery after iSCI. As part of the program, children participate in extensive testing and 60 sessions of LT over a 12 week period (5 days/week). In addition to the LT, the

children will practice the task of walking in over-ground environments as they work closely with therapists, researchers and trainers (Kids STEP Study, 2008). As this rehabilitation program is just in the research phase, the full impact LT has on the participating child and his family has not been fully examined.

Pediatric LT - Psychosocial Research

Limited information has been reported on the impact LT can have on the psychosocial factors of children participating in this form of rehabilitation. Day and colleagues (2004) identify some subjective findings in their case study of a child with cerebral palsy participating in LT. Therapists noted that the child's motivation toward traditional therapy after participation in LT became more positive and attention and ability to work on difficult tasks improved (Day et al., 2004).

However, the psychosocial challenges associated with children with iSCI are very different from those of children with different disabilities or of their adult counterparts. With the shift in the approach to rehabilitation for children with severe, chronic iSCI, it would seem likely there would be a shift in the psychosocial adaptation that influences the rehabilitation of those children. The current literature lacks a full examination of the psychosocial influences associated with children with iSCI and their families participating in LT as it is a new form of therapy for children who were previously considered non-ambulatory.

Psychosocial Adaptation to Pediatric iSCI Pediatric after Participation in LT

As previously discussed, the literature is rich in discussion on the psychosocial factors impacting children with iSCI as it relates to traditional rehabilitation. Again, traditional rehabilitation is guided on the concept that recovery of function was unattainable (Behrman & Harkema, 2007; Harkema, 2001; Alexander & Molnar, 1999).

Recent rehabilitation research has shifted the focus from the adaptation to functional loss in iSCI patients to the recovery of function, to pre-morbid movement patterns, after injury (Levin, Kleim, & Wolf, 2009; Behrman & Harkema, 2007; Barbeau 2003; Harkema, 2001). The literature has supported a new theory of psychosocial adaptation for iSCI patients participating in LT among the adult population, yet there are no current studies relevant to children participating in this form of therapy.

Further, Livneh and Antonak's theory of adaptation has focused on adults with disability and the adult's ability to adjust to and cope to SCI. Livneh and Antonak's theory does not specifically represent the adaptation process of children with disabilities.

Future research in this area is warranted on both the long term health benefits and the psychosocial benefits associated with LT among children with severe, chronic iSCI. Qualitative inquires are one means by which researchers can better understand this particular intervention and the impact this form of rehabilitation has on children with iSCI.

Qualitative Research

Qualitative studies can provide a valuable contribution to rehabilitation research in: 1) giving value to subjective realities (Hanley-Maxwell, Hano, & Skivington, 2007; Hannold, 2004); generating or modifying theory (Hanley-Maxwell et al., 2007; Hannold, 2004; Patton, 2002, Glaser & Strauss, 1967); and offering a way to more fully understand the lives of the people being researched (Hanley-Maxwell et al., 2007; Hannold, 2004). Hanley-Maxwell (2007) and colleagues further explain that the process of actively interviewing the participants of an intervention not only provides a better understanding of the lives of the people with the disability but it also involves the people

being researched in the research process. As the Hannold (2004) study noted that patients responded favorably to be engaged in the therapeutic process.

Qualitative research provides a powerful means to examine a new phenomenon (Patton, 2002). This examination allows for the development of grounded theory, an inductive process of gathering information on the topic to be studied through researcher interviews and observations in the natural setting of the particular phenomena (Hanley-Maxwell et al., 2007; Patton, 2002; Glaser & Straus, 1967). Qualitative studies provide a perspective into rehabilitation research that may not be drawn out through traditional quantitative means. Qualitative inquiry provides that real world insight into an area often unexplored, as Patton states, “how you study the world determines what you learn about the world” (p.125). In studying the patient’s perspective, researchers will better understand how the rehabilitation intervention influences the patient’s daily life.

The patient’s perspective plays a strong role in the outcome of the rehabilitation process and emphasis needs to be placed on the child and family when assessing the effects of a particular intervention (Steiner et al., 2002). With more research emerging on children participating in LT, research is needed to address these psychosocial aspects associated with this rehabilitation program. In-depth qualitative studies could provide more information on the psychological, social, emotional and societal factors influencing the rehabilitation of these children with iSCI participating in the LT.

Qualitative Studies Focused on Children

Typical qualitative interviews are one-on-one discussions with those associated with a particular phenomenon. However, qualitative inquiry of children can be more difficult. Children often need the reassurance of a parent in the room or discussion in a small group setting to engage in conversation (Glesne, 1998). Researchers have

generated various methods to enter a child's world in order to gain better understanding of his or her experiences. These include art and play therapy, parent feedback, behavioral observation and direct interaction with the child (Docherty & Sandelowski, 1999; Axline, 1969). Children tend to be the best source for information regarding themselves and the culture they live in, especially as it relates to health care issues (Docherty & Sandelowski, 1999; Yamamoto, Soliman, Parsons, & Davies, 1997).

The literature presents additional factors to consider in interviewing children: 1) make clear to the child the purpose of the interview (Docherty & Sandelowski, 1999); 2) children as young as two years old begin to form memories of an experience (Docherty & Sandelowski, 1999); 3) children younger than six may withhold information regarding negative experiences because they do not want the interviewer to think negatively of them (Docherty & Sandelowski, 1999; Cole, 1986); 4) for more intense experiences, one should elicit more detail from the child being interviewed (Docherty & Sandelowski, 1999; Steward & Steward, 1996); 5) free recall or unstructured interviews tend to elicit more unique perspectives from the child (Docherty & Sandelowski, 1999, Engel, 1995); 6) understand the developmental age of the child and how he or she will comprehend the questions (Docherty & Sandelowski, 1999); and 7) incorporating play in the interview can allow a child to express himself through the most natural medium of the child (play therapy) (Axline, 1974). This final factor, involvement of play, allows the child to feel more comfortable in a new setting and build rapport with the child and the interviewer (Alkine, 1974). As the literature shows, children can provide a wealth of information into the topic being researched, through play, direct interviews, parental feedback and direct observations.

Utilizing Grounded Theory in Qualitative Studies

One way of examining the effects of LT on children with iSCI is through the use of grounded theory. As previously mentioned, grounded theory seeks to generate a general explanation of a specific topic being analyzed through an inductive process (Cresswell, Hanson, Clark, Plano, & Morales, 2007; Pidgeon & Henwood, 2004; Morrow, 2007; Patton, 2002; and Glaser & Strauss, 1967). This theory “emphasizes steps and procedures for connecting induction and deduction through the constant comparative method, comparing research sites, doing theoretical sampling, and testing emergent concepts with additional fieldwork” (Patton, 2002, p. 125). Grounded theory does not look at one specific type of human behavior, as other theories may do; rather, grounded theory focuses on generating theory itself (Patton, 2002). Pidgeon & Henwood (2004) discuss some general areas of interest to a researcher utilizing grounded theory: 1) identify participants’ perspectives on a specific topic; 2) investigate social phenomena associated with a specific setting; 3) explore areas of research not yet examined; or 4) develop explanatory schemes related to real problems.

Figure 2-5 shows a detailed conceptual map of grounded theory as developed by Pidgeon and Henwood (2004, p.631). Pidgeon and Henwood identify all the key concepts of the grounded theory process.

It is through the grounded theory process that the researcher attempts to develop a theory that provides an accurate portrayal and clear explanation of a particular phenomena or social process (Hanely-Maxwell et al., 2007; Glasser, 1998).

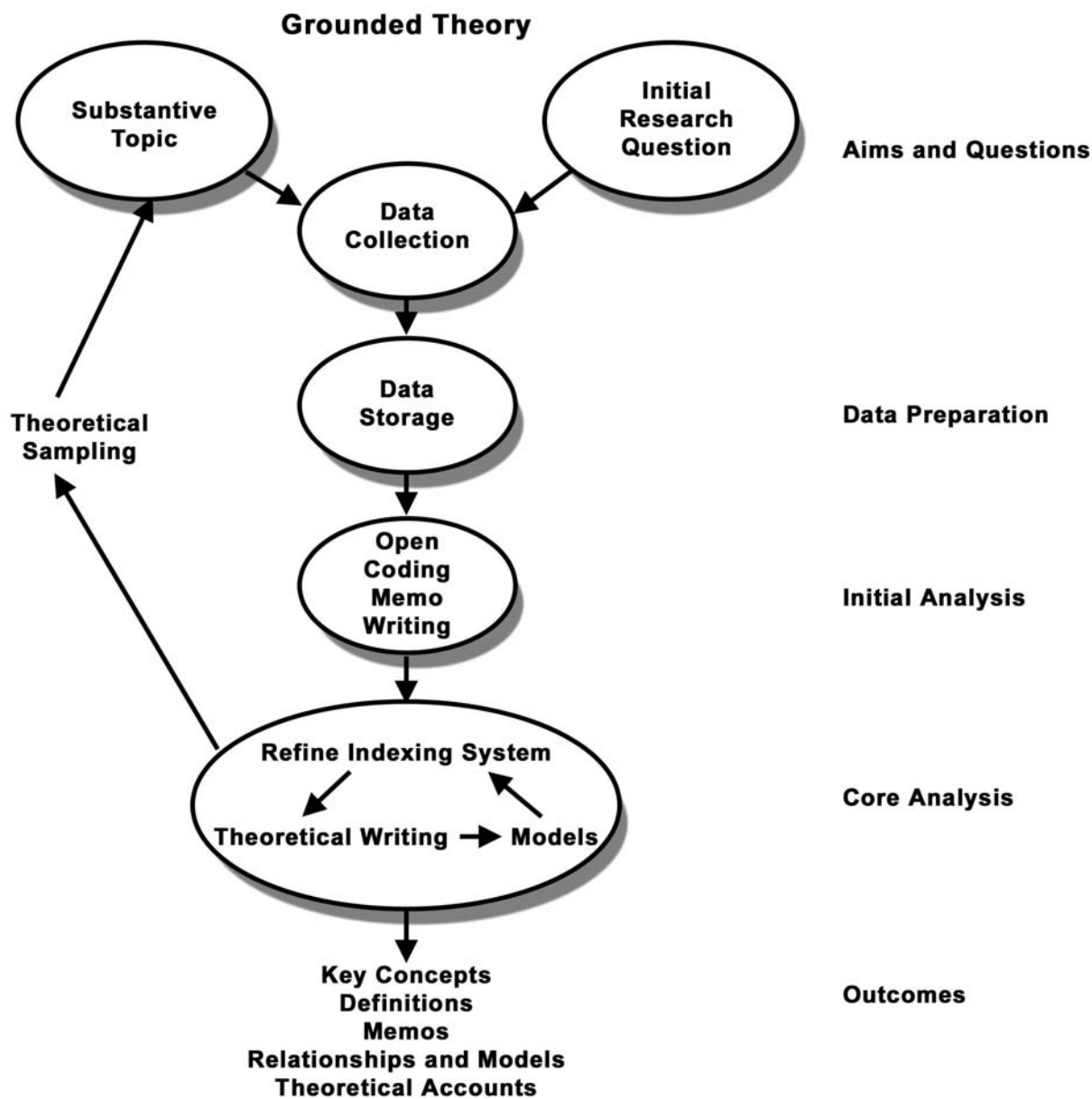


Figure 2-5. Grounded theory conceptual map (Pidgeon & Henwood, 2004)

Utilizing Grounded Theory in Studying Children Participating in LT

This present exploratory study utilized grounded theory to better understand the rehabilitation process from the patient’s perspective. As a qualitative inquiry, this study examined the therapeutic intervention of LT in pediatric patients with severe chronic iSCI. Grounded theory helped to guide the exploration of LT as a form of rehabilitation

among these children. This research focused on the psychosocial impact a walking recovery program has on the children participating in the KSS.

A useful theory is one that tells an enlightening story about some phenomenon. It is a story that gives you new insights and broadens your understanding of the phenomenon (Anafara & Mertz, 4, 2006).

This story is “grounded” in data collected directly from the participants of the KSS. Again, grounded theory is a qualitative research design that develops a general explanation for a particular phenomenon being studied (Creswell et al., 2007; Creswell, 2007; Strauss & Corbin, 1998). In researching the participants of the KSS, grounded theory has been utilized to build an emerging theory of adaptation to iSCI for the children participating in LT.

Research Objective

The goal of this study was to develop a more in-depth perspective of the new concept of “walking recovery” for children with iSCI who are participating in LT with the KSS. The KSS has taken one of the most difficult populations to study the effects of LT on: non-ambulatory, children with severe, chronic iSCI. In simple terms, the KSS is trying to determine if kids who traditionally have been told they will never walk again have the potential for walking recovery. This dynamic study presents the potential for a new concept of psychosocial adaptation to disability for these children and their families. What impact does the participation in LT research have on a child’s (and family’s) concept of recovery after an iSCI? Analysis as to the impact this therapeutic intervention has on these individuals is essential for a better understanding of these children overall. There is certainly potential for positively impacting the quality of life for the child and his or her family.

CHAPTER 3 METHODOLOGY

Introduction

Study Design

This investigator conducted an exploratory study which involved an in-depth qualitative assessment of the children participating in LT as a therapeutic intervention at the Kids STEP Study. Specifically, my research explored the psychosocial factors influencing this new form of rehabilitation for children with severe, chronic iSCI and the impact this walking recovery program has on the child and the family. This study also identified the role the child, the family and the therapy team played throughout the rehabilitation process and addressed the parent's and the child's perceived benefits of the locomotor training.

Organization of Chapter

This chapter is organized in four main components: 1) Participants, 2) Instrumentation, 3) Procedures and 4) Limitations. The Participants section addresses sampling design, relevance for sample, inclusion and exclusion criteria for participants, demographics of sample, and justification of sample size. The Instrumentation section summarizes the type of interviews and use of the interview guide, participant observation, the use of field notes and the use of qualitative software to assist in organizing and analyzing the data collected. The Procedures section discusses participant recruitment, consent, data collection, data analysis and interpretation and efforts to ensure trustworthiness. The final section of this chapter addresses the limitations of the methodology.

Participants

Sampling Design

A convenience sample consisting of five children participating in locomotor training with the KSS at the University of Florida was used for this study. In addition, one primary caregiver was interviewed for each child and two physical therapists participating in this study were interviewed as part of the convenience sample. The two therapists interviewed were selected based on their high level of involvement in the study.

Relevance of Sample

The sample for this study included a total of 12 participants recruited from Dr. Andrea Behrman's Neilsen-funded Kids STEP Study, "Restoring Walking in Non-ambulatory Children with Severe Chronic SCI (Kids STEP Study)," a research study investigating the recovery of walking in children with iSCI at the University of Florida. All participants who were enrolled and participated in this study had experiences with the similar phenomena of having participated or been involved in this walking recovery research of children with an iSCI. One participant (KSS1) took part in the locomotor training prior to the development of the KSS, but under the same protocol as the above mentioned study. The other participants were followed throughout the LT study and provided relevant data. Participants completed between 40 to 60 sessions of training, consisting of 30 minutes of treadmill training, followed by approximately ten minutes of over the ground training. Locomotor training took place five days per week over a 12-week period.

Inclusion and Exclusion Criteria for Participants

For the current study, inclusion and exclusion criteria for participants were consistent with the Kids STEP Study. Inclusion criteria for pediatric participants included:

1. Pre-adolescent children, age 3 to 13 years old and within Tanner's Stages of Puberty 1 or 2;
2. A diagnosis of first time, non-progressive SCI, upper motor neuron lesion, including, but not limited to, etiology from trauma, inflammation, vascular, surgical re-section due to localized tumor removal, or orthopedic pathology resulting in clinical signs of lower cervical or thoracic spinal cord injury
3. Non-ambulatory or impaired ambulation for greater than one year, such that physical assistance and the use of assistive devices (i.e., walker) and/ or leg braces (i.e., knee ankle foot orthoses [KAFOs]) are required to ambulate;
4. A SCI as defined by the American Spinal Injury Association (ASIA) Impairment Scale category B or C;
5. 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
6. Documented medical approval from the participant's personal physician verifying the participant's medical status; and
7. Parent's informed consent for children.

Exclusion criteria for the pediatric participants included:

1. Is currently participating in a rehabilitation program or another research protocol that could interfere or influence the outcome measures of the current study, or
2. Has a history of congenital SCI (e.g., Chiari malformation, myelomeningocele, intraspinal neoplasm, Frederich's ataxia) or other degenerative spinal disorder (e.g., spinocerebellar degeneration or syringomyelia) that may complicate the treatment and/or evaluation procedures or children who are diabetic or have implants, pacemakers, or devices which are not NMR/MRI compatible and are not suitable for the study.

Sample Demographics

Table 3-1 summarizes the demographics for this study. To ensure confidentiality, each participant is identified only by his or her pseudonym. The majority of the participants acquired their injuries at a young age, less than five years old for four of the five participants. All of the participants in the KSS were male at the time this research was conducted.

Table 3-1. Sample demographics

Participant	Age During KSS	Age at Onset	Level of Injury	Gender	Etiology
KSS1	4 ½	3 ½	C-7 Asia C	Male	gun shot wound
KSS2	5 ½	4 ½	T-11 Asia C	Male	motor vehicle accident
KSS3	4 ½	3 ½	C-7 Asia B	Male	motor vehicle accident
KSS4	11 ½	8	T-4 Asia C	Male	tumor resection
KSS5	6 ½	6 months	C2-T4	Male	Unknown

Justification of Sample Size

In determining sample size in qualitative research, some factors to consider are: 1) what you want to know; 2) the purpose of the study; 3) what is at stake; 4) what will be useful; 5) what will have credibility and 6) what can be done with available time and resources (Patton, 2002). There are no fixed rules as to sample size in qualitative research; of paramount importance is full disclosure as to how sample size and sample make-up were determined (Patton, 2002). Each child who has participated in the KSS while I was researching the program over a year and a half period was interviewed. In addition, I interviewed at least one parent of each child. For each participant, three to four interviews were conducted. With the exception of one participant, whose data was collected subsequent to his participation in the KSS, each child had a parent who was

interviewed at four points in time and there were two primary therapists selected by me who were interviewed as well.

Instrumentation

Interviews and the Use of Interview Guides

Semi-structured interviews were conducted to obtain information on the influence of LT on each participant in the KSS. These interviews were conducted with the child participating in the KSS, with at least one parent of the child and with two therapists. Specifically, two interviews were conducted with children participating in the KSS. The other children were too young to participate in formal interviews. In these cases, information was gathered through direct observations, parental feedback and informal play sessions with the child (field notes were recorded).

Semi-structured interviews were conducted with the mothers of all five children and one father of one of the children. In addition, KSS5's siblings also provided feedback into that one family's experiences. Semi-structured interviews were also conducted with two physical therapists participating in the KSS, who continued to be interviewed until saturation was met.

Interviews were conducted at four points in time: within the first week after beginning LT, approximately halfway through the 60-session training program, during the last week of the training program and one month after the completion of the LT. Each interview maintained direction through the use of an interview guide (Appendices A, B and C). In qualitative research, the interview guide serves to maintain a basic line of inquiry for each person interviewed (Patton, 2002). The questions in the interview guide were pilot-tested in the Spring of 1997 with the mother of KSS1 (formerly K19, who participated in LT with an adult LT study with Dr. Behrman). These questions were

tested and refined based on feedback from KSS1's mother and based on discussion with my Dissertation Committee in May 2007. The study protocol and interview guide were approved by the University of Florida IRB-01 in July 2007. Official data collection for this study began in October 2007. KSS1 and mother were then re-interviewed on their past experience with the "K19 Study" and their current experience with the KSS. Additional participants were interviewed throughout their participation in the KSS.

Each of these interviews lasted approximately 30 to 60 minutes in length. These interviews were recorded in digital format. I conducted all interviews to maintain consistency. Each interview was transcribed verbatim and labeled by the participant's pseudonym, date of interview and point of participation (i.e. first week of LT, one month follow-up) to prepare for analysis.

