

Key Considerations in the Rehabilitation of Children with a Spinal Cord Injury

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ABSTRACT

There is abundant reference and research material available on adult spinal cord injury and its rehabilitation management. By comparison there is very little published about paediatric spinal cord injury (pSCI). This paper is intended to provide the rehabilitation professional with an overview of the specialised needs of the paediatric SCI client and how those needs differ from the adult with a SCI. The long-term effects of SCI on children and their families are particularly devastating as many years of growth and development lie ahead. Very young children with SCI who are still to experience significant skeletal growth present with their own unique rehabilitation challenges.

It is imperative that rehabilitation services are directed and coordinated in a collaborative family-centred manner, as the child is ultimately part of a complex family system. Knowledge of a child's normal growth and development is essential in order to tailor a child's rehabilitation goals to an age-appropriate level. Regular reviews with an interdisciplinary team and the child and family are required to minimise the physical and psychological effects of SCI.

Key words: spinal cord injury, paediatric nursing, rehabilitation

INTRODUCTION

Spinal cord injury (SCI) is a life altering and devastating event that has lasting implications for the child and their family (Alander & Stauffer in Betz & Mulcahey, 1994). No other disability acquired in childhood results in "abrupt motor paralysis; sensory loss; bowel bladder and sexual dysfunction; temporary cessation of developmental; scholastic and social milestones; and eventual alteration of development..." (Mulcahey & Betz, 1997 p. 31). SCI in infants, young children and adolescents fortunately remains an uncommon occurrence (Zejdlik, 1992, Scheinberg 2001; Flett, 1992; Pang in Betz & Mulcahey, 1994); but the anatomical differences of the paediatric spine and other developmental factors in children pre-dispose them to injury of the upper cervical spine (Scheinberg, 2001; Smith, Freiden, Nelson & Tilbor

in Betz & Mulcahey, 1994). Young children are therefore more likely to experience "catastrophic neurological loss such as quadriplegia" (Zejdlik, 1992, p. 550) as the result of a spinal insult. Improved emergency retrieval techniques have also contributed to the increase in the number of children with quadriplegia living in the community who remain permanently ventilator-dependent (Botel, Glaser, Neideggen & Meindel, 1997).

Paediatric rehabilitation has only evolved as a specialty area of nursing within the last 20 years (Hertzberg & Edwards in Edwards, Hertzberg, Hays & Youngblood, 1999; Ricci-Balich & Behm in Hoeman, 1996). The distinguishing features of paediatrics are that the patient is growing and developing and that professional relationships are established with both the child and family (Molnar & Kaminer, in Molnar, 1992; Hoeman in Molnar, 1992). With these fundamental considerations in mind this paper reviews the unique aspects of the care and rehabilitation of the child with a spinal cord injury.

Incidence, aetiology, life expectancy and life satisfaction

Incidence:

Statistical data regarding the incidence of SCI in children in Australia is sparse. Flett (1992) reports that the injury rate is between 0.5-1.0 per million. The Motor Accidents Authority of New South Wales compiles statistics relating solely to spinal cord injuries sustained in motor vehicle accidents. Between June 1989 and June 2002, there were 41 reported injuries in the 16 and under age group (Motor Accidents Authority, 2003). It is encouraging to report that the incidence of SCI in Australia has fallen since the early 1980s, which is directly attributable to the introduction of compulsory wearing of seatbelts (1975) and random breath testing (1985), (Yeo, 1994).

Aetiology:

Most cord injuries in children aged one to 15 years occur as the result of a motor vehicle accident or

fall (Scheinberg, 2001). In the United States the most common cause of pSCI is motor vehicle accident, followed by sports injuries and violence (Vogel & DeVivo in Betz & Mulcahey, 1994).

Life Expectancy and Life Satisfaction:

Children with SCI can expect to enjoy a healthier and longer life than those who sustained their injury 10 years ago (Scheinberg, 2001), due to advances in early medical treatment and rehabilitation (Alander & Stauffer in Betz & Mulcahey 1994; Yeo, 1994). A child with tetraplegia is anticipated to have a life expectancy of 85 % of the average population and more than 95 % for a child with paraplegia (Scheinberg, 2001).

