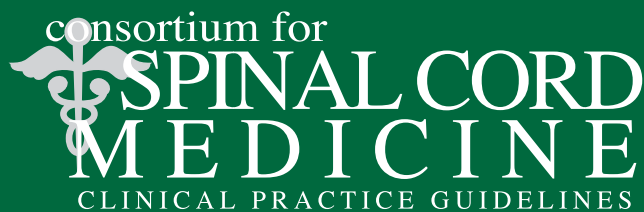


Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals



Administrative and financial support provided by Paralyzed Veterans of America

Consortium for Spinal Cord Medicine Member Organizations

American Academy of Orthopedic Surgeons

American Academy of Physical Medicine and Rehabilitation

American Association of Neurological Surgeons

American Association of Spinal Cord Injury Nurses

American Association of Spinal Cord Injury Psychologists and Social Workers

American Congress of Rehabilitation Medicine

American Occupational Therapy Association

American Paraplegia Society

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Association of Academic Physiatrists

Association of Rehabilitation Nurses

Congress of Neurological Surgeons

Eastern Paralyzed Veterans Association

Insurance Rehabilitation Study Group

Paralyzed Veterans of America

U.S. Department of Veterans Affairs

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July 1999

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This guide has been prepared based on scientific and professional information known about outcomes following traumatic spinal cord injury and its treatment in 1999. Users of this guide should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice.

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Foreword

What outcomes can be expected after spinal cord injury (SCI)? What extent of recovery can be anticipated? What activities can be performed independently? What equipment and assistance will be needed? What degree of productivity and community integration can be accomplished? What quality of life can be achieved? These are the questions that face each person who survives SCI. These are the challenges that face each SCI rehabilitation team. These too are the issues faced by case managers and third-party payers.

The first purpose of these clinical practice guidelines is to provide the best available answer to the question, “What functional and psychosocial outcomes can be expected after SCI?” based on evidence in the literature, information from large SCI databases, and consensus opinions of experts. The second purpose is to make recommendations regarding the management of outcomes through appropriate assessment, goal setting, and documentation.

The approach taken by this panel has been to focus on demonstrated, achievable rehabilitation outcomes rather than on the rehabilitation process. No attempt has been made to define the components, character, or quantity of rehabilitation treatments, interventions, or processes that result in successful outcomes after SCI. Instead, the panel’s aim has been simply to quantify the outcomes produced by comprehensive systems of spinal cord injury care. These outcome statistics have been reported in the literature or documented in databases, and they coincide with the consensus expectations of clinical practitioners. The panel considers the evidence from the Model Systems’ database on functional outcomes to be very strong descriptive data and quite appropriate for establishing generalized functional expectancies.

The domains of outcome considered by the panel were broad, including motor recovery, functional independence, social integration, and quality of life. Each domain was considered in turn, examining methods of assessment, establishing guidelines for goal setting, and recommending documentation that facilitates comparing individual and program outcomes with these expectations. By articulating clear expectations and offering methods of measurement, it is the hope of the panel that more consistent achievement of these expected outcomes can be fostered.

Gale Whiteneck, PhD
Chair, Guidelines Development Panel

Preface

From early days in my residency training, the fascination of SCI rehabilitation for me has been the direct relationship of the level and severity of the spinal cord lesion and the functional outcomes that a given patient could eventually achieve. Years of experience with and observation of highly motivated people with SCI resulted in empirical correlations that seemed to be helpful in predicting what the outcome would be for the next patient with a specific level of spinal cord injury. However, those years of experience also led to a deeply held conviction that a certain outcome is what “ought to happen.”

Fortunately, some investigators have taken the time to publish outcome studies that demonstrate actual outcomes by level of injury. These new clinical practice guidelines (CPG) on outcomes following traumatic spinal cord injury draw together the relevant literature on outcomes for various levels of SCI and their resulting impairment. These guidelines suggest expectations of functional outcome, equipment needs, and hours of personal care and homemaking that may be appropriate to each level of injury. In a sense, these guidelines set benchmarks for outcomes that may be achieved by people with certain levels of injury and what their minimal equipment and attendant care requirements will be at the first anniversary of the injury.

However, the ideal outcome for each patient may not always be achieved. Patient outcomes may fall short of target levels of performance because of such coexistent conditions as cognitive impairment, obesity, age, upper extremity injury, or pre-existing medical conditions. Secondary conditions such as depression, spasticity, or contractures also may hinder achievement of long-term outcomes. Allowance must also be made for personal choice in the target outcomes, allowing latitude for patients to set their own goals. Personal choice and coexistent conditions are recognized in these guidelines as variables that should be documented as causing variances from expected outcomes. Documentation of variances enables a program to evaluate outcomes and compare them to normative data when they are available. Such comparisons may also define how one population of patients might differ from another population that generated the normative data.

Another fascination of mine over years of practice is that the rehabilitation team is able to evaluate the individual patient and define expected outcomes, then “reverse engineer” the rehabilitation program to achieve those outcomes. When we were taught that a person with a C7 spared SCI should be able to X, Y, Z by discharge from acute rehabilitation, we held an ideal process in mind that has been seriously challenged by the relentless decline in allowable inpatient days under managed care programs. By taking the “expected outcomes” approach, the team can define the “destination” or target outcomes and design a variety of programs or “routes” that could all reach the target goals. This focus on outcomes estimates the destination by the first anniversary of the person’s injury. It does not define the “appropriate” length of inpatient stay nor when a person should reach each destination. Health-care professionals need no longer try to compress the whole rehabilitation program into fewer inpatient days. Frustration for the health-care provider, patient, and family member may therefore be decreased. Creativity in program design is encouraged, and the person with SCI is given the freedom to pace his or her progress as allowed by emotional and physical recovery from the trauma of the loss.

The intended audience for these guidelines is interdisciplinary team members, but many others will find them useful. Trainees in each of the professions will benefit from the comprehensive review of the literature and clarity of presentation. Life-care planners, case managers, and claims adjusters will benefit from seeing what the rehabilitation field has taken as the “medically necessary and appropriate” outcomes for each level of injury. Patients and their families will benefit from

seeing what a number of their peers have been able to achieve and what is not recommended because of lack of efficacy data. The estimated hours of attendant care will assist the patient, the family, and their counselors in the optimal allocation of resources for safety and conservation.

The consortium continues its commitment to providing guidelines based on the best research currently available in order to assist people with SCI to achieve optimal quality of life. We can expect new developments in technology and rehabilitation techniques in the future. When such advances have been demonstrated to alter expected outcomes through studies with vigorous research designs and reliable measurement tools, this document will be updated.

Kenneth C. Parsons, MD
Chair, Steering Committee
Consortium for Spinal Cord Medicine

Acknowledgments

The chair and members of the guideline development panel wish to express special appreciation to the individuals and professional organizations who were involved in the Consortium for Spinal Cord Medicine and to the expert clinicians and health-care providers who reviewed the draft document. A special thanks to the consumers, advocacy organizations, and the staffs of the numerous medical facilities and spinal cord injury rehabilitation centers who contributed their time and expertise to the development of these guidelines. The panel also expresses appreciation to John E. Dahlberg and Larry Cervelli for their cogent advice on technical aspects of the document.

Andrea K. Biddle and her Colleagues at the Department of Health Policy and Administration, University of North Carolina at Chapel Hill, served as the methodology team. They masterfully conducted the initial and secondary-level literature searches, evaluated the quality and strength of the scientific evidence, constructed evidence tables, and graded the quality of research for all identified literature citations.

Members of the Consortium steering committee, representing 18 professional, payer, and consumer organizations, were joined in the guidelines development process by 50 expert reviewers. Through their clinical analysis and thoughtful comments, the recommendations were refined and additional supporting evidence from the scientific literature was identified. The quality of the technical assistance from these dedicated reviewers contributed significantly to the professional consensus building that we hope to achieve through the guidelines development process. Attorney William H. Archambault, of Goodman, West, and Filetti, Charlottesville, Virginia, conducted a comprehensive analysis of the legal and health policy issues associated with this complex, multifaceted topic.

The guidelines development panel is grateful for the many technical support services provided by various departments of the Paralyzed Veterans of America (PVA). In particular, the panel recognizes J. Paul Thomas and Dawn M. Sexton in the Consortium coordinating office for their help in organizing and managing the process; John L. Carswell for his astute analysis of the draft recommendations; Fred Cowell in the Health Policy Department for his cogent comments reflecting the consumer perspective; James A. Angelo, Patricia E. Scully, and Sue England in the Communications Department for their guidance in writing, formatting, and creating art; and medical editor Joellen Talbot for her excellent technical review and editing of the CPG. Appreciation is expressed for the steadfast commitment and enthusiastic advocacy of the entire PVA board of directors and of PVA's senior officers, including National President Homer S. Townsend, Immediate Past President Kenneth C. Huber, Executive Director Gordon H. Mansfield, and Deputy Executive Director John C. Bollinger. Their generous financial support has made the CPG Consortium and guideline development process a successful venture.

Panel Members

Gale Whiteneck, PhD

(Chair)

(Research)
Craig Hospital
Englewood, Colorado

Carole Adler, BA, OTR

(Occupational Therapy)
Santa Clara Valley Medical Center
San Jose, California

Andrea K. Biddle, PhD, MPH

(Methodologist)

University of North Carolina at Chapel Hill
Department of Health Policy
and Administration
Chapel Hill, North Carolina

Sharon Blackburn, PT

(Physical Therapy, Spinal Cord Injury)
Craig Hospital
Englewood, Colorado

Michael J. DeVivo, DrPH

(Epidemiology)
Spain Rehabilitation Center
Birmingham, Alabama

Stephen M. Haley, PhD, PT

(Physical Therapy)
Boston University
Sargent College of Health
and Rehabilitation Sciences
Boston, Massachusetts

Robert D. Hendricks, PhD

(Health Systems Specialist)
VA Puget Sound Health Care System
National Spinal Cord Injury and
Disorders Strategic Health Group
Seattle, Washington

Allen W. Heinemann, PhD

(Health Services Research)
Rehabilitation Institute of Chicago
Northwestern University Medical School
Department of Physical Medicine
and Rehabilitation
Chicago, Illinois

Kelly Johnson, RN, MSN, CFNP, CRRN

(Nursing, Spinal Cord Injury)
Craig Hospital
Englewood, Colorado

Ralph J. Marino, MD

(Physical Medicine and Rehabilitation)
Department of Rehabilitation Medicine
Mount Sinai School of Medicine
New York, New York

Harley Thomas, BA

(Consumer)
Paralyzed Veterans of America
Washington, D.C.