Participant Observations and the Use of Field Notes

In addition to conducting interviews with these individuals, I made observations of the child participating in the LT and field notes were taken on the child, the parent and the therapy team in the lab. These observations provided triangulation in evaluating the child, the family and the therapists participating in the KSS.

Patton (2002) and others note that triangulation can strengthen the credibility of a qualitative study by combining methods or approaches to viewing the same information. Triangulation in social sciences refers to using and comparing observations from different theories, methods, investigators, as well as different spatial, time, and personal vantage points to assess phenomena (Denzin, 1978). As Denzin writes, "No single method ever adequately solves the problem of rival causal factors. Because each method reveals different aspects of empirical reality, multiple methods of observations must be employed. This is termed triangulation." (Denzin, 1978, p. 28).

Field notes were recorded during and immediately following the observations in the training lab. In addition, field notes were taken after talking to the child in the lab or playing with the child participants in the study. These field notes were recorded to document: participants' feelings and attitudes toward the LT, his or her current life situation, the structure and atmosphere of the therapy team, interactions between team members, interactions between the therapy team and the child and family, and any other associated data.

Use of NVIVO 8 Software

As previously mentioned the qualitative software of NVIVO 8 was utilized in this study to organize the data collected and structure the analysis process of the interviews and field notes. Qualitative data software does not analyze the data; rather it facilitates the storage of data, provides a means to code and categorize the data, record memos and organizes themes associated with the data collected. This software was selected based on the recommendation of other qualitative researchers who have had success with previous versions of NVIVO products.

Procedures

Protection of Participants and Confidentiality

This study was approved by the University of Florida Internal Review Board (IRB-01) prior to the enrollment of participants. Once participants were identified and consented to participate, their child and parents names were coded with a letter/number combination and the therapists were given pseudonyms. All data related to individuals was secured. The computer utilized in the study was double password protected and encrypted. All written materials associated with the study were secured in a locked

filing cabinet. Any data reported on the study participants was de-identified utilizing the established code letter/number combination.

Participant Recruitment

These children were voluntarily recruited from the already established KSS participants. The children and the parents were informed that the participation or non-participation in this study would have no impact on their opportunity to participate in the KSS. Each of the child participants was between the ages of 3 and 12 years old. This investigator interviewed the child participants, at least one family member of that child and two therapists associated with the KSS as identified by this researcher.

Consent to Participate

Written informed consent (or assent) was obtained from the child, the parent and the therapist participants before any interviews or observations were recorded. I met with each participant in Gainesville, Florida at the Physical Therapy Locomotor Lab during the orientation process for the Kids STEP Study. I explained this particular study with the parent, child (if age permitted), and therapist and discussed his or her role in the current study. I provided each participant with a written copy of the informed consent and each participant was given an opportunity to ask any questions. If the individual chose to participate, I asked him or her to sign the informed consent (assent) form. I provided each participant a copy of the signed informed consent (assent) and kept a copy per IRB protocol.

Three separate informed consent forms were developed. One form targeted the child participating in the locomotor training in the KSS. A parent signature was required for the child consent form, as well as an assent signature from the child, if age permitted. The second informed consent form targeted the parent of the child

participating in the KSS, while the third informed consent form targeted the physical therapist participating in KSS training.

Data Collection

Data were collected on five children, six parents and two therapists, through interviews, observations and field notes. Table 3-2 outlines the interviews and observations conducted. The information from each interview was recorded and transcribed. The data were then coded and categorized using the NVIVO 8 software.

Table 3-2. Data collected: interviews and observations

Participant	Pre-KSS Int.	Midway Int.	Post-KSS Int.	1-month Int.
KSS1	Observations	Observations		
KSS1 Mom	Post KSS Interview	Post KSS Interview		
KSS2	Attempted Interview Observations	Observations	Observations	Feedback from Mom
KSS2 Mom	Interview 1 Observations	Interview 2 Observations	Interview 3 Observations	Emailed Interview 4 – feedback via email correspondence
KSS2 Dad	Interview 1 Observations	Observations	Observations	
KSS3	Observation	Observation	Observation	
KSS3 Mom	Interview 1 Observations	Interview 2 Observations	Interview 3 Observations	Contacted 3 times – one update received after 6 months via email
KSS4	Interview 1 and Observations	Interview 2-3 Combined as they left early Observations	Interview 2-3 Combined as they left early Observations	Interview 4 in his home Observations
KSS4 Mom	Interview 1	Interview 2-3 combined as they left early	Interview 2-3 combined as they left early	Interview 4 in the home
KSS5	Interview 1 and Observations	Interview 2-Play Conversations Observations	Interview 3- Play Conversation Observations	Contacted family three times and no response
KSS5 Mom	Interview 1 Observations	Interview 2 Observations	Interview 3 Observations	Contacted three times and no response
Therapist PT1	Interview 1 For KSS1 and 2 Observations	Interview 2 For KSS1 and 2 Observations	Interview 3 For KSS1 and 2 Observations	Interview 4 For KSS1 and 2 Observations
Therapist PT2	Interview 1 For KSS1 and 2 Observations	Interview 2 For KSS1 and 2 Observations	Interview 3 For KSS1 and 2 Observations	Interview 4 For KSS1 and 2 Observations

Note there are variations in the above Table. These differences were impacted by the participants' level of involvement in the current study. In the case of KSS1, he participated in initial LT prior to the development of the KSS. Interviews and observations on this family were conducted in the child's 3-year follow up visit. Further, two families left the KSS prior to the full completion of the child's 60 training sessions, resulting in the combination of interviews 2 and 3 in this study. Finally, this investigator had difficulty reaching two families after study completion, despite several attempts to contact.

Interview Procedures

Interviews with the children were conducted either in the locomotor training lab during or after training or at the Ronald McDonald House where the child was staying. These interviews typically revolved around a form of play with the child, including outdoor play, playing over computer games or play during the training itself. These interviews were sporadic in nature and conducted over ten minute intervals as permitted by attention span. I recorded interview notes during or directly after each interview, as it was often difficult to record interviews during play sessions.

The first three interviews with the parents took place either at the therapy lab or at the Ronald McDonald House. The child was sometimes present during portions of the interviews. Each interview followed the interview guide to maintain consistency but had variations, based on the responses of the parents. These interviews typically lasted an hour in length. The final interview was conducted either in the home, by phone, or via email, depending on the schedule and location of the participant. The interview in the home was recorded and transcribed for analysis, while copious notes were taken for interviews conducted via phone or email.

Interviews with the therapists were conducted either in the therapy lab or in the offices of the participants. Interviews were recorded and transcribed for analysis. On two occasions, phone interviews were required and notes were taken during the interview.

Participant Observation Procedures

Observations were made of all the participants in the therapy lab, the Ronald McDonald House and at other locations around Gainesville as schedules permitted. The interactions between the child and therapist, the child and the parent, the therapist and the parent and the therapist and other team members were all recorded in field notes. Participant observations were recorded until saturation was reached. All observations were recorded in a field journal.

Data Analysis/Interpretation Procedures

I followed a traditional qualitative inquiry process. Data collection, data analysis and theory formation were components of an ongoing process that constantly compared the information being researched in order to generate theory of adaptation as it relates to locomotor rehabilitation (Cresswell et al., 2007; Pidgeon & Henwood, 2004; Morrow, 2007; Patton, 2002; Glasser, 1998). I began collecting data on participants in October of 2007. As interviews were recorded, transcription followed with continuous analysis. Analysis after each interview or observation led to consideration of changes in questioning in future interviews. Data were coded and interpreted in order to build a coding framework. Through this evolving process, a theoretical framework began to emerge from the data.

Data were then placed in Case Study format in a Word document. Case Studies were defined by the KSS child participant number (i.e. KSS 1 would be placed in Case

Study 1). Within each Case Study, I placed all interviews and field notes pertaining to that particular child, the family of that child and therapist interviews associated with that child. Once Case Studies were fully identified, each interview was then broken down and coded by reoccurring themes.

Coding and Data/Analysis. After data was transcribed or imported into NVIVO 8, each interview was labeled according to participant identification code and type of data (interview or observation). Each NVIVO 8 allows researchers to develop coding nodes to organize data collected and allows for comparison across different sources of information. Quotes could be labeled with one coding theme or multiple coding themes. After all Case Studies were coded in Word, this information was imported into the NVIVO 8 software. The same codes were then individually classified in NVIVO 8. Tree Nodes of Child, Family and Therapy Team were then formed in the NVIVO software. Under each Tree Node, primary categories were identified and individual nodes were then placed in each of these categories, forming the essence of a Tree Node. Data was continually analyzed throughout the process and the refinement of these Tree Nodes was made as categories and codes were further tightened.

The outline for the findings of this dissertation was directly drawn from the subcategories of these Tree Nodes. Further, the model for adaptation of children with iSCI after participation in LT was formed with NVIVO directly from the coded nodes.

Memoing. Memoing was utilized throughout the analysis process. Memoing allows the recording of researcher thoughts, for example, on how and why I coded information a particular way. Memoing also provided a means to reflect on the decisions made in the data analysis process.

Efforts to Ensure Trustworthiness

In quantitative research, key concepts essential for evaluating one's data are reliability and validity. These are the benchmarks or "measuring sticks" for determining the trustworthiness of quantitative findings. In qualitative research, integrity and trustworthiness are found through different means (Guba & Lincoln, 1981; Miles & Huberman, 1994). Table 3-3 compares the common terminology researchers use to ensure trustworthiness in both quantitative and qualitative research.

Table 3-3. Quantitative measures vs. qualitative measures

Quantitative Measures in Research	Qualitative Measures in Research
Objectivity	Confirmability
Reliability	Dependability/Auditability
Internal Validity	Credibility/Authenticity
External Validity	Transferability/Fittingness
Pragmatic Validity	Utilization/Application/Action Orientation

Objectivity/Confirmability. The main issue in this category is neutrality – has the researcher established “reasonable freedom from unacknowledged” bias? (Miles & Huberman, 1994, p.278). Miles and Huberman go on to indicate this category is often referred to as “external reliability” and a key factor is whether the study can be replicated. Miles and Huberman (1994) identify those standards as to Objectivity/Confirmability as criteria that should be met. Criteria selected for the current study are:

1. Detailed methods and procedures were established such as techniques for recruitment, sample size, data collection and data analysis, including the software utilized to process this information. In addition, I have recorded extensive field notes to document my thought processes throughout this research;

2. An audit trail was developed as the data was recorded and summarized. The NVIVO 8 software documents the date and time in tracking all changes to the coding process;
3. Comments as to biases I may demonstrate have been included in the Introduction section of this Dissertation—this identifies a baseline for bias and values for any further analysis; and
4. All data recorded was maintained for future examination after completion of the present study.

Reliability/Dependability/Auditability. The main focus in this section is whether the study is consistent and stable over time and across researchers and methods (Miles & Huberman, 1994). Miles and Huberman also label this as “quality control.” Criteria proposed to assess this category are:

1. Research questions were clearly identified in the Introduction. The utilization of a grounded theory approach for data collection and analysis was consistent with the exploratory nature of this study;
2. The researcher’s role and status within the site was explicitly described in the Introduction;
3. Data were collected across a consistent, pre-established time frame for the participants as it related to their locomotor training scheduled; and
4. One researcher (I) was utilized throughout all interviews and observations to maintain consistency throughout the study. To enhance rigor, weekly meetings were established with Dr. Mary Ellen Young as a basis for reviewing data, coding and analysis. In addition, periodic peer debriefing meetings were held throughout the analysis process with a qualitative research group and with two outside faculty members emeritus.

Internal Validity/Credibility/Authenticity. According to Miles and Huberman (2004) Internal Validity/Credibility/Authenticity can be described as “truth value”—do the findings make sense? Are they credible to those being studied and to the reader?

Criteria used to assess this category are:

1. Descriptive data were context-rich and detailed. Again, peer debriefing meetings were scheduled on a regular basis throughout the analysis phase of this research;

2. Diligent efforts were made to provide thorough, meaningful accounts of each individual's perceptions of their experience; and
3. Triangulation was used to produce converging conclusions.

External Validity/Transferability/Fittingness. This is the concept of knowing whether the conclusions of the study can have any larger purpose. Are they transferable and do they "fit" into other contexts (Miles & Huberman, 1994; Lincoln & Guba, 1985)? Miles and Huberman identify the following criteria, which I incorporate by reference:

1. Characteristics of the sample, settings, and process are clearly described to allow comparison with other samples at different settings; and
2. Comparison with a similar adult study has been made and future comparisons between the two populations will be made.

Utilization/Application/Action Orientation. Miles and Huberman (1994) define Utilization/Application/Action Orientation as the "need to know what the study does for its participants, both researchers and researched – and for its consumers" (p. 280). This is also termed as "pragmatic validity" (Kvale, 1989). Criteria identified by Miles and Huberman to establish standards are incorporated by reference and are:

1. Study findings will be intellectually and physically accessible to potential users. All data of interviews and observations will be maintained on computer hard drive based on IRB protocol. In addition, written field notes will be maintained in hard copy and electronic form. Efforts will be made to disseminate study findings through scholarly journals and oral presentation of findings upon completion of the study; and
2. Findings from this study will be disseminated in journal articles and presentations as permitted.

Limitations to Methodology

Limitations to the methodology of this study arise largely from the fact that a convenience sample of participants was utilized. This study's sample size is limited. I

had access to only a small group of participants at the KSS, as this is an emerging area of research. Unfortunately, only boys have participated in the KSS to date—the perspectives of girls with iSCI participating in LT have not been examined. Further, the fact that I was the only researcher, and the Kids STEP Study was the only source of participants, could be viewed as limitations despite the valuable consistency brought by the same. The sample was also not representative of the general population of children with severe, chronic, iSCI in terms of race, ethnic background or socioeconomic status. Additional research is needed to gain further insight into the experiences of more diverse groups of children.

CHAPTER 4 KSS CASE STUDIES

Introduction

In order to provide perspective to the data analysis section of this dissertation, this chapter provides a description of each “Case Study” that participated in the Kids Step Study. In effect, a summary of these case studies should provide a basis for understanding each family and its unique perspective of the child’s participation in LT.

Every child who has been a part of the KSS has his own unique set of circumstances: with individual characteristics that make him the boy that he is. Each child has his own parents, siblings, grandparents, family and friends. Each family has its own set of financial and outside resources available to them. And each child has his own story on how he acquired his iSCI and the events that have led him to this new form of rehabilitation. Understanding these stories provides a context for the presentation of Chapters 5, 6, 7 and 8 addressing the theoretical findings as related to the child, the family and the therapy team. In addition, this background knowledge will paint a picture for the presentation of the global findings in Chapter 9.

The KSS Participants

KSS1 – The New Frontier

KSS1 is a vibrant 9-year-old young man whom I first met at 7 ½ years old. He lives in the mid-west United States with his Mom, Dad and two sisters. He attends a private Christian school, participates in school activities, hangs out with his friends and for the most part acts like every other boy his age.

However, things have not always run so smoothly. At 3 ½ years of age, KSS1 sustained a self-inflicted gunshot wound. He and his family were at the home of a family

friend, unaware that the owner of the home had a small pistol on the counter of his master bathroom. As the children were watching a movie in the master bedroom, the adults were dining in the kitchen. KSS1 wandered into the bathroom and saw a small pistol on the counter. KSS1 and his father always played with water guns in his parents' shower, and he assumed this was the same thing. As he walked back to the bedroom, he climbed on the bed, pistol in hand, to watch the movie. In the other room, all the adults heard a "pop" – KSS1's Dad and Uncle jumped and ran to the room, instantly aware a gun had been fired. Soon ambulances, immediate surgeries, fearful nights, critical care stays and long term rehabilitation became part of the next eight months of this child's and his family's life.

Prior to his injury, KSS1 was an outgoing, energetic, adventurous little boy. He loved to swim, play football and roughhouse with his Dad. After this traumatic event, KSS1 became quite, reserved and fearful of interacting with his environment. Mom expressed she was "a mess" and her husband decided to take the first four months of his child's hospitalization off from work to help as the family coped with all the challenges they would face. Both parents chose to be there for their child during those initial four month of acute care and Dad took an additional four months off from his union job, after they returned home and began more of KSS1's rehabilitation.

Mom remembers,

We left that day with a healthy normal crazy kid and then when we came back four months later we had to do everything. He lost so much weight, I mean you could every bone in his spine. We had to help him, I mean everything. I mean he just sat and he had no balance and he had a brace and he had a neck brace. He was just so different. His mind was different too, as far as he was just so afraid of everything because his body was different and he didn't know how to control it. - KSS 1 Mom

During this time, Mom would cry to herself in the evenings, after the children had to go to bed. At the time of the accident, KSS1 was 3 ½, and his two sisters were 2 months and 7 years old. Mom felt an overwhelming sense of responsibility for this child. The turning point for Mom came one night when she saw a special on T.V. on LT for patients with iSCI.

I thought if these guys can do it, who is to say. They all had low injuries, KSS1's is really high. He's a C6, C7. But even then I thought, well who is to say he can't get there. - KSS1 Mom

This show sparked a hope in Mom that there were more treatments available for her son. The next morning she called up to twenty universities with Physical Therapy departments asking if they did LT on children. PT1 at the University of Florida was the only person to take her call.

While PT1's research did involve LT, her focus at the time was on adult iSCI patients. Despite her lack of experience in working with children, PT1 was open to "giving it a try" and brought KSS1 to UF under another grant, the K-Study and KSS1 was given his first pseudonym, K19. KSS1 first came under PT1's care at the age of 4 ½, one year post injury with a Level C, iSCI. Prior to LT KSS1 was unable to sit sturdily and was only able to army crawl along the floor.

The initial treatment for KSS1 was intensive locomotor training utilizing a body-weight supported treadmill training and over the ground training utilizing a supported walker. KSS1 met with the team 5 days a week for approximately 2 hours at a time. In addition, KSS1 received three days of traditional physical therapy at a local outpatient center and two days a week of respiratory therapy. After two months of training KSS1 took his first steps at the University of Florida. At the age of 9, KSS1 is walking with a rolling walker, is mainstreamed in regular education classes, and is participating in a

number of extracurricular activities, including swimming and riding ATVs. It was from the success of KSS1 and that Mom's one phone call that led to development of the Kids STEP Study.

KSS1's experience opened the door to future LT research with other children with iSCI – as the KSS opened its doors to four more boys in similar, yet unique situations.

KSS2 – Mission Possible

KSS2 came to the KSS all the way from an larger city in a European country. His family found the KSS while researching alternative treatments for children with iSCI. KSS2 was 3 ½ when he, his sister and his mom were riding in a car that was hit head on by a delivery truck, during rainy weather. His had the most significant injury in the accident, however, his sister sustained a mild brain injury and his mother sustained significant damage to her knees that required surgery and rehabilitation. KSS2 was initially given a grim prognosis for survival and then once his health stabilized the doctors were pessimistic regarding his rehabilitation. Mom was adamant that KSS2 maintain consistent family support during his recovery.

We had this thing where we didn't want to have KSS2 left alone in the hospital because we believe that a good part of recovery is a positive attitude and we wanted to be there with him all the time. We had someone in the hospital at all times to keep him positive. He was completely immobile, laying completely flat. That is one thing with kids - if they are really hurt they are really quiet. That is how he was. He sensed how serious it was and he remained very quiet. - KSS2 Mom

These parents began researching non-traditional treatment early on in their child's hospitalization, as his home country is not known to have a significant rehabilitation system. Essentially, individuals are expected to adapt as best as possible post injury and patients are expected to adhere to the doctors' limited treatment of the child after

diagnosis. Needless to say, this family tended to “butt heads” with the medical system and challenged themselves to find more appropriate treatment for their child.

They would give us all these facts, which is a good thing but there was this one guy. There was one guy we called the Grim Reaper (laughs) he was a young guy which was interesting and he just, I will give the example, I was in the ER and they brought KSS2 in and this is the first time I saw him (since the accident) and he was lying flat and and he had a neck brace and all he could move was his little eyes and mouth and he was just so scared (mom got teary-eyed). And the man met me and said ‘I won't lie to you this is a very serious injury and this could be what you have to deal with the rest of his life’ and points to KSS2 on the stretcher. - KSS2 Mom

Mom and Dad believed there was more potential in their son's body and they hoped to find that potential at the KSS. Mom believed it was her responsibility to find out what rehabilitation programs were available for her son. She used her internet savvy to locate the KSS and immediately called to see if her son met the criteria for the program.

