

Long-Term Outcomes of Pediatric-Onset Spinal Cord Injuries: Implications for Life Care Planning

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Abstract:

Development of a life care plan for youth with spinal cord injuries (SCI) requires a thorough understanding of the natural history of pediatric-onset SCI, including psychosocial outcomes and secondary health conditions. The life care plan must be comprehensive and individualized, accounting for the unique developmental aspects of youth with SCI across their lifespan. From birth through young adulthood and into late adulthood, changes occur in all domains of an individual's life including cognitive, psychosocial, familial, cultural, physical, and medical. Understanding the natural history, unique features, and long-term outcomes of pediatric-onset SCI assists in identifying future needs, including allocation of resources for the prevention and management of secondary health conditions, potential for employment and independent living, and the effect of aging. Therefore, the objective of this paper is to describe long-term outcomes of individuals with pediatric-onset SCI and discuss the implications of these outcomes on life care planning, with an emphasis on developmental issues throughout the lifespan.

Developing Life Care Plans for Youth with Spinal Cord Injuries

Developing life care plans for youth with spinal cord injuries (SCIs) requires a thorough understanding of the natural course of the disorder, including psychosocial outcomes and secondary health conditions, as well as stages of human development (Riddick-Grisham, & Deming, 2011; Vogel, Reed & Krause, 2014). A life care plan for a child with a SCI must be comprehensive and individualized, accounting for the unique developmental aspects of youth with SCI across the lifespan. From birth through young adulthood and into late adulthood, changes occur in all domains of an individual's life including cognitive, psychosocial, familial, cultural, physical, and medical. For example, due to physical growth, young children will outgrow their wheelchair at a faster rate than adults with SCI. Moreover, older adults with paraplegia may be more likely to use a power wheelchair due to upper extremity overuse syndrome than adolescents. Understanding the natural history of pediatric-onset SCI assists in identifying future needs, including allocation of resources for the prevention and management of secondary health conditions, potential for employment and independent living, and the effect of aging.

Developmental stages are typically categorized as infancy and early childhood (0 to 5 years), early school-aged children (6 to 12 years), adolescence (13 to 17 years), emerging adulthood (18 to 25 years), young adulthood (26 to 39 years), middle adulthood (40-64), and late adulthood (65 years of age and older). Certain developmental stages are characterized by significant psychosocial and cognitive changes such that additional interventions, such as physical and occupational therapy and psychological treatment, should be considered to maximize independence and successful progression through these transitional times. As an example, during emerging adulthood, normative milestones include employment, independent living, financial independence, and meaningful social relationships. Therefore, psychological and vocational counseling are useful in facilitating independence and self-management.

A life care plan must also take into account secondary health conditions that may affect individuals with an SCI along with preventative measures and treatment, including medications, rehabilitation, bracing, surgery, or hospitalization. Lastly, the individual's neurological impairment, cognitive functioning, age at injury, and life expectancy, which is impacted by neurological impairment, need to be taken into consideration when developing a life care plan.

The objective of this paper is to describe long-term outcomes of individuals with pediatric-onset SCI and discuss the implications of these outcomes on life care planning. The unique features of pediatric-onset SCI that impact life care planning, especially developmental issues throughout the lifespan, will be highlighted.

Materials and Methods

Since 1996, our research team has conducted a longitudinal study of the outcomes of adults aged 19 years of age or older who sustained a SCI during childhood or adolescence (0-18 years) (Zebracki, Chlan, & Vogel, 2014). This is the largest known database of medical and psychosocial outcomes of pediatric-onset SCI. Participants received care at one of the three pediatric SCI specialty programs at Shriners Hospitals for Children, did not have significant brain injuries, and were English speaking. The sample was economically diverse and from a broad geographical area, from several regions in the United States as well as abroad. On an annual basis, the adults with pediatric-onset SCI were interviewed in person or by