Robert L. Waters, MD

(Steering Committee Liaison)
(Orthopedic Surgery)
Rancho Los Amigos Medical Center
Downey, California

Gary M. Yarkony, MD

(Physical Medicine and Rehabilitation)
Schwab Rehabilitation Hospital
Chicago, Illinois

Contributors

Consortium Member Organizations and Steering Committee Representatives

American Academy of Orthopedic Surgeons
Robert L. Waters, MD

American Academy of Physical Medicine and Rehabilitation
Margaret A. Turk, MD

American Association of Neurological Surgeons
Paul V. C. McCormick, MD

American Association of Spinal Cord Injury Nurses
Audrey Schmerzler, RN, MSN

American Association of Spinal Cord Injury Psychologists and Social Workers
Helen Bosshart, LCSW

American Congress of Rehabilitation Medicine
Marilyn Pires, MS, RN, CRRN–A

American Occupational Therapy Association
Susan L. Garber, MA, OTR, FAOTA

American Paraplegia Society
Todd A. Linsenmeyer, MD

American Physical Therapy Association
Montez Howard, PT, MEd

American Psychological Association
Daniel Rohe, PhD

American Spinal Injury Association
Kenneth C. Parsons, MD

Association of Academic Physiatrists
Kristjan T. Ragnarsson, MD

Association of Rehabilitation Nurses
Audrey Nelson, PhD, RN

Congress of Neurological Surgeons
Paul V. C. McCormick, MD

Eastern Paralyzed Veterans Association
Vivian Beyda, DrPH

Insurance Rehabilitation Study Group
Louis A. Papastrat, MBA, CDMS, CCM

Paralyzed Veterans of America
R. Henry Bodenbender, MD

U.S. Department of Veterans Affairs
Margaret C. Hammond, MD

Expert Reviewers

American Academy of Orthopedic Surgeons
Robert Waters, MD

American Academy of Physical Medicine and Rehabilitation
David Chen, MD
Daniel P. Lammertse, MD
Michael M. Priebe, MD

American Association of Spinal Cord Injury Nurses
Kathleen L. Dunn, MS, RN, CRRN

American Association of Spinal Cord Injury Psychologists and Social Workers
Stanley H. Ducharme, PhD
Marcia J. Scherer, PhD, MPH
Hugh B. Taylor, LCSW

American Congress of Rehabilitation Medicine
Doreen Casuto, RN
Marilyn Pires, MS, RN, CRRN–A

American Occupational Therapy Association
Janine Evert, MOT, OTR
Theresa L. Gregorio-Torres, MA, OTR
Kirsten M. Kohlmeyer, MS, OTR/L

American Paraplegia Society
Douglas B. Barber, MD
Steven Kirschblum, MD
Daniel P. Lammertse, MD

American Physical Therapy Association
Sarah A. Morrison, PT
Martha F. Somers, MS, PT
James D. Tomlinson, MS, PT

American Psychological Association
Frances Marks Buck, PhD
Paul R. Sachs, PhD, ABPP, ABPN

American Spinal Injury Association
Samuel G. Colachis, III, MD
Michael Y. Lee, MD
Kenneth C. Parsons, MD

Association of Academic Physiatrists
Steven Kirschblum, MD
Michael Y. Lee, MD
Michael M. Priebe, MD

Association of Rehabilitation Nurses
Christina M. Mumma, PhD, RN, CRRN

Eastern Paralyzed Veterans Association
Selig Landsman
James J. Peters
Melvyn Tanzman
Paul Tobin

Insurance Rehabilitation Study Group
Louis A. Papastrat, MBA, CDMS, CCM
James Urso
Jan Wood, CRC, CDMS, CCM

Paralyzed Veterans of America
Ann C. Adair, RN, BSN, MEd
Craig Bash, MD
Karen E. Bridges, RN, BSN

U.S. Department of Veterans Affairs
Bernard A. Nemchausky, MD, FACP
Sunil Sabharwal, MD
Robert Woolsey, MD

Special Reviewers

Larry Cervelli, OTR
Paradigm Health Corporation

John E. Dahlberg, MA
Rehabilitation Consultant

Summary of Recommendations

Expected outcomes and their measurement are divided into four domains—motor recovery, functional independence, social integration, and quality of life. Within each domain, recommendations are offered regarding appropriate assessment, goal setting, and documentation. An overarching principle for all outcome assessment and documentation is that the measurement instruments should be standardized, well-validated, and reliable.

Expected Motor Recovery Outcomes

1. Perform a neurological examination to establish the diagnosis as soon as possible after a suspected spinal cord injury, ideally within 6 hours.
2. Perform a comprehensive neurological examination according to *International Standards for Neurological and Functional Classification* between 3 and 7 days after injury.
3. Monitor neurological status periodically until recovery has reached a plateau.
4. After neurological plateau has been reached, conduct periodic evaluations of neurological status throughout the individual's lifetime.

Expected Functional Independence Outcomes

5. Establish short- and long-term functional goals with the participation of the person served based upon a comprehensive, individualized assessment by a team of health-care professionals experienced in the care and treatment of people with SCI.
6. Monitor functional ability throughout the rehabilitation process, modifying treatment strategies to maximize functional outcome.

7. After achievement of functional goals, conduct periodic evaluations of functional status throughout the individual's lifetime.
8. Document deviations in the achievement of functional outcomes (with reference to the normative data in Table 6) by groups of individuals receiving rehabilitation. Address such deviations in terms of improvement of clinical processes of care or unique population characteristics requiring risk adjustment.

Expected Social Integration Outcomes

9. After the initial acute care and rehabilitation phase, discharge individuals with SCI back into the community.
10. Focus on providing opportunities for societal participation in meaningful roles.
11. Document deviation in social participation and integration (with reference to the normative data in Figures 5-8) by groups who have completed rehabilitation. Address such deviations in terms of improvement of clinical processes of care or unique population characteristics requiring risk adjustment.

Expected Quality-of-Life Outcomes

12. Assess quality of life for individuals with SCI using direct perceptions of the individual involved.
13. Facilitate opportunities for optimal quality of life within the full continuum of health-care and rehabilitation programs.

The Spinal Cord Medicine Consortium

Guidelines Development Process

The guidelines development process adopted by the Spinal Cord Medicine Consortium consists of 12 steps, leading to panel consensus and organizational endorsement. After the steering committee chooses and explicates a topic, a panel of experts is selected who have demonstrated independent scientific investigation, publication, and leadership in the topic area. Following a detailed explication and specification of the topic by select steering committee and panel members, the methodology team review the international literature, prepare evidence tables, grade and rank the quality of research, and conduct statistical meta-analyses and other specialized studies, as warranted. The panel chairperson then assigns specific sections of the topic to the panel members, based upon their area of expertise, and writing begins on each component using the references and other materials furnished by the methodology team.

The panel members complete their sections, and a draft document is generated during the first meeting of the panel. The panel incorporates new literature citations or other evidence-based information not previously available. At this point, charts, graphs, algorithms, and other visual aids, as well as a complete bibliography, are added, and the full document is sent to legal counsel for review.

After legal review to consider antitrust, restraint-of-trade, and health policy matters, the draft document is reviewed by predetermined clinical experts from each of the consortium organizations plus other select clinical experts and consumers. The review comments are assembled in a database and analyzed, and the document is revised to reflect the reviewers' comments. Following a second legal review, the document is distributed to all consortium organization governing boards. Final technical details are negotiated among the panel chair, members of the organizations' boards, and expert panelists. If substantive changes are required, the draft is given a final legal review. The document is then ready for editing, formatting, and preparation for publication.

The benefits of clinical practice guidelines for the spinal cord medicine practice community are numerous. Among the more significant applications and results are the following:

- Clinical practice options and care standards
- Medical and health professional education and training

- Building blocks for pathways and algorithms
- Evaluation studies of clinical practice guidelines use and outcomes
- Research gap identification
- Cost and policy studies for improved quantification
- Primary source for consumer information and public education
- Knowledge base for improved professional consensus building

Methodology

The methodology team's strategy for finding evidence relating to the management of functional outcomes in individuals with SCI closely resembles the methods recommended by the Agency for Health Care Policy and Research (AHCPR) and by the National Academy of Sciences' Institute of Medicine. First, a preliminary literature search of the MEDLINE database from 1966 to the present was conducted. The purpose of this initial search was to enable the methodology team to estimate the volume of literature available on the subject and to identify the main issues associated with the topic.

The results of this initial search were discussed at a panel meeting held on March 13–14, 1997, in Denver, Colorado. At this meeting, the methodology team worked with the panel chair and members to develop the topic outline and to define specifically the literature search topics. Key topic areas identified were:

- Functional outcomes and rehabilitation expectations for individuals with SCI
- Interventions, complications, and equipment that affect (either positively or negatively) expected functional outcomes
- Types of personnel and equipment necessary to achieve functional goals
- Studies of outcome instruments (e.g., the Functional Independence Measure (FIMSM) and the Craig Handicap Assessment and Reporting Technique (CHART)).
- Time-related considerations in determining the prognosis of expected functional gains

- Patient satisfaction, quality of care, quality of life, self-care, and self-concept
- Comorbidities that limit achievement of functional outcomes or quality of life

Subsequent consultation with the panel chair clarified that articles of particular interest were those that analyzed and discussed functional outcomes by injury level. Topics ruled out of consideration were articles evaluating drugs, programs, or devices.

The panel specified the guidelines' primary audience as the interdisciplinary health-care providers who treat individuals with SCI. Third-party payers, including case managers and discharge planners, may find the outcomes and resource guidelines useful when working with health-care providers to develop rehabilitation strategies. Consequently, only articles dealing with adults and adolescents (age ≥ 13 years) were included. Animal studies, though generally excluded, were used in several instances where they constituted the only evidence to support conclusions regarding biological mechanisms. The search was limited to articles published in English. Study designs employing clinical trials (randomized and nonrandomized), cohort studies, case control, case series, and cross-over studies were included. Case reports, instructional articles, and "n-of-one" studies were excluded.

Though qualitative research (e.g., that employing phenomenological, anthropological, and grounded theory approaches) provides important and useful insights into developing realistic rehabilitation strategies with SCI survivors, evidence-based medicine and clinical practice guidelines development do not yet recognize the evidence value of qualitative research. Consequently, articles describing qualitative research were excluded from the systematic literature review.

Review articles and overview articles examining functional outcomes for individuals with SCI were identified and retrieved if functional outcomes were topics of discussion. It is important to note that, although review articles were included, they were not intended for use as evidence for the guidelines. Rather, they served to orient the methodology team to the topic, to identify "gray literature," and, finally, to cross-reference with the literature search to ensure that all relevant articles on the topic had been identified and retrieved for analysis.

Key topic areas and words identified by the panel were translated, when necessary, into Index Medicus subheadings (MeSH subheadings) to search the MEDLINE (1966–1999) and the CINAHL (1982–1999) databases. Whenever

possible, "exploded" MeSH subheadings were used, allowing the inclusion of more relevant literature than would be discovered using text word searches. Second-level searches were conducted using the major and minor MeSH subheadings retrieved from relevant articles.

More than 480 articles were identified through this search and their abstracts were reviewed, using the inclusion/exclusion criteria, for relevance to the management of functional outcomes. Of these articles, 145 articles met the inclusion/exclusion criteria and were retrieved. An additional 45 articles were retrieved for further analysis because they either did not have an abstract or their relevance was unclear.

Standardized data forms were used to extract relevant information from the articles found in the literature searches and the extracted information was then compiled into evidence tables. Once the evidence tables had been created, the methodology team, panel chair, and PVA staff categorized the articles according to the guideline topic areas. The evidence tables and articles then were sent to the panel members charged with writing the specific guideline sections. This enabled panel members, when drafting their individual sections, to rely on the available evidence base relevant to their topic area. Panel members were strongly encouraged not only to rely on the data presented in the evidence table, but to critically review the articles. During the subsequent period, the methodology team responded to queries from the panel chair and members. The methodology team reviewed additional articles identified by panel members and created and disseminated supplemental evidence tables as necessary.

Evidence Analysis

A number of approaches exist for evaluating the quality of research studies and the evidence derived from them (Feinstein, 1985; Sackett, 1989). Most employ a hierarchy of evidence that places more weight on certain study designs than others. Generally, the greatest weight is placed on randomized, controlled trials, followed by observational studies, uncontrolled case series, and finally case reports.