He came to us energetic, full of spunk and ready to do battle, literally and metaphorically. He came decked out in camouflage his first day – we knew he loved war movies and James Bond and we worked to keep the training fun for him. Mom, Dad and his seven-year-old sister all came over the first two weeks to establish him in the program. The family chose to rent a furnished apartment and a car locally rather than stay at the Ronald McDonald House. KSS2's grandparents flew over for one month of the stay and then Dad and sister came for three weeks over the winter holidays.

This is one committed family. “Grampy” loved to come to the LT sessions and keep KSS2 motivated and distracted, as KSS2 was like any other 5-year-old wanting to be outside playing rather than be 4000 miles from home walking or standing on a treadmill for two hours in the basement of a hospital. It took a lot to keep this little guy

up beat and motivated but the team worked with him to keep his interest peaked. This was a learning process for the KSS Team as well, since KSS1 was a completely different child who was highly motivated, positive and did not talk back to or complain to the trainers.

KSS2 on the other hand was more “feisty” and at times belligerent. However, with the guidance of the team and encouragement of his family, KSS2 was able to finish the 4 month program. He was well liked by the therapy team and came to his going away party in his very own tuxedo – a.k.a. his “James Bond” disguise!

At the completion of the program, KSS2 was unable to bear weight well enough to utilize a rolling walker, yet he did gain better hip extension, improved overall tone and the ability to pull to and maintain knee standing while doing activities. Further, KSS2 gained more independence and self-confidence as a result of the program. In addition, Mom and Dad learned to take some time out to be a family again. Prior to coming to the KSS, KSS2 had spent some rehabilitation time in Switzerland utilizing the Lokomat, a robotic device that simulates and supports walking over a treadmill. During that experience the family gained insight into more effective ways of teaching their child Activities of Daily Living (ADLs), while here at the KSS, the family found a level of empowerment from the therapy team - an ability to let go of some desire to find the ultimate “fix” for their child and once again take time to be at home and “live their new reality.” This process seemed to help the entire family accept KSS2’s abilities and disabilities at their fullest.

Now back home, KSS2 has found new independence with a renovated bathroom on the first floor – where he gets himself ready for school, brushing his hair, washing his

hands and brushing his teeth “all by himself”. He now has chores at home, just like his older sister. His parents continue to work with his stretching, his exercises and finds new therapies, but they also encourage him to have friends over and spend time at home with his family.

KSS3 – Mind/Body Reconnection

KSS3 was approximately 3 ½ years old when he and his family were hit by a car that had run a stop a stop sign in the mid-west region of the United States. The other vehicle slammed into the driver’s side as Dad was driving and KSS3 was sitting behind him. The family’s car spun and took hits all over. The dashboard fell onto Mom’s knees as she was sitting in the passenger seat and their 9-month old son was in his rear facing car seat behind Mom. The only one unscathed from the accident was the baby. Mom and Dad both sustained traumatic brain injuries, leg injuries, and significant internal damage. Both of the parents were hospitalized for a number of months and required additional care at home once they were discharged.

KSS3 was critically injured as well and the stability of his health was “touch and go” the first week. The extended family of this child held vigil for a number of days and nights, as the doctors did not know if any of the three would survive. The maternal grandparents took charge of caring for the baby, the paternal grandmother did not leave KSS3’s bedside the first few months and the rest of the family supported Mom and Dad. KSS3 was diagnosed with C6-C7 ASIA B injury. He was in acute care for one and half months and then was transferred to a local rehabilitation hospital for follow-up care.

The paternal grandmother continued to be primary caregiver for KSS3 as Mom and Dad did not have the strength to be at his bedside every day and night. The family

was not happy with the initial rehabilitation hospital and they began to take the initiative to search the internet for alternative rehabilitation programs in their region.

I was just looking around and seeing what else was out there - we weren't happy with what he was getting - we were not happy with what they were doing. It was like we were telling them certain things and they weren't listening. Like what we were seeing him do - but they were like well if we don't see him do it, you know it is like - they didn't believe us. So we found the place (in a larger Midwest city) and moved him there. It was just crazy like in the first day we were there, we learned more than being two months at the other place. They got us involved in the process – we gained so much knowledge in just the first day. - KSS3 Mom

After the long term rehabilitation stay, KSS3 came home to his whole family recovered and healing from one traumatic car accident.

Once home, KSS3's family found an outpatient facility that focused on iSCI rehabilitation and while this facility did not have any pediatric patients, they were open to treating him. It was a therapist there that informed the family of the KSS. The parents researched locomotor training and the KSS before contacting the program, but just a little over one year post injury, KSS3 was scheduled to arrive. This time, Mom would be able to travel as the primary caregiver while the paternal grandmother would come along to provide emotional support and give mom some extra help with the little brother, now two. Unfortunately, grandma was diagnosed with terminal cancer just six weeks before the family was scheduled to arrive in Florida.

On the encouragement of Grandma and the rest of the family, KSS3 came to the program on time, and his Aunt offered to come in place of Grandma. KSS3 was quite shy in training in the beginning and soon became frustrated and at times belligerent with the process. His angst against the training came out one day as he said:

“I don’t know why I am doing this; my legs are never going to work again. Those doctors told me I would never walk” – KSS 3 referenced some physicians who spoke with his mother two months prior regarding long-term prognosis. Mom was unaware that he had overheard that conversation.

The KSS team worked diligently to keep him motivated and engaged in the process as they reminded him to keep telling his legs to move and providing him with stickers, coloring pages and games to keep him motivated.

The family faced a number of challenges during their stay at the KSS – one month into the program, the paternal Grandma, who had cared for KSS3 those five months after the accident, passed away from the cancer she had been diagnosed with just months earlier. The family encouraged KSS3 and his parents to stay and complete the study – “it is what she would want” her husband had said. Soon after Grandma passed, KSS3 contracted pneumonia and was hospitalized in the PICU for a week. Training was delayed, yet the family continued to persevere despite the challenges they were confronted. They had a steady stream of family and friends that came to Florida to visit them and keep their spirits high. Mom always seemed to have a positive attitude regardless of their circumstances; “I just try to be patient and I just try to be positive and I just try to look at what he CAN do and not at what he CAN'T do.”

The family wanted to be kept informed of his physical progress throughout their four month stay with the KSS and were constantly educating themselves on what more they could do for him back home. While the family had an outstanding support system back home, they also had significant financial resources. Due to the nature of the

original accident, insurance provided almost any resources the family and therapists requested.

Unfortunately, KSS3 did not leave with a walker, but he did leave with many benefits including, but not limited to: improved trunk strength; improved fine motor control; and more awareness associated with bowel/bladder activity. In addition, Mom mentioned he was trying new activities such as pulling up on his knees and pushing himself around the room in the dynamic stander that was introduced to him in the program. Further, KSS3 learned that there may still be a connection to his legs. On two occasions I witnessed him communicate this reconnect with the team. As he was suspended in the harness walking on the treadmill when he said:

Whoa – did you see my leg do that? – KSS3

His leg had extended on its own while walking. One week later on the treadmill walking KSS3 again made a connection as he expressed excitement:

I can feel that go down and up my spine. – KSS3

This connection was not only physical but seemed to also be an emotional connection. KSS3 left this program a stronger child, both physically and emotionally. The family was ready to go home and be “a family again.” They ordered some of the equipment used at the KSS, including a dynamic stander, and a lite-gait treadmill. At the same time, the family got ready for a new addition to the family as Mom headed back home 2 months pregnant. After going home, the family continued with therapy and entered back into “regular” family life. The family welcomed a baby sister about the same time KSS3 started kindergarten. KSS3 continues in outpatient therapy as his therapy team there continues to work to restimulate his neurological system on the premise of what

they have learned at the KSS – which his neurological system is malleable and able to readjust to life after injury.

KSS4 – Boy Scout on a Mission

At the age of 8, KSS4 began to trip more frequently and walked more clumsily than usual. His mother assumed he was going through an awkward stage. However, one day his school called and told Mom he was not able to stand up straight and was having great difficulty walking. She took him directly to his pediatrician – the pediatrician told her he needed an immediate neurological evaluation. They were sent directly to a pediatric neurologist. The neurologist watched KSS4 walk down the hall one time and sent him to the Children’s Hospital for an MRI. After the MRI, Mom took KSS4 home, but by the time they walked in the door, the Neurologist called to say he would need to admit KSS4 immediately to the hospital. The MRI had shown KSS4 had a tumor and the doctor was pretty sure it was an aggressive form of cancer. Within days of being in the hospital, the neurosurgeon told Mom his prognosis was “grim - he would probably never have sex, he would never have kids, he would never walk again and he said that KSS4’s future was pretty bleak.” KSS4 Mom

This began a long battle for KSS4 – his Mom, Step Dad, little sister and the rest of his family. KSS4 recovered from the cancer – but after the tumor was removed he was unable to walk, was diagnosed with a T4, ASIA C injury and was transferred to a pediatric rehabilitation hospital where he learned his activities of daily living and began to adjust to life after having cancer and a spinal cord injury.

At almost four years post SCI/Cancer, the patient was informed of the KSS from the rehabilitation hospital he had once had contact with. He came to the KSS excited, motivated, determined, and confident that he would walk as result of this program. His

Mom was confident as well, but also cautious. She was excited to offer him this opportunity, as money was tight and he had not been consistently receiving therapy at the time he was enrolled in the KSS. KSS4 was focused during each of the sessions and listened intently to the trainers. He was talkative, friendly and fun to be around during the trainings. The team enjoyed training him and they quickly built a strong rapport with him and his Mom.

Unfortunately, within a month, KSS4 began to experience severe headaches and a change in blood pressure during and/or after the locomotor training sessions. He was sent home to determine the cause of these changes. After a month off from training, it was as the KSS therapists had first assumed; KSS4 was experiencing Autonomic Dysreflexia (AD). AD is a dysfunction among SCI patients that impacts those with lesions at or above T6 (Molnar & Alexander, 1999). Essentially AD is an over-activity of the Autonomic Nervous System that can lead to the narrowing of the blood vessels which in turn can lead to an increased blood pressure and decreased heart rate (Molnar & Alexander, 1999). This is a serious condition that can cause stroke or even death. KSS4's physicians thoroughly examined him and determined he could continue in the program, if the KSS team closely monitored his blood pressure and were able to manage his headaches. This was accomplished, however, the time off disrupted the family dynamics. Mom had been off work during this entire time, the sister was home with the Step Dad, and school was starting – due to these extenuating circumstances KSS4's family decided to end his participation a few sessions early.

KSS4 was still unable to walk as a result of this program – yet he left feeling confident that he may still walk one day. After returning home, Mom began to work on

getting him into outpatient therapy. KSS4 did show improved strength and his mom reports he has been taking more risks in his daily life. While prior to the program, he would ask for help to make transfers into bed, he is now doing these on his own. He continues to maintain a positive outlook on his future and is more determined than ever to show others what his “abilities” are in life.

KSS5 – What is Normal?

KSS5 entered the KSS program at 6 ½ years of age. He, as with every other child that participated in the KSS, has his own unique story. KSS5 was born a healthy baby, but at six months of age life changed dramatically. Two days prior to onset of paralysis, he was in a car accident but was evaluated and deemed healthy. After those two days, he woke with a high fever, was belly breathing and was extremely lethargic. At this point KSS5 was unable to roll over or cry. His parents immediately took him to the local military hospital. At that point he was treated for pneumonia and sent home the next day. KSS5’s motor skills improved slightly but his arms weren’t working well and his parents were unaware that his leg had not moved – they attributed the lack of movement to his illness. Three days later, he continued to get worse, the fever jumped back to 103 and the parents began to realize the significance of the lack of movement in his body. The parents knew there was something more going on as they rushed him to the local civilian hospital.

I knew it was serious because KSS5 looked over at me and just a single tear came down his face. I just knew something was bad. I knew when I took him in it was something else. I just knew. I just knew. They did an MRI at the civilian hospital and it showed a lesion on the spine and I didn’t know what that meant. It could have been cancer, so we made the decision then to take him to the regional Children’s Hospital. We realized he needed special care. - KSS5 Mom

Mom's friend took their two older girls while Dad followed the ambulance to what would lead to a long hospital stay with numerous sets of lab work, two more MRIs, a spinal tap and various evaluations from doctors and therapists. At the Children's Hospital, the parents were told KSS5 had a spinal cord injury without radiological abnormality, meaning something happened but nothing was left on the MRI to show it. The doctors explained it to them that a virus came into KSS5's body and attacked it and left it damaged but left no sign of the damage on the spinal cord. "They basically said lots of therapy and good luck." – KSS5 Mom

That is exactly what the family did. They sought out the best doctors, specialists and therapists in each area that they have lived (they are military – so they often move every three years) and held on to the hope that their son was young and his neurological system was still growing and maturing. It is this mentality that continues to drive the family's care for their son.

One year prior to coming to the KSS, the family chose to take KSS5 to a LT program in Kentucky. The family had seen a program on television and waited a year to get their insurance to cover the expense of this program and get the logistics worked out to take him there. This trip led to temporarily separating the family – Dad stayed home to work, the oldest sister went to the grandparents and Mom took KSS5, his other older sister and his newborn sister to the LT program out of state. As a result of this intensive program in Kentucky, KSS5 was able to begin walking with a rolling walker. It was also there that they met Dr. Behrman with the KSS and decided to leave Kentucky early and get on the wait list for the KSS as it was closer to their home, and the family could all stay together when they attended the program in Florida. Family is obviously a

priority for this family, as it guides many of the parents' decisions in their child's care. Mom also explained she wanted to be a part of the KSS because it was not strictly therapy (as the Kentucky program was), but was also a research study and she has been adamant about finding out as much about her child's SCI and about how his body works, so they can best treat him.

He arrived at the KSS with his entire family, Mom, Dad, two older sisters (10, 9), younger sister (2) and Mom was pregnant with sister number four. He was quite shy on the initial visit and let his parents and sisters do most of the talking. At the beginning of the training, KSS5 walked with a rolling walker and utilized a wheelchair for longer distances. Despite arriving at the KSS with the ability to walk with assistance, he still didn't feel this was "normal" as mentioned at the opening of this research report. He came to this program with the hope of one day being able to walk more typically – like his friends.

KSS5 was an extremely polite little boy who cooperated during the LT sessions and respected the entire therapy team. Throughout the program, he showed improved strength and ability. In fact during one of my interviews with Mom he was able to go from standing independently for three seconds to standing independently for 12 seconds. He loved to "show off" his new abilities. The family decided to leave a few sessions early, as it was close to the winter holidays and they were ready to be home again. At this time, KSS5 continues to walk with a rolling walker now with improved strength and focus and the parents continue to challenge their son's body and focus on what he can do in life.

Summary

Each of these five young men had their own unique set of characteristics and unique set of circumstances that make them who they are. The summary of these boys' experiences provide a point of reference when discussing the present study's findings.

CHAPTER 5 FINDINGS: CHILD DYNAMICS

Introduction

As depicted in the previous chapter, each child who participated in the KSS had his own set of experiences, each of which shaped and molded his rehabilitation after iSCI. This chapter will discuss the findings of the present study from the perspective of the child participating in the locomotor training. These findings are based on interviews and/or observations with the child, interviews with the family of the child and interviews and/or observations with the physical therapists training the child in LT.

The Kids STEP Study: First Impressions

The Physical Therapy Lab at the University of Florida's Shands Hospital is the home to the Kids STEP Study. As previously mentioned, the aims of the KSS are to determine: 1) the use of locomotor training for restoring ambulation in children with chronic, severe SCI, and 2) the neural substrates underlying walking function. These children participating came to a new rehabilitation program unaware of all that was in store for them during the next four months.

On the first day of orientation, each child and his family was met in the lobby of Shands Hospital by me, the Rehabilitation Counselor Intern, and/or the Project Coordinator. Each orientation was geared toward the child's interests based on an interest inventory the family and child completed prior to coming. Orientation themes included Pirate Voyages, Army Missions or Gator Sports Excitement.

The child and family were then led to the basement of the hospital -- down a maze of hallways to the physical therapy lab. As they enter the lab, the first thing the child saw was an enormous machine in the center of the room. "That thing is a monster!

Cool,” claims KSS2 upon arrival. “Am I going to be up in that?” Above the machines a large section of the ceiling is elevated to allow room for the treadmill and body weight support system. Each boy showed a mixture of excitement and hesitation as the realization they would soon be suspended from the apparatuses in the middle of the room.

A mirror had been placed at the front of the treadmill so participants could see themselves while walking or standing on the treadmill. An independent mirror on wheels sat on one side of the unit so the physical therapists and child could recognize proper posture and alignment during training. There were two seats to the side of the treadmill for the therapists who would manually assist the child at the legs and to provide sensory input in walking and standing. In addition, a bench was placed at the back of the treadmill for a therapist to assist with hip alignment and balance during training bouts.

The lab itself had been painted a light shade of blue, with sporadic framed posters decorating the wall. Tim Tebow of Gator Football, Dash from the Incredibles, and the cast of High School Musical grace the walls on three sides. Another wall had a large white board with various markers in the tray, along with a poster presentation of the first child to participate in LT at the University of Florida – the child whose success is the basis of the KSS. Various filing cabinets with stuffed animals atop surrounded the room, while computers and electronic equipment with wires and electrodes protruding occupied space. A therapy table and two therapy benches decorated in “Gator” and Camouflage fabric sat against one wall.

Despite some of the overwhelming feeling the boys felt that first day, they all soon learned to navigate their way through the halls of Shands hospital as the blue basement room became a second home to him and his family for the next four months.

The Child

Characteristics of the Child

The children participating in the KSS each had their own unique sets of traits that make him the boy that he is: shy, outgoing, determined, scared, funny, belligerent, and so much more. Prior to their injuries, four of the five boys were described as adventurous, independent, athletic, risk-takers that tended to be full of life. Yet, with each child, the iSCI seemed to alter his personality in ways, as he became more cautious, unaware of the changes in his body and confused at a young age about his lower extremities' inability to move.

Before the accident he was active and would try anything. He was not shy – he was more the center of attention. He was more of a ham - to make himself the center of attention. Now he's more reserved and quiet. He doesn't want attention brought to him. - KSS3 Mom

The impact the injury has on the child is influenced, in part, by the age at the time of injury (Almqvist, Hellnas, Stefansson, & Granlund, 2006; Russell, 2005; Simeonsson et al., 2002). Developmental age at the time of participation in the KSS is also a factor contributing to the rehabilitation process (Almqvist et al., 2006; Russell, 2005; Simeonsson et al., 2002). These patients' ages at time of participation in the KSS ranged from 3 ½ to 11 ½. Younger children have more difficulty cognitively processing the significance and severity of their injury (Almqvist et al., 2006; Simeonsson et al., 2003).

Concrete vs. Abstract Thinking

The younger children in this study had more difficulty understanding the overall purpose of the research - to determine their potential for walking recovery. As previously mentioned, in rehabilitating children with disabilities, it is important to assess their level of development at the time of treatment. The child's interaction and involvement with the rehabilitation process can be impacted strongly by his specific stage of development (Simeonsson et al., 2003). A study by Almqvist and colleagues (2006) found younger children, up to 8 years of age tend to view health and illness as two separate entities – implying these children are unable to view someone who has an illness (or health condition) also as someone who can be healthy in other respects (Almqvist et al., 2006; Lasky & Eichelberger, 1985; Natapoff, 1978). Essentially, this suggests that young children with SCI can have a difficult time understanding that their bodies with now limited function can also be bodies that provide healthy experiences in their daily life. Most young children's perceptions of health are concrete and egocentric rather than abstract as with an adult counterpart (Almqvist et al., 2006). Despite their young age, a child's perception of his health condition can be additionally impacted by his personal attitudes, behaviors and previous experiences to health and disability, along with those communicated by his family (Almqvist et al., 2006). The boys in this study had a strong family support network that continually provided positive feedback in discussing their child's future ambulation.