telephone beginning at 19 years of age, utilizing a structured questionnaire and standard measures. A structured questionnaire designed for this study assesses demographic, injury-related, medical, and social factors. Impairment is measured using neurological level and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) as defined by the International Standards for the Neurological Classification of Spinal Cord Injury (American Spinal Injury Association, Revised 2011). The Patient Health Questionnaire-9 (PHQ-9) assesses depressive symptoms using the diagnostic criteria for major depressive disorder per the Diagnostic and Statistical Manual, Fourth Edition (Kroenke et al., 2001). Anxiety symptoms are measured using the short self-report Beck Anxiety Inventory (BAI) (Beck et al., 1988). The SF-12v2® Health Survey assesses the individual's perception of his/her health-related quality of life (Ware et al., 2009). The Craig Handicap Assessment and Recording Technique (CHART) assesses community participation and consists of 6 separate subscales of physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency (Whiteneck et al., 1992). The sample utilized for this report includes 457 individuals aged 19 to 48 years of age at follow-up, with a mean age at injury of 13.9 years and a mean duration of injury of 17 years (Table 1).

Secondary Health Conditions

In adults with pediatric-onset SCI, secondary health conditions negatively impact long-term outcomes including employment, independent living, income and life-satisfaction (Vogel, Krajci, & Anderson, 2002). Risk of experiencing secondary health conditions varies over time and among injury severity groups (Hwang, Zebracki, Chlan, & Vogel, 2014a; Vogel, Zebracki, Chlan, & Anderson, 2011). Individuals with pediatric-onset SCI are at risk for the same secondary health conditions that affect the adult-onset SCI population, including those directly related to the SCI, such as pressure ulcers, pain, pathological fractures, and urinary tract infections, as well as conditions specific to pediatric-onset SCI. Owing to their young age at onset and longer duration of living with an SCI, those with pediatric-onset SCI will live with their secondary health conditions for a greater length of time compared to those with adult-onset SCI. In addition, individuals with pediatric-onset SCI will experience accelerated aging due to overuse (e.g., shoulder pain) and chronic health conditions due to their sedentary life-styles (e.g., obesity and cardiovascular disorders).

The pediatric-onset SCI population is at greater risk of developing some unique complications such as scoliosis (i.e., 100% of children who sustain SCI prior to skeletal maturity develop scoliosis and 67% require surgical intervention) and hip instability (i.e., dislocation and subluxation; 93-100% of those injured at 10 years and younger), which often requires bracing, surgery, and medical/surgical follow-up (Betz, & Murray, 2014; Pahys, Betz, & Samdani, 2014). These

musculoskeletal complications and related treatments may result in secondary health conditions such as pressure ulcers due to uneven sitting or pain which, in turn, may affect independent living or employment. Because of the young age at onset they may be at risk of complications such as a small bladder requiring extensive urological care (e.g., botulinum toxin or bladder augmentation).

Secondary health conditions occurring in our population of adults with pediatric-onset SCI are shown in Table 2 based on neurological impairment (Zebracki, Chlan, & Vogel, 2014). The most common secondary health conditions affecting at least one-third of the participants are urinary tract infections, autonomic dysreflexia, pain, spasticity, sleep disorders, urinary incontinence, and pressure ulcers. A life care plan should encompass both the prevention and management of these secondary complications as well as their impact on activity and participation of adults with pediatric-onset SCI.

Shoulder pain. Shoulder pain was reported in 52% of this sample and commonly affects adults with pediatric-onset SCI, negatively impacting independent living, employment and life satisfaction (Vogel, Krajci, & Anderson, 2002). Prevention of shoulder pain may encompass a wide variety of interventions including proper transfers, pressure reliefs, and wheeled and upright mobility. Depending upon age, neurological severity, and body habitus (obesity), transfers may be most appropriately accomplished with a transfer board or mobile or ceiling-mounted lifts and may require the assistance of a trained caretaker. Adults with pediatric-onset SCI who utilize wheelchairs for some or all of their mobility may benefit from progression to power-assist or power wheelchairs as they age in order to prevent shoulder pain so that they can maintain their community mobility. Progression to powered wheelchair mobility may also result in the need for another form of a motor vehicle; for example, one with a wheelchair lift.