With the life expectancy of a child with SCI nearing that of the average individual, it is important to be aware of factors which significantly affect life satisfaction in this group. In a small pilot study conducted by Vogel, Klaas, Lubicky and Anderson (1998), there was no indication that age at injury, or duration of injury had an impact on adult outcomes. Although the severity of neurological deficit did have an impact on some outcomes such as driving and employment, it was suggested that this did not directly relate to emotional status or life satisfaction. The factors identified as ultimately affecting life satisfaction were education, satisfaction with future employment, income, recreational opportunities and avoidance of medical complications. This has important implications for those involved in the long-term rehabilitation planning for the child with a SCI. Clearly the utmost importance must be placed on including opportunities for continuing social and recreational integration, optimal educational experiences, and ultimately, vocational options. Additionally, parents need to be encouraged to view their child as having a physical disability and not as a 'sick' child (Molnar, 1992).

Differences between adult and paediatric spinal structures.

SCI in infants, young children and adolescents fortunately remains an uncommon occurrence (Zejdlik, 1992, Scheinberg 2001; Flett, 1992; Pang in Betz & Mulcahey, 1994); but the anatomical differences of the paediatric spine and other developmental factors in children (noted below), pre-dispose them to injury of the upper cervical spine (Scheinberg, 2001; Smith, Freiden, Nelson & Tilbor in Betz & Mulcahey, 1994), and make early diagnosis difficult (Zejdlik, 1992; Pang in Betz & Mulcahey, 1994).

Structural characteristics of the spine in children under 10 years include greater elasticity of neck muscles, ligaments and joint capsules; incomplete ossification of vertebral bodies, and underdevelopment of the uncinat processes. These differences result in greater extension, flexion, rotational and movements as well as traction and thus marked risk of injury following impact. If a cervical spine injury is detected, there

is also a 10-15 % incidence of an associated thoracic or lumbar spine injury (Babcock in Zejdlik, 1992).

Radiological evidence of a fracture, or dislocation, is frequently lacking or difficult to identify in children, thus traction and ischaemic injury of the spinal cord can occur to produce permanent dysfunction for up to four days before the injury is discovered (Pang in Betz & Mulcahey, 1994)¹. This mandates early and close monitoring for sensory and motor deficits in the awake, injured child with impact history (Zejdlik 1992).

Developmental issues

The essential distinguishing feature of paediatric rehabilitation is the continuing growth and development of the child (Molnar & Kaminer in Molnar, 1992). Children all develop at different rates, but milestones are generally achieved in a reasonably predictable order with acceptable ranges of time and age (Easton in Molnar, 1992). Children need to grow and develop physically, cognitively, socially and emotionally in order to develop into well-functioning adults (Ricci-Balich & Behm in Hoeman, 1996). Concentration on one aspect of a child's development to the detriment of the others will constitute a risk to their balanced development.

The child who sustains a SCI at a young age has all the normal work of childhood ahead of them in addition to learning to adapt to their newly acquired physical limitations. The rehabilitation nurse therefore needs to consider the following broad developmental goals when planning rehabilitation/habilitation interventions for a child with SCI.

- **Independence in mobility** is essential to facilitate learning experiences in children and restriction of mobility may have a direct affect on their personality and perpetuate emotional immaturity and dependence (Alexander, Nelson & Shah in Molnar 1992). The concept of mobility in paediatrics must include crawling (initial mobilisation and exploration), standing (viewing the world from height); walking (getting from one place to another) and running (getting somewhere quickly) (*op cit.* 1992). Safe, age-appropriate mobility devices will need progressive upgrading as each milestone is passed. The child is at risk for pressure sores with both current and new devices, with the latter being introduced gradually according to skin tolerance. Community mobility must also be of paramount consideration for young adults in order to decrease societal isolation (Vogel, *et al.*, 1998).