Despite the parents' positive input, the younger children still viewed their body as "ill" and unable to achieve walking. KSS3's Mom reports that regardless of the parents' conscientious decision to remain positive about their child's future prognosis as it relates to walking recovery, KSS3 did not completely understand the potential for his

body. Upon arrival to the KSS he presented as a bright, yet emotional young boy who was acutely aware of the severity of his injury. He tended to take in all that went on around him, from the doctors, his parents, the therapists and others he interacted with. He expressed to both me and PT2, the KSS Project Coordinator, during the beginning weeks of training: “Why are you doing this? My legs are never going to work again.” This reflected the concrete thinking of this young child and a sense of disconnect between his mind and body.

Mind body connection

Throughout the LT, the KSS therapists attempted to help these young boys develop a new way of thinking as it relates to their disability. In a discussion with PT2 regarding KSS3’s remarks she emphasized one of her goals in the LT.

I told him today, ‘we are going to remind your body to do that again’ and he said, ‘my body doesn’t remember anymore.’ We have to get past that view of his body. There are some physical as well as emotional issues that we need to get through quickly to work on this walking. – PT2, Project Coordinator with KSS

Later into the LT program, KSS3 began to show this reconnection during a walking bout on the treadmill. Suspended in the body weight supported harness over the treadmill, he began a walking bout with assistance as he watched himself in the mirror. Within a few minutes into the session, KSS3 exclaimed: “Whoa – did you see my leg do that?” PT2 explained that KSS3 was getting more flexion and extension during the LT. The whole room of trainers showed a spark of excitement as KSS3 made that reconnection between his mind and body. KSS3’s leg had extended on its own while walking. Five days later, KSS3 further displayed a reconnection between his mind and body below the level of lesion. While walking, KSS3 said with excitement and a bit of confusion, “I can feel that go down and up my spine.”

As training progressed, KSS3 also reconnected with his emotions and began to communicate better with the KSS team. On one occasion, he told them he did not want to wear the harness because he was scared. Further, near the end of his training in Gainesville, KSS3 initiated discussions with the KSS team as he shared that his Grandma had died and that he would no longer see her. He continued to open up and share with the team in his last few weeks. This showed that the steps KSS3 was taking at the KSS were not just physical ones but were also emotional steps, as he brought down some of his emotional barriers.

Some of the other young children had difficulty grasping the importance of the LT and the implications this rehabilitation could have on their long-term prognosis. KSS2's family indicated that their son did not fully appreciate the purpose of being at the KSS and was not fully aware of the severity of his injury.

The older children tended to come into the program with expectations of walking recovery or improved walking ability. When asked whether he thought he would walk again, KSS4 responded,

Yeah! I have a friend whose mom used to be PT at Shands and he said that is a really good hospital and so I know I am in a good place and will walk again. – KSS4

By the end of his training with the KSS, KSS4 continued his positive outlook towards walking one day,

I may not be walking yet – but I will one day. I really believe that. But even if I don't it won't stop me from doing whatever I want to in life. – KSS4

He continued to be determined in his goal of recovery but at the same time was confident that regardless of his prognosis, he would still be successful in life.

KSS5's family believes one of his roles while here at the KSS was to learn more about his body and to work on forming that mind/body connection.

I think he is more of a student, than a patient. I think they (the KSS team) do more teaching here and are not here just to work the body. Here they are talking to him, like telling him to focus on moving his legs, and keeping his shoulders back and his hips lined up- which is good because that is something he can carry with him when we leave. - KSS5 Mom

Sense of hope

The child's ability to understand and grasp a future hope of walking recovery is more apparent in the older boys. They reported a stronger understanding of the science behind the therapy they participated in at the KSS and the potential for their bodies to recover function as explained to them by the therapy team. These are boys whose parents emphasized and encouraged them to meet their highest potential in walking recovery. The younger boys also had the support and encouragement of their families, yet their minds were not quite ready to grasp the severity of the matter. KSS2's father notes this with his own son, when asked how KSS2 copes with the rehabilitation, Dad responded:

Great! You very seldom see him down. He doesn't comprehend the enormity of his situation. - KSS2 Dad

The child's ability to grasp this sense of hope does not deter the parents from hoping for their child. All the families that participated in the KSS came in with a sense of hope and, regardless of their child's abilities at the end of the training that sense of hope persevered. Interestingly, the parents emphasized a hope beyond walking recovery as they expressed a strong desire for their child to improve their bowel and bladder function as a result of the LT.

Bowel/Bladder Control

All the boys, whether they discussed it openly or not, were self-conscious about their dependency on undergarments. Surprisingly, four of the parents reported that their desire for their child to regain bowel and bladder control was almost greater than their desire for their child to regain walking ability.

He hates wearing pull-ups at 7 now. That bothers him more than a wheelchair at this point, he gets embarrassed. - KSS1 Mom

He hates wearing nappies – he tries to hide it from his friends - if he could regain some control that would be amazing for his self confidence. - KSS2 Mom

He feels a little different from his friends and all. I think it is really the cathing and the suppository and the pull ups. Those goofy training pants. He doesn't feel normal. - KSS4 Mom

When asked what she hoped her child will be able to do after this rehabilitation program, her Mom responded:

Um, I would say physically for KSS4 if he could gain the use of the bladder back that would make him feel the same as other kids. People love the chair - it's the pull ups. If that could happen that would be unbelievable to me. – KSS4 Mom

The locomotor training may, in fact, aid the development of bowel/bladder function.

On one occasion, KSS3's Mom came into to the lab to report on his increased sensations after locomotor training. Mom had taken KSS3 to run errands after one training session and he had fallen asleep in the car.

He woke up out of a dead sleep saying 'I am wet – I am wet – change me!' I looked in the rear view mirror shocked...how did he know he was wet? I asked him if he had his hands down his pants and he said 'No, I just feel wet...change me.' While he didn't act too nice, I didn't care, this is the first time he has had a sensation of wetness since the accident. Oh if he could regain the bowel and bladder control he would be so excited. He would feel so much better about himself. He had been potty trained before the accident and was so proud of his big boy underwear and now -

his little brother is starting to potty train and it would just mean so much to him. - KSS3 Mom

The child's self –confidence resides in being as typical as possible – fitting in with their peers, especially as it relates to a managing incontinence (Vogel et al., 2004). KSS5's Mom reports he had been able to potty train himself a year and a half prior to the KSS. One day he just told his mother, "I can do this you know." He had become more acutely aware of his body's abilities and KSS5 was determined to show others what he "can do."

Challenges Self

The ability to challenge one's body and abilities was one characteristic seen in all the boys after they had participated in the LT. A combination of the LT, the feedback from the therapists, and the child's ability to form a reconnect with his body has led to these boys testing the limits of their ability. They have gathered a heightened sense of awareness of what their bodies can and can not do.

KSS1 showed this heightened awareness during his initial stay with the KSS. After 20 sessions he began to initiate independent stepping on the treadmill and began to test the limits of his body outside the therapy lab. On one occasion, he attended a party with his mother, where she allowed him to stand at a table, as she stood behind him giving him the support he needed to maintain balance. At one point he put his hands on the table and told his mom she could move away. As she did, KSS1 was able to maintain standing without her assistance. He took it upon himself to challenge his body's ability outside the therapy setting. On instinct, he motioned his mom to come back in to aid in supporting him once he knew he could no longer maintain balance on his own. A reconnect had been made by KSS1 between his mind and body. Not only

had the KSS team guided him through this reconnection process but they had empowered him through the training to take these concepts and awareness into his daily life and challenge his own abilities.

This sense of empowerment was seen again with KSS1. On another occasion, KSS1 had begun walking with a rolling walker. He was supported in the walker with a tether tied to his waist which was held by a therapist or his mother. During an outing to a local hardware store, he told his mother “okay you can let go of me now” and he walked on his own, without the tether, from that moment on. This ability to challenge themselves has been seen in each of the KSS participants.

KSS2 had been working with the therapists on kneeling against a bench after one LT session. The following evening he pushed himself up onto his knees without anyone asking. He came in the next day to share his accomplishment with the team. When asked why he decided to try that at home, his response was,

“No one was around to help me up and I just did it.”

On another occasion, KSS2 tried to stand up with no harness. He then pushed himself up to kneeling without much support. “I can stand by myself” his remark was accompanied by a huge smile as he beamed with pride. Mom reported that his self-confidence was “through the roof lately.” Mom attributed some of the changes in his behavior to being more engaged in the process.

He was off in his imaginary world and didn't know what they were doing with him. He needs to know why he's doing something and he gets excited about it. He is so proud of his accomplishments now. He sees the difference in himself. - KSS2 Mom

KSS2 continued to challenge himself even at home. Mom reported he is still exploring what he can do now that his range of movement and confidence has

improved. Some abilities are pulling himself up to kneeling to open doors, climbing from his wheelchair into the car and pulling himself into kneeling position at benches of different heights. All this is without any prompting from the parents.

This sense of empowerment and confidence in himself was also noted with KSS5 as he showed the desire to challenge himself. During an interview with his mother, I noticed KSS5 out of the corner of my eye balancing between two chairs.

Look Ms. Jill, I can stand up on my own – watch, 1, 2, 3. – KSS5

I praised his accomplishment and then continued the interview with Mom but I could see him continuing to practice standing on his own without his hands on the chairs. Soon he said,

Excuse me, Ms. Jill – I can do it more! 1, 2, 3, 4, 5, 6! – KSS5

Before I could finish another sentence KSS5 was at it again,

Okay I got it. I can make it to ten now. 1, 2, 3, 4, 5, 6, 7, 8, 9, 10! – KSS5

While he said those last few digits in rapid fire, I saw that he stood taller, with his shoulders back, proud of his accomplishment. This ability to challenge themselves, for the boys, was often encouraged by their desire to show off the “new skills” they acquired as a result of LT. At the end of the LT program, the parents reported their boys were coping positively with their life situation.

On a regular day – I’m surprised he’s as happy as he is – dealing with everything. His strength that will carry him very far – the fact that he thinks he can do anything. Even if he is in a chair the rest of his life he thinks he can do anything now! - KSS4 Mom

Child Coping

Each of these young men found a way of coping through out the rehabilitation process post-iSCI. Coping is the process of managing difficult circumstances through

the use of specific behaviors that attempt to alter an external environment or utilizing cognitive strategies to refocus interpretations of existing environments (Gorski et al., 2005).

Initially, the parents of KSS participants all reported their child's coping as a sense of control. One way some of the boys found control in their initial recovery post-iSCI was through refusing or limiting what they ate. This regressive behavior is common for children with SCI as they attempt to introduce their own level of control into the situation (Molnar & Alexander, 1999). KSS2's mom reported he was not eating or drinking after the accident, because everything was monitored and "all this stuff was shoved at him" and food was the one thing he could control. KSS4's mom reported her son turned to negative coping strategies as he pulled his hair out during bouts of frustration associated with his life situation.

While parents also reported their children had positive coping strategies. KSS2 has a "fabulous imagination and is full of energy" that keeps him going even on the toughest of days he "just wants to be with his friends and just be a kid." One positive coping element for these boys is their families.

I don't know - but we say all the time he is totally our role model. He is four but he is our role model - he handles it better - there are days when he has had enough - but he is four and we just handle it - we just try to tell him this is only going to help him. In the beginning he didn't like the rehab and they were making him do stuff and we just tried to explain to him it is only going to help him. We worked to keep him up beat. Our whole family pulled together during those first few months. -KSS3 Mom

The literature confirms that positive adjustment of children with SCI is often reflexive of the families' ability to handle the stress of the situation and is often influenced by family support, positive family coping strategies, personality type of the child, peer interactions, and involvement in family and community events (Gorski et al.,

2005). Research further indicates a supportive rehabilitation program positively aids in the adjustment to SCI (Gorski et al., 2005; King et al., 2007).

The therapists with the KSS worked to reframe the negative coping strategies while at the same time, encouraged the adaptive methods of coping. The KSS team tried to meet the child's need for control with a positive outlet for increased independence in the actual LT process. The therapists worked with each child to allow him more control over the rehabilitation program, by offering him opportunities to either walk or run, or provided him with opportunities to select the activities to do during standing bouts. The control was then placed back in the child's hands.

The ability to cope with disability at a young age can be daunting (Gorski et al., 2005). These boys displayed both positive and negative ways of coping. One child tended to keep to himself and then explode either at his family or with the trainers in the lab when he hit his limit. Others tried to keep a positive attitude while coping with his challenges and often the boys would turn to their family for encouragement and support.

He has a very positive attitude, I don't know how much denial is going on because I don't know how much he really knows what a SCI is. I think he copes by doing, you know like on the swing set. His upper body strength is great and he will try to show others how he can climb over and do things upper body strength. He goes above and beyond because it makes him feel normal you know like everybody else. And I think in a negative way he will remove himself because he knows what he can do like if everyone is playing tag he will go play video game. - KSS5 Mom

Each of these young men have strengths and weaknesses in their persona that make them who they are and shape how they deal with the rehabilitation process and with their disability in general.

Strengths

All these boys are fighters – they are determined to be the strongest, funniest, or smartest kid they can be. KSS4’s mom calls this his ‘I can do anything attitude.’ Other strengths described by the parents include: positive, outgoing, sense of humor, happy, intelligent, great imagination, empathetic, ability to get along with others and a desire to just be a kid.

His strength that will carry him very far – the fact that he thinks he can do anything. - KSS4 Mom.

These strengths are also utilized as coping styles by these young men. KSS5’s Mom reports that one of his strengths is his positive thinking and intelligence – which is incorporated into motivation and determination as it relates to his LT.

He has to understand what this program is going to do for his body – with the strenuous therapy it helps to have the desire to be better. - KSS5 Mom

Weaknesses

The child’s weaknesses tend reflect a barrier in the rehabilitation process. KSS5’s Mom reports his temper gets the better of him and when he “gets down” about his life situation he “gets really down.” While KSS2’s Dad reports one of his son’s weaknesses is his inability to fully understand the purpose of the KSS and rehabilitation in general.

Like how do we get him to take this very serious while we are here and how do you explain that to him – he is only 5. He just wants to play with his friends and be a kid. - KSS2 Dad.

Another parent reports her son’s weakness is he doubts himself and his abilities. This self doubt may be based on previous experiences of the child and his inability to think more abstractly and how science may be able to change those legs that won’t move. KSS4 reports,

My weakness, I think, is I can't walk. That's my weakness – I can't you know.
- KSS4

Regardless of the weakness, the KSS team focused on getting to know each child as an individual and took into account the various physical, psychological, social and emotional needs he may have. The team was determined to understand the child as a whole. One benefit of this holistic approach was the therapists' ability to work with the child and the family in finding creative and effective ways to motivate the child during long training sessions.

Child's Motivators

The parents were one of the best resources for information on what motivates the child. The KSS team attempted weekly meetings with the family and all the primary trainers involved in his care. These meetings allowed the team to update the parents on the child's progress and allow the therapists' time to tap into the main resource of information for this child: the family. The family has a wealth of information on the child's abilities, motivators and experiences that can be important to his rehabilitation program (King et al, 2007; Goldstein et al., 2004; Majnemer & Limperopoulos, 2002);

The parents are a huge information resource on their child. What makes a child tick - he will respond to this kind of thing or that - giving you insight into what motivates him. Knowing those kinds of things helps us in how we approach his treatment. – PT1, Principal Investigator KSS

For each child those motivators vary – based on his personality and experiences with rehabilitation prior to the KSS. Some of these motivators included: playing “hoops,” coloring, stomping on bugs on the treadmill, video games after training, stickers, treats, bubble blowing and verbal praise from the team and parents. As one parent said it can be different “day to day – he's a kid, it can be unpredictable” KSS3 Mom. The important component for the KSS team was that they are willing to get to know each child

personally and find what worked best for him. Assessing these motivators and any attitudinal issues related to child's disability can lead to more successful rehabilitation outcomes (Goldstein et al., 2004; Lawlor et al., 2006).

Child's Role in Kids STEP Study

Despite what motivates a child to participate in the LT, the KSS considers the child to be an integral part of the team. This role is defined differently by the child, the parent and the therapists involved. The children involved in the KSS are there to be a kid. They want to have fun, play and spend time getting to know the new people they meet. The parents expect their child to listen, behave, and follow the instructions of the KSS team during the training. One mom also noted the importance of her child being a student while he was in the program, to learn more about his body and what it is capable of doing.

For the most part, the physical therapists are on the same page as the child and family. Their main goal is for the child to just "be a kid." In addition, they expect the kids to follow instructions, play and have fun with the process. PT1 explains,

We may ask them to engage with us at times but not like a willful thing like you have with an adult. - PT1, Principal Investigator, KSS

While PT2 further emphasizes the need to keep the training age appropriate,

We don't have expectations but we want them to do the best they can within the context of being a kid – that he is respectful, listens, that kind of thing. – PT2 Project Coordinator, KSS

The child's overall purpose in the KSS is to just be himself and participate willingly in the training. The KSS team works to keep the children engaged in the process and keep the rehabilitation experience fun. Through this involvement in LT, many benefits to the child have been identified.

Perceived Benefits of LT

One of the five participating children was able to walk with a rolling walker as a result of this LT program. Another child entered the program already walking with a rolling walker, but showed signs of improved strength and walking ability after participation in the LT. Regardless of the ability or inability to ambulate after completion of the KSS, a number of other benefits of the LT were reported by the children, the parents and the therapy team. The physical benefits reported include: increased blood flow to the lower extremities, increased muscle tone above and below the level of lesion, increased fine motor skills, improved ADLs, increased appetite, a reconnection with the mind and body, improved stepping, standing and arm swing, improved weight bearing and loading, improved balance and improved bowel/bladder sensation. In addition to the physical benefits participants reported psychological, social and emotional benefits to the LT program including: improved self-confidence, a return of personality traits not seen since the iSCI; including: risk taking, restored confidence to try new things, and restoring the family to a new sense of normalcy.

After the accident, we were grieving the loss of our son, because he wasn't the same kid that he was before the accident. Before he was a daredevil and he would try anything. He jumped out of trees and scratched his knees up and he was a total boy and then after wards he was just afraid of everything. - KSS1 Mom

So his personality changed. - Jill Heilman

YES!!! He was... He thought will I get hurt if I try that or what if I get off the couch this way or will I bang my head. Now though - (mom laughs).
- KSS1 Mom

Do you think the training here has helped that? – Jill Heilman

Oh Yes, Definitely!!! Because it helped his balance and it helped him feel so much more confident about 'I can control my legs now,' and 'I can walk away if I need to.' They (The KSS Team) gave me my son back! - KSS1 Mom

Summary

Locomotor training as a therapeutic intervention provides a new opportunity for recovery in children with severe, chronic iSCI. This concept of recovery of function has provided these children and their families with a renewed sense of hope in the long-term prognosis of the child. The KSS has shown to make dramatic changes in the psychosocial issues relating to the participating child. Through a combination of the actual LT program and the interaction with the therapy team, the children have developed a reconnection between their mind and body below their level of lesion. This reconnection has given these boys a renewed self confidence in their abilities and provided them with a sense of empowerment in rediscovering who they are and what their bodies can do.

CHAPTER 6 FINDINGS: FAMILY DYNAMICS

Introduction

This chapter will discuss the findings of the present study as it relates to the family of the children participating in the locomotor training at the Kids STEP Study. These findings are based on interviews and observations with at least one family member of each child.

The Kids STEP Study: The Parent's First Impression

The parents of the children participating in the KSS began contact with the program months prior to their child's arrival to the University of Florida. These parents sought out this research study as they were advocates for their child. They were the ones' who focused on what their child's body *could* do rather than focus on what it could not do. We first met the parents with the child and sometimes the siblings in the lobby of the hospital ready to acquaint them to the world of research and all their child would be doing over the next four months

As we entered the KSS lab, the parents began to focus on the enormity of their child's participation in a research study that could eventually lead to their son walking again. The first thing most parents spotted as they entered the room, other than the huge apparatus their child would be suspended in, was a poster presentation on one wall. This poster highlighted KSS1's initial study which resulted in the walking recovery of that child. "Is this the child that first started up this program?" KSS2's mom asked that first afternoon in the lab – curious if her son would be the next.