Pressure ulcers. Pressure ulcers affect one-third of our sample annually, and they are associated with significant morbidity and mortality in addition to significantly interfering with an individual's activity and participation including employment and independent living. Prevention of pressure ulcers throughout the life of an individual is critical and evolves from adult supervision of infants, toddlers and children to caregiver supervision of the aging adult. Furthermore, prevention of pressure ulcers also requires a variety of equipment that must be individualized including seating systems, sleeping surfaces, and transfer schemas as well as urinary and bowel continence.

Autonomic dysreflexia. Autonomic dysreflexia (AD) is a consequence of uncontrolled sympathetic activity characterized by acute severe paroxysmal hypertension associated with signs and symptoms, such as throbbing

headaches, flushing of the skin above the level of lesion, and bradycardia. AD affects close to two-thirds of those with T6 and higher SCI and can be life-threatening (Krassioukov, Rapidi, Wecht, & Vogel, 2015). Therefore, the individual with a SCI as well as their caregivers must be competent in preventing, identifying and managing episodes of autonomic dysreflexia. Depending upon the neurological status and age, caregivers may include parents, siblings, friends, partners and spouses to paid care attendants or skilled nursing.

The Rehabilitation Process

Youth with pediatric-onset SCI should receive care from a transdisciplinary team including physical, occupational, speech and recreation therapists, social workers, psychologists, nurses, dieticians, orthotists, and physician specialists such as pediatric orthopaedic surgeons, orthopaedic spine surgeons, neurosurgeons, neurologists, physiatrists or urologists. The frequency of these healthcare services depends upon a variety of factors including the age of the individual, the neurologic severity and associated secondary health conditions. In general, more frequent healthcare encounters are needed for individuals when they are experiencing dramatic physical, physiologic, and cognitive changes related to development, particularly adolescence and the aging adult. For the aging adult, in addition to the need for more frequent healthcare services, loss of independence may require additional services such as skilled nursing care, a personal care attendant, or a housekeeper.

Individuals who undergo surgical procedures to enhance their function, such as upper extremity reconstruction, a Mitrofanoff procedure or lower extremity orthopaedic surgery, frequently benefit from additional therapy postoperatively. Although the purpose of these procedures are to enhance function, the individual may experience a decrease in their functional abilities postoperatively and require additional rehabilitative services to regain their prior level of function and then to improve on their prior functional level. These services may be provided in an outpatient setting or in the home for those with limitations in driving. For some individuals, a short period of rehabilitation in an inpatient setting may be required.

Transition. During later adolescence and emerging adulthood, as youth approach adulthood, they need to transition into adult healthcare services, including gynecological/obstetrical care. Females with tetraplegia or thoracic level SCI who become pregnant must be cared for by an obstetrician experienced in caring for women who are at risk of autonomic dysreflexia during labor and delivery. Men with SCI who plan to father children may need interventions ranging from medications and treatments for

erections and ejaculation to fertility specialists to accomplish pregnancy. In addition to healthcare needs of an adult with SCI, this transition process must also address psychosocial issues such as independent living, employment, dating/socialization and autonomy.

Environment and Transportation

Architectural, home furnishings and accessories. For individuals with pediatric-onset SCI, architectural modifications (ramps, door widening, accessible bathrooms and kitchens) or acquisition of an accessible home is generally required during childhood. In addition, architectural modifications or acquisition of an accessible home may be needed additional times in the future as they become adults and acquire their own home and then eventually further needs associated with the aging adult. Home furnishings and accessories could include hospital beds, ramps, or exercise mat tables.

Home or facility care. Requirements for caregivers (personal care attendants and skilled nursing) and facility care are a function of age, severity of neurological impairment and associated secondary health conditions. When an adolescent goes away to college, the type and amount of care required is dependent upon the degree of functional impairment. Because of the importance that college-aged individuals become as independent as possible, they need to assume the responsibility for this care, which may include the hiring, training, and supervision of personal care attendants.