¹ This is commonly known as spinal cord injury without radiological abnormality or SCIWORA.

- **Independence in activities of daily living (ADL).** Whilst ADL are considered the realm of the occupational therapist, quite often it is the nurse or family member who follows through with ADL supervision. It is important that the child achieves as much independence as possible in tasks such as showering, toileting, dressing, hair-brushing, teeth cleaning, simple meal preparation and general organisational skills in line with the same developmental expectations as their peers (Easton in Molnar, 1992).
- **Education** must be considered within the context of any child's rehabilitation program as the classroom provides an environment for learning social skills and opportunities for peer interaction (Easton in Molnar, 1992). Success in school is more dependent on intelligence and social skills than on the extent of a physical disability (*op cit.* 1992). Therapies and other health-related activities should be scheduled such that they do not compromise education and peer relationships (Ricci-Balich & Behm in Hoeman, 1996).
- **Sexual Development** is addressed later in this article.

Health maintenance for the child with SCI

The impact of such a severe disability at a young age directly affects the health status of the paediatric client over many decades (Vogel *et al.*, 1998). With recent medical advancements in the care of the person with SCI, most complications are preventable and only the most common health maintenance issues in paediatric SCI are discussed below.

Childhood illnesses

Children with SCI are still susceptible to normal childhood illnesses and should be immunised according to the recommended schedule (Scheinberg, 2001). An annual flu vaccination could be considered for those at respiratory risk. Other childhood illnesses or problems may be difficult to diagnose due to lack of sensation below the level of injury, for example appendicitis or fractures (*op cit.* 2001). Careful assessment of other signs and symptoms will be necessary for timely diagnosis

Bladder Care

In line with developmental expectations, a child should have achieved bladder continence by school entry. Children with SCI will therefore need to have a suitable bladder program in place by the time they start school. Unlike adults, the method of choice for bladder management in children is clean intermittent catheterisation (CIC) (Zejdlik, 1992; Scheinberg, 2001; Flett, 1992). Children with good hand function, adequate trunk control, and good cognitive skills can be taught to self-catheterise as young as five years old (Flett, 1992; Zejdlik, 1992;

Scheinberg, 2001). Time constraints, distractibility and motivational factors, even surgical intervention (such as scoliosis surgery) may limit achievements in the mastery of self-catheterisation (Lubicky & Betz in Betz & Mulcahey, 1994). CIC is usually performed four to six times per day (whilst awake) with urine volumes of less than 400mls expected in the adolescent. For children under the age of 10 bladder capacity should be less than their (age + 2 x 30 mls), (Shriner's Self Care Manual, 1999). Medications may be prescribed in conjunction with CIC to either promote bladder emptying or increase storage capacity (Flett, 1992).

Bowel care

As with the bladder, bowel continence is socially important for children by the time they start school. Children can be commenced on a bowel program as soon as they are medically stable (post-injury) to prevent the complications of spontaneous bowel emptying or constipation and impaction (Zejdlik, 1992). Bowel care for a child with SCI is similar to that of the adult with SCI. Bowel emptying should be planned for the same time every day or every second day and each bowel program must be tailored to suit the individual's lifestyle, type and level of injury. Consideration must be given to the amount of time required to perform bowel care as it can take anywhere from five minutes to one hour (Shriner's Hospital for Crippled Children, 1989). A high fibre diet and plenty of fluids can assist with bowel regulation and utilisation of the gastro-colic reflex can be advantageous (Flett, 1992; Zejdlik, 1992).

Scoliosis

Incidences of scoliosis in SCI appears to be age-related (Flett, 1992). The following have been reported: 91% occurrence in pre-adolescent children, with 100% occurrence in those injured before the age of 10. Incidence decreases markedly in those injured between 10-16 years and is lowest in those injured at over 17 years (Campbell & Bonnett in Lubicky & Betz, 1994). During growth spurts scoliosis may progress rapidly (Scheinberg, 2001), altering posture, which in turn can cause pelvic obliquity, pain and pressure ulcers (Lubicky & Betz in Betz & Mulcahey, 1994). Thoraco-lumbar bracing can improve sitting posture and function. Corrective surgery for scoliosis may be required in up to 67% if the SCI was sustained prior to reaching skeletal maturity, but is usually delayed until the child is over 10 years old (*op cit.* 1994).