Initially, most parents said they brought their child to the KSS with no expectations trying to hide their hopes inside and protect themselves from disappointment. But as

the program progressed, each family began to open up about their true desire to have their child walk again.

Mentality of the Parents

The families came to the KSS with an optimistic attitude towards their child's recovery. They saw the potential in their child and they were determined to find others with a similar perspective.

Traditional Clinical Perspective

These parents are acutely aware of their child's physical capabilities despite some of the pessimistic perspectives they previously encountered. Each parent came into this research program optimistic that their young child's body had the potential for recovery of function. In some cases, these families had to overcome negativity of those in the medical profession during acute care and throughout the rehabilitation process.

There was one guy we called the Grim Reaper (laughs) he was a young guy which was interesting and he just, I will give the example: I was in the ER and they brought KSS2 in and this is the first time I saw him and he was lying flat and and he had a neck brace and all he could move was his little eyes and mouth and he was just so scared (mom became emotional). - And the man met me and said 'I won't lie to you this is a very serious injury and this could be what you have the rest of his life' and points to KSS 2 on the stretcher.

We noticed KSS 2 started having his reflexes come back and he was playing a playstation game and his legs would move ...and the Grim Reaper said "You are in the top place for all this" "You might see something in 72 hours but after it, that is it" I was like KSS2 was lying there and and I was like "f@*k you," well in my head. And he said 'people mortgage their house for stem cell and all and it's a waste.' - KSS 2 Mom

KSS2's mom was a lot like the other parents' in this study. She had a sense that there was more to her son's injury than what some of the medical professionals were indicating. She had seen the movements in her child's lower extremities and had hope that a connection was still there. This mentality of knowing the capabilities of their child

is coupled with the parents' instinct that science is continually progressing and the treatments for iSCI are constantly expanding.

At first we thought, with the spinal cord you only have so much time and then his body won't change anymore, but now I just feel like it is an on going process. We don't know his potential lifelong. This is only what he has shown us in 6 ½ years, but who knows where he will be. I got very depressed at that one year mark but then 6 months later he started to wiggle his toes. It wasn't like Run Forest Run and your braces fall off - it was just putting him in the car seat, just he and I, and I saw his little toes move! - KSS5 Mom

After that day in the car seat, KSS5's Mom saw that those labels and guidelines the physicians gave them, were not necessarily the true path for her son's iSCI recovery. At that point she began to comprehend that science is not black and white, but rather many shades of gray and the contrast in gray varies patient to patient, injury to injury. It gave her a sense of hope that her young child had more potential for recovery of function.

Sense of Hope – Optimism

Hope has long been accepted as an essential component of human development (Erickson, 1964; Stephenson, 1991). The concept of hope is defined as a prospective orientation toward future improvements (Lohne, 2001). Within the literature, Turner (2005) and others identified several constructs of hope: futuristic (Holt, 2000); motivating (Stotland, 1969); self-sustaining (Hall, 1990); pervasive (Cutcliffe); action or goal-oriented (Farran et al., 1995); necessary to life (Obayuwana, 1980); and involves expectancy (McGee, 1984). These constructs of hope are evident in the families whose children participated in the KSS.

Each family had an instinct to look beyond the initial prognosis from the professionals and refocus on the potential for future improvements in their child's

functional ability below the level of injury. They were motivated that this newer form of rehabilitation, LT, would provide the hope that their child would continue to show improvement.

The more we are doing for him, the more he shows us – it gives us hope. - KSS2 Dad

Hope was the thread that held the families together during some of the most difficult times. These families expressed a passion to try new treatments while their children were young – hoping their body could repair itself. All the families emphasized the fact that they would not tell their son that he would never walk again, often explaining

They (the doctors) don't know what there is for him in the future - how medicine is always changing. He is so young we can't say never to him. We just keep that hope out there. - KSS3 Mom

These families repeatedly expressed their desire to stay positive and optimistic as it relates to their son's prognosis. KSS1's Mom explained the importance of staying positive as her son often fed off her own attitude.

If I had a bad day, he would have one. If I had a good attitude that day, he often did to. So I just did my best to stay positive throughout the entire time we are here – well I guess in all of life (laughs). - KSS1 Mom

This sense of hope and optimism was often grounded with a realistic perspective of their child's abilities. All of the parents educated themselves on the severity of their child's injury and all of them became the primary advocate of their child during rehabilitation. However, they continued to hold on to some level of hope even if their child was unable to walk as a result of this form of intervention.

We still feel like he will walk one day. To me it was the start of this program - that - I had no idea until I found you all that I ever knew there may be something out there that could help his body and his movement.

But with the start of this program – I don't know – now that we are leaving - of course I know it's not going to be that way (walking recovery) – but I feel like it's a little bit coming back and I think more will.- KSS4 Mom

Holding on to a sense of hope does not have to show an immediate response, hope allows for events to unfold in their own time (Turner, 2005; O'Hara, 2001). These families developed a new awareness of the potential for their child's ability while at the KSS. Whether the child walked or not as a result of the program, each of these families maintained an optimistic attitude towards their child's future potential.

The family's hope for recovery is often the first source for the child's own hope as it relates to his health (Russinova, 1999). Further, the literature highlights that hope and recovery are often interconnected and hope itself is often the starting point for recovery (Russinova, 1999). The family's renewed sense of hope may be the starting point for their child's recovery and acceptance as it relates to his iSCI.

Family Coping Mechanisms

This sense of hope is one of the driving forces for these families as they navigate through the world of iSCI. This hope for a healthier, stronger future for their child allows the family to better cope with the uncertainty of his long-term prognosis. These families sought after a realistic perspective of their child's prognosis with a hint of optimism and that sense of hope can be viewed in as a positive coping mechanism for them all.

These families displayed other positive coping mechanisms as they relate to their child's disability and rehabilitation after iSCI. Some of these coping mechanisms included: cognitive reframing, support systems, financial and material resources and protective walls.

Cognitive Reframing

Cognitive coping strategies are ways families may reframe their perceptions of a difficult life situation (Summers, Behr, & Turnbull, 1989; McCubbin Caulble, Comeau, Patterson, & Needle, 1980). For example, KSS1's Mom reported the importance of her husband's perspective after the accident in coping with her son's disability.

I remember saying to him "why couldn't it of been just a couple of inches below where it is now, because then he would have had full use of his hands, why?" and he said to me, he is really good making me think differently, he said, "what if it had been just a little bit higher her would be on the ventilator." I said, "your right," I mean, he would say you need to stop thinking of the past and start thinking of the future and what he can be instead of what he once was. – KSS1 Mom

Other families utilized cognitive reframing throughout the rehabilitation process. KSS4's mom was dealing with the severity of her son's cancer and whether he would survive his illness. In that context, she was able to accept his iSCI more easily than if it had been his only medical issue.

Support Systems

Another method of coping for these families was through their extensive support systems. All the families expressed the importance of the physical, emotional and financial support they received from their families, friends and communities. The primary support for each family was the parents, grandparents, aunts, uncles, and siblings, all who rallied when needed. These families were not only there for the child during the initial diagnosis but they have continued to maintain a strong support system through out the ongoing rehabilitation process.

Three families had relatives travel to the KSS to support them through the four-month program. While four of the families shared their reliance on their faith and the prayers of their friends and families back home. All the families reported the strong

support of friends back home, that offered to help with the spouse and siblings that did not travel to the program. When asked who she considered her support system,

KSS3's mom stated:

Uhm, I would say everybody, parents, brothers and sisters, aunts and uncles to great grandparents. I mean it was just that they wanted to help- the church my husband went to growing up they totally offered to bring in meals, give us rides and we weren't involved with them at the time. I mean it, just anything we needed and they still are there for us. They all constantly provided us support. It means so much. – KSS3 Mom

It was evident that each of these families had a strong emotional support system in place, prior to arriving at the KSS.

Family Resources

By contrast, each family had a different set of financial and material resources available. Two of the families were more financially stable and able to provide for their child's disability in regards to equipment, treatment options, healthcare expenses and so much more. One of the families that had been in a motor vehicle accident had more resources available than the others as the auto insurance provided a great deal of coverage. That particular family had not been denied any resource requested for their child.

Unfortunately, this was not the norm for all the families. The others often had to fight for their child's rights to proper equipment and needed outpatient therapies. Further, some of the families were still paying off their child's initial hospital and acute care stays. In fact, the one of the most frequent complaint of having a child with iSCI was negotiating the insurance companies.

Protective Wall

Coping for these families was not always a positive experience. Some of the moms reported difficulty in fully sharing their experiences with family and friends. They knew how much information they were willing to share with others, and then they would put up an emotional wall. It was still painful for these moms to discuss the stories behind their child's injury with me, but they explained it is more difficult sharing with people who had not personally experienced the challenges they faced.

Unless you have been through it, you don't understand. Like with your daughter you must know how difficult it is to watch your child struggle and suffer. You just want them to be happy and to be accepted by their peers. Unless you have been through that as a mom – you just don't get it. My friends back home and even my family can't truly get what it is like for my husband and I. They try. - KSS1 Mom

Other moms expressed that same feeling, as they described their lives with a child with iSCI as a “constant roller coaster of hopes and disappointments” throughout the recovery and rehabilitation process. One mom explained her ability to deal with her son's rehabilitation as,

I put up a wall. I just can't go there in my mind sometimes. I take what comes, deal with it and move on. It's hard to think about everything at once.
- KSS4 mom

KSS5's mom shared her apprehension in discussing her son's future:

I don't think I let myself go that far into the future with him. I don't know if that is self protective. You know the girls I think college, getting married, starting a family. For KSS5 I stop. I think about him walking I think about his physical situation on how his goals go. I want to start thinking dating, high school or a car. But then I don't want to go there because what if he can't? What if he is in a wheelchair or can't drive? I just don't go there. - KSS5 Mom

Coping is different for every person, but these parents share the commonality of all having children with iSCI and this study found many of their coping mechanisms to be similar. Further, the KSS provided encouragement in these coping areas, whether it

was through the support of a “surrogate family” while they were in the program or through a referral of resources to get the necessary equipment needed for home. This will be discussed in more detail in Chapter 7.

Role of the Family: “The Home Team”

These families take seriously their role as primary caregiver. Within the medical system, the parents know: they are their child’s advocate; they are responsible for all the decisions regarding their child’s care and treatment; and they must educate themselves in all areas of their child’s disability. Their primary concern is for the health and safety of their child and the impact any form of treatment will have on him in the short-term and the long-term.

I am his mouth piece, his investigator, his motivator, his facilitator. We don’t just stop here (at the KSS). We go home, do stretches, put the ankle things on, do the stander, investigate - is this something that will help him, or is this something that is going to hurt you – will this have long term damage, not just physically but I have to consider emotionally and not just on him but how does impact our whole family. - KSS5 Mom

These parents also feel a sense of responsibility for being the advocate for their child, a responsibility to do everything possible for him. They are “the voice of their child.”

Advocate for the Child

Being their voice is being their advocate. Merriam -Webster’s defines advocate as one who pleads the cause of another or one who supports and promotes the interests of another (2009). All the families involved in the KSS were strong advocates for their children. If the parents felt their child was not receiving the best treatment possible or if they felt the medical staff was not listening to them they would find

alternative treatments. KSS3's family explained they were not happy with the initial rehabilitation facility their son was sent to.

We weren't happy with what he was getting. We were not happy with what they were doing. It was like we were telling them certain things we saw him doing and they weren't listening. So we found an even better facility and from day one at the new place we learned more in that first day than we had a few weeks at the other. They listened to us – they involved us. - KSS3 Mom

Each family took a stand for their child and his care. It was as an advocate that these parents came to the KSS. Each family sought out participation in the program knowing it was their role to explore rehabilitation options. As an advocate, these parents, not only found treatments for their children, but they also supplied resources once they returned home. After the completion of the KSS the families requested treatment plans to take to their therapists back home to maintain as much consistency in treatment.

Will they give us a discharge report when we leave? I want his doctors back home to know what you all have been doing and keep them on the same page mentality wise with his treatment. - KSS2 Mom

These parents took the initiative to build on what they learned of their child's potential abilities at the KSS and worked to maintain that once home. Some things they put in place for their home were: ordering a dynamic stander, building a bench for kneeling, ordering a lite-gait treadmill and remodeling a bathroom to allow for the child's independence.

We ordered the dynamic stander already. He loves being in that thing... being able to look his brother in the eye and I know it will help with the weight bearing, he needs that. It should be there by the time we get home. We also ordered a bigger lite-gait so he will use it now. - KSS3 Mom

Education

The parents took advantage of the wealth of information available during the KSS program. KSS2's Mom shared she "took something from each rehabilitation program" her son participated in. She explained, the KSS taught her to give her son more opportunities for weight bearing and loading. In addition, she learned the value of providing her son more opportunities for independence as she saw him challenge his own body when given the chance.

A reoccurring theme with the participating families was education. They all had an intense desire to learn from their child's experience at the KSS, to make the most of this research study, and to take that knowledge gained home to better serve their child.

I watch and learn. I want to learn. This is fascinating to me. I want to help him be the best he can possible be. - KSS4 Mom

Challenge the System

These are non-traditional parents. They want to learn from professionals in the field of medicine, but they also want to question them. KSS1's Mom explained when her son was in a children's rehabilitation hospital the professionals told her,

This is how it is going to be and I said, well I am not going to accept that. I am sorry you can say give him the adaptive silverware, you know they wanted to give him all this adaptive stuff and my husband said why are you doing this, you haven't even tried the regular utensil. – KSS1 Mom

KSS1's Mom questioned the rehabilitation therapists– "why were they stretching his legs and not his hands" she would ask herself. Mom was told based on her son's level of injury he would never have functional use of his hands. Therefore, they explained, it was in his best interest to allow his hands to tighten into a ball so he could use adaptive devices. Mom did not accept this explanation and every evening she would go back to his room and stretch out his hands. When they returned home, Mom found a therapist

with a mentality similar to hers. KSS1 is now in fourth grade and writing cursive. Mom reports he even got A's in handwriting. Moms know their children and this mom listened to her instinct on what was best for her child, despite what the medical system presented her.

Challenging the system was evident with all these families. They love their children and want to find the best treatment possible for them. KSS2's Mom explained:

At home you are the victim. You just take what they tell you and do as you are told. I have never been that kind of person. I am the more dynamic - I say screw the system. I wouldn't like to be his primary - but the thing is nobody is going to care as much as we do. – KSS2 Mom

This concept of challenging the “system” is coupled with the parents' desire to provide the best possible care and their sense of responsibility for making major life decisions that will impact their child's health condition in the long-run. As KSS3's mom explained, “we don't want to look back and say we wish we did that.”

Altruistic Attitude

Being a part of the KSS has been a commitment for these families: a commitment of time, a commitment of resources and a commitment of their child. Each family found participation in the study to be healing. This was true despite the sacrifices they made to be part of the program. KSS1's Mom expressed her excitement that so many other boys are able to participate in the LT as a result in the outcome of her child's participation.

To think that one phone call to PT1– and now look at where we are. It's like icing on the cake after everything. - KSS1Mom.

KSS2's Mom was grounded in her perspectives towards her son's prognosis. By the end of the KSS she realized walking recovery may not occur in her son.

He's not walking now. But he has improved. It's exciting to see what he has gained in just the past two days. I want to show the doctors and therapists back home that he has made some significant progress towards rehabilitation that he would have never got if he hadn't come here. - KSS2 Mom

This mom sees her son's rehabilitation as an opportunity to change the mentality of the medical professionals in her home country. To show them there is an opportunity for some level of recovery after an iSCI.

Another mom shared her excitement towards being part of such ground breaking research.

I think it is unbelievable and I hope with KSS4 and with other kids you are looking at you find a way to help kids like him. I am just glad to be apart of the KSS. Even if it's mentally I think he will benefit from it – yeah physically and mentally. I guess I just hope you can get every thing you need from KSS4 to help other kids. I just hope it helps other kids too. - KSS4 Mom

The mother of KSS5 expressed the contrast between the LT programs in Florida compared to the LT program in Kentucky. The Kentucky program she explained was strictly rehabilitation while the KSS program was both research and rehabilitation driven. Her emphasis was on the fact that not only would her son benefit from the intervention itself but she would learn more about his actual injury. Further, she expressed the cathartic feeling she had that her son's participation in the KSS would also help so many other individuals with SCI.

There is something about being part of something bigger than you. - KSS5 Mom

Summary

The families that seek out a rehabilitation program in the research phase are the families that are already going above and beyond for their child's well – being. It takes an enormous amount of energy to survive the diagnosis and regular care and treatment

of a child with an iSCI. It takes that much more from these families to leave their homes, families, jobs and lives to commit to four months of therapy for that one child.

These families have a unique perspective towards their child's disability. Despite being told their child will not walk again, they hold on to a hope that science and new forms of treatment may offer their child more functional recovery. They view rehabilitation as an ongoing process and their child's level of injury does not dictate his ability to recover. Rather, science and medicine are continually changing and their children are too young to definitively define their limitations.

The parents' mentality for recovery is grounded in hope, and it is this hope that helps them cope with the uncertainty of their child's future. Coping with a child with iSCI can be daunting, but these families have chosen other positive coping strategies: including cognitive reframing, relying on strong social supports and an internal desire to "open doors" for their child's functional recovery.

Throughout the entire rehabilitation process, these families have taken their role as advocates seriously. The parents feel a sense of responsibility to provide the best possible treatment for their child. They have educated themselves in the LT process and supported their child to the best of their ability. Further, these families' feel a sense of pride in their son's participation, knowing he is part of something bigger than himself. They know his rehabilitation, whether he walks or not, will benefit other children with iSCIs. This altruistic attitude is one thing that seemed to provide the parents meaning to their life's situation.

The KSS is offering an opportunity for recovery, which in turn offers a renewed sense of hope to these families. The entire therapy team shows a sense of

responsibility to help this child and the entire family. LT is a non-traditional form of rehabilitation and no guarantees are offered. However, it does allow families an opportunity to explore new avenues for their child's care. When KSS1's mom was asked if there was a fear of putting too much hope into this rehabilitation program, before they knew the outcome, her response was "No, because at least I know that I tried everything I could to make him the best person he can be both physically and emotionally."

CHAPTER 7 FINDINGS: THERAPY DYNAMICS

Introduction

This chapter will discuss the findings of the present study as it relates to the Kids STEP Study's therapy team. These findings are based on interviews with the primary therapists in the program, observations in the KSS lab and feedback from the parents and children on the KSS Team.

KSS Program Dynamics

KSS – Kid Friendly

The KSS team worked to make their program “kid friendly” and tried to create an atmosphere inviting to incoming patients. They painted the walls of the lab blue in the attempts of softening the sterile hospital atmosphere. In addition, the team decorated the walls with posters that reflect the interests of each incoming child. As only one child goes through the program at a time, there is flexibility in curtailing the program to each child's specific interests. Before the child arrives, the team takes an informal interest inventory on the child; i.e. favorite color, best friend, favorite treats, and some of these “favorites” were incorporated into the KSS atmosphere. Orientation was often geared towards the child's interests. In one instance, KSS2 reported he loved anything military and camouflage. His orientation was centered on a military operative, his mission, to identify his team, map out the hospital and locate various stations throughout the “battle field.” General Behrman, Commander Fox and Lieutenant Heilman guided him on this mission. The KSS team embraced the “theme” of the experience and worked to make the entire four months relevant to that child.

The KSS team worked to keep children motivated during the LT and tried to keep things fun – after all, as PT2 explained “they are just kids – they just want to have fun!” The fun during training included: bubble blowing; coloring; stickers; stomping on chalk drawn bugs on the treadmill; puddle splashing in over-ground walking; costumes; humor; music; and so much more.