Individuals with high level SCI who require specialized services such as ventilator care and tube feedings or who are not independent in catheterization and bowel program are dependent upon others for many or all of their needs. The role of family members (usually parents) as care-providers needs to be defined particularly for youth who are ventilator-dependent. These individuals require 24 hours per day of skilled care but usually receive at most 16 hours per day of skilled nursing care, requiring the remainder of care to be provided by the parents posing undue stress and burden on the family. As parents age or die, individuals who are ventilator-dependent will require 24 hours per day skilled care. An important aspect of home or facility care for those with pediatric-onset SCI is to promote throughout their lifespan their autonomy and independence in all of their daily activities.

Transportation. At all ages, individuals with SCI should have access to appropriate motor vehicles including access (such as wheelchair lifts) and restraints (including wheelchair tie downs and personal restraint devices). Adolescents of driving age should undergo a comprehensive adapted driver's evaluation to determine their capability to

drive given their physical and cognitive abilities and to identify appropriate adaptations. Those adolescents capable of driving should undergo adapted driving training with a qualified instructor. Individuals who use manual wheelchairs will benefit from physical and occupational therapy for transfer training and storage of their wheelchair. Individuals with tetraplegia who use power wheelchairs will require an adapted van with a wheelchair lift and automatic wheelchair locking system. As individuals age, transportation needs may change such that the adult with paraplegia who previously used a manual wheelchair and a standard motor vehicle with hand controls will transition to a power wheelchair and an accessible van with a wheelchair lift.

Psychosocial Outcomes

Mental health. Sustaining and living with a SCI places significant psychological demands on individuals as well as their families. Consequently, a life care plan should address the psychological needs of the developing child and adult. While the majority of individuals with SCI demonstrate resiliency and positive psychological outcomes, it is not without effort. For example, depression is the most common form of psychopathology in individuals with SCI, with prevalence ranging from 10%-38% in adult-onset SCI (Bombardier, Richards, Krause, Tulskey, & Tate, 2004; Fann et al., 2011; Saunders, Krause, & Focht, 2012) and 38% of those with pediatric-onset SCI experience at least mild symptoms (January, Zebracki, Chlan, & Vogel, 2014). Moreover, in our sample 11% of adults reported mild symptoms of anxiety and 4% reported moderate to severe symptoms. Factors, such as positive and challenge-focused appraisals, meaningful participation, and social support, are critical to psychological adjustment and can be addressed with individual and family therapies.

Participation. Participation as defined by the World Health Organization is involvement in a life situation and is an essential component of living a meaningful life. Table 3 demonstrates participation characteristics of adults with pediatric-onset SCI.

Education and employment are quintessential milestones for adults and are critical for independent living, socialization, financial autonomy, emotional well-being and life satisfaction (Hwang, Zebracki, Chlan, & Vogel, 2014b; Vogel, & Anderson, 2005). The rate of college graduation for this pediatric-onset SCI population (41%) is significantly higher than the general population (25%) yet the employment rate of those with pediatric-onset SCI is only 47% (Zebracki, Chlan, & Vogel, 2014). Because employment is related to better overall health and higher quality of life, the life care plan should include sufficient resources to ensure there is the opportunity to maximize educational and vocational attainment. This counseling should be directed not only to finding post injury employment, but also for employment

retention and to maximize employment outcomes. Vocational rehabilitation evaluation and counseling should be performed by a counselor who has experience in evaluating children and adolescents who have not had any prior work experience.

Recreation/leisure time. Because most individuals with SCI have relatively sedentary lifestyles that increase their risk of obesity and cardiovascular complications, appropriate fitness interventions should be included in a life care plan throughout the lifespan. This could include equipment that facilitates fitness, such as a hand-propelled bicycle, recreation-specific wheelchair (e.g., basketball, rugby, or track) or functional electrical stimulation (FES) cycles. For those who would benefit from aquatic therapy or swimming, a membership to a fitness facility with a handicap accessible pool would be appropriate.

