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ORIGINAL ARTICLE

State of the science in spinal cord injury rehabilitation 2011: informing a new research agenda

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Study design: This manuscript summarizes recommendations from the State of the Science Conference in Spinal Cord Injury Rehabilitation 2011.
Objectives: To develop an agenda for spinal cord injury (SCI) rehabilitation research in the next decade.
Setting: Participants scheduled planning meetings and then gathered at the 2011 joint meeting of the American Spinal Injury Association and International Spinal Cord Society in Washington DC.
Methods: Recommendations were made by an international, multidisciplinary team that met in large plenary sessions and breakout groups during the meeting.
Results: Recommendations are organized by conference track, including neurological and functional recovery; technology issues; aging with spinal cord injury; and employment, psychosocial and quality of life issues.
Conclusion: A number of themes emerged across the conference tracks, including the need for improved measures of process and outcome constructs, application of qualitative and quantitative research designs, and use of contemporary statistical analytic approaches. Participants emphasized the value of collaborative research that uses the latest methods, techniques and information.
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INTRODUCTION

As described in the 'State of the Science Conference in Spinal Cord Injury Rehabilitation 2011: Introduction',[1] an international multidisciplinary team worked to develop an agenda for spinal cord injury (SCI) rehabilitation research in the next decade. As explained in the introduction, the conference was organized around four tracks, neurological and functional recovery, technology for mobility and function, aging and secondary conditions, and psychosocial, vocational and quality of life (QOL) outcomes. The following is a synopsis of the discussions for each track and the final recommendations.

NEUROLOGICAL AND FUNCTIONAL RECOVERY

The plenary presentations provided an opportunity for participants to begin considering priority research goals and current barriers to success in order to develop research approaches that will provide the necessary achievements 10 years from now. Mary Galea[2] and Armin Curt,[3] selected to bring two of many possible perspectives on this problem, provided their personal visions, which are available in this focus issue.

In brief, Dr Galea focused on the need for ongoing, active rehabilitation after inpatient rehabilitation. She emphasized that rehabilitation of effector organs (for example, cardiovascular, respiratory and musculoskeletal systems) is equally fundamental to recovering independent activities of daily living as the functional repair of damaged central nervous system (CNS) circuits. Dr Curt focused on the recent escalation in translational research activity, as an increasing number of novel therapeutic interventions are being moved to human studies and clinical trial validation processes. He emphasized that effective translation is a two-way, iterative process between 'bench' and 'bedside' that is dependent on close interactions between scientists and clinicians, working as a team.

In all, four panelists followed with complimentary perspectives. Dr Kim Anderson amplified the need for greater research efforts on improving the neurological control of bladder, bowel and sexual function with the goal not just to manage these functions but also to restore voluntary control. She articulated how neurological recovery not only facilitates improved rehabilitation outcomes, but rehabilitation training also affects neurological status.

Dr Keith Tansey focused his presentation on the need for a better understanding of the neurophysiology of the normal and injured spinal cord, as such knowledge will be the foundation for directing enhanced neuroplasticity after SCI. Neuroplasticity is recognized widely as an important contributing mechanism to CNS repair processes and includes reorganizing residual connections by changing synaptic strengths and generating new neural circuits through axonal sprouting and new synapse formation to enhance normal and decrease abnormal function. Many of these and other neuroplasticity events are likely to occur simultaneously or sequentially.

As there is more to functional recovery than improved somatic sensory and motor function, Dr Andrei Krassioukov directed

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participants' attention to the autonomic nervous system. After SCI, many organ systems are influenced by alterations in autonomic nervous system activity. He described the need for accurate and sensitive outcome measures to reliably monitor changes in autonomic nervous system function. These measures are needed to determine the validity and clinical benefits of any therapeutic agent acting on the CNS.

Dr Eric Hoffman ended the panel discussion with a synopsis of the rapidly evolving field of molecular systems biology, which integrates data sets involving kinetic changes and sequence interactions between the genome, proteome, secretome and microbiome in what can be described as 'time-lapse molecular movies.' Molecular systems biology provides the momentum toward personalized health care, where custom solutions will be targeted to the specific requirements of individual patients (for example, pharmacogenomics). Many of these advanced high-throughput technologies can be applied to defining better clinical targets for therapeutic approaches to improve not only neurological outcomes, but also treatments for medical challenges to other organ systems such as urinary tract infections.

Neurological and functional recovery workshop outcomes

In each of the four tracks, the audience was invited to participate in discussions of the track material, (in this first instance) the vision for the future of neurological function and functional recovery research. The diverse opinions reflected the heterogeneous interests of the participants.