Hip Joint instability

Children who are skeletally immature at the time of their SCI are also at high risk for developing hip joint instability (Miller & Betz in Betz & Mulcahey, 1994). Jacques and Betz reported in an unpublished review that there was an 87% incidence of hip subluxation or dislocation when the SCI occurred before the age of 10 years (*op cit.* 1994). The risk fell to just 10% if injury occurred after the age of 10. The average time of

developing hip subluxation was five years after the SCI with females being at risk 1.5 times more than males (*op cit.* 1994).

Prevention of pressure ulcers and other skin damage

In a summary of skin-related problems in children with SCI, condensed from Benner (in Betz & Mulcahey, 1994) causes of skin damage go beyond obvious contributing factors such as immobility and loss of sensation, to include developmental stages and associated typical childhood activities. Pressure areas in infants can occur on the scalp. Infants are at risk of carpet burns while 'commando' crawling. Heaters and sun-heated surfaces, such as strollers and wheelchairs, are a risk for all children with SCI. As adolescents assert their independence and try to fit in with their peers, they may neglect important aspects of their self-care which were previously mastered. Buying shoes a size larger may prevent pressure ulcers if feet swell. Finally, skin damage associated with pressure point on new remedial equipment must be anticipated and monitored. New devices should be introduced slowly and for short periods of time until comfort and skin integrity can be confirmed.

Temperature Regulation

People with spinal cord injury above the level of T8 have difficulty in regulating their body temperature, and children are particularly sensitive to thermoregulatory dysfunction. A child's normal baseline temperature may vary, thus possibly making it more difficult to detect a fever associated with an infection (Zejdlik, 1992). Adequate heating/cooling systems within the home and school environment (Scheinberg, 2001) should be provided.

Respiratory Care

People with a spinal injury above the level of T12 have weakened respiratory function (Shriner's Hospital for Crippled Children, 1989). Prevention of respiratory infections in the child with SCI can be difficult due to the exposure they receive to infectious peers in school and social situations. Parents must be taught to be vigilant about assessing 'colds' and seeing a doctor if fever, shortness of breath, thick yellow or green secretions are detected. Percussion and drainage can also be taught to assist in the removal of secretions (*op cit.* 1989).

Nutrition

A well-balanced diet, consistent with growth and development needs and adequate fibre and fluid assists in promoting healthy skin, bowel and bladder function (Shriner's Hospital for Crippled Children, 1989). Obesity can become a problem for an inactive child in a wheelchair and encouragement to participate in wheelchair sports or hydrotherapy can assist in weight control (Scheinberg, 2001). Obesity can cause an increased risk in pressure ulcer development,

impair circulation and make it difficult to transfer (Shriner's Hospital for Crippled Children, 1989). Research has shown that a dietary plan that is devised for the whole family is much more likely to be successful than placing the child on a separate eating plan (Scheinberg, 2001).

Autonomic Dysreflexia

Autonomic dysreflexia (AD) is a life-threatening complication of SCI that can occur in people with a spinal cord lesion at or above the level of T6 (Zejdlik, 1992; Flett, 1992; Scheinberg, 2001). It should be noted that children can experience the onset of autonomic dysreflexia beyond the first 3-4 months after injury (Flett, 1992) which is particularly important to note as parents, schools and children will need to be re-educated from time to time about the potential management of AD. The rehabilitation nurse should be familiar with the physiology and treatment of this serious complication.

Sexuality

The literature suggests that health professionals continue to view people with disabilities as 'asexual beings' (Shakespeare, Gillespie-Sells & Davies; 1996, Tepper, 1999). Additionally, children are generally not considered sexual beings and this component of a child's rehabilitation is often ignored (Shakespeare *et al.*, 1996). It is important that parents adopt an expectation that their child will develop sexually in the same way that other children do. Some parents feel that a child with a physical disability should not be expected to date, marry and have a family (Yarkony & Anderson in Betz & Mulcahey, 1994). Assurance can be given to parents that by providing a healthy and positive attitude towards sexuality issues they are assisting with their child's normal development.