Conclusion

The development of the life care plan is the process of identifying lifetime needs and associated costs related to the underlying health condition. For children with disabilities, the life care plan must take into account the dynamic impact of development throughout the individual's life from birth to childhood, adolescence, emerging adulthood, adulthood and finally, late adulthood.

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Table 1
Characteristics of Participants

	N=457
<i>Demographic</i>	
Male	289 (63%)
Caucasian	387 (85%)
Age at interview	31.3 years
<i>SCI characteristics</i>	
Age at injury (mean)	13.8 years
(range)	(0-18)
Duration of injury (mean)	17.0 years
(range)	(2-42)
<i>Neurologic impairment</i>	
C1-C4 ABC	66 (14%)
C5-C8 ABC	159 (35%)
T1-S5 ABC	191 (42%)
AIS D	41 (9%)
<i>Etiology of SCI</i>	
Motor vehicle	226 (50%)
Sports	111 (24%)
Medical/ surgical	41 (9%)
Violence	40 (9%)
Falls	30 (7%)
Other/ unknown	9 (2%)

Table 2
Secondary Health Conditions

	N=457
<i>Physical</i> ^a	
Autonomic dysreflexia ^b	215/328 (66%)
Bladder incontinence ^c	172 (38%)
Bladder/kidney stones	45 (10%)
Bowel incontinence ^c	63 (14%)
Bone fractures	25 (6%)
Cardiovascular disease	27 (6%)
Hyperhidrosis	79 (17%)
<i>Pain</i>	
Shoulder pain	236 (52%)
Elbow pain	77 (17%)
Wrist pain	103 (23%)

Pressure ulcer	150 (33%)		
Respiratory complications	15 (3%)		
Sleep difficulties	67/157 (43%)		
Spasticity	213 (47%)		
Urinary tract infections	322 (71%)		
Number (mean)	3.6		
(range)	(1-24)		
SF-12® Physical component ^d	45.0		
(range 14-63)			
Number of medications (mean)	4.1		
Psychological			
Anxiety: BAI	3.7 (6.4)		
(range 0-37) ^e	N=157		
Mild (8-15)	18 (11%)		
Moderate/ severe (>16)	7 (4%)		
Depression: PHQ-9	3.2 (4.3)		
(range 0-23) ^e	N=351		
Mild (5-9)	59 (17%)		
Moderate/ severe (>10)	28 (8%)		
SF-12® Mental component	53.3 (8.9)		
(range 13-74) ^d			
a Occurring in past year unless otherwise noted			
b T6 and higher			
c Occurring at least monthly			
d Higher score = better functioning			
e Higher score = worse functioning			

Table 3
Participation

	N=457
Education	
High school diploma or equivalent	442 (97%)
Bachelor's degree or higher	189 (41%)
Economic life	
Employment status	
Employed (full- or part-time)	214 (47%)
Student	54 (12%)
Homemaker	30 (7%)
Unemployed	154 (34%)
Personal annual income (US\$, median)	\$19,000
Household annual income (US\$, median)	\$33,600
Personal maintenance	
Lives independently	299 (65%)
Paid attendant care	165 (36%)
mean hours/ day ^a	4.5 (4.2)
(range)	(1-24)

Mobility	
Wheelchair use ^b	
Manual wheelchair	267 (58%)
Power wheelchair	167 (37%)
Does not use wheelchair	15 (3%)
Drives motor vehicle	287 (63%)

Social	
Married/ domestic partner	116 (25%)