KSS1 loves her. PT1 doesn't have kids, she's goofy, she's crazy, he loves her. What they do I am surprised by not having kids how great they have all acted with him, like some of the guys are like kids themselves. They like to have fun and be goofy and stuff. But I think just kept him focused on the task at hand but not so serious I mean, they still let him be a kid. - KSS1 Mom

KSS Therapist Perspective

PT1, KSS Principal Investigator, has been a Physical Therapist since 1980 and has been working in the area of LT research since 1997. However, PT1's primary experience with LT research up until contact with KSS1 was with the adult population. She brought KSS1 in initially on an adult study in hopes that they could learn something from this young child.

PT2, KSS Project Coordinator, has been working in the area of LT research since 1998. While her focus with locomotor training had been primarily with the iSCI adult population, PT2 had done work with a child with cerebral palsy training on the treadmill prior to her involvement with KSS.

Child vs. Adult in LT

One aspect the research team hoped to learn from the KSS was how children approach the task of LT different than the adult population and how that difference may impact the outcome of the intervention.

The child typically comes without preconceived expectations about walking, the process, etc. An adult comes in thinking ‘this going to work’ and ‘it is

going to take a lot of effort' and 'I should work very hard.' Adults put in a lot of cognitive effort. The child puts in what they are already doing in life. They are playing, pretending, their energy level is so high, his imagination so many elements they all play a role in their rehab. We are looking at the neuro system. Walking is not a cognitive process and we don't want them think too much. The kids also have the whole role of the family involved in the process. - PT1, Principal Investigator, KSS

This difference in cognitive processing is unique in the pediatric population, especially with the younger children (under 8 years) (Almqvist et al., 2006). These children have not fully grasped the enormity of their disability and they tend to approach the rehabilitation process as another time to play. Understandably they did not view LT as typical play, but they brought their energy and imagination into the experience just the same. The therapists were able to tap into this ability to distract the child from the cognitive process of walking when necessary and then brought awareness to the child when focus was required (i.e. in posture, alignment, concentration on moving lower extremity). PT1 did express a similarity between the adult and pediatric population.

There is a piece similar between adults and kids, when they make an improvement. They are able to transfer their acquired skill out into real life situations. They take a skill they learn in therapy and transfer it over in their everyday activities. They start to get it and work on it outside the lab. – PT1, Principal Investigator, KSS

This component of recovery was discussed in Chapter 5 as the child challenged himself in every day life on the new skills acquired in training. A qualitative assessment of the adult population reported this finding and termed it a sense of empowerment (Hannold, 2004). Hannold described the therapist roles as multifaceted: “coach,” “teacher,” and “therapist” (2004).

Therapists' Role in the Locomotor Training Process

As with the child and the family, the therapist has a specific role in the LT process. The obvious responsibilities include: recruiting participants, training therapy team,

coordination of team members, facilitating training sessions, providing experienced sensory input during training bouts, ensuring the safety of participants, and maintaining the integrity of the science behind the training. However, in working with children, the therapists of the KSS expressed a stronger sense of responsibility for the welfare of these young patients.

I think the most difficult element is an emotional one - feeling responsible for a child's well being and safety. The family has come here and entrusted their child with me. This is very different than working with adults. They are responsible for themselves and now this is a vulnerable population. The vulnerability in this population is strong and my role is to protect child – from testing to intervention. - PT1, Principal Investigator, KSS

Further, the lead therapists in the KSS, PT1 and PT2 expressed the importance of effective communication with all members of the team, including the child and the family, to maintain a strong training program. The therapists considered the child and family as critical parts of that team.

KSS Team – Second Family

One unique aspect of the KSS team is the fact that they treated their participants like family. They understood these families were making a significant commitment of their time and energy. Being away from home can be difficult for the participants so the team created a sense of family within the program. The KSS team worked to identify the needs of the family during their four month stay and assisted the families in locating resources to meet those needs. The team conducted weekly “check ins” with the families to keep the lines of communication open. Information communicated in those meetings included everything from how the child and family were coping emotionally to the impact of the training program itself.

Everyone here is so hospitable and welcoming - like yourself. You have opened your lives to us, which is very unusual. It is sort of like

you throw your whole heart in to your work and I don't know how you all can keep doing that. The time here, it's been really - incredible. You are really great people. - KSS2 Mom

The families expressed appreciation of the team's willingness to go beyond the lab and making them feel at ease during their four month stay. .

It's a great team, very dedicated - there are hard workers on the team. KSS2 and the team – it's like one big family. This program is not something to be entered into lightly. It is a lot of work. But it is still something I am continuing to recommend highly and hope more children get the chance to benefit from. - KSS2 Mom

This sense of family is important to the team members as well, as PT2 remarked, “On a personal note, I adore him. We have a good rapport and that is meaningful to me.” This connection is felt by all who are involved in the study.

KSS – Team Effort

It was a team effort - it all worked out because they work together. One of the most important elements I believe is Claire (outpatient PT) and Sarah (LT Therapist and outpatient PT). They help him see he is in control of his body and his therapy. The best person for the job at the time is the one doing it, it doesn't have egos hurt. The fact is this team - you all just didn't give up on him. You know - that's amazing (crying). – KSS2 Mom

KSS team formed strong connections with each of the families involved in the LT.

The strength behind the KSS team is that each member of the team is valued and communication is the center of treatment. As a research program, the KSS is understandably an educational process. The team leaders are open to discovering what works and what does not. Feedback is received from all parties involved, including from the child, the family and the volunteers. The project coordinator held meetings with the LT trainers before and after each training sessions to maintain consistency and cohesion in treatment. In addition, the KSS team attempted to meet periodically with the parent to keep her informed and involved in the process. Involving

the parents in the rehabilitation process provides the family's sense of ownership over the treatment plan and gives more meaning to their child's therapeutic intervention (King et al., 2007; Goldstein et al., 2004).

We focus on empowering patients, even 5 year olds. I value every team member – even the janitor emptying the trash. I will stop to thank him, because he plays a role in this process. We all have a role and no one can do it alone. – PT1, Principal Investigator, KSS

This concept of team effort includes everyone in the process. Each person's role is supported and encouraged to maintain a cohesive and well functioning team.

KSS Team Mentality – Glass Half Full

He is only 5 – we can't confine these kids to a chair at this young of an age. Even if he doesn't walk after LT – we can't give up on him – science is always changing and we don't know what will be out there for him in 5 years and then he is still only 10! - Sonali, P.T., KSS

An overriding theme seen throughout this study was a mentality of hope and potential. The children reflected this in their innocence, the families displayed this in their love for their child and the therapists grounded this in science. Prior to coming to the KSS, most of these children had been assessed and classified by what their body was unable to do. As they entered the KSS, a shift in focus occurred for these patients.

In KSS2 parents' first meeting with PT1, she entered the room with a t-shirt with a half glass of water and the words "Glass Half-Full" written on it.

I told them 'this is how I see the nervous system – half full. Therapy in the world is opposite. Our emphasis is on the half full part and I am helping you focus on what your child has!' These kids are too young for giving up on.
– PT1, KSS

It is this mentality that drives the research at the KSS. The glass is half full mentality is embedded in the whole process: communication with parents, communication with child, communication with team, and the LT itself. This sense of optimism embodies the

team and their efforts. At one point, after asking PT2 whether she thought another incoming patient would walk as a result of the LT – her response was,

You know, I don't mean to be rude, but I am kind of tired of that question. I have to believe that every kid can walk, or I wouldn't be doing this type of research. If I believed a kid can't walk, then he probably won't walk. It's not like a faith thing, if I don't put forward that our goal for you is to walk fulltime, independently, over ground...then how can I get them to believe that and work towards that. – PT2, Project Coordinator, KSS

As mentioned previously, the families come to this program with the same mentality.

These parents also believe their child is young, and science is continually progressing in the area of walking recovery for patients with severe, chronic iSCI. At the KSS the family and therapists share similar perspectives on rehabilitation and recovery.

Mind/Body Reconnection

PT1 explained traditional therapy often has patients do a specific task during a session then the patient is sent home with specific tasks to further practice. The patient is dependent on the therapist for their thought process and rehabilitation activities.

While in the LT the patient understands what their bodies are capable of as a result of the heightened awareness during the LT sessions. The patient takes that confidence with them and tests their newly acquired skills in the real world.

Part of this heightened awareness patients are developing comes in part by the therapists' ability to encourage a reconnection between the patient's mind and body below their level of injury. All the parents reported their excitement during the training to see the team work at helping their children communicate with their legs and helping them concentrate on getting them to move. In turn, the kids developed a sense of confidence and control again over their own body.

On one occasion, KSS4 came into the lab ready to show off new movement he had in both legs. He sat on the edge of the therapy table, focused on his legs and slowly they began to move. He was beginning to get the mind - body connection and took pride in showing off these new skills. When asked how he knew he could do this, his response,

I just remembered PT2 talking about focusing on getting my legs to move, so I tried it at home and they started to move. – KSS4

KSS5's mom also emphasized this component of the program as she explained the KSS team talked to her child and taught him to focus on moving his legs during training and noted he would carry this over to activities outside the lab. One example of this was in the lab during LT:

I want you to think about it. Think about moving your legs. – PT2

Remember what PT2 said – think about your legs. - KSS5 Mom

Mom reinforced what was encouraged by the trainer. KSS5 remained focused and determined during this session. It became a real team effort between, therapist, mom and child. This type of interaction occurred often in the lab. PT2 worked on communicating directly with the kids, telling them to think about their legs and then reinforcing this by directing them to watch those movements in the various mirrors set up around the treadmill. The children have developed the ability to identify what their bodies can do and are encouraged to focus on their abilities.

Components of a Successful Locomotor Training Session

In addition to the mind set of the physical therapists involved in the KSS, there are several elements that constitute a successful LT session as identified by the KSS therapy team. One of the most significant elements is an organized, well prepared

leader and a well trained team. Providing the child with an experienced therapy team can lead to more successful rehabilitation outcomes (King et al., 2007).

Further, training sessions tended to run smoother with an experienced team. Regardless, of the level of experience, each therapist or trainer is expected to be present in his or her role and to be adaptable if roles need to change.

A LT session was also deemed successful by the therapists if they were able to provide the child with 30 minutes of stepping and 20-30 minutes of standing while on the treadmill. In addition, it was expected to have 10 minutes of over the ground training with the child, if applicable.

Throughout the training, therapists interviewed expressed an element of a successful session is a focused session. PT1 reported a key component in training is to be present for the child.

People get so automated but everything is about the child right now – you walk in the room and it's about him. You leave the world behind because this is their moment. – PT1, Principal Investigator KSS

Finally, a successful session is one where the kids have had fun, were engaged in some of the process, developed a relationship with the team and formed a level of trust with the team. The therapists also deemed a session as positive if they had provided a safe, fun and comfortable environment for the child.

Future of Locomotor Training

The benefits of locomotor training are evident in both the literature and the outcomes of the children in the KSS. While LT after iSCI is used in some rehabilitation programs, the therapists of the KSS hope to see it become standard practice and utilized as a rehabilitation tool to help recover walking after neurological injury.

Summary

The KSS provided a strong team dynamic as it relates to LT and children with severe, chronic, iSCI. The team worked to provide the child and family with solid, scientifically based treatments. In addition, they provide the family with the physical and emotional support needed to face a four month rehabilitation program.

The focus of the rehabilitation program was to determine the potential for walking recovery in these children and this focus was guided on the principle that the body can repair itself after injury. The physical therapists associated with the LT had a “Glass Half Full” mentality. They chose to focus on the child’s abilities rather than his disabilities. This mentality was also shared by the child and the family.

The KSS team provided these children with a new sense of awareness to their body below the level of lesion. The participants developed physical benefits as a result of the training but also developed a renewed self-confidence in their body and abilities. The KSS team empowered these young men to challenge their body’s abilities in the lab and outside the lab, in their everyday lives. The combination of the child, family and therapists’ perspectives and approaches to LT now leads to an emerging theory of adaptation for children with severe, chronic, iSCI, as presented in Chapter 8.

CHAPTER 8 EMERGING THEORY OF ADAPTATION IN PEDIATRIC ISCI

Introduction

LT as a therapeutic intervention opens the door to new perspectives on the adaptation of children with iSCI. This study examined the child participating in the LT, the family of that child, and the therapy team associated with the LT at the KSS. The participating children are learning to reconnect with the body they did not know could function. This connection has led to increased self-confidence and the exploration of their bodies' abilities. The participating families have focused on the hope and a future with the potential of walking recovery in their child. Further the therapists associated with the KSS support this sense of hope as they believe in the concept of neuroplasticity and the potential of the nervous system to biologically adapt to the loss of function after iSCI. This is a group of individuals not complacent with traditional rehabilitation and looking for new ways of dealing with pediatric iSCI.

Psychosocial Adaptation

Again, for the purpose of this study, psychosocial adaptation is operationally defined 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. (Livneh & Antonak, 8, 1997)

This study compared Livneh and Antonak's theory of adaptation to the participants in the KSS to determine if their phases were relevant to children with iSCI participating in LT. As discussed in Chapter 2, the phases of adaptation are nonexclusive, nonsequential and overlapping. According to their theory, an individual can be in one or

more phase at one point in time and it is not necessary to go through each phase to achieve successful adaptation to disability (Livneh & Antonak, 1997). As identified by Livneh and Antonak, adaptation to SCI is measured by the following standards: 1) degree of life satisfaction, 2) vocational or avocational productivity, 3) prevention of medical complications, 4) use of activities of daily living skills, 5) coping styles, 6) degree of disability acceptance and 7) degree of emotional stress. Within this realm, positive adaptation would be an individual's ability to accept his or her current limitations and work to reintegrate himself back into his daily life activities.

Theory Development

Livneh and Antonak (1997) present a formal theory of psychosocial adaptation to disability as defined by Glaser and Strauss (1967). Glaser and Strauss' Grounded Theory utilizes the constant comparative method of data analysis to form concepts, categories and themes associated with the data collected. There are two types of theory; substantive and formal. Substantive theory is developed from a specific area of interest, such as adaptation to iSCI after LT or adaptation to organ transplant in children. Formal theory is for a conceptual area of inquiry such as a thorough theory of adaptation to pediatric disabilities (Glaser & Strauss, 1967).

It is often best to begin with generating substantive theory from data and then let formal theory or revisions to existing formal theory emerge from the constant comparison of the substantive theories instead of using logic to deduce substantive theory from formal theory (Glaser & Strauss, 1967). More studies generating substantive theory will ultimately generate and/or improve on formal theory.

Background on Psychosocial Adaptation Research

In examining a child's psychosocial adaptation towards his or her disability, the literature unfolded itself in three layers. The first layer of the literature investigated the psychosocial adaptation to disability across various health conditions as it relates to the adult population (Dell Orto & Power, 2007; Bishop 2005; Smart, 2001; Livneh & Antonak, 1997). The second layer of literature examined the adaptation process for the parents with children with various disabilities, essentially assessing the impact a child's disability has on the family. (Vermaes, Janssens, Bosman, & Gerris, 2005; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999; Wallander, 1999; Rodrigue, Morgan & Geffken, 1992). Families with children with disabilities are at risk for depression and their level of social support can influence this factor (Manuel et al., 2003). Families with children with disabilities also reported financial strain and disruption of family activities as compared to families with developmentally normal children (Rodrigue et al., 1992; Theofanidis, 2007). The families' coping strategies and attitudes towards a child's disability can have an influence on the child's own ability to accept and adapt to his or her disability (Gorski et al, 2005; Lund et al., 2005). The third layer unfolded literature pertaining to the psychosocial impact a specific disability has on the children themselves (Qvist, Jalanko, & Holmberg, 2003; Patterson & Blum, 1996; MacLean, Perrin, Gortmaker, & Pierre, 1992; Rosenkranz, Bonzel, Bulla, Michalk, Offner, Reichwalkd-Klugger, & Scharer, 1992; McAnarney, Pless, Satterwhite, & Friedman, 1974). Children with chronic illness may experience: fear of rejection, low self-esteem, fear of restrictions, and anxiety on how others will react to their disability (Theofanidis, 2007). Adaptation to disability is influenced by the child's ability to understand his or her limitations and be involved in

the rehabilitation process (Theorfanidis, 2007; King et al., 2007; Goldstein et al., 2004). Further, social, financial and demographic factors can impact the child's ability to cope with chronic illness (Vogel et al., 2004; Qvist et al., 2003). Despite the saturation in the literature regarding the psychosocial adaptation to disability, the literature currently lacks a formal theory of adaptation specifically focused on children with disabilities.

Psychosocial Adaptation of Children with Severe, chronic iSCI after Participation in Locomotor Training

As previously discussed, a recent study formed a new theory of adaptation as it relates to the adults with iSCI participating in LT (Hannold, 2004). However, the impact LT has on the psychosocial adaptation of children with severe, chronic iSCI has not been evaluated until this current study.

Utilizing the constant comparative method of ground theory (Glaser & Strauss, 1967), a substantive theory emerged from the experiences, relationships and themes of the participants in the KSS: the child, the family and the therapy team. The combination of studying the impact LT has had on all the participants has led to a new perspective on adaptation. Figure 8-1 represents this emerging substantive theory of adaptation for children with iSCI participating in LT that surfaced from this research.

Input

According to Livneh and Antonak, all the KSS participants would be at some phase of the adaptation (shock, denial, anxiety, anger, acknowledgement, and acceptance) process prior to starting the KSS. The child participants were at least one year post-iSCI. The boys either through direct response, parent report or behavioral communication, reported some level of acceptance to the idea that recovery of function would not occur. Parents, prior to knowledge of LT and the KSS, reported an

acceptance of their child's limitations. The therapy team comes to the KSS with a different perspective than the child and family. The therapists, based on previous research, and prior LT experience with adult iSCI patients had optimism in regards to the recovery of walking after LT. In Figure 8-1, this prior level of awareness/acceptance to iSCI is represented as "Input." Each individual comes to the program with some level of expectation based on his or her prior experiences, level of knowledge of LT and neuroplasticity, environmental influences, level of social supports and attitudes towards rehabilitation (Lund et al., 2005; Simeonsson et al., 2003; Livneh & Antonak, 1997).

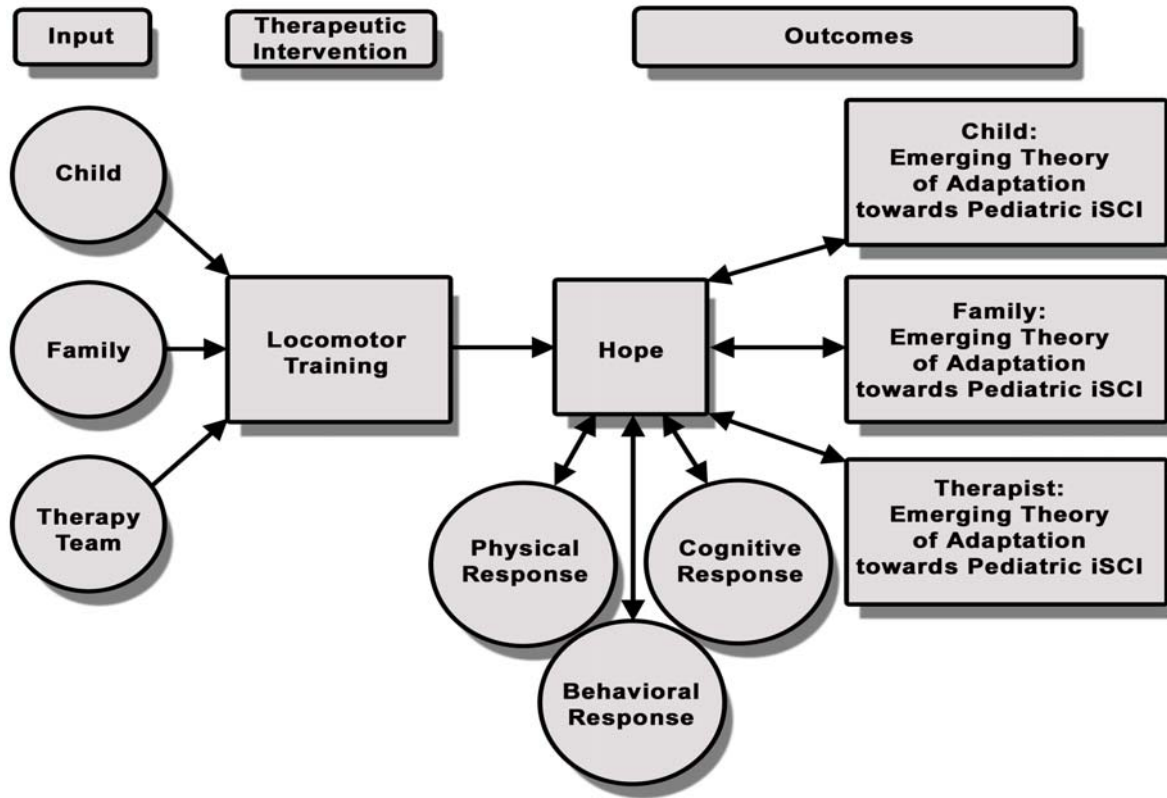


Figure 8-1. Pediatric Adaptation to iSCI after participating in LT with the KSS

Therapeutic Intervention

In Figure 8-1, the therapeutic intervention represents the LT implemented as part of the KSS. Within this model, LT encompasses 3 primary elements: 1) the intervention

itself as a therapeutic process; 2) the therapy team dynamics (grounded in science, kid-friendly, focused and trained team); and 3) education (teaching children a reconnect with their mind and body, educating the family and child of the potential for brain and spinal cord recovery – neuroplasticity).