GRADING THE EVIDENCE

For all evidence presented in this guideline, the methodology team employed the hierarchy first discussed by Sackett (1989) and later enhanced by Cook et al. (1992) and the U.S. Preventive Health Services Task Force (1996). These levels of scientific evidence are presented in Table 1. Additionally, each study was evaluated for internal

and external validity. Factors affecting internal validity (i.e., the extent to which the study provides valid information about the patients and conditions studied) included sample size and statistical power; selection bias and inclusion criteria; selection of control groups, if any; randomization methods and comparability of groups; definition of interventions and exposures; definition of outcome measures; attrition rates; confounding variables; data collection methods and observation bias; and methods of statistical analysis. External validity (i.e., the extent to which the study findings are generalizable to conditions other than the setting of the study) was evaluated through an examination of the characteristics of the study population, the clinical setting, and the environment. The resulting rankings were provided to the panel members during the writing and deliberation process.

TABLE 1
Hierarchy of the Levels of Scientific Evidence

Level	Description
I	Large randomized trials with clear-cut results (and low risk of error)
II	Small randomized trials with uncertain results (and moderate to high risk of error)
III	Nonrandomized trials with concurrent or contemporaneous controls
IV	Nonrandomized trials with historical controls
V	Case series with no controls

Sources: Sackett, D. L., Rules of evidence and clinical recommendation on the use of antithrombotic agents; *Chest* 95 (2 Suppl) (1989): 2S-4S; and the U.S. Preventive Health Services Task Force, Guide to Clinical Preventative Services, 2d ed. (Baltimore: Williams and Wilkins, 1996).

The Sackett rating scheme, as well as other grading schemes, contains an implicit hierarchy of quality indicating greater value for specific study designs than for others. In particular, randomized controlled trials serve as the “gold standard,” with designs employing nonrandomized control groups (e.g., case-control studies) and large prospective/retrospective cohorts receiving relatively less evidence value.

This somewhat simplistic approach ignores several issues that are of paramount importance to the evidence presented in these guidelines. The first is that particular research topics may not be amenable to the use of randomized, controlled clinical trials. For example, avenues of research examining the use of an intervention, such as the evaluation of neurological recovery and expected gains in function and social integration, are most frequently (and appropriately) studied using large,

multicenter cohorts or case-control designs. Thus, even well-designed and appropriate studies will be rated as “lower” quality on Sackett and other schema and inappropriately appear to be less credible and less likely to be adopted by clinicians (Lomas, 1993).

Additionally, the Sackett rating scheme lacks the ability to distinguish, within a particular category, well-conducted studies from poorly conducted ones. Consequently, poorly conducted studies mistakenly appear to be more credible (i.e., of greater evidence value) than they are.

Finally, recommendations that have strong theoretical or applied clinical bases (e.g., the monitoring of functional ability throughout the rehabilitation process and modification of treatment to maximize outcomes) frequently will not have strong, randomized clinical trial research evidence yet represent best/appropriate practice based on large, well-conducted, prospective cohort studies. In crafting these recommendations, the panel has attempted to incorporate the most appropriate types of scientific evidence. Because the traditional rating schemes may not appropriately evaluate and rank the evidence, care has been taken to outline the details regarding the quality of the research, including internal and external validity considerations.

GRADING THE GUIDELINE RECOMMENDATIONS

After panel members had drafted their sections of the guidelines, each recommendation was graded according to the level of scientific evidence supporting it. The framework used by the methodology team is outlined in Table 2 (Sackett, 1989; U.S. Preventive Health Services Task Force, 1996). It should be emphasized that these ratings, like the evidence table ratings, represent the strength of the supporting evidence, not the strength of the recommendation itself. The strength of the recommendation is indicated by the language describing the rationale.

TABLE 2
Categories of the Strength of Evidence Associated with the Recommendations

Category	Description
A	The guideline recommendation is supported by one or more level I studies
B	The guideline recommendation is supported by one or more level II studies
C	The guideline recommendation is supported only by level III, IV, or V studies

Sources: Sackett, D. L., Rules of evidence and clinical recommendation on the use of antithrombotic agents; *Chest* 95 (2 Suppl) (1989): 2S-4S; and the U.S. Preventive Health Services Task Force, Guide to Clinical Preventative Services, 2d ed. (Baltimore: Williams and Wilkins, 1996).

Category A requires that the recommendation be supported by scientific evidence from at least one properly designed and implemented randomized, controlled trial, providing statistical results that consistently support the guideline statement. Category B requires that the recommendation be supported by scientific evidence from at least one small randomized trial with uncertain results; this category also may include small randomized trials with certain results where statistical power is low. Category C recommendations are supported by either nonrandomized, controlled trials or by trials for which no controls are used.

If the literature supporting a recommendation comes from two or more levels, the number and level of the studies are reported (e.g., in the case of a recommendation that is supported by two studies, one a level III, the other a level V, the “Scientific evidence” is indicated as “III/V”). In situations where no published literature exists, consensus of the panel members and outside expert reviewers was used to develop the recommendation and is indicated as “Expert consensus.”

GRADING OF PANEL CONSENSUS

The level of agreement with the recommendation among panel members was assessed as either low, moderate, or strong. Each panel member was asked to indicate his or her level of agreement on a 5-point scale, with 1 corresponding to neutrality and 5 representing maximum agreement. Scores were aggregated across the panel members and an arithmetic mean was calculated. This mean score was then translated into low, moderate, or strong, as shown in Table 3. A panel member could abstain from the voting process for a variety of reasons, including, but not limited to, lack of expertise associated with the particular recommendation.

TABLE 3
Levels of Panel Agreement with the Recommendations

Level	Mean Agreement Score
Low	1.0 to less than 2.33
Moderate	2.33 to less than 3.67
Strong	3.67 to 5.0

Recommendations

Expected outcomes and their measurement for individuals with traumatic spinal cord injury are divided into four domains—motor recovery, functional independence, social integration, and quality of life. Within each domain, recommendations are offered regarding appropriate assessment, goal setting, and documentation. An overarching principle for all outcome assessment and documentation is that the measurement instruments should be standardized, well-validated, and reliable. It is beyond the scope of these clinical practice guidelines to review all the validity and reliability literature related to measurements of impairment, activity restrictions, societal role functioning, and quality of life. The reader is referred to texts such as Fuhrer (1996) for a broad overview of possible measures and to specific literature reviews for each of the four outcome domains—e.g., for quality of life one might refer to Dijkers (1997), Evans et al. (1994), or Fuhrer (1996).

Expected Motor Recovery Outcomes

1. **Perform a neurological examination to establish the diagnosis as soon as possible after a suspected spinal cord injury, ideally within 6 hours.** (Scientific evidence—III/V; Grade of recommendation—C; Strength of panel opinion—Strong)

The diagnosis of spinal cord injury must be made promptly in order to initiate early interventions, to minimize the neurological impairment, and to prevent secondary complications. The initial neurological examination serves as a baseline for evaluation over the first hours to days after injury. It should be sufficiently detailed to detect deterioration in neurological status, using the *International Standards for Neurological and Functional Classification of Spinal Cord Injury* (American Spinal Injury Association [ASIA], 1996) as the clinical situation allows. Deterioration should initiate reevaluation of spinal column stability and spinal cord compression and may be an indication for surgical or medical intervention.

An extensive body of research using animal models of SCI indicates that secondary conditions such as ischemia, edema, and lipid peroxidation contribute to the neurological deficit after traumatic SCI (Tator and Fehlings, 1991). Studies also indicate that preservation of a small proportion of spinal axons can support neurological recovery (Young, 1993). Methylprednisolone, a potent inhibitor of lipid peroxidation, has been shown to

improve recovery of motor function below the injury level if initiated within 8 hours after injury (Bracken and Holford, 1993; Bracken et al., 1997).

Studies investigating acute spinal cord compression injury in rats have demonstrated that decompression is beneficial, but recovery is reduced with increasing force and duration of compression (Dolan et al., 1980). In a canine model of compression of the spinal cord, paralysis recovered if the compression was released within 9 hours (Tarlov, 1954). Early decompression in traumatic SCI is therefore theoretically beneficial, although it has not been investigated in controlled studies in humans. Closed reduction of cervical facet dislocations using high weight traction and close neurological monitoring has been accomplished without neurological compromise (Cotler et al., 1993). Several subjects improved neurologically subsequent to the reduction, although the improvement could not be directly attributed to the intervention given the uncontrolled nature of the study.

2. **Perform a comprehensive neurological examination according to *International Standards for Neurological and Functional Classification between 3 and 7 days after injury*.** (Scientific evidence—V; Grade of recommendation—C; Strength of panel opinion—Strong)

The initial examination in the emergency department may be difficult if the patient has sustained other injuries or is under the influence of drugs or alcohol. Neurologic status may change over the first few days and is influenced by resuscitative procedures. The period from 72 hours to 1 week postinjury is the earliest time postinjury when detailed neurological evaluations can reliably be performed to predict neurological recovery (Brown et al., 1991; Herbison et al., 1992; Maynard et al., 1979).

A standardized evaluation and classification of SCI is important to facilitate communication among caregivers and researchers. *The International Standards for Neurological and Functional Classification of Spinal Cord Injury* (ASIA, 1996) has gained widespread acceptance as the preferred system for SCI. The examination elements (e.g., the sensory and motor testing) are reliable, but training and experience are needed to classify individuals correctly according to the standards (Cohen et al., 1996).

- 3. Monitor neurological status periodically until recovery has reached a plateau.** (Scientific evidence—monitoring frequency: None; overall recovery: V; zone-of-injury recovery: V; ambulation potential: V; Grade of recommendation—monitoring frequency: expert consensus; overall recovery: C; zone-of-injury recovery: C; ambulation potential: C; Strength of panel opinion—Strong)

The literature does not specifically address the optimum timing or frequency of neurological assessments after traumatic SCI. The frequency of assessments depends upon the rate of change of neurological function and will decrease with greater time postinjury. To document neurological recovery (e.g., where impairment is the outcome), evaluations should be conducted using established measures at fixed time points after injury. Common time points are 4–6 weeks, 6 months, and 1 year after injury (Bracken and Holford, 1993; Bracken et al., 1997; Geisler et al., 1991; Herbison et al., 1992; Waters et al., 1994a; Waters et al., 1994b).

OVERALL RECOVERY

Several studies have documented recovery over the first few months after traumatic SCI. At the group level, for those with incomplete injuries, one-half to two-thirds of the 1-year motor recovery occurs within the first 2 months after injury (Bracken and Holford, 1993; Bracken et al., 1997; Dam et al., 1997; Geisler et al., 1991). Recovery continues, but slows after 3–6 months (Waters et al., 1994a; Waters et al., 1994b). Recovery of motor function has been documented up to 2 years postinjury (Ditunno et al., 1992; Piepmeier and Jenkins, 1988; Waters et al., 1994a).

Lengths of stay (LOS) for SCI have been decreasing, both for acute care and rehabilitation. In the Model SCI Systems, comparing the 1973–1977 to 1989–1992 time periods, average acute care LOS decreased from 25 to 19 days, while rehabilitation LOS decreased from 122 to 63 days (Stover et al., 1995). An admission-to-discharge time interval therefore represents a changing segment of time during a period of rapid recovery in SCI. Although these intervals are useful for clinical purposes, neurological assessments at such variable and diminishing time intervals do not provide useful information concerning the course of neurological recovery.