CHART^c	
Physical	91.3 (12.9)
Cognitive	97.7 (4.9)
Mobility	88.7 (17.9)
Occupation	74.7 (31.3)
Social integration	90.7 (15.3)
Economic	73.0 (34.2)

a Means and range for those with paid attendant care

b Wheelchair used >50 % of the time

c Higher score = better functioning

About the Authors

Lawrence C. Vogel, M.D., FAAP, CLCP, has been the Chief of Pediatrics at the Chicago Shriners Hospitals for Children since 1981, the Medical Director of the Spinal Cord Injury program since its inception in 1983, and in 2005 became the Assistant Chief of Staff, Medicine. Dr. Vogel received his B.A. degree with distinction from Northwestern University in 1969 and his Medical Degree from the University of Illinois in 1973. He served as a pediatric resident at Yale-New Haven Hospital and subsequently completed a fellowship in pediatric infectious diseases at Michael Reese Hospital and the University of Chicago. Dr. Vogel is a diplomate of the American Board of Pediatrics and is certified in the Subspecialty of Spinal Cord Injury Medicine (American Board of Physical Medicine and Rehabilitation). Dr. Vogel is a Professor of Pediatrics at Rush Medical College and an Adjunct Professor of Biomedical Engineering at Marquette University. Dr. Vogel is Past President of the Chicago Pediatric Society. He was a member of the Board of Directors of the American Paraplegia Society (1998-2011) and was the President from 2007-2009. He was a member of the Board of Directors of the American Spinal Injury Association (2003-2015) and was the President from 2011-2013. Dr. Vogel was a member of the steering committee of the Consortium for Spinal Cord Medicine from 2004-2014 and was Chairman from 2007-2014. Dr. Vogel is the incoming Editor of *Topics in Spinal Cord Injury Rehabilitation*, and he is on the Editorial Board of the *Journal of Life Care Planning*. Dr. Vogel is a Certified Life Care Planner.

Over the past three decades, Dr. Vogel has dedicated his time to the care of children and adolescents with spinal cord injuries. He has authored over 150 articles in peer-reviewed

journals, 25 book chapters, over 400 presentations or posters and 20 instructional courses at national and international medical meetings, and co-edited one book. A major interest of Dr. Vogel's is long-term follow up of children and adolescents with spinal cord injuries. Over the past decade, he has been the principal investigator of a grant studying the psychological, educational, vocational and sexual adjustment of patients with spinal cord injuries and their families. In addition, he has investigated long-term use of various braces for ambulation (walking) for children with spinal cord injuries and medical complications and psychosocial outcomes of children and adolescents with spinal cord injuries.

Kathy Zebracki, Ph.D., CLCP, is Director of Psychology at Shriners Hospitals for Children, Chicago, and Clinical Associate Professor at Rosalind Franklin University of Medicine and Science. She received her bachelor's degree from Northwestern University and Ph.D. in Clinical Psychology from Case Western Reserve University. Dr. Zebracki completed her psychology residency at Children's Memorial Hospital in Chicago (now Ann & Robert H. Lurie Children's Hospital of Chicago) and an NICHD-funded fellowship at Loyola University Chicago. Dr. Zebracki is the

incoming Editor of *Topics in Spinal Cord Injury Rehabilitation* and an Associate Editor of *Developmental Medicine and Child Neurology*, as well as member of several editorial boards, including *Journal of Pediatric Psychology*. She serves as Director at Large of American Academy for Cerebral Palsy and Developmental Medicine, Chair of the Pediatrics Committee of the American Spinal Injury Association, and Chair of the Professional Advisory Council and Board Member of the Illinois Spina Bifida Association. She is also a Certified Life Care Planner.

Dr. Zebracki is an active clinician, researcher, and educator. Her primary clinical interests are in the care of children and adolescents with physical disabilities and chronic health conditions. Her research focus is in the area of psychosocial and medical outcomes of youth with spinal cord dysfunctions, including spinal cord injury and spina bifida. She also serves as a clinical and research mentor for clinical psychology doctoral students and postdoctoral fellows. Dr. Zebracki has authored over 40 peer-reviewed journal articles, 10 book chapters, and 96 presentations or posters at national and international meetings. Dr. Zebracki is a Co-Editor of the textbook, *Spinal Cord Injury in the Child and Young Adult*.