LT has proven to stimulate connections within the nervous system as this therapeutic intervention creates stepping patterns that stimulate walking (Harkema, 2007; Behrman & Harkema, 2007, Dromerick et al., 2006; Edgerton et al., 2004; Barbeau & Fung, 2001; Finch & Barbeau, 1985). The therapists have provided this intervention in a positive, kid friendly atmosphere that elicits participation in the children. These therapists have a strong understanding of the science behind LT and communicated this knowledge to both the parent and the child. As a result of this intervention, each participant developed a heightened awareness of the body's ability to regain function and formed a renewed sense of hope.

Hope

Figure 8-1 shows the concept of hope came directly out of the LT itself. As previously mentioned, hope is defined as a prospective orientation toward future improvements (Lohne, 2001). Within this study, LT as an intervention led to a renewed sense of hope in the child and family. Hope was centered on three main elements associated with rehabilitation: 1) physical response; 2) cognitive response; and 3) behavioral response. Figure 8-2 depicts hope as a central theme of the LT process and highlights the impact these psychosocial influences had between two components of the ICF model: activity and participation. In between these two factors there are the many dynamics that unfolded as part of this study.

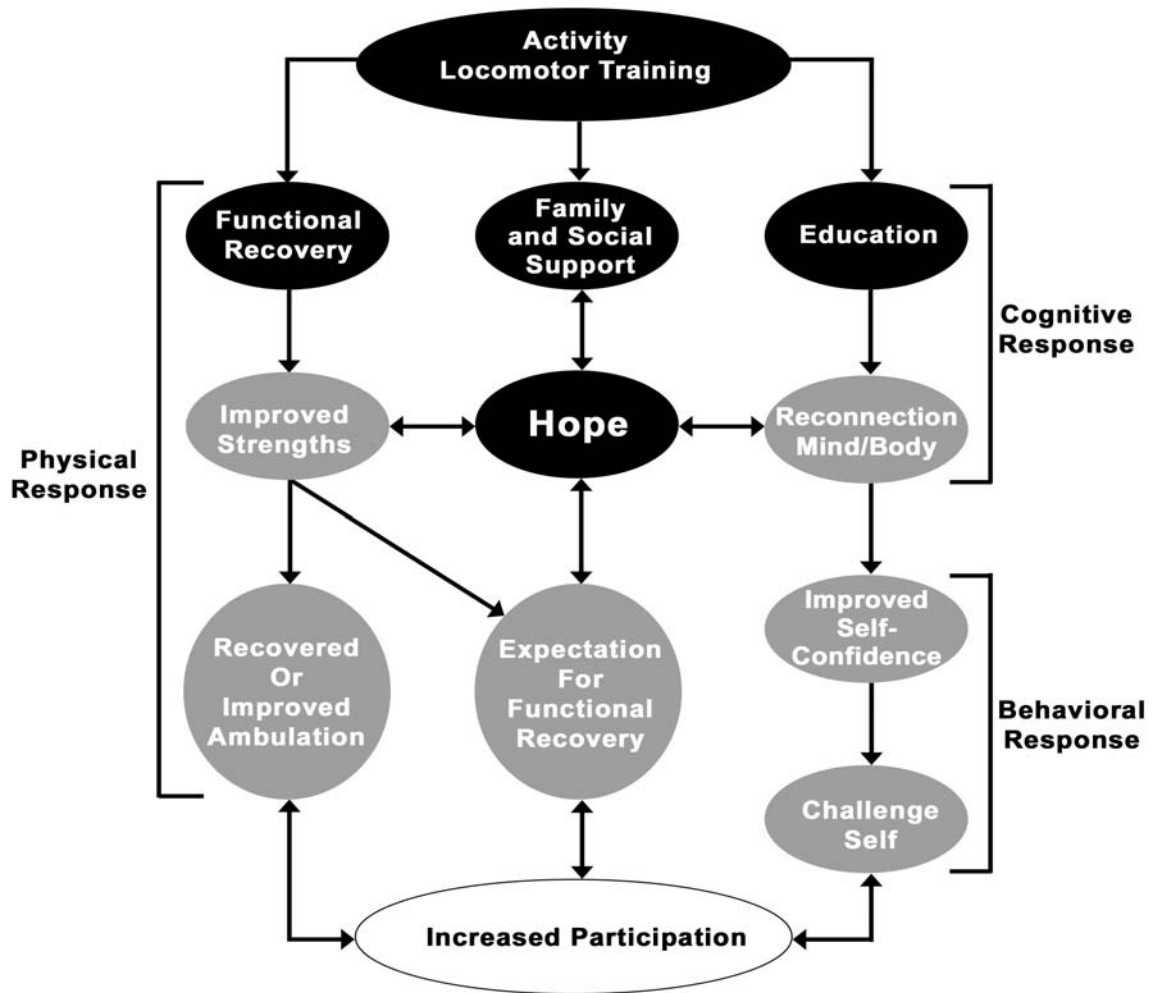


Figure 8-2. Hope as the center of the locomotor training process

Physical response

The child’s physical response to the LT is classified as functional recovery. This includes: increased muscle strength below level of injury, improved fine motor abilities, improved trunk strength, independent flexion and extension while walking; and walking with rolling walker. As LT leads to a number of physical improvements, the child has attained recovery of ambulation or has developed an expectation for functional recovery. This expectation may be for ambulation or may be an expectation for

continual progress. LT is offering these children and families the opportunity for continual recovery, beyond the traditional time frame.

The families with children who did not achieve walking recovery left the KSS with a more realistic understanding of their child's potential. While at the same time, these families maintained a renewed sense of hope that their child is still young and rehabilitation is a long-term, circular process that they are willing to revisit as their child grows. There is a renewed sense of optimism towards future opportunities for recovery. The therapists also maintain an optimistic attitude towards the child's recovery. PT2 commented on KSS2 after he completed his LT at the KSS.

The reality is he may not walk as a result of this program, but that doesn't mean he didn't gain tremendous abilities from the KSS. I think the biggest asset he will leave here with is his self-confidence. He sees himself differently. He has become more independent. He relies less on his mom and doesn't just say "I can't do that" when faced with a new challenge. He has grown tremendously these last few months. PT2, Project Coordinator, KSS

PT2 went on to discuss that there is still potential for KSS2 walk, as he is young and his body could continue to respond positively to treatment.

Cognitive response

The child's cognitive response to the LT is noted by the child and families' education on the LT process. As noted earlier, children are often concrete thinkers and once the injury has occurred, a disconnect was made with the mind and the body below the level of injury (Almqvist et al., 2006; Lasky & Eichelberger, 1985; Natapoff, 1978). Figure 8-2 highlights the impact the therapy team had on the child's knowledge of the LT process and how that led to the child's reconnection of his mind and body.

The therapists were able to communicate the importance of that reconnection to the children in order to continue towards the rehabilitation goal of walking recovery.

If he was concentrating on what he's doing, um, I found when his toes were moving he was concentrating on them then you know. - KSS2 Dad

This heightened awareness of their body's abilities gave these young men the ability to develop a hope for their body's future potential.

Behavioral response

This reconnection with the mind and body often led to increased self-confidence of the child participants and the child began to “try out” his new abilities. As the boys improved strength and began to view his body as a whole, there was shift of focus between what he could do versus what he could not do.

The fact that he is kneeling at himself in the mirror. It just opened a world of possibility. It was just that – it was like electric. It was just amazing and just two days later he tries to stand by himself. He feels good about himself, so happy. – KSS2 Mom

As the boys began to challenge themselves and their new found abilities (i.e. improved strength, movement in legs, increased desire for independence), they reported a greater level of participation in their daily life (participation in family chores, more interactive play with siblings and peers, etc). This increased participation led back to a hope for future recovery. The children themselves maintained a realistic, yet optimistic perspective of their long-term prognosis post LT.

What are you taking from here? – Jill Heilman

My legs are moving more. – KSS4

Do you feel better about yourself? – Jill Heilman

Yeah (he smiles) I still think I will walk. I'm not ruling out walking – but I know I will be okay no matter what. – KSS4

Outcome – Emerging Theory of Adaptation to iSCI for Children Participating in LT

In Figure 8-1, the outcome of LT as an intervention for these children led to a substantive, emerging theory of adaptation to iSCI for all the participants. LT has

helped the child and family obtain a “new reality” – one with 1) increased participation and positive involvement in society and 2) continued assessment of the child’s abilities and increased potential for future recovery. Further, this emerging theory continues to build on the scientific knowledge of the therapists’ and their optimistic perceptions of walking recovery in children with iSCI.

Increased participation

Parents stated an increase in the child’s daily living activities including but not limited to: transfers, daily living activities such as brushing teeth, opening doors, setting tables, and other daily chores. Of those children who are able to walk with a rolling walker, parents reported continual progress in the child’s strength and ability (participating in kickball games, chasing siblings, riding ATVs and more). Most parents reported their child’s ability to increase his level of participation was enhanced not only by the strength he gained as a result of the LT, but also from the education the parent received from the team to allow their child more opportunities to challenge his body.

Uhm I would say I’ve learned to let him be more independent – PT2 gave us things to work on – she helped me see him as a more independent young man. They help us see his potential and celebrate his abilities and it’s tremendous what he may do one day. We don’t really know what was severed in surgery. We are now hopeful the connections can be remade – that they may be there. We don’t know when that will happen but we are hopeful – KSS4 Mom

With improved strength and a heightened awareness of their body after LT, these children were now excited to explore their world at home. Parents reported their children approached outpatient rehabilitation differently after the KSS. At the one-month follow-up, KSS4’s mom reported her son had new focus and determination as it relates to his physical body. He wanted to maintain his new strength and ability and continues to “talk to his legs” to get them to move. KSS4’s mom’s also reported her

son's desire to do all transfers on his own, no longer requesting her assistance. In a follow-up with KSS2's mom, she reported her son's ability to get himself ready for school once they returned home. He took pride in his independence and in turn began to explore other activities around the house.

Regardless of the ability to walk, 4 of the 5 parents reported their child was mainstreamed in school and were treated age appropriately by his peers. The other family, not enrolled in public education, home schools all of her children by choice. This family also encouraged community participation through activities and friendships outside the home.

Continual recovery

Beyond school, the families continued to seek out opportunities to enrich their child's body through out-patient rehabilitation programs. In some cases, they had to find new programs that supported the mentality of the KSS, one that sees the potential in their child's recovery.

I have no idea – what I am going to do. I am going to have to find something brand new and because the place we went to was against the walking therapy and they were nasty with the braces and took it all too personal. We aren't going back there. - KSS5 Mom

A SCI in a child, changes the entire family dynamic. The families participating in the KSS must face the same challenges any other family with a child with a disability must face. When asked to describe her family life prior to her son's diagnosis, KSS5's mom immediately responded: "Joy." However, when asked to describe life after his diagnosis of iSCI, mom said:

I can't give you a word, but I'll give you a picture. It is more Pooh Bear with a rain cloud – you want to be happy but then you are reminded about reality. You always know there is something that, it's not the way it could be or was but we have him and we have hope. – KSS5 Mom

These families possess something a bit different. They have researched treatment programs for their child, educated them on LT and given their child the opportunity to participate in this research intervention at the KSS. These families have a sense of hope towards their child's future. They are not ready to accept their child's limitations, but rather challenge those limitations to determine the best potential recovery outcomes.

He has gone from having nothing from the neck down to this. What is to say it won't improve; he is only 7-years-old. He is only going to get stronger. He is going to be a teenager and he will want to make himself as strong as he can. – KSS5 Mom

Adaptation for these families is an ongoing process, one they are willing to challenge and question throughout their child's life-time, while at the same time, they work to keep their son's life as normal as possible.

He needs to do therapy but we need to balance that with he has to be a normal kid. A little normalcy but now, what is normal? – KSS2 Mom

Normalcy for these families has yet to be determined. They are open to continuing to challenge their child's medical prognosis and providing new avenues of recovery as science permits. The family and child maintain a sense of hope for recovery of function even after completion of the LT. The KSS has shown them the possibilities of progressing science and instilled in them an attitude of determination towards new methods of treatment. At the same time, these families work to keep their child grounded in daily life and maintain as much of a family routine and sense of normalcy as possible.

Therapists' Perspective

The therapists maintain the "glass half-full" mentality throughout the KSS program, regardless of the child's ability to walk as a result of the LT. The therapists continue to

challenge the concept of neuroplasticity as they look for new methods of treatment and recovery after iSCI.

Summary

Prior to families' knowledge of LT and understanding of the neuroplasticity of the brain and spinal cord, these families' had a different perspective of adaptation. These families expressed adaptation to their child's iSCI as a loss of hope as related to their child's walking recovery or an acceptance of their child's current level of function. The children themselves felt a disconnect from their body below their level of injury and had reported no hope of regaining function.

The LT research at the KSS has challenged the Livneh and Antonak model of adaptation, based on the understanding of the traditional medical process after iSCI. Within that framework, patients are expected to adjust and adapt to their injury after rehabilitation is completed (Livneh & Antonak, 1997). Now a new concept has formed, patients do not have to accept the limitation of an iSCI, as science and medicine is continually progressing. These patients and their families have a renewed hope in walking recovery as rehabilitation is viewed as an ongoing process that can be revisited by patients well after their injury has occurred.

LT has provided these children and their families with three main components: Education, Functional Recovery and Hope. The children, along with their parents, are educated by the therapy team on the scientific component –on the repair of the neurologic system and the benefit LT has on that recovery and repair. Further, detailed explanation and encouragement on the reconnection of the mind and body are given to the child participants.

As Livneh and Antonak defined, adjustment is considered the final phase of adaptation in which the individual understands his functional limitations and has: reestablished self-worth, discovered potential, considered social and vocational goals; and successfully overcome obstacles associated with their condition.

Adults with spinal cord injuries are expected to return to their role in society after rehabilitation from injury. This includes supporting and providing for their family, reengaging in vocational pursuits and participating in their established roles in the family and society. Children on the other hand have not yet defined their roles in society. Their purpose is to grow, develop, learn, and have fun as they explore different avenues of development. Therefore their rehabilitation does not include regaining their ability to function in specific roles in society as they are still navigating and defining those roles. Their level of responsibility is not as great as their adult counterpart. Children have more time to participate in non-traditional rehabilitation. Therapists, family members and the child himself are not ready to set a limit on their level of recovery as there is more time for them to explore the future of rehabilitation.

The rehabilitation and recovery of children with iSCI is no longer considered finite, but rather is on-going process. The KSS offers a new approach to treatment of children with iSCI, based on the concept of neuroplasticity. With this new approach to treatment of children with severe, chronic, iSCI, there is change in the psychosocial adaptation to their injury.

CHAPTER 9 SUMMARY AND CONCLUSIONS

Introduction

In conclusion, this study found that LT provided hope to families to view their child's rehabilitation as long-term, ongoing process. LT and the KSS provided families with a more realistic perspective of their child's abilities, while at the same time gave these children and families a renewed sense of hope towards the child's potential for walking recovery. Further this study found a primary commonality among the therapists, parents, and children – a commonality of optimism and hope. These therapists believe in the potential for walking recovery: that the brain and spinal cord are plastic and malleable and able to renegotiate those neurologic pathways for recovery of function. The therapists have this mentality that walking recovery is a potential for these children. This mentality goes beyond adaptation to functional loss after injury and sees the possibility for recovery of function, recovery well after initial diagnosis. This mentality was shared by the families involved and has been developed in the children in the KSS by the completion of the LT.

Summary of Findings

Findings Regarding the Child

The KSS has provided these children with a renewed sense of self, regardless of their ability to recover ambulation. A combination of the child's innate personality traits, the support of the family, the dynamics of the therapy team and the actual LT process has led to a reconnection of the child's mind and body. This renewal led to increased self-confidence and interest in challenging himself and his abilities. Participation in the LT program has led to increased participation in home, community and society for these

participants. Further, the participants have a greater understanding of their body and their disability – leading to the maturation of their cognitive thinking as it relates to their iSCI. With this increased awareness, the children are less likely to accept their limitations, and are now more inclined to challenge themselves and their bodies throughout their life.

Findings Regarding the Family

The assessment of the families revealed a set of parents committed to and optimistic towards their child's potential for recovery. These parents maintain a positive attitude towards rehabilitation as they are aware of the influence their behavior has on their child's recovery process. The family has a strong sense of responsibility for their child's health care and the parents have assumed numerous roles in the rehabilitation process: advocate, support system, educator, caretaker, counselor, investigator and overall team leader. Further, these families' appreciate the role their child plays in benefiting other children dealing with similar disabilities. This altruistic attitude is one thing that provides meaning to their life's situation. Regardless of their child's ability to walk after completion of this program, all the families expressed a hope for their child to continue to recover function throughout his life-time. They are optimistic in the body's ability to repair itself and in scientists' ability to discover how that can occur.

Findings Regarding the Therapy Team

The KSS embodies the essence of teamwork, as they provide participating children and families with a cohesive, kid-friendly, well trained team. In addition to sound therapeutic treatment, the KSS provided families with the physical and emotional support needed to function in a four-month rehabilitation program. Essentially, the KSS team provided the participants with a "second family" during their stay. This

consideration of the psychosocial needs of the family provided a more comfortable treatment environment for all those involved during a long rehabilitation stay.

The focus of the rehabilitation program was to determine the potential for walking recovery in these children and this focus was guided on the principle that the body can repair itself after injury. The physical therapists associated with the LT maintained a “Glass Half-Full” mentality; as they chose to assess the child’s abilities rather than his disabilities. The KSS team also guided these children through the process of reconnecting their mind with the body they once thought was lost. The child participants developed physical benefits as a result of the training as well as renewed self-confidence in their bodies and abilities. The combination of the child, family and therapists’ perspectives and approaches to LT led to an emerging theory of adaptation.

Findings Regarding Emerging Theory of Adaptation

This study has led to an emerging substantive theory of adaptation to iSCI for children with severe, chronic, iSCI. These children have developed a stronger understanding of their body’s abilities and limitations. With the combination of their own intrinsic desire learn more about their body, the support from their family, the education from their therapy team and the physical input of the locomotor training process, these children are able to better comprehend their prognosis and the future of their recovery.

LT at the KSS has tested the traditional model of adaptation as presented by Livneh and Antonak. No longer are individual’s expected to accept their life with its limitations. LT provided a new concept of adaptation, one that allows patients to challenge their limitations and continually look for new opportunities for recovery of function.