ZONE-OF-INJURY RECOVERY

Recovery of motor function in the zone of injury has been studied in complete tetraplegia. Because there are no key muscles in the thoracic region and lumbar level lesions usually represent

cauda equina injuries, it is not possible to clinically study zone-of-injury motor recovery in paraplegia. Studies have focused on recovery in muscles with less than grade 3 strength located one level below antigravity (grades 3 or better) muscles. Muscles with some motor power below an antigravity muscle have a better prognosis than muscles with no motor power (Table 4). Of muscles with some initial strength (grade 1 or 2), 90 percent will reach antigravity strength by 1 year (Ditunno et al., 1992; Mange et al., 1990; Mange et al., 1992). Of the group with zero initial strength, 64 percent will gain antigravity strength by 2 years (Ditunno et al., 1992; Wu et al., 1992).

Recovery is faster in those with incomplete injuries. The median time to reach antigravity strength is 2 months for motor complete individuals, but only 2 weeks for motor incomplete subjects (Mange et al., 1990).

**TABLE 4
Percent Recovery to Grade 3 or Better in Complete Tetraplegia**

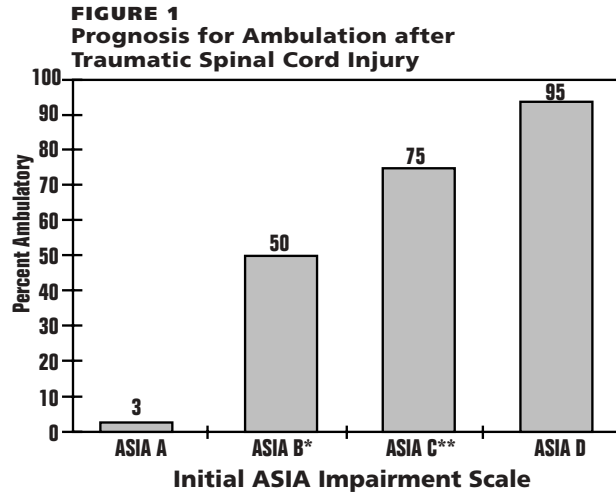
Initial Strength	Time Postinjury		
	2 Months	6 Months	12 Months
First-level Muscle*			
Grade 1 or 2	50%	82%	90%
Grade 0	11%	36%	45%**

*Most rostral key muscle with < grade 3 strength
 **Recovery continues past 1 year, reaching 64 percent by 2 years
 Sources: Ditunno et al., 1992; Mange et al., 1990; Mange et al., 1992; Wu et al., 1992

Evaluation of zone-of-injury recovery using 1 month postinjury as a baseline indicated in one study continued good prognosis for recovery in muscles with some activity (Waters et al., 1993). In individuals with motor complete tetraplegia, 97 percent of upper extremity key muscles with a muscle grade 1 or 2 at 1 month recovered to at least grade 3 by 1 year. Only 10 percent of upper extremity muscles with no motor power at 1 month reached grade 3 strength by 1 year. This recovery occurred almost exclusively at the first level below the motor level. The recovery rate for first level versus lower level muscles with zero strength at 1 month was 30 percent versus 0.5 percent.

AMBULATION POTENTIAL

Based upon neurological assessment within the first week of injury, 80 percent to 90 percent of those with complete injuries (ASIA A) will remain complete. Of those who convert to incomplete injuries, only 3 percent to 6 percent will recover



*Prognosis influenced by presence or absence of pin sensation (see text)

**Prognosis influenced by age (see text)

functional strength in the lower extremities (Ditunno et al., 1995; Maynard et al., 1979).

Sensory incomplete, motor complete (ASIA B) individuals comprise about 10 percent of all new injuries. This group has a mixed prognosis. Overall, approximately 50 percent of those who are initially classified as ASIA B will become ambulatory (Maynard et al., 1979). Prognosis depends upon the type of sensory sparing. Those motor complete subjects with preserved sacral pin sensation, indicating partial function in the spinothalamic tracts, have a prognosis for lower extremity recovery approaching that of motor incomplete individuals (Crozier et al., 1991). For those without pin sensation, prognosis for recovery of ambulation ranges from 10 percent to 33 percent (Crozier et al., 1991; Folman and el Masri, 1989).

The majority of individuals with motor incomplete injuries upon initial examination recover the ability to ambulate. For individuals with motor incomplete, ASIA C injuries, about 75 percent will become community ambulators (Burns et al., 1997; Curt and Dietz, 1997; Roth et al., 1990; Waters et al., 1994a; Waters et al., 1994b). A community ambulator is generally defined as a person using braces and crutches when walking is the primary mode of mobility in the home and community. Age and the amount of preserved spinal cord function below the lesion influence recovery of ambulation. The greater the amount of function preserved, the better the prognosis for recovery of ambulation. At minimal levels of initial function, recovery is generally poor (Daverat et al., 1988; Waters et al., 1994a; Waters et al., 1994b). Prognosis is excellent for those initially classified as ASIA D. Younger individuals have a better prognosis for ambulation with a similar injury

severity. Prognosis is poorer in those above 50–60 years of age (Burns et al., 1997; Daverat et al., 1988; Penrod et al., 1990; Waters et al., 1994a; Waters et al., 1994b).

The preceding information on expected neurological recovery can help in setting long-term goals during the acute period. For example, someone with a C5 motor level at 1 month, with grade 2/5 wrist extensors, would be expected to function at the C6 level by 1 year.

4. **After neurological plateau has been reached, conduct periodic evaluations of neurological status throughout the individual's lifetime.** (Scientific evidence—V; Grade of recommendation—C; Strength of panel opinion—Strong).

Recovery of motor function has been documented up to 2 years postinjury (Ditunno et al., 1992; Waters et al., 1994a). Changes in neurologic status may continue beyond 2 years (Piepmeyer and Jenkins, 1988). Deterioration also may occur. Late neurological deterioration may occur due to cord tethering or syringomyelia (Wang et al., 1996). Secondary conditions, particularly carpal tunnel and ulnar nerve entrapment syndromes, are common in individuals with paraplegia (Davidoff et al., 1991). These conditions may result in changing capacities and needs. Periodic evaluations of neurological status may facilitate early detection and intervention for such needs. In selected individuals with tetraplegia, function may be enhanced by upper extremity reconstructive procedures (Treanor et al., 1992; Vanden Bergh et al., 1991). Recent developments in neuroprostheses may allow for functional abilities beyond those achievable by reconstructive procedures alone (Crago et al., 1998; Kilgore et al., 1997).

Individuals with SCI should receive periodic, routine health evaluations for non-SCI and SCI-related health needs (Lanig et al., 1996). The purpose of periodic evaluation includes screening for secondary impairment and secondary disability and early detection of neurologic changes. The intervals for periodic health screening must be individualized, but at a minimum should follow the recommendations of the U.S. Preventive Services Task Force (1996) as outlined for the general population.

Expected Functional Independence Outcomes

The establishment of expected functional outcome goals, the assessment of progress toward those goals, and the maintenance of functional abilities over a lifetime form a complex process. Many authors have suggested a predictable rela-

tionship between the level (and completeness) of injury and the likely functional independence a person with SCI can be expected to achieve (Adler, 1996; Colorado Spinal Cord Injury Early Notification System, 1995; Craig Hospital, 1989).

Although the typical degree of independence expected for each level of SCI can be specified for large groups of individuals, any general expectations must be individualized based on the unique characteristics of the case. The panel has therefore developed a table of expected functional outcomes at several levels of complete SCI. The panel emphasizes that the outcomes suggested in the expected functional outcomes table (Table 6) must be individualized to the unique characteristics, circumstances, and capabilities of each person with SCI. Therefore, prior to presenting a table of expected functional outcomes, a recommendation is made that describes the individualized process of comprehensive assessment and goal setting.

5. **Establish short- and long-term functional goals with the participation of the person served based upon a comprehensive, individualized assessment by a team of health-care professionals experienced in the care and treatment of people with SCI.** (Scientific evidence—V; Grade of recommendation—C; Strength of panel opinion—Strong)

Long-term goals, mutually established between the individual with SCI and the treatment team, describe an outcome the individual with SCI strives to obtain. Long-term functional goals direct the patient's rehabilitation toward achieving expected functional outcomes. Short-term goals are progressive steps that must be met to achieve long-term goals.

A comprehensive assessment is essential to determine the specific factors that may make it necessary to adapt or modify an individual's goal of achieving those expected functional outcomes identified in Table 6. The assessment must be comprehensive, individualized, and performed by an interdisciplinary team of health-care professionals experienced in working with individuals with SCI. No one member of the team has the depth of knowledge or range of skills to independently assess or treat an individual with SCI. The collective wisdom of the interdisciplinary team will provide the individual with SCI the best possible chance of achieving expected functional outcomes.

Many factors can impede individual progress toward the functional outcomes expected for a particular level of injury. These contextual factors include, but are not limited to, pre-existing medical conditions, concomitant injuries, secondary complications, injury-related and pre-existing cognitive

impairment, age, body type, psychological and social factors, availability of financial resources, and cultural factors. Some individuals may not attain their expected functional outcomes because they choose not to attempt certain tasks. Numerous factors may be involved in an individual's choosing not to participate in learning a functional skill or not to use that ability. Factors involved include energy conservation, personal taste, fear, anxiety, the availability of attendant care, and psychological factors (Welch et al., 1986). Highly motivated individuals may exceed expected functional outcomes for their respective level of injury (Rintala and Willems, 1987). Psychological, social, and environmental support may be factors that facilitate patients obtaining higher than expected levels of functional outcome.

EXPECTED FUNCTIONAL OUTCOME TABLES

Outcome-based practice guidelines can provide estimates of the effect of rehabilitation on functional status or activity restrictions. In the accompanying Table 6, the panel has put forth its best description, based on outcome studies and expert clinical judgment, of the expected outcomes of people with motor complete SCI at 1 year after injury. These outcome guidelines are presented with the full recognition that outcomes are not fully under the influence or control of health-care providers. Differences in patient characteristics; the course of medical events; psychological, social, and environmental supports; and cognitive abilities have strong influences on outcomes.

These outcome-based guidelines can be used to establish goals, provide information for quality improvement, and compare performance across facilities with similar populations. When used appropriately, outcome-based practice guidelines provide a benchmark for comparing programs and services while improving both the processes and outcomes of care that have an enduring impact on long-term functioning in the community. Disability outcome measures are generally focused on the degree to which a person can independently complete an important function or activity of daily living (ADL). This definition of disability is consistent with the World Health Organization (WHO) model of disablement in which disability is measured at the level of the person interacting with the environment during daily routines. In the completion of daily tasks, adaptive equipment becomes a crucial adjunct to the independence of the person with SCI.

Table 6 presents expectations of functional performance of SCI at 1 year postinjury and at each of 8 levels of injury (C1-3, C4, C5, C6, C7-8,

T1-9, T10-L1 and L2-S5). The outcomes reflect a level of independence that can be expected of a person with motor complete SCI, given optimal circumstances.

The categories presented reflect expected functional outcomes in the areas of mobility, activities of daily living, instrumental activities of daily living, and communication skills. The guidelines are based on consensus of clinical experts, available literature on functional outcomes, and data compiled from Uniform Data Systems (UDS) and the National Spinal Cord Injury Statistical Center (NSCISC).

Within the functional outcomes for people with SCI listed in Table 6, the panel has identified a series of essential daily functions and activities, expected levels of functioning, and the equipment and attendant care likely to be needed to support the predicted level of independence at 1 year postinjury. These outcome areas include:

■ **Respiratory, bowel, and bladder function.**

The neurologic effects of spinal cord injury may result in deficits in the ability of the individual to perform basic bodily functions. Respiratory function includes the ability to breathe with or without mechanical assistance and to adequately clear secretions. Bowel and bladder function includes the ability to manage elimination, maintain perineal hygiene, and adjust clothing before and after elimination. Adapted or facilitated methods of managing these bodily functions may be required to attain expected functional outcomes.

