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Spinal Cord Injury in the Child and Young Adult



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Randal R Betz, and MJ Mulcahey**

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FOREWORD

Twenty-nine years ago, a 3-year-old boy was run over by a bicycle while playing near the beach. He sustained a spinal cord injury (SCI) and suffered tetraplegia. In the years after the incident, he attended numerous rehabilitation and medical facilities and overcame one complication after another. Today, he is married, a father of two children, and working as a computer programmer. His story shows what is possible when a child or young adult sustains an SCI. However, this cannot happen without a lot of dedicated care, as demonstrated clearly in the story of Bridget Harrington in the first chapter of this book.

Spinal Cord Injury in the Child and Young Adult is a proper and timely addition to the *The Child with a Spinal Cord Injury*, published in 1996 and edited by Randal Betz and MJ Mulcahey, who, with Lawrence Vogel and Kathy Zebracki, share the editorship of this new volume.

Real progress has been made in improving the knowledge and understanding of SCI in recent decades, and this book contains information on all aspects of comprehensive care.

Children and young adults are distinct from adults with SCI in one major respect: they will, as all children do, develop physically and psychologically as they age. An SCI, however, will influence the maturation process in various ways. This ongoing 'double evolution' means that, over 10 or more years, the limitations caused by the SCI will change and new challenges for care will develop. The purposes of care will evolve as children develop into adulthood and will present an extra challenge for both achieving specific goals and management.

Section 1 of this volume gives an overview of SCI, looking at epidemiology, assessment, and life care planning, and includes the International Spinal Cord Injury data sets. Children and young adults are a minority of the overall population with SCI, and they represent an age-specific incidence of under 10 new cases per million children (age 0 to 15 years) and about 20 to 25 new cases per million children (age 0 to 19 years) in the USA. This still results in hundreds of new cases per year.

Section 2 gives specific information on the early management of SCI, focusing on pathophysiology, acute management, and principles of treatment of spine stability in children. Early management is of utmost importance, as it always has consequences for future care.

Section 3 provides unique perspectives on non-traumatic causes of pediatric SCI, the management of high tetraplegia, and concomitant brain injury.

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Valuable information on medical management, including nutrition, is given in Section 4, including for the bladder and bowel, spasticity, autonomic dysfunction, medical complications, skin integrity, pain, and metabolic complications. These are major factors affecting a person's quality of life and frequently resulting in re-admission during follow-up. Children differ from adults in all these areas and the knowledge needed to offer proper care is well presented in the chapters of this section.

Section 5 focuses on neuromusculoskeletal management, including upper extremity function and orthopedic complications unique to children, such as neuromuscular scoliosis and hip subluxation.

Section 6 focuses on all aspects of physical rehabilitation, describing precisely and practically the recommendations on how to implement specific rehabilitation treatment. The psychosocial aspects of SCI are discussed in Section 7, including education, emotions, leisure/recreation, and long-term outcomes.

The final section deliberates on research priorities and future directions.

This volume provides a thorough examination of the current knowledge on SCI. It will be a great help for emergency services, healthcare providers, rehabilitation physicians, neurosurgeons, orthopedic surgeons, and allied professionals, such as nurses, physical therapists, occupational therapists, and psychologists involved in the care of children and young adults with SCI. It will be a useful resource for clinical researchers, teachers, and students interested in this topic. It is a must for libraries in specialized services.

The book is easy to read, with comprehensive information presented in an attractive and understandable way. The case vignettes illustrate the challenges experienced by specific groups of individuals with SCI and those who care for them. The headings make quick consulting of the content possible. The tables contain useful extra information; the figures help clarify specific topics.

The evolution of the treatment of SCI will continue and one can hope that further achievements will improve the quality of life and life expectancy of this group of individuals with SCI.

The editors and the contributors are to be congratulated for this fine work.

Professor Jean Jacques Wyndaele
President of the International Spinal Cord Society

PREFACE

Since the publication of *The Child with a Spinal Cord Injury* in 1996 (Betz and Mulcahey 1996), there have been significant advances in the management of young people with spinal cord injuries (SCIs). These advances have enhanced functional abilities and have facilitated greater community-wide participation, which have improved the lives of young people with SCIs and their families. Since the mid-1990s, the management of young people with an SCI has become more comprehensive, embodying the principles of the World Health Organization's International Classification of Functioning, Disability and Health model. Emphasis has shifted toward activity and participation within young people's environments, taking into account personal factors such as family values and culture. For example, the goal of upper extremity interventions such as therapy, bracing or reconstructive surgery expands beyond accomplishing a better grip to improve function and independence to effortless and spontaneous use of the hands for performance in play, school, chores, and self-care activities. Another example is that the goals of ambulation or wheelchair training are not merely to move by walking or wheeling, but to increase community access and participation and to improve ergonomics to prevent future secondary health conditions such as chronic shoulder pain and dysfunction.

Since the mid-1990s, we have also seen a steady increase in pediatric SCI research and scholarly activities associated with evidence-based pediatric SCI care. Notable examples include the development and validation of SCI pediatric-specific evaluation tools such as the Needs Assessment Checklist and large item-banks of daily routines; inclusion of pediatric considerations in the development of International SCI Core Data Sets and International Perspectives on SCI pediatric psychometric testing of the International Standards for Neurological Classification of Spinal Cord Injury and other notable adult SCI measures; systematic reviews and reports on pediatric SCI epidemiology; and the gathering of data on the psychosocial outcomes of children and adolescents with an SCI along with their caregivers and on the long-term outcomes of adults who sustained pediatric injuries and the implication of these outcomes on pediatric SCI rehabilitation and habilitation.

Despite all of the advances since the 1990s, of which many will be discussed in this book, there are several major areas that need to be addressed in the future. It is the editors' hope that this book will stimulate young clinicians and researchers to take the progress made and build on this further in the future. There is a compelling need for our interventions to be more

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evidence based and to be accessible and affordable for all young people with SCI worldwide. Increased efforts must be made to prevent SCIs. This requires a thorough understanding of the epidemiology of SCI throughout the world and attention to be paid to emerging technologies that will facilitate prevention, as well as those that cause SCI, such as the mobile phone and distracted driving. Greater emphasis must be put on preventing premature death and secondary health conditions. Management of young people with SCI must include comprehensive transition planning that assures successful passage from adolescence into adulthood. Because of the relatively long lifespan of young people with SCI, the issue of aging must be addressed in the lives of young people with SCI to avoid overuse syndromes and premature cardiovascular disease so that they may enjoy a full, healthy, and satisfying life.

This book, *Spinal Cord Injury in the Child and Young Adult*, will address a variety of topics relevant to pediatric-onset SCI including epidemiology, medical, surgical, urologic, rehabilitative and psychosocial issues, and future directions. Our intended audience is those in the myriad disciplines who constitute the interprofessional teams that care for young people with SCI from the scene of a crash, through acute care and initial rehabilitation, to long-term follow-up. We hope this book will benefit both students and senior clinicians, as well as the professional who regularly or infrequently cares for young people with SCI. The first chapter sets the tempo by providing an insight from a young adult with pediatric-onset SCI and her family; this perspective should uphold our focus on this book's central theme, namely young people with SCI and their success as individuals and family and community members.

Lawrence C Vogel, Kathy Zebracki, Randal R Betz and MJ Mulcahey
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