Three main elements the KSS provided to the LT process were: Education, Functional Recovery and Hope. The children and parents were educated on the body's ability to repair itself after injury and on the potential contribution LT can play in this process. These children reported positive outcomes from the intervention, both physical and emotional. These outcomes have led to increased participation in the child's daily life activities and provided the child and the family with the hope for continual recovery well after the injury occurred.

The rehabilitation and recovery of function in children with iSCI is no longer considered predetermined, but rather, rehabilitation is a continually changing process that can be revisited by the child at different points in his development. After completion in the KSS the child and family left with a more realistic perspective of the child's abilities, while at the same time they left with a renewed sense of optimism towards functional recovery. The child and family's adaptation to this disability is found to have been altered as a result of the LT. They are not fully accepting of the child's limitations, but rather they continue to hope for some level of functional recovery during his lifetime.

Study Limitations

As identified in Chapter Three, the primary limitations of the present study stem from the use of a convenience sample of participants. This sample was also all male participants from a similar socioeconomic demographic. Further, these participants are all enrolled in one training location limits the transferability of the study. However, this was not the purpose of the present study or for qualitative research in general.

Efforts to Ensure Trustworthiness

Also discussed in Chapter Three, several steps were taken to ensure trustworthiness of the present study. The 5 standards of Miles and Huberman (1994)

to ensure the quality of the conclusions in qualitative data were adhered to. A summary of the criteria relevant to the present study once again presented.

Objectivity/Confirmability

1. Detailed methods and procedures were established such as techniques for recruitment, sample size, data collection and data analysis, including the software utilized to process this information. In addition, I have recorded extensive field notes to document my thought processes throughout this research;
2. An audit trail was developed as the data was recorded and summarized. The NVIVO 8 software documents the date and time in tracking all changes to the coding process;
3. Comments as to biases I may demonstrate have been included in the Introduction section of this Dissertation—this identifies a baseline for bias and values for any further analysis; and
4. All data recorded was maintained for future examination after completion of the present study.

Reliability/Dependability/Auditability

1. Research questions were clearly identified in the Introduction. The utilization of a grounded theory approach for data collection and analysis was consistent with the exploratory nature of this study;
2. The researcher's role and status within the site was explicitly described in the Introduction;
3. Data were collected across a consistent, pre-established time frame for the participants as it related to their locomotor training scheduled; and
4. One researcher (I) was utilized throughout all interviews and observations to maintain consistency throughout the study. To enhance rigor, weekly meetings were established with Dr. Mary Ellen Young as a basis for reviewing data, coding and analysis. In addition, periodic peer debriefing meetings were held throughout the analysis process with a qualitative research group and with two outside faculty members emeritus.

Internal Validity/Credibility/Authenticity

1. Descriptive data were context-rich and detailed. Again, peer debriefing meetings were scheduled on a regular basis throughout the analysis phase of this research;

2. Diligent efforts were made to provide thorough, meaningful accounts of each individual's perceptions of their experience; and
3. Triangulation was used to produce converging conclusions.

External Validity/Transferability/Fittingness

1. Characteristics of the sample, settings, and process are clearly described to allow comparison with other samples at different settings; and
2. Comparison with a similar adult study has been made and future comparisons between the two populations will be made.

Utilization/Application/Action Orientation

1. Study findings will be intellectually and physically accessible to potential users as specified by the IRB. All data of interviews and observations will be maintained on computer hard drive. In addition, written field notes will be maintained in hard copy and electronic form. Efforts will be made to disseminate study findings through scholarly journals and oral presentation of findings upon completion of the study; and
2. Findings from this study will be disseminated in journal articles and presentations as permitted.

Discussion

The KSS and LT as form of rehabilitation helped these five young men and their families, both physically and emotionally. The potential this form of treatment can have on the long term impact of these children is still unseen. Yet the optimism surrounding all participants of this treatment leads to an excitement in transferring this intervention into clinical practice in future years. In order to make the transition from research to clinical practice, a number of factors will need to be addressed. Primarily, "buy in" from all parties involved in treatment of these children must be made. Insurance companies must support and be willing to pay for this labor intensive, expensive treatment. Professionals must be able to justify the benefits justify the cost. Families and patients must be willing to commit to the time and energy required to participate in the long-term

rehabilitation program. Finally, clinical professionals must be educated on this treatment program and support the mentality of hope and optimism that drives this rehabilitation intervention. While there are several steps to transfer this method of treatment into clinical practice, the KSS provides the next step in the overall process to reach a greater population of children with iSCIs.

The findings of this study as it relates to the psychosocial influences this method of treatment had on the outcomes of the participants has similarities to the Hannold study that examined the adult counterparts. Each group of participants was able to transfer the skills they learn in the lab into their “real world” environments. The Hannold study labeled this empowerment, while the current study labeled this the child’s ability to challenge self as a result of education, reconnection with mind/body and an increase in self-confidence as a result of the impact of LT and the KSS team. Another similarity in the findings was found in the reported increase in sensations by the participants. As one child reported “I can feel that go down and up my spine,” and adults in the Hannold study described increased sensations as “burning, tingling or soreness.” The adult participants reported these improved sensations as positive outcomes as they were new sensations post-injury. A four-year-old child was not able to articulate his response as descriptively, but he was able to reflect his excitement in the improved sensations through body language and inflection of voice.

Differences between these two populations were evident in how they engaged the overall rehabilitation process. The adults are cognitively aware of the potential significance this type of treatment can have on their recovery. The adults put cognitive

effort into their LT. Children on the other hand bring who they are into the LT process, the essence of childhood, play, energy, and in some sense, naivety.

The literature highlights the psychosocial adaptation is often influenced by the individual's own coping mechanisms along with the attitudes and behaviors of the family. In the case of the KSS and the Hannold study, this adaptation is also influenced by the attitudes and behaviors of the therapists and their approach to iSCI and treatment of this disability. The LT participants and their families embrace the concept of hope and optimism towards recovery of function. The therapy teams in both this study and the Hannold study provide this optimism towards treatment as part of the process of the LT itself, and through their education and encouragement to participants and their families.

Study Implications

Implications for Children with Severe, Chronic iSCI

The current study found children participating in LT reported a number of perceived benefits from this intervention regardless of their ability to walk at study completion. Results indicate that LT can provide children with iSCI with numerous physical and emotional benefits from this form of intervention over one year post injury. Offering a therapeutic intervention that allows children and their families the ability to challenge the child's potential for recovery can change the process of adaptation for these families.

This form of rehabilitation has the potential for integration in clinical rehabilitation for children with iSCI. Further, results from the current study imply children with severe, chronic iSCI have the potential to develop more abstract thinking as it relates to their bodies' ability to recover function. With the encouragement of their family and the

education and encouragement of the therapy team, children are able to view their bodies as both “sick” (impaired, limited in function) and healthy at the same time. This view provides children the perspective needed to face the concept of walking recovery.

Implications for Clinical Practice

This current study found five elements needed for transition of LT into clinical practice. These elements include the need for a therapy team that educates its participants, a therapy team that provide a positive, kid friendly environment and the therapy team’s ability to meet the psychosocial needs of the family while participating in this intervention. In transferring this therapeutic intervention into clinical practice will require a well trained child focused team.

The first implication for clinical practice suggests child participants reported a negative perception of their body’s ability to recover function at the onset of the LT process. Efforts to educate the child on his body’s ability to regain function below the level of lesion at the start of LT would ensure a more conducive training environment. The therapy team’s ability to communicate to the child the lower extremities ability to regain function would engage these children in more active participation.

The second implication for clinical practice relates to the difference in training needs for child LT participants as compared to their adult counterparts. Children participating in LT do not fully comprehend the purpose of the extensive training program, rather they are there to play and have fun. LT programs geared towards children should embody the essence of childhood: creating a positive, kid-friendly environment; providing games and activities during the training sessions and appropriate training length based on the child’s energy level and attitude during a particular day.

The third implication pertains to the results of this study highlighting the need to consider the various psychosocial factors associated with the child with an iSCI when utilizing LT as a method of therapeutic intervention. The inclusion of the family and child as part of the “team” ensures the likelihood of the child and family taking ownership of the program. In addition, the family will be more likely to make the same level of commitment to the training program that the therapy team has made to them.

A fourth implication revolves around the importance of individuality of training in the clinical practice. The KSS worked to individualize treatment for these children based on the child’s particular age and specific interests at the time of treatment. The individuality of treatment leads to a stronger level of engagement in LT participation for the children.

Finally, the concept of hope is one that can be difficult to communicate to a child and his or her families when balancing that with the medical professionals need to realistically communicate the child’s prognosis after injury. The fifth implication would therefore revolve around the need to educate medical professionals on the importance of conveying some level of hope for recovery after initial diagnosis.

Implications for Rehabilitation of Children with Disabilities

A more global implication pertaining to this study surrounds the concept of hope in rehabilitation. This study’s findings indicate families with children with various disabilities may want to revisit their child’s rehabilitation goals and long-term prognosis throughout their child’s lifetime. Science continually progresses and the availability of new treatments for children with iSCI may provide hope to other families with children with disabilities. The initial prognosis of a child with a disability may change over time as rehabilitation science progresses. The results of this study further leads to the

concept of rehabilitation years after initial diagnosis. The results further encourage parents of children with disabilities to revisit their child's prognosis at different points of the child's development to reassess the need for additional rehabilitation treatment.

With the emerging theory of adaptation to iSCI after participation in LT, we can only set up the building blocks for a child's rehabilitation outcome; physically, emotionally and psychologically. As rehabilitation progresses, technology and treatment challenge traditional notions of recovery, this implies a need for newer models of adaptation that reflect that changing dynamic. The current study is a spring board for future research that could lead to a more formal theory of adaptation to pediatric disability.

Recommendation for Future Research

For this study a convenience sample of 5 children, 6 parents and 2 therapists from one LT study site was utilized for research purposes. While an in-depth analysis of all these participants was conducted, this study was limited by the size and scope of the participants. As previously identified, the child participants were all Caucasian boys from similar socioeconomic demographics, showing this study does not represent the general population of iSCI patients. Research of other LT programs that include female participants and children from a more diverse racial, ethnic and socioeconomic demographic would provide more breadth to the current study. Replicating the present study at other treatment sites would allow an opportunity to compare the LT experience in different regions and across separate therapy team dynamics. This would allow for comparing and contrasting similar treatment programs. In addition, future research that offers a comparison between children with iSCI participating in LT with their adult

counterpart may provide a better understanding of two populations with a shared experience.

In regards to the current study, it is also recommended that longitudinal studies that follow these children throughout different stages of development may provide additional feedback on the significance this type of rehabilitation program has on the children across their life-span.

This particular LT program provided children with very individualized treatment programs, tailored to each child's interests and needs to engage the participants in the LT process. Future research that focuses on how best to deliver patient centered care is recommended to further engage the child in the rehabilitation process and lead to positive rehabilitation outcomes.

In addition, this study identified the need to research better ways to reeducate medical professionals on the importance of conveying some level of hope after initial diagnosis to iSCI. Finding a balance between providing hope without communicating false hope is strongly needed for professionals treating children with iSCIs.

The current study has formed a substantive, emerging theory of adaptation for children with iSCI participating in LT. It is recommended that future research focus on comparing the current study to other studies addressing the psychosocial adaptation to iSCI as it relates to children participating in LT to further build on this theory. In addition, to better understand pediatric adaptation to disability on a more global perspective, future research needs to focus on the comparison of this study with other studies examining the psychosocial impact newer forms of treatment and rehabilitation has on children across the spectrum of disabilities. The current study begins to develop

the basis for future research for a more formal theory of pediatric adaptation to disability, one that is current with the 21st century treatment and rehabilitation goals.

APPENDIX A INTERVIEW GUIDE: CHILD

Interview Guideline – Child – Interviews 1 - 3

This is intended to be a guide for interviewing the pediatric participants in the locomotor training. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed. Further, the wording each question will be based on the age of the child and some questions may need to be eliminated.

Rehabilitation Experience - Attitudes

- “What type of therapy have you had before coming here?”
Probing Question: “Was it fun to go to therapy?”
- “What do you think of the therapy here with Dr. B.?”
- “Can you tell me what you do during the day while you’re here?”
- “What are some things you like about the treadmill? Some things you don’t like?”
- “In what ways has your SCI affected your life the most? Your family’s life?”
- “How do you cope with bad days after your injury?”

Goals for Rehabilitation – Expectations

- “What do you hope to be able to do after this therapy?”
- Probing Question: “Can you think of things you may be able to do with your friends when you get back home?”
- “What do you hope to be doing in 5 years? 10 years?” Varies on age of child.
- “What do you want to be when you grow up?”
Probing Question: “Is that what you have always wanted to be?”

Thought Process in Rehabilitation – Motivations

- “What keeps you going during therapy?”
Probing Question: “Is your mom/dad in the room with you?”
- “What made you want to come here?”
- “How does feel about being in this program?”
Probing: “You’re glad to be here? Tell me more about what makes you glad to be here?”

Background Information

- Age
- Age at onset of injury
- Level of injury
- Functions impaired (their view of impairments)
- Family (who live with)
- Support systems in place
- Grade level
- How injury occurred?
- Race/Ethnicity

Offer time for additional comments on their part.

Interview Guideline – Child – Follow Up Interview

This is intended to be a guide for interviewing the pediatric participants after the completion of the locomotor training program. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed. Further, the wording each question will be based on the age of the child and some questions may need to be eliminated.

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Rehabilitation Experience - Attitudes

- “What did you think of the Kids STEP Study?”
- “What did you think of Dr. B?”
- “What do you think about going to therapy now that you are back at home?”

Goals for Rehabilitation – Expectations

- “Did you get what you expected out of the program?”
 - “Is your life any different now that you are back home?”
 - “What do you hope to be doing in 5 years? 10 years?”
 - “What do you want to be when you grow up?”
- Probing Question: “Is that what you have always wanted to be?”

Thought Process in Rehabilitation – Motivations

- “What kept you going during your therapy?”
- “Do you like going to therapy now that you are back home?”
- “How do you feel to have been apart of this program?”

Offer time for additional comments on their part.

APPENDIX B INTERVIEW GUIDE: PARENTS

Interview Guideline – Parent – Interviews 1-3

This is intended to be a guide for interviewing the parents of the pediatric participants in the locomotor training. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed.

Rehabilitation Experience - Attitudes

- “I would like to start by asking you to give me some background on your child’s spinal cord injury.”

Probing Question: “What have these rehab experiences been like?”

- What do you see as your role in the rehabilitation process?
“In what ways has your child’s SCI affected your life the most?”
- “Tell me a little about your child’s personality and how his/her strengths and weaknesses play a role in his/her rehab?”
- “What was your daily life like before the injury compared to life today?”
Probing: “Could you tell me what you did for fun as a family before the injury?”
- “How does your child cope with his/her injury and struggles associated with it?”
- “What do you see as your coping mechanisms in dealing with these life issues?”
- “How are you different pre and post injury?”

Goals for Rehabilitation – Expectations

- “What do you hope your child will be able to do after this therapy?”
Probing Question: “Did you come into this with expectations?”
- “What are your goals for your child?”
- “Where do you see your child in 5 years? 10 years?”
- What will he be when he grows up?

Thought Process in Rehabilitation – Motivations

- “What keeps you going during the rehabilitation process?”
Probing Question: “Do you have a support system at home?”
- “What keeps your child motivated during rehab?”
- “What are your coping mechanisms?”
Probing Question: “Do you have support systems at home?”

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Interview Guideline – Parent – Follow Up Interview

This is intended to be a guide for interviewing the parents pediatric participants after the completion of the locomotor training program. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed. Further, the wording each question will be based on the age of the child and some questions may need to be eliminated.

Rehabilitation Experience - Attitudes

- “What did you think of the Kids STEP Study?”
- “What did you think of the therapy team?”
- “Is your child in therapy now that he/she is back home?”

Goals for Rehabilitation – Expectations

- “Did you get what you expected out of the program?”
- “Is your child’s life any different now that you are back home?”
- “What do you see your child doing in 5 years? 10 years?”
- “What do you want them to be when they grow up?”

Probing Question: “Is that what you always saw them doing?”

Thought Process in Rehabilitation – Motivations

- “What kept you going during your therapy?”
- “What kept your child going during the training?”
- “How do you feel to have been apart of this program?”

Offer time for additional comments on their part.

APPENDIX C
INTERVIEW GUIDE: PHYSICAL THERAPIST

Interview Guideline – Therapist – Interviews 1-3

This is intended to be a guide for interviewing the therapists in the locomotor training program. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed.

Rehabilitation Experience - Attitudes

- “What experience do you have in locomotor rehabilitation?
Probing: “Have you worked with kids before?” “Does it differ from working with adults?”
- “What is your role in this program?”
- “What do you see as the parent’s role in the rehabilitation process?”
Probing Question: “Do you include them in the therapy session?”
- “What do you expect from the kids participating in the program?”
- “What factors do you think make a training session successful?”

Goals for Rehabilitation – Expectations

- “What are your goals for the Kids STEP program?”
- “What are your goals for this child participating?”
- “Do you expect everyone to benefit from this type of rehabilitation?”
- “Where do you see this form of rehabilitation in 5 years? 10 years?”
- “Do you expect everyone enrolled in the study to benefit from this therapy?”

Thought Process in Rehabilitation – Motivations

- “What keeps you motivated during the rehabilitation process?”
Probing Question: “How do you deal with patients who don’t change as a result of this intervention?”
- “What does it feel like to be part of this program?”

Offer time for additional comments on their part.

Interview Guide – Therapist– Interviews 4

Interview Guideline – Therapist – Follow Up Interview

This is intended to be a guide for interviewing the therapists after the completion of the locomotor training program. The order and/or wording of these questions may change with each interview but the foundation for these interviews is listed in the following questions. Depending on the responses by the participants, follow up probing questions may be added to elicit more information, some examples are listed.

Rehabilitation Experience - Attitudes

- “What was this experience, the past 12 weeks of the Kids STEP Study, like for you?
Probing: “How was working with children?”
- “Were you able to utilize the parents in this rehabilitation program?”
Probing Question: “How did you incorporate them?” “Did they choose to be involved?”
- “What did you expect from the kids participating in the program?”
- “What factors do you think made a training session successful?”

Goals for Rehabilitation – Expectations

- “Did you fulfill goals you set for the Kids STEP program?”
- “Did the kids meet the goal you set for them?”
- “Did everyone benefit from this type of rehabilitation?”
Probing Question? “How? Did it vary for each participant?”
- “Where do you see this form of rehabilitation in 5 years? 10 years?”

Thought Process in Rehabilitation – Motivations

- “What does it feel like to be part of this program?”
- “Will you continue with this type of rehabilitation?”

Offer time for additional comments on their part.

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BIOGRAPHICAL SKETCH

Jillian Lillibridge Heilman is an eternal student at the University of Florida. She received her bachelor's degree in family, youth and community sciences at UF, with a specialization in child development in 1997. She continued her studies in Gainesville as she obtained her master's degree in agricultural education and communication in 1999, specializing in youth at risk. Upon graduation in '99, Dr. Heilman became an Instructor in the Department of Family, Youth and Community Sciences at UF where she taught and advised students in the department.

After a year of teaching at the University of Florida, Dr. Heilman took six years "off" to start a family. It was during this time that she redirected her academic interests and began to focus on children with disabilities – as she herself has three children with various medical conditions. In 2006, Dr. Heilman entered her doctoral program in rehabilitation sciences with a focus on Rehabilitation Counseling, specifically interested in working with children with disabilities and assisting their families in navigating the world of disabilities.

For the past two and a half years, Dr. Heilman has worked with the Kids STEP Study rehabilitation program at the University of Florida – where she has spent her time researching the psychosocial impact the new form of rehabilitation, locomotor training, has on the children with severe, chronic, incomplete spinal cord injuries. Further, Dr. Heilman's research has analyzed the impact this therapeutic intervention has had on the family of these children and the impact the actual therapy team has on the child himself.

Dr. Heilman resides in Valrico, Florida with her husband John and their three children, Halle, Neeley and Ben.