Little is known about the sexual concerns of young children (Zejdlik, 1992), but parents have reported that children as young as eight have asked questions about how their SCI will affect their sexuality (Yarkony & Anderson, in Betz & Mulcahey, 1994). Basic information about fertility and sexuality should be provided to parents (and the child, if appropriate) as part of the initial SCI teaching program (Flett, 1992).

Adolescents are less likely to receive adequate sex education and counselling (Harrison, Glass, Owens & Soni, 1995, Berman, Harris, Enright, Gilpin, Cathers & Bukovy, 1999, McCabe 1999); are more likely to suffer sexual abuse (Shakespeare *et al.*, 1996, Sobsey, 1995); are less likely to have the opportunity to develop dating and social skills (Rintala, Howland, Nosek, Bennett, Young, Foley, Rossi & Chanpong, 1997); and are more likely to possess negative feelings towards their sexuality (McCabe, 1999). Thus it is imperative for the rehabilitation nurse to understand that children with disabilities are at high risk for exclusion from achieving normal sexual developmental milestones.

Very few formal teaching materials that relate solely to sexuality and the spinal cord injured child are available and there is still uncertainty amongst health care professionals whose role it is to address these issues when they arise (Zejdlik, 1992). The rehabilitation nurse is in a privileged position to provide information and counselling on sexual matters, because his or her contact with the child and family is usually sustained over a long period of time. This position allows for the development of longer-term relationships that assist to foster openness and mutual trust.²

CONCLUSION

While children with SCI share many of the same physical complications and rehabilitation requirements as the adult SCI population, they have special age-related rehabilitation needs. Planning and goal-setting needs to be family-centered in order to achieve meaningful rehabilitation outcomes. This article has presented the most common differences affecting rehabilitation planning when caring for a child with SCI, paying particular attention to those which are less well documented in the literature.

ENDNOTE

This article has been abridged specifically for this publication. If you would like to obtain a copy of the full text or information on any of the references cited, contact the author directly.

References

Alander, D. H. & Stauffer, E. S. (1994). Long Term Follow-Up of Spinal Cord Injury. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 613-617). Illinois:American Academy of Orthopaedic Surgeons.

Alexander, M. A., Nelson, M. R. & Shah, A. (1992). Orthotics, adapted seating and assistive devices. In

Molnar, G. (Ed). (2nd Ed.). Paediatric Rehabilitation. Baltimore:Wilkins & Wilkins.

² A Sexual Counselling Guide was published by the Shriner's Hospital for Crippled Children in 1988. Contact the author for further information.

Benner, L. (1994). Pressure ulcer prevention. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 285-292). Illinois:American Academy of Orthopaedic Surgeons.

Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., & Bukovy, G. (1999). Sexuality and the adolescent with a physical disability: Understandings and misunderstandings. Issues in Comprehensive Pediatric Nursing, 22(4), (pp. 183-196).

Botel, U., Glaser, E., Neideggen, A., Meindl, R. (1997). The cost of ventilator-dependent spinal cord injuries-patients in the hospital and at home. Spinal Cord, 35, (pp.40-42).

Easton, J. K. M. (1992). Psycho-social issues. In Molnar, G. (Ed). (2nd Ed.). Paediatric Rehabilitation. Baltimore:Wilkins & Wilkins.

Flett, P. J. (1992), The rehabilitation of children with spinal cord injury Journal of Paediatric and Child Health, (28), (pp. 141-146).

Hertzberg, D. L. & Edwards, P. A. (1999). Introduction to pediatric rehabilitation nursing. In Edwards, P. A., Hertzberg, D. L., Hays, S, R., Youngblood, N. M. (Eds.). Paediatric Rehabilitation Nursing. Philadelphia:WB Saunders.