■ **Bed mobility, bed/wheelchair transfers, wheelchair propulsion, and positioning/pressure relief.**

The neurologic effects of spinal cord injury may result in deficits in the ability of the individual to perform the activities required for mobility, locomotion, and safety. Adapted or facilitated methods of managing these activities may be required to attain expected functional outcomes.

■ **Standing and ambulation.** Spinal cord injury may result in deficits in the ability to stand for exercise or psychological benefit or to ambulate for functional activities. Adapted or facilitated methods of management may be required to attain expected functional outcomes in standing and ambulation.

■ **Eating, grooming, dressing, and bathing.**

The neurologic effects of spinal cord injury may result in deficits in the ability of the individual to perform these activities of daily living. Adapted or facilitated methods of managing these activities of daily living may be required to attain expected functional outcomes.

■ **Communication (keyboard use, handwriting, and telephone use).** The neurologic effects of spinal cord injury may result in deficits in the ability of the individual to communicate. Adapted or facilitated methods of communication may be required to attain expected functional outcomes.

■ **Transportation (driving, attendant-operated vehicle, and public transportation).** Transportation activities are critical for individuals with SCI to become maximally independent in their community. Adaptations may be required to facilitate the individual in meeting the expected functional outcomes.

■ **Homemaking (meal planning and preparation and home management).** Adapted or facilitated methods of managing homemaking skills may be required to attain expected functional outcomes. Individuals with complete SCI at any level will require some level of assistance with some homemaking activities. The hours of assistance with homemaking activities are presented in Table 6.

■ **Assistance required.** Table 6 presents the number of hours that may be required from a caregiver to assist with personal care and homemaking activities in the home. Personal care includes hands-on delivery of all aspects of self-care and mobility, as well as safety interventions. Homemaking assistance is also included in the recommendation for hours of assistance and includes activities previously presented. The number of hours presented in both the panel recommendations and the self-reported CHART data is representative of skilled and unskilled and paid and unpaid hours of assistance. The 24-hour-a-day requirement noted for the C1-3 and C4 levels includes the expected need for nonpaid attendant care to provide for safety monitoring.

Adequate assistance is required to ensure that the individual with SCI can achieve the outcomes set forth in Table 6. The hours of assistance recommended by the panel do not reflect changes in assistance required over time as reported by long-term survivors of SCI (Gerhart et al., 1993), nor do they take into account the wide range of individual variables mentioned throughout this document that may affect the number of hours of assistance required. The Functional Independence Measure (FIM) estimates are widely variable in several of the categories. One does not know whether the representative individuals with SCI in the individual categories attained the expected functional outcomes for their specific level of injury nor whether there were mitigating circumstances such as age, obesity,

or concomitant injuries, that would account for variability in assistance reported. An individualized assessment of needs is required in all cases.

- Equipment requirements.** Minimum recommendations for durable medical equipment and adaptive devices are identified in each of the functional categories. Most commonly used equipment is listed, with the understanding that variations exist among SCI rehabilitation programs, and that use of such equipment may be necessary to achieve the identified functional outcomes. Additional equipment and devices that are not critical for the majority of individuals at a specific level of injury may be required for some individuals. The equipment descriptions are generic to provide for variances in program philosophy and financial resources. Rapid changes and advances in equipment and technology will be made and therefore must be considered.

Health-care professionals should keep in mind that the recommendations set forth in Table 6 are not intended to be prescriptive, but rather to serve as a guideline. The importance of individual functional assessment of people with SCI prior to making equipment recommendations cannot be over emphasized. All durable medical equipment and adaptive devices must be thoroughly assessed and tested to determine medical necessity, to prevent medical complications (e.g., postural deviations, skin breakdown, or pain), and to foster optimal functional performance. Environmental control units and telephone modifications may be needed for safety and maximal independence, and each person must be individually evaluated for the need for this equipment. Disposable medical product recommendations are not included in this document.

- FIM.** Evidence for the specific levels of independence provided in Table 6 relies both on expert consensus and data from FIM in large-scale, prospective, and longitudinal research conducted by NSCISC. FIM is the most widely used disability measure in rehabilitation medicine, and although it may not incorporate all of the characteristics of disability in individuals recovering from SCI, it captures many basic disability areas.

FIM consists of 13 motor and 5 cognitive items that are individually scored from 1 to 7. A score of 1 indicates complete dependence and a score of 7 indicates complete independence (see Table 5). The sum of the 13 FIM motor score items can range from 13, indicating complete dependence for all items, to 91, indicating complete independence for all items. FIM is a measure usually completed by health-care professionals; different observers,

including the patient, family members, and caregivers, can contribute information to the ratings. Each of these reporters may represent a different type of potential bias.

It should also be noted that although the sample sizes of FIM data for certain neurologic level groups are quite small, the consistency of the data adds confidence to the interpretation. Other pertinent data regarding functional independence must be factored into outcome analyses, including medical information, patient factors, social role participation, quality of life, and environmental factors and supports.

In Table 6, FIM data, when available, are reported in three areas. First, the expected FIM outcomes are documented based on expert clinical consensus. The second number reported is the median FIM score, as compiled by NSCISC. The interquartile range for NSCISC FIM data is the third set of numbers. In total, the FIM data represent 1-year postinjury FIM assessments of 405 survivors with complete SCI and a median age of 27 years. The NSCISC sample size for FIM and Assistance Data is provided for each level of injury. Different outcome expectations should clearly apply to different patient subgroups and populations. Some populations are likely to be significantly older than the referenced one. Functional abilities may be limited by advancing age (Penrod et al., 1990; Yarkony et al., 1988a).

- Home modifications.** To provide the best opportunity for individuals with SCI to achieve the identified functional outcomes, a safe and architecturally accessible environment is necessary. An accessible environment must take into consideration, but not be limited to, entrance and egress, mobility in the home, and adequate setup to perform personal care and homemaking tasks.

TABLE 5 FIM LEVELS

7) Complete independence (timely, safely)	No
6) Modified independence (device)	Helper
Modified Dependence	
5) Supervision	
4) Minimal assist (Subject = 75% or more)	
3) Moderate assist (Subject = 50%–74%)	Helper
Complete Dependence	
2) Maximal assist (Subject = 25%–49%)	
1) Total assist (Subject = 0%–24%)	

Source: *Guide for the Uniform Data Set for Medical Rehabilitation (including the FIMSM instrument)*, Version 5.0. Buffalo, NY 14214: State University of New York at Buffalo, 1996.

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Sternocleidomastoid; cervical paraspinal; neck accessories

Movement possible: Neck flexion, extension, rotation

Patterns of weakness: Total paralysis of trunk, upper extremities, lower extremities; dependent on ventilator

FIM/Assistance Data: Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range

NSCISC Sample Size: FIM=15 / Assist=12

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	<ul style="list-style-type: none"> • Ventilator dependent • Inability to clear secretions 	<ul style="list-style-type: none"> • 2 ventilators (bedside, portable) • Suction equipment or other suction management device • Generator/battery backup 			
Bowel	Total assist	Padded reclining shower/commode chair (if roll-in shower available)	1	1	1
Bladder	Total assist		1	1	1
Bed Mobility	Total assist	Full electric hospital bed with Trendelenburg feature and side rails			
Bed/Wheelchair Transfers	Total assist	<ul style="list-style-type: none"> • Transfer board • Power or mechanical lift with sling 	1	1	1
Pressure Relief/ Positioning	Total assist; may be independent with equipment	<ul style="list-style-type: none"> • Power recline and/or tilt wheelchair • Wheelchair pressure-relief cushion • Postural support and head control devices as indicated • Hand splints may be indicated • Specialty bed or pressure-relief mattress may be indicated 			
Eating	Total assist		1	1	1
Dressing	Total assist		1	1	1
Grooming	Total assist		1	1	1
Bathing	Total assist	<ul style="list-style-type: none"> • Handheld shower • Shampoo tray • Padded reclining shower/commode chair (if roll-in shower available) 	1	1	1
Wheelchair Propulsion	Manual: Total assist Power: Independent with equipment	<ul style="list-style-type: none"> • Power recline and/or tilt wheelchair with head, chin, or breath control and manual recliner • Vent tray 	6	1	1-6
Standing/ Ambulation	Standing: Total assist; Ambulation: Not indicated				
Communication	Total assist to independent, depending on work station setup and equipment availability	<ul style="list-style-type: none"> • Mouth stick, hightech computer access, environmental control unit • Adaptive devices everywhere as indicated 			
Transportation	Total assist	Attendant-operated van (e.g., lift, tie-downs) or accessible public transportation			
Homemaking	Total assist				
Assist Required	<ul style="list-style-type: none"> • 24-hour attendant care to include homemaking • Able to instruct in all aspects of care 		24*	24*	12-24*

*Hours per day

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Upper trapezius; diaphragm; cervical paraspinal muscles

Movement possible: Neck flexion, extension, rotation; scapular elevation; inspiration

Patterns of weakness: Paralysis of trunk, upper extremities, lower extremities; inability to cough, endurance and respiratory reserve low secondary to paralysis of intercostals

FIM/Assistance Data: Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range
NSCISC Sample Size: FIM=28 / Assist=12

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	May be able to breathe without a ventilator	If not ventilator free, see C1–3 for equipment requirements			
Bowel	Total assist	Reclining shower/commode chair (if roll-in shower available)	1	1	1
Bladder	Total assist		1	1	1
Bed Mobility	Total assist	Full electric hospital bed with Trendelenburg feature and side rails			
Bed/Wheelchair Transfers	Total assist	<ul style="list-style-type: none"> • Transfer board • Power or mechanical lift with sling 	1	1	1
Pressure Relief/ Positioning	Total assist; may be independent with equipment	<ul style="list-style-type: none"> • Power recline and/or tilt wheelchair • Wheelchair pressure-relief cushion • Postural support and head control devices as indicated • Hand splints may be indicated • Specialty bed or pressure-relief mattress may be indicated 			
Eating	Total assist		1	1	1
Dressing	Total assist		1	1	1
Grooming	Total assist		1	1	1
Bathing	Total assist	<ul style="list-style-type: none"> • Shampoo tray • Handheld shower • Padded reclining shower/commode chair (if roll-in shower available) 	1	1	1
Wheelchair Propulsion	Power: Independent Manual: Total assist	<ul style="list-style-type: none"> • Power recline and/or tilt wheelchair with head, chin, or breath control and manual recliner • Vent tray 	6	1	1–6
Standing/ Ambulation	Standing: Total assist Ambulation: Not usually indicated	<ul style="list-style-type: none"> • Tilt table • Hydraulic standing table 			
Communication	Total assist to independent, depending on work station setup and equipment availability	Mouth stick, hightech computer access, environmental control unit			
Transportation	Total assist	Attendant–operated van (e.g., lift, tie-downs) or accessible public transportation			
Homemaking	Total assist				
Assist Required	<ul style="list-style-type: none"> • 24–hour care to include homemaking • Able to instruct in all aspects of care 		24*	24*	16–24*

*Hours per day.

