SCI : Considerations for Adolescents and Transition to Adulthood

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DISCLOSURES

NONE

Objectives

Review areas of fears, frustrations, and losses for adolescents with spinal cord injury including :

- Developmental issues
- Peer group relationships
- School reintegration issues
- Self –sufficiency issues

Review common medical issues facing adolescents with SCI that are seen more often in this age group :

- Hypercalcemia
- Scoliosis
- Contractures
- Heterotopic ossification

Review considerations for transition to adulthood

SCI under Age 18

- It's a group not typically given a lot of attention by the larger spinal cord injury community, in part because experts say only about 20 percent of spinal cord injury patients are children.
- Model SCI Systems national data :
  - 20% (2,200) of all new traumatic SCI cases per year (about 11,000) occur in people under age 20
  - 2%-5% (250-500) in kids 0-15 years old
  - 14%-18% (1500-2000) in the 16-20 age group
  - These numbers do not include data from the Shriners Children's hospital system, which cares for a lot of pediatric SCI in the large urban areas of Philadelphia, Chicago, and Sacramento, so actual numbers are likely higher.
- These numbers do not include children with non-traumatic SCI from medical conditions such as transverse myelitis, spinal cord infarct and spinal tumors. Such patients have virtually the same rehabilitation needs as those with traumatic SCI.

SCI under Age 18

- Etiology : # 1 motor vehicle crash (MVC). The second highest cause varies by age group: medical/surgical complications in children 0-5 years; violence in ages 6-12; sports in ages 13-15; and violence again in ages 16-21.
- Etiology : 0-15 age group as a whole, the top three causes are MVC (44%), followed by sports (23%) and violence (21%).
- Etiology : Over the last 30 years, the percent of injuries due to MVCs has increased in the 0-15 year age group while violence has decreased. Within sports, diving has remained the top cause, but the percent of cases due to both diving and football have decreased, while those due to skiing have increased.
- Type of injury :
  - Under age 12,: 65% paraplegia vs. 35% tetraplegia
  - Teens: typical adult ratio 45% paraplegia vs. 54% quadriplegia
  - Age 0-5 have about 67% complete injuries, and from 6-12 about 62% complete.
  - > age 12: typical adult ratio about 56% complete and 44% incomplete
  - Greater occurrence of complete injuries in younger children due to the relatively less stable vertebral column compared to the large size of a child's head and the fact that the bones are not yet completely ossified and the ligaments and spinal muscles are not as strong as in adults, resulting in more damage to the spinal cord with trauma

Unique Medical Topics in Teens with SCI

- **Scoliosis**
  - Will occur in nearly 100% of children injured before puberty*
  - Teens , especially boys, may still be growing . Preteen/Teens incidence ages 10-16 20%*, ages 17+ 12%
  - Bracing (TLSO) can help improve sitting and function; won't correct existing deformity but can delay the time to surgical correction of the deformity
- **Contractures**
  - Greater risk in periods of rapid growth
  - Braces and splints are outgrown due to growth
- **Bladder /Bowel**
  - Adult bladder capacity reached at about age 10
  - In children injured young , bladder may not grow to adult size
  - Bladder augmentation surgery can help in teen patients
  - Mitrofanoff procedure (umbilical stoma) in outpt setting
  - Malone procedure (ACE or MACE) for bowel management in outpt setting (vs colostomy)
- **Heterotopic Ossification**
  - Overall less incidence in peds (3%) study groups compared to adults (20%) and often later onset (14 months in peds compared to 1- 4 months in adults)
  - Some suggestion of increased incidence in teens compared to younger pts
  - No unique interventions; no routine prophylaxis
  - Concerns about growth plate effects of etidronate disodium/Didronel in actively growing children
- **Immobilization Hypercalcemia**
  - Teens, notably males , are especially prone - first 3 months
  - Elevated levels of serum calcium from increased bone resorption due to immobilization (increased turnover in growing kids, large and active bone mass)
  - Nausea , abdominal pain, vomiting, lethargy/malaise, polydipsia/polyuria, dehydration. Kidney stones if untreated . Can be asymptomatic
- **Phrenic nerve pacers**
  - Less cumbersome, more appealing alternative to ventilator tubing (vent for night, illness, pacer failure) – outpt setting

* Dearolf WW 1990, Campbell J 1975

Resources for Teens during Rehab

- School
- Psychology
- Family counseling
- Child life
- Play
- Medical and Behavior Health specialists who will see patients and are comfortable/knowledgeable with patients under age 18
- Incorporation of parents, siblings and friends in rehab environments

Rehab Goals

- Healthy teens can spend only a brief period of time in the acute care setting
- Teens can be expected to achieve similar functional skill levels as adults
- Teens in early adolescence will likely need some supervision and reminders for care
- Preventive practices (pressure relief measures, splint use , preventative medicine, etc) can be especially challenging to instill in kids and teens due to lack of insight and lack of focus on the future
- Teens need to have their privacy respected and often need a program-wide approach to problem behaviors to enhance compliance with therapies
- Teens will experience feelings of loss, powerlessness, frustration
- Loss of control can lead to anxiety , fear, and embarrassment within the fragile adolescent ego which is in constant flux (same biological, hormonal, emotional, social , and cognitive changes as any teen)
- Skills learned as an early teen can be effected by growth /weight gain later
- Growing teens need growth adjustments and replacement of DME /orthotics

Major Tasks of Adolescents

- Develop a basic self –image including sexual identity
- Select a vocational choice
- Separate from parents

All three are disrupted by SCI !