Harrison, J., Glass, C. A., Owens, R. G., & Soni, B. M. (1995). Factors associated with sexual functioning in women following spinal cord injury. Paraplegia, 33(12), (pp. 687-692).

Lubicky, J. P., & Betz, R. R. (1994). Spinal deformity in children and adolescents after spinal cord injury. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 363-369). Illinois:American Academy of Orthopaedic Surgeons

Miller, F. & Betz R. R. (1994). Hip Joint Instability. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 139-159). Illinois:American Academy of Orthopaedic Surgeons.

McCabe, M. P. (1999). Sexual knowledge, experience and feelings among people with disability. Sexuality and Disability, 17(2), (pp.157-171).

Molnar G., & Kaminar, R. K. (1992). Growth and development. In Molnar, G. (Ed). (2nd Ed.). Paediatric Rehabilitation. Baltimore:Wilkins & Wilkins.

Motor Accidents Authority of New South Wales (2003). [On-line]. Available World Wide Web. <http://www:maa.nsw.gov.au>

Mulcahey, M. J., Betz, R. R. (1997). Considerations in the rehabilitation of children with spinal cord injuries. Top Spinal Cord Injury Rehabilitation, 3, (2), (pp. 31-36).

Pang, D. (1994). Spinal cord injury without radiological abnormality (SCIWORA) in children. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 139-159). Illinois:American Academy of Orthopaedic Surgeons.

Ricci-Balich, J., Behm, J. A. (1996). Paediatric Rehabilitation Nursing. In Hoeman, S. P. (2nd Ed.). Rehabilitation nursing: Process and application. St Louis: Mosby

Rintala, D. H., Howland, C. A., Nosek, M. A., Bennett, J. L., Young, M. E., Foley, C. C., Rossi, M. S., Chanpong, M. S. (1997). Dating issues for women with physical disabilities. Sexuality and Disability, 15(4), (pp. 219-242).

Shriner's Hospital for Crippled Children, (1989), Self Care Manual Spinal Cord Injury Unit, San Francisco: Author

Shriners Hospitals for Children, (1999), SCI Teaching Manual, San Francisco: Author.

Scheinberg, A. (2001). Managing wheel power. Australian Doctor, (26/01/01), (pp. 49-51).

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). The sexual politics of disability: Untold desires. London: Cassell.

Smith, Q. W., Frieden, L., Nelson, M. R., & Tilbor, A. G. (1994). Transition to adulthood for young people with spinal cord injury. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 601-611). Illinois: American Academy of Orthopaedic Surgeons.

Sobsey, D. (1995). Enough is enough. There is no excuse for a hundred years of violence against people with disabilities. In Sobsey, D. Wells, R. Lucardie, & S. Mansell. Violence and disability. An annotated biography, (pp. 9-17). Baltimore: Paul H. Brookes.

Tepper, M. S. (1999). Letting go of restrictive notions of manhood: male sexuality, disability and chronic illness. Sexuality and Disability, 17(1), (pp. 37-51).

Vogel, L. C., & DeVivo, M. J. (1994). Etiology and demographics. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 601-611). Illinois: American Academy of Orthopaedic Surgeons.

Vogel, L. C., Klaas, S. J., Lubicky, J. P., Anderson, C. J. (1998). Long-term outcomes and life satisfaction of adults who had paediatric spinal cord injuries. Archives of Physical Medicine and Rehabilitation, 79, (pp. 1496-1503).

Yarkony, G. M., & Anderson, C. J. (1994). Sexuality. In Betz, R. R., Mulcahey, M. J. (Eds.). The child with a spinal cord injury (pp. 601-611). Illinois: American Academy of Orthopaedic Surgeons.

Yeo, J. D. (1994). Spinal cord injuries: diagnosis and first aid. Modern Medicine of Australia, August. (pp. 36-45).

Zejdlik C.P (2nd Ed.). (1992). Spinal Cord Injury in Children. Management of Spinal Cord Injury, (pp. 549-568). Boston: Jones and Bartlett.

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