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Deltoid, biceps, brachialis, brachioradialis, rhomboids, serratus anterior (partially innervated)

Movement possible: Shoulder flexion, abduction, and extension; elbow flexion and supination; scapular adduction and abduction

Patterns of weakness: Absence of elbow extension, pronation, all wrist and hand movement
Total paralysis of trunk and lower extremities

FIM/Assistance Data: Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range
NSCISC Sample Size: FIM=41 / Assist=35

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Low endurance and vital capacity secondary to paralysis of intercostals; may require assist to clear secretions				
Bowel	Total assist	Padded shower/commode chair or padded transfer tub bench with commode cutout	1	1	1
Bladder	Total assist	Adaptive devices may be indicated (electric leg bag emptier)	1	1	1
Bed Mobility	Some assist	<ul style="list-style-type: none"> • Full electric hospital bed with Trendelenburg feature with patients control • Side rails 			
Bed/Wheelchair Transfers	Total assist	<ul style="list-style-type: none"> • Transfer board • Power or mechanical lift 	1	1	1
Pressure Relief/ Positioning	Independent with equipment	<ul style="list-style-type: none"> • Power recline and/or tilt wheelchair • Wheelchair pressure-relief cushion • Hand splints • Specialty bed or pressure-relief mattress may be indicated • Postural support devices 			
Eating	Total assist for setup, then independent eating with equipment	<ul style="list-style-type: none"> • Long opponens splint • Adaptive devices as indicated 	5	5	2.5-5.5
Dressing	Lower extremity: Total assist Upper extremity: Some assist	<ul style="list-style-type: none"> • Long opponens splint • Adaptive devices as indicated 	1	1	1-4
Grooming	Some to total assist	<ul style="list-style-type: none"> • Long opponens splints • Adaptive devices as indicated 	1-3	1	1-5
Bathing	Total assist	<ul style="list-style-type: none"> • Padded tub transfer bench or shower/commode chair • Handheld shower 	1	1	1-3
Wheelchair Propulsion	Power: Independent Manual: Independent to some assist indoors on noncarpet, level surface; some to total assist outdoors	Power: Power recline and/or tilt with arm drive control Manual: Lightweight rigid or folding frame with handrim modifications	6	6	5-6
Standing/ Ambulation	Total assist	Hydraulic standing frame			
Communication	Independent to some assist after setup with equipment	<ul style="list-style-type: none"> • Long opponens splint • Adaptive devices as needed for page turning, writing, button pushing 			
Transportation	Independent with highly specialized equipment; some assist with accessible public transportation; total assist for attendant-operated vehicle	Highly specialized modified van with lift			
Homemaking	Total assist				
Assist Required	<ul style="list-style-type: none"> • Personal care: 10 hours/day • Homecare: 6 hours/day • Able to instruct in all aspects of care 		16*	23*	10-24*

*Hours per day.

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Clavicular pectoralis supinator; extensor carpi radialis longus and brevis; serratus anterior; latissimus dorsi

Movement possible: Scapular protractor; some horizontal adduction, forearm supination, radial wrist extension

Patterns of weakness: Absence of wrist flexion, elbow extension, hand movement; total paralysis of trunk and lower extremities

FIM/Assistance Data: Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range

NSCISC Sample Size: FIM=43 / Assist=35

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Low endurance and vital capacity secondary to paralysis of intercostals; may require assist to clear secretions				
Bowel	Some to total assist	<ul style="list-style-type: none"> • Padded tub bench with commode cutout or padded shower/commode chair • Other adaptive devices as indicated 	1-2	1	1
Bladder	Some to total assist with equipment; may be independent with leg bag emptying	Adaptive devices as indicated	1-2	1	1
Bed Mobility	Some assist	<ul style="list-style-type: none"> • Full electric hospital bed • Side rails • Full to king standard bed may be indicated 			
Bed/Wheelchair Transfers	Level: Some assist to independent Uneven: Some to total assist	<ul style="list-style-type: none"> • Transfer board • Mechanical lift 	3	1	1-3
Pressure Relief/ Positioning	Independent with equipment and/or adapted techniques	<ul style="list-style-type: none"> • Power recline wheelchair • Wheelchair pressure relief cushion • Postural support devices • Pressure-relief mattress or overlay may be indicated 			
Eating	Independent with or without equipment; except cutting, which is total assist	Adaptive devices as indicated (e.g., u-cuff, tendonosis splint, adapted utensils, plate guard)	5-6	5	4-6
Dressing	Independent upper extremity; some assist to total assist for lower extremities	Adaptive devices as indicated (e.g., button; hook; loops on zippers, pants; socks, velcro on shoes)	1-3	2	1-5
Grooming	Some assist to independent with equipment	Adaptive devices as indicated (e.g., U-cuff, adapted handles)	3-6	4	2-6
Bathing	Upper body: Independent Lower body: Some to total assist	<ul style="list-style-type: none"> • Padded tub transfer bench or shower/commode chair • Adaptive devices as needed • Handheld shower 	1-3	1	1-3
Wheelchair Propulsion	Power: Independent with standard arm drive on all surfaces Manual: Independent indoors; some to total assist outdoors	Manual: Lightweight rigid or folding frame with modified rims Power: May require power recline or standard upright power wheelchair	6	6	4-6
Standing/ Ambulation	Standing: Total assist Ambulation: Not indicated	Hydraulic standing frame			
Communication	Independent with or without equipment	Adaptive devices as indicated (e.g., tendonosis splint; writing splint for keyboard use, button pushing, page turning, object manipulation)			
Transportation	Independent driving from wheelchair	<ul style="list-style-type: none"> • Modified van with lift • Sensitized hand controls • Tie-downs 			
Homemaking	Some assist with light meal preparation; total assist for all other homemaking	Adaptive devices as indicated			
Assist Required	<ul style="list-style-type: none"> • Personal care: 6 hours/day • Homecare: 4 hours/day 		10*	17*	8-24*

*Hours per day.

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Latissimus dorsi; sternal pectoralis; triceps; pronator quadratus; extensor carpi ulnaris; flexor carpi radialis; flexor digitorum profundus and superficialis; extensor communis; pronator/flexor/extensor/abductor pollicis; lumbricals [partially innervated]

Movement possible: Elbow extension; ulnar/wrist extension; wrist flexion; finger flexions and extensions; thumb flexion/extension/abduction

Patterns of weakness: Paralysis of trunk and lower extremities; limited grasp release and dexterity secondary to partial intrinsic muscles of the hand

FIM/Assistance Data: **Exp** = Expected FIM Score / **Med** = NSCISC Median / **IR** = NSCISC Interquartile Range
NSCISC Sample Size: FIM=43 / Assist=35

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Low endurance and vital capacity secondary to paralysis of intercostals; may require assist to clear secretions.				
Bowel	Some to total assist	<ul style="list-style-type: none"> • Padded tub bench with commode cutout or shower commode chair • Adaptive devices as needed 	1-4	1	1-4
Bladder	Independent to some assist	Adaptive devices as indicated	2-6	3	1-6
Bed Mobility	Independent to some assist	Full electric hospital bed or full to king standard bed			
Bed/Wheelchair Transfers	Level: Independent. Uneven: Independent to some assist	With or without transfer board	3-7	4	2-6
Pressure Relief/ Positioning	Independent	<ul style="list-style-type: none"> • Wheelchair pressure relief cushion • Postural support devices as indicated • Pressure-relief mattress/or overlay may be indicated 			
Eating	Independent	Adaptive devices as indicated	6-7	6	5-7
Dressing	Independent upper extremities; independent to some assist lower extremities	Adaptive devices as indicated	4-7	6	4-7
Grooming	Independent	Adaptive devices as indicated	6-7	6	4-7
Bathing	Upper body: Independent; Lower extremity: Some assist to independent	<ul style="list-style-type: none"> • Padded transfer tub bench or shower/commode chair • Handheld shower • Adaptive devices as needed 	3-6	4	2-6
Wheelchair Propulsion	Manual: Independent all indoor surfaces and level outdoor terrain; some assist with uneven terrain	Manual: Rigid or folding lightweight or folding wheelchair with modified rims	6	6	6
Standing/ Ambulation	Standing: Independent to some assist Ambulation: Not indicated	Hydraulic or standard standing frame			
Communication	Independent	Adaptive devices as indicated			
Transportation	Independent car if independent with transfer and wheelchair loading/unloading; independent driving modified van from captain's seat	<ul style="list-style-type: none"> • Modified vehicle • Transfer board 			
Homemaking	Independent light meal preparation and homemaking; some to total assist for complex meal prep and heavy housecleaning	Adaptive devices as indicated			
Assist Required	<ul style="list-style-type: none"> • Personal care: 6 hours/day • Homecare: 2 hours/day 		8*	12*	2-24*

*Hours per day.

TABLE 6. Expected Functional Outcomes

Functionally relevant muscles innervated: Intrinsic of the hand including thumbs; internal and external intercostals; erector spinae; lumbricals; flexor/extensor/abductor pollicis

Movement possible: Upper extremities fully intact; limited upper trunk stability. Endurance increased secondary innervation of intercostals

Patterns of weakness: Lower trunk paralysis. Total paralysis lower extremities

FIM/Assistance Data: Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range
NSCISC Sample Size: FIM=144 / Assist=122

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Compromised vital capacity and endurance				
Bowel	Independent	Elevated padded toilet seat or padded tub bench with commode cutout	6-7	6	4-6
Bladder	Independent		6	6	5-6
Bed Mobility	Independent	Full to king standard bed			
Bed/Wheelchair Transfers	Independent	May or may not require transfer board	6-7	6	6-7
Pressure Relief/ Positioning	Independent	<ul style="list-style-type: none"> • Wheelchair pressure relief cushion • Postural support devices as indicated • Pressure-relief mattress or overlay may be indicated 			
Eating	Independent		7	7	7
Dressing	Independent		7	7	7
Grooming	Independent		7	7	7
Bathing	Independent	<ul style="list-style-type: none"> • Padded tub transfer bench or shower/commode chair • Handheld shower 	6-7	6	5-7
Wheelchair Propulsion	Independent	Manual rigid or folding lightweight wheelchair	6	6	6
Standing/ Ambulation	Standing: Independent Ambulation: Typically not functional	Standing frame			
Communication	Independent				
Transportation	Independent in car, including loading and unloading wheelchair	Hand controls			
Homemaking	Independent with complex meal prep and light housecleaning; total to some assist with heavy housekeeping				
Assist Required	Homemaking: 3 hours/day		2*	3*	0-15*

*Hours per day.

TABLE 6. Expected Functional Outcomes**Level T10-L1****Functionally relevant muscles innervated:** Fully intact intercostals; external obliques; rectus abdominis**Movement possible:** Good trunk stability**Patterns of weakness:** Paralysis of lower extremities**FIM/Assistance Data:** Exp = Expected FIM Score / Med = NSCISC Median / IR = NSCISC Interquartile Range**NSCISC Sample Size:** FIM=71 / Assist=57

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Intact respiratory function				
Bowel	Independent	Padded standard or raised padded toilet seat	6-7	6	6
Bladder	Independent		6	6	6
Bed Mobility	Independent	Full to king standard bed			
Bed/Wheelchair Transfers	Independent		7	7	6-7
Pressure Relief/ Positioning	Independent	<ul style="list-style-type: none"> • Wheelchair pressure-relief cushion • Postural support devices as indicated • Pressure-relief mattress or overlay may be indicated 			
Eating	Independent		7	7	7
Dressing	Independent		7	7	7
Grooming	Independent		7	7	7
Bathing	Independent	<ul style="list-style-type: none"> • Padded transfer tub bench • Handheld shower 	6-7	6	6-7
Wheelchair Propulsion	Independent all indoor and outdoor surfaces	Manual rigid or folding lightweight wheelchair	6	6	6
Standing/ Ambulation	Standing: Independent Ambulation: Functional, some assist to independent	<ul style="list-style-type: none"> • Standing frame • Forearm crutches or walker • Knee, ankle, foot orthosis (KAFO) 			
Communication	Independent				
Transportation	Independent in car, including loading and unloading wheelchair	Hand controls			
Homemaking	Independent with complex meal prep and light housecleaning; some assist with heavy housekeeping				
Assist Required	Homemaking: 2 hours/day		2*	2*	0-8*

*Hours per day.