Psychological Issues – Developmental Stages

- Adolescence – can be a period of turmoil and any illness or functional change will accentuate it
- Social pressures, desire to not be different, desire to be “normal”
- Increased risk of secondary medical complications due to rebellion
- Peer group issues:
  - biases related to physical appearance
  - Premorbid friendships may change
  - limited clothing options
  - functional aids/wheelchair
  - transportation restrictions
  - physical access barriers at places young people visit
  - reduced peer group interaction leads to isolation, depression, and interferes with progress toward independence
- Sexuality and reproductive questions/ issues and education
  - Period of sexual identity development
  - Varied amount of premorbid experience and knowledge
  - Issues: functional limitations, altered body image, physical/privacy and transportation barriers, biases and discrimination related to physical appearance
  - Status of premorbid relationships may change
- Independence from parents: may have to revert back to dependence , may never achieve independence
  - Reliant on family members for personal assistance care
  - Teen and parent discomfort with intimacies of bowel /bladder management and ADL care
  - Psychological and emotional support is still most often provided by family
  - Need provisions for inclusion of parents, siblings , and friends in the rehabilitation process

Psychological Issues – Developmental Stages

- Teen's adjustment is strongly affected by the parents' ability to cope, so it's essential to address the parents' emotional needs as well. Teens will sense how their parents are feeling and coping, could be opposing how teen is coping – can interfere with rehab process
- Important to have family support but with an appreciation that the teen needs to learn coping skills, develop independence: overindulgence and overconcern can lead to passivity and dependence of the teen, hampering future opportunity to live independently
- No studies as to whether children <18 have a higher or lower incidence of post traumatic stress disorder, depression, or adjustment problems after SCI compared to adults. Teens are probably at greater risk than younger children for psychological concerns after SCI because of issues of sudden dependency, concerns about appearance and sexual function, and lost roles such as participation in team sports (peer group issues)
- Important to reconnect kids to their peers, activities, and adapted sports as soon as possible because participation in the community is a key factor in making a good adjustment and helps to set the stage for life satisfaction in adulthood.
- Reaction to disability will change as the patient ages, new concerns may arise at crisis points (family /school/peer stress) or at later developmental stages. Anticipatory guidance for potential complications and transitions (ambulation in younger pts to w/c in older pt)
- Knowledge base will change : need to review SCI physiology and bladder, bowel and sexual function issues, because they may not have learned all of this when they were first injured.

School Issues

- School is the vocation/work of children
  - Education is critical element for attainment of optimal independence and maximum career opportunities
  - School environment important for social skills
- The hospital stay can be a huge hit to school attendance
- Need to plan for successful make up of missed work
- Hard to keep up with school work during inpatient rehab
- Emphasis on helping teens to prepare for the successful return to school - physically, socially, academically
- School visit/staff and student education for successful re-entry
- School IEP plans, accessibility issues, transportation issues, caregiver assistance, nursing support (if needed)
- Changes in premorbid plans: precollege employment, sports scholarships, location of college
- Connection to Voc Rehab

SCI with TBI

- Incidence of a dual diagnosis may approach 60% with certain risk factors
- Diagnosis of mild-moderate severity TBIs may be missed during acute care hospitalizations of SCI
- Neuropsychological symptoms of a missed TBI diagnosis may be perceived during rehabilitation as noncompliance, inability to learn, maladaptive reactions to SCI, and poor motivation
- Literature from the last 40 years reports incidence rates from 16% to 59%. The marked variability in these rates results from differences in sample populations and varying diagnostic methods

Transition into Adulthood

- Independent living
- Employment
- Financial resources
- Socialization
- Healthcare

Transition to Adulthood

- Research shows that positive outcomes and life satisfaction in adulthood after childhood SCI are more strongly related to functional independence and involvement in community than to injury level or severity.
- Need to help families realize this and plan for the future by maximizing education, participation, and independence.
- Need to help parents gradually transition care to the child. Adjustment issues may crop up years after the injury, as may risk taking behaviors such as smoking, drug use/abuse, or alcohol use.
- Persons injured as teens , along with their support systems (counselors, family, etc.), can begin early on thinking about jobs that will be within the teen's capacity to perform and about the associated educational requirements
- Teens with SCI may not get same prevocational experiences
- Adults who sustained SCI as children attain higher education levels than adults in the general population. Persons with childhood injuries have a higher employment rate than those injured as adults.
- Still concern for large number of severely disabled persons ages 16-64 not gainfully employed

Transition to young adult

- Revisit independence skills needed – delayed or aborted independence?
- Begin transition early – parents previously “in charge “ of health care
- Finding adult medical providers if needed
- School plans:
  - ? Complete HS on time
  - ? Timing of college entrance exams – time off
  - ? Go away for college, change location/choice)
  - ? Change in ability to earn money for college (change choice)
  - ? Ability to live in dorm, arrange for assistance
- Vocational plans – change?
- Love relationships , dating (? Experience)
- All complicated even more if TBI involved

References and Resources

- **References**

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  - Kirshblum S, Campagnolo DI, Delisa JA (eds) Spinal Cord Medicine . Philadelphia , PA. Lippincott Williams & Wilkins, 2002

- **Resources**
  - Adolescent Health Transition Project , Center on Human Development and Disability, University of Washington, Box 357920, Seattle, WA 98195. 206-685-1242; healthtr@u.washington.edu ; http://depts.washington.edu/healthtr/ . This program is designed to help smooth the transition from pediatric to adult health care for adolescents with special health care needs.
  - National Spinal Cord Injury Association (NSCIA), 6701 Democracy Blvd, Suite 300-9, Bethesda, MD 20817; (800) 962-9629; info@spinalcord.org ; http://www.spinalcord.org/

Teen SCI and Transition to Adulthood

Thank you !

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