TABLE 6. Expected Functional Outcomes**Level L2–S5**

Functionally relevant muscles innervated: Fully intact abdominals and all other trunk muscles; depending on level, some degree of hip flexors, extensors, abductors, adductors; knee flexors, extensors; ankle dorsi, flexors, plantar flexors.

Movement possible: Good trunk stability. Partial to full control lower extremities.

Patterns of weakness: Partial paralysis lower extremities, hips, knees, ankle, foot

FIM/Assistance Data: **Exp** = Expected FIM Score / **Med** = NSCISC Median / **IR** = NSCISC Interquartile Range
NSCISC Sample Size: FIM=20 / Assist=16

	Expected Functional Outcomes	Equipment	FIM/Assistance Data		
			Exp	Med	IR
Respiratory	Intact function				
Bowel	Independent	Padded toilet seat	6–7	6	6–7
Bladder	Independent		6	6	6–7
Bed Mobility	Independent				
Bed/Wheelchair Transfers	Independent	Full to king standard bed	7	7	7
Pressure Relief/ Positioning	Independent	<ul style="list-style-type: none"> • Wheelchair pressure-relief cushion • Postural support device as indicated 			
Eating	Independent		7	7	7
Dressing	Independent		7	7	7
Grooming	Independent		7	7	7
Bathing	Independent	<ul style="list-style-type: none"> • Padded tub bench • Handheld shower 	7	7	6–7
Wheelchair Propulsion	Independent on all indoor and outdoor surfaces	Manual rigid or folding lightweight wheelchair	6	6	6
Standing/ Ambulation	Standing: Independent Ambulation: Functional, independent to some assist	<ul style="list-style-type: none"> • Standing frame • Knee-ankle-foot orthosis or ankle-foot orthosis • Forearm crutches or cane as indicated 			
Communication	Independent				
Transportation	Independent in car, including loading and unloading wheelchair	Hand controls			
Homemaking	Independent complex cooking and light housekeeping; some assist with heavy housekeeping				
Assist Required	Homemaking: 0–1 hour/day		0–1*	0*	0–2*

*Hours per day.

- 6. Monitor functional ability throughout the rehabilitation process, modifying treatment strategies to maximize functional outcome.** (Scientific evidence—None; Grade of recommendation—Expert consensus; Strength of panel opinion—Strong)

Throughout the rehabilitation process there is ongoing assessment to gather functional, clinical, and psychological/social data that will assist health-care professionals in determining the effectiveness of treatment interventions and strategies and identifying whether treatment approaches, techniques, and outcome expectations should be modified. A standard instrument to measure attainment of functional goals can assist the team in objectively measuring functional outcomes.

- 7. After achievement of functional goals, conduct periodic evaluations of functional status throughout the individual's lifetime.** (Scientific evidence—III/V; Grade of recommendation—C; Strength of panel opinion—Strong)

Individuals with SCI may experience changes in functional abilities over time for a variety of reasons. These reasons may include changes in neurologic status, psychological/social status, environment, personal choice, health and wellness, and equipment modifications. The potential impact of these changes on health and functional status will best be addressed by periodic assessment to either optimize potential functional gains or alleviate potential functional losses.

Medical and physical complications may lead to temporary immobility or hospitalization and may impair adjustment to spinal cord injury (DeVivo et al., 1992). Individuals with spinal cord injuries are at risk for numerous medical complications that may limit functional abilities (Levi et al., 1995).

Pain after spinal cord injury may be described as neurogenic (dysesthetic) or non-neurogenic from musculoskeletal or other causes (Davidoff et al., 1987; Levi et al., 1995). Neurogenic pain may impair participation in therapy and functional activities. Musculoskeletal complications such as tendonitis, nerve entrapments, sprains, and strains cause pain and limit performance (Bayley et al., 1987). Spasticity is a particularly common problem that may limit functional outcome (Parke et al., 1989).

Functional abilities may be limited by advancing age (Penrod et al., 1990; Yarkony et al., 1988a). More complex skills, such as dressing, transfers, and ambulation may be limited as age increases, particularly in those individuals above age 50.

Physical assistance and attendant-care needs increase with age (Gerhart et al., 1993; Whiteneck et al., 1992a). Transfers, mobility, dressing, and toileting are more commonly affected. Older

individuals at time of injury will need more attendant care sooner after injury. Younger individuals at time of injury will require more attendant care as they age. Factors that have an impact on the decreasing abilities and increased attendant-care needs include musculoskeletal problems and medical complications such as pressure ulcers. Psychological adjustment is affected by aging and this will affect functional abilities (Krause and Crewe, 1991). With increasing age, people with SCI tend to become less active.

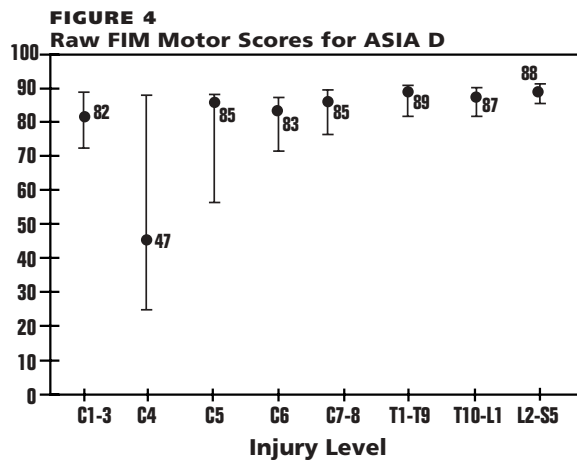
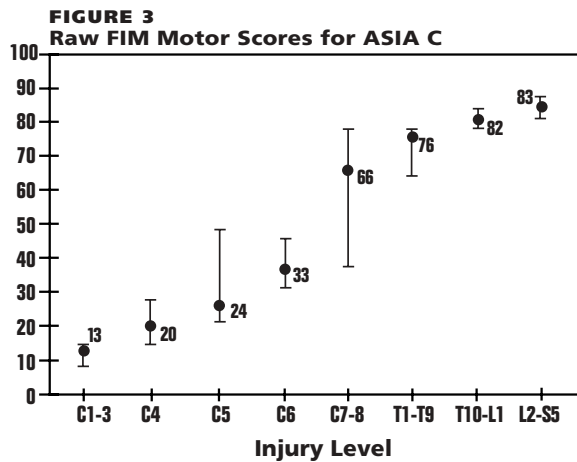
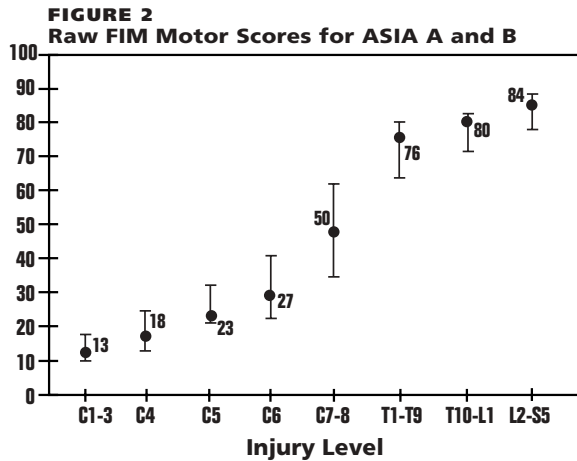
- 8. Document deviations in the achievement of functional outcomes (with reference to the normative data in Table 6) by groups of individuals receiving rehabilitation. Address such deviations in terms of improvement of clinical processes of care or unique population characteristics requiring risk adjustment.** (Scientific evidence—Unpublished data from the NSCISC system; Grade of recommendation—Expert consensus; Strength of panel opinion—Strong)

When selecting published normative data for comparison with a rehabilitation program's group outcomes, careful attention should be given to the reliability, validity, and sample size of the published outcome results from reputable sources. The same careful attention also should be given to the degree of similarity between the sample from which these normative data have been derived and the characteristics of the population served by the specific rehabilitation program. Risk factors that are likely to result in better or worse outcomes for the population served by individual rehabilitation programs should be carefully noted and addressed.

Outcomes can be affected by levels of severity and complexity of disorders or illnesses, various forms of clinical conditions and comorbidities, sociocultural and sociodemographic differences, resources available, and personal goals and preferences of the people served. Different outcome expectations should clearly apply to different patient subgroups and populations. If rigid conformance to published normative data is expected without attention to these risk factors and the process of severity adjustment, certain populations at risk for poor outcomes may be underserved by the health-care/rehabilitation system with undue attention given only to populations that can easily meet these published outcome goals (Palmer, 1997; Schneider and Epstein, 1996).

An example of severity-adjusted functional outcomes, taking into account level and completeness of SCI, is illustrated here using Model SCI Systems data. Figures 2 through 4 illustrate the median and the 25th and 75th percentile discharge FIM motor scores for patients who were treated at Model SCI Systems facilities during a 2-year period ending in

1998, distinguished by neurologic injury levels and ASIA impairment levels. The sum of the 13 FIM motor items can range from 13, indicating complete dependence on all items, to 91, indicating complete independence on all items.



Discharge FIM motor scores are strongly related to neurologic level for people with complete (ASIA A) and sensory incomplete lesions (ASIA B) as well as motor incomplete lesions (ASIA C); mean scores increase as neurologic injury level decreases from cervical to thoracic to lumbar regions. In contrast, people with motor incomplete impairment levels and muscle grades greater than or equal to 3 (ASIA D) were discharged with relatively high and consistent discharge FIM motor scores regardless of neurologic level.

In brief, Figures 2 through 4 illustrate the separate effects of SCI level (greater function is associated with more caudal lesions) and completeness (greater function is associated with more incomplete lesions). The variable sizes of the interquartile ranges reflect the varying sample size of each group and the variability of outcomes within each group. Rehabilitation programs can use this information to document deviations in the functional outcomes of groups served and take appropriate action to enhance their outcomes, as needed.

9. After the initial acute care and rehabilitation phase, discharge the individual with SCI back into the community. (Scientific evidence—III/V; Grade of recommendation—C; Strength of panel opinion—Strong)

“Community” is defined as private residences and group living facilities other than nursing homes that are commensurate with the individual’s functional level of independence, personal preference, and social support. The vast majority of individuals with SCI are discharged to private residences within the community (96 percent of those treated at Model SCI Systems and 90 percent of individuals with SCI treated at Uniform Data System subscribing facilities) (DeVivo, 1999; Fiedler and Granger, 1998). Based on national data, factors that increase the likelihood of nursing home discharge include higher neurological level, dependence in activities of daily living, inability to ambulate, being unmarried or living alone, Medicare or Medicaid funding, and residing outside the southeastern United States (DeVivo, 1999). Moreover, 94 percent to 97 percent of individuals with SCI who are less than 60 years of age continue to reside within the community on a long-term basis, while 84 percent of individuals between 61 and 75 years of age and 72 percent of individuals at least 76 years of age currently reside within the community (DeVivo et al., 1992). Institutional placement should only be considered when supportive resources for community discharge are not available.

Expected Social Integration Outcomes

The purpose of the health-care system must be to “continuously reduce the impact and burden of illness, injury, and disability and to improve the health and functioning of the people” (President’s Advisory Commission on Consumer Protection and Quality in Health Care, 1998). For a long time, rehabilitation seemed to focus primarily on stabilization of impairments and reduction in caregiver needs by focusing on activity limitations, but increasingly rehabilitation is referred to as “the quality-of-life profession.” The World Health Organization has recognized, since 1980, the importance of a broad-based conceptualization of outcomes, including impairments, activities, and societal participation, while the recent revision of this classification system notes the importance of linking these outcome domains with quality-of-life concepts and the measurement of subjective well-being (WHO, 1997).

- 10. **Rehabilitation should focus on providing opportunities for societal participation in meaningful roles.** (Scientific evidence—meta-analyses and unpublished data from NSCISC; Grade of recommendation—Expert consensus; Strength of panel opinion—Strong)

The use of a broad-based approach to outcomes is particularly important since there are mild to weak relationships between domains (impairment, activities, participation, and quality of life), indicating lack of a causal chain between these outcome domains (Dijkers, 1997). This is particularly the case since findings from one domain alone often do not predict important variables, such as health-care use, work performance, or social integration (WHO, 1997). Many people with spinal cord injury will be able to participate in meaningful social roles beyond those expected by level of injury.

- 11. **Rehabilitation programs should document deviation in social participation and integration (with reference to the normative data in Figures 5-8) by groups who have completed rehabilitation. Address such deviations in terms of improvement of clinical processes of care or unique population characteristics requiring risk adjustment.**

(Scientific evidence—meta-analyses and unpublished data from NSCISC; Grade of recommendation—Expert consensus; Strength of panel opinion—Strong)

Several measures of community integration and societal participation exist. One such measure, the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al., 1992b), evaluates the participation emphasized by the WHO (1997), has psychometric validity and reliability, and has well established normative data for four

impairment groups of individuals with spinal cord injury [high tetraplegia with ASIA A, B, or C; low tetraplegia with ASIA A, B, or C; paraplegia with ASIA A, B, or C; and motor functional incomplete injuries at any level (ASIA D)].

For these reasons, Figures 5 through 8 are reproduced, displaying median and interquartile range information for CHART scores in these four diagnostic groups using Model SCI Systems data from NSCISC. Percentile scores on CHART range from zero, indicating lowest levels of societal participation, to 100, indicating a full level of participation. Five scales are measured that distinguish physical, mobility, occupational, social, and economic aspects of participation in societal roles. Rehabilitation programs can use this information to document deviations in societal participation of groups served and take appropriate action to enhance their outcomes, as needed.

FIGURE 5
CHART Component Scores for High Tetraplegia (C1-4) ASIA A, B, and C

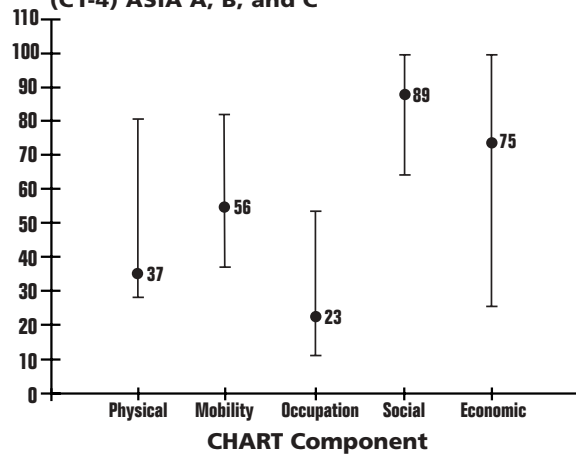


FIGURE 6
CHART Component Scores for Low Tetraplegia (C5-8) ASIA A, B, and C

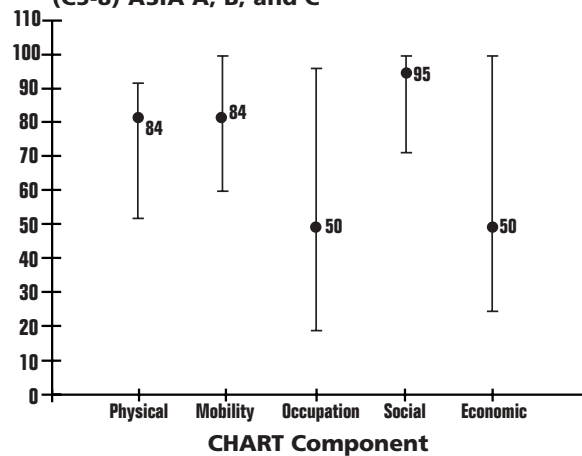


FIGURE 7
CHART Component Scores for Paraplegia
(ASIA A, B, and C)

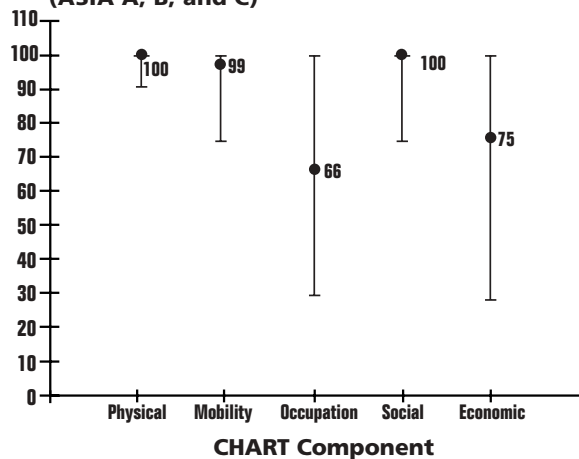
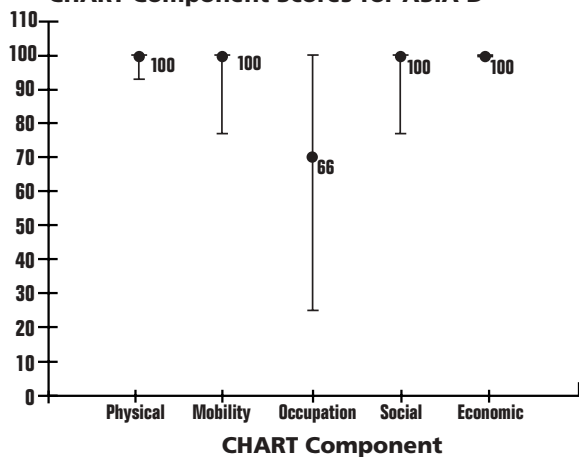


FIGURE 8
CHART Component Scores for ASIA D



Expected Quality-of-Life Outcomes

Quality of life is a personal, global evaluation of well-being or general satisfaction with life experienced by people under their current life conditions (Lehman, 1983; McDaniel and Bach, 1994). Health-related quality of life is related to perceived health, physical impairments, or disease/disorder. Health-related quality of life is only 1 of at least 11 components that are contributory to overall quality of life (Hammell, 1995).

12. Assess quality of life for individuals with spinal cord injury using direct perceptions of the individual involved. (Scientific evidence—III/V and meta-analyses; Grade of recommendation—C; Strength of panel opinion—Strong)

Assessments of quality of life may not necessarily reflect changes from pre-injury reference points or contexts since, by definition, quality of life is “experienced by people under their current life conditions.” Quality of life from the perspective of observers without spinal cord injury (surrogate measures) are best addressed by other assessments that can subsequently be correlated with direct,

phenomenological, quality-of-life measures completed by individuals with spinal cord injury.

Composites of surrogate measures are likely to confound and cloud the direct assessment of quality of life (Campbell, 1976). This is particularly true since quality-of-life definitions may differ dramatically from person to person (Warren et al., 1996). A professional who looks only at component measures is likely to misinterpret the needs of a person with a spinal cord injury (Laman and Lankhorst, 1994; Stensman, 1985). Health-care professionals significantly underestimate the quality of life of individuals with spinal cord injury (Bach and Tilton, 1994; Gerhart et al., 1994; Gerhart and Corbett, 1995). Most research regarding quality of life and spinal cord injury has used multi-item scales for optimal reliability (Evans et al., 1994).

13. Facilitate opportunities for optimal quality of life within the full continuum of health-care and rehabilitation programs. (Scientific evidence—III/V and meta-analyses; Grade of recommendation—C; Strength of panel opinion—Strong)

Although data indicate that people with spinal cord injury, on average, report a lower level of quality of life than the average person without an injury (Dijkers, 1997), a spinal cord injury does not necessarily diminish quality of life (Brown et al., 1987). Goal-setting and treatment planning should focus on achieving the highest level of quality of life possible considering appropriate normative data, the person’s choices, comorbidities, age, culture, and premorbid functioning (Gerhart et al., 1993; Whiteneck et al., 1992a).

Analysis of the factors that are likely to influence quality of life may help to focus interventions that could maximize quality of life outcomes. The relationship between quality of life and social role barriers is stronger ($r = -0.32$) than the association between quality of life and activity limitations ($r = -0.21$). The relationship between quality of life and impairment is not statistically significant (Dijkers, 1997). Prior findings have emphasized associations with the components of social support, social integration, mobility, occupation, and family roles (Dijkers, 1997). Other research has emphasized the potential contributions of psychological coping, achievement, health, age, activity, affect, attitude, pain, beliefs, and behavior as important components contributing to quality of life (Anke et al., 1995; Noreau and Shephard, 1995; Robnett and Gliner, 1995; Warren et al., 1996).

Improvements in subjective well-being may result in reduced secondary complications, activity limitations, and social role barriers due to increased engagement in self-care and health-maintenance

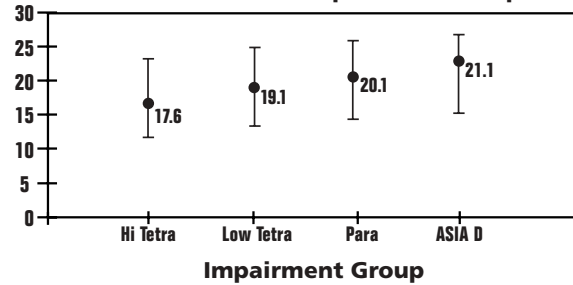
activities (Tate et al., 1994). Likewise, if barriers to performance of social roles are decreased, impairments related to secondary complications might be prevented or diminished (Anson et al., 1993; Bach and Tilton, 1994; Stover et al., 1995).

An instrument that can be used to describe subjective well-being is Diener's Satisfaction with Life Scale (Diener et al., 1985). The Diener scale is a 5-item scale with each item rated on a scale that ranges from 1 to 7 with a total score that ranges from 5 to 35, with higher scores implying greater satisfaction with life. Normative data from the Model SCI Systems (NSCISC) provide rehabilitation programs an opportunity to adjust life satisfaction by severity of spinal cord injury.

Figure 9 illustrates median and 25th and 75th percentiles on Diener's Satisfaction with Life Scale for NSCISC patients distinguished by neurologic level and completeness of injury (high tetraplegia [ASIA A, B, C], low tetraplegia [ASIA A, B, C], paraplegia [ASIA A, B, C], and ASIA impairment

grades of D regardless of injury level). NSCISC patients are asked to complete the instrument 1 year after spinal cord injury, on average. Rehabilitation programs can use this information to document deviations in the life satisfaction of groups served and take appropriate action to enhance their outcomes, as needed.

FIGURE 9
Diener Scores Across Impairment Groups



Recommendations for Future Research

The approach taken by the panel for these clinical practice guidelines on outcomes following traumatic spinal cord injury was to use large-scale, prospective, descriptive research to document achievable outcomes in four domains—motor recovery, functional independence, social integration, and quality of life. Two lines of research are recommended to improve this document and maximize positive outcomes in the future.

First, treatment effectiveness research is needed to better understand which program strategies efficiently produce the best outcomes. Second, research quantifying the expected impact of personal injury and environmental characteristics on the outcomes achieved is needed for greater accuracy in predicting outcomes and severity and for adjusting comparisons among programs.

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Administrative and financial
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July 1999