Consensus on process. However, several points of consensus emerged, including the need for:

(1) Active dialogue between all stakeholders—scientists, clinicians, allied health professionals, caregivers and people living with SCI,
(2) More effective networking—in comparison with some CNS disorders, the incidence of SCI is small and requires collaboration across multiple clinical centers to speed progress,
(3) Active rehabilitation training—physical and occupational therapy are fundamentally important to maximizing therapeutic interventions whether the experimental treatment is directed to the CNS or a specific effector organ,
(4) Improved electrophysiological methods, higher resolution-imaging technologies and accurate biomarkers to accurately detect neurological and functional changes after SCI, and
(5) Better characterization of functional outcome measures that are correlated with providing a clinically meaningful benefit.

Priority research goals. In short, the workshop comments centered on unmet research needs and research processes that can facilitate improved research efforts. Less progress was achieved defining a vision for what neurological and functional recovery will look like at the end of the second decade of the 21st century.

Likewise, when it came to defining the highest priority research goals, participants reached no consensus. The list of goals reflected the aspirations of the workshop participants and ranged from a better understanding of basic neuroscience to improving health after SCI. A partial list of research goals included upper and lower limb function; bladder and bowel function; pain, sexual health; autonomic function; peripheral nerve dysfunction; and musculoskeletal integrity. This list parallels or reiterates the goals articulated by other track workshops.

Activity-based rehabilitation. Nevertheless, the near-term advancements for functional recovery are likely to reflect many of the current experimental interventions that have shown promise for improving the recovery of independent activities of daily living. Promising techniques are centered on forms of active rehabilitation and include task-specific, active physical and occupational therapy; constraint-induced movement therapy; body-weight supported locomotor training; sensory stimulation (for example, functional electrical stimulation); repetitive transcranial magnetic stimulation; and virtual-reality, robot-assisted movement therapy.

There are many unresolved issues associated with the activity-dependent rehabilitation approaches listed above. Answers to the following question will facilitate the development of specific and valid rehabilitation prescriptions that can be delivered in a more effective fashion.

- When is the optimal time to start physical and occupational rehabilitation after acute SCI?
- Which rehabilitation regimen is best for each type of SCI (for example, severity or level) and when should training of compensatory behaviors be included?
- Are achieved benefits only specific for the trained task or can multiple functional activities and modalities be trained simultaneously or concurrently?
- What is the best measure of the patient's rehabilitation effort?
- What duration is required for each session of therapy regardless of discipline?
- What frequency of sessions is required per day or week?
- How many weeks of in-patient and/or out-patient rehabilitation are required to recover a specific functional capacity or activity of daily living?
- How long will any beneficial effects be sustained?
- What type of maintenance program is required? What are the reasons for lack of compliance or maintenance?

Other interventions. There are several achievements that can be realized over the course of the next decade. The following list might be better achieved with combined interventions. None of the following visions promises a 'cure'; rather, these lines of investigation, if successful, should incrementally improve outcomes and the QOL for people living with SCI.

- Customized medical treatments based on personal genomic/proteomic profile (for example, pharmacogenomics),
- First generation neuroprotective interventions—limiting secondary neural tissue damage through biochemical and pharmacological actions, likely delivered by release from 'homing' nanospheres injected into the blood stream,
- Augmentation of functions that are preserved after SCI, such as pharmacological and/or electrical/electromagnetic stimulation of residual hand function,
- Neural repair: first generation progenitor cell transplants to replace lost neural cells after SCI (autografts and allografts); and biocompatible guidance channels to support the axonal outgrowth from transplanted or surviving cells as they bridge damaged CNS regions.
- First generation therapeutics that alter injured adult CNS tissue to establish an appropriate environment for neural repair, such as transient suppression of inhibitory factors within the adult CNS and addition of supportive trophic influences,
- Neural circuit remodeling (neuroplasticity) involving axonal sprouting and changes in synaptic connectivity through directed activity-dependent training, and

- Telehealth for the early detection of medical challenges to facilitate rapid, cost-effective treatment without hospitalization, or telerehabilitation to maintain long-term functional capacities.

TECHNOLOGY ISSUES

Assistive technology has an amazing potential to reduce disability and enable full life participation. Advances in technology have already affected people with SCI in substantial ways, and as technology improves, this trend will accelerate. In the paper entitled 'Technology for Mobility in SCI 10 Years from Now'[4] advances in assistive technology are discussed by an expert group. Also in this focus issue, an expert in engineering technology not related to SCI was asked to review and comment on this paper.[5] What follows is abstracted from the discussions that occurred after the panel wrote the paper and the responder presented his work. The panel included physicians, therapist, rehabilitation engineers and consumers. Subsequently, breakout sessions discussed this topic. The output of these discussions is organized in three sections: (1) changes conference attendees would make to the paper,[4] (2) gaps that are preventing advances in the field, and (3) specific recommendations that would maximize the positive impact technology can have on individuals with SCI.

Changes to the paper based on feedback from the conference

Attendees agreed that the paper presented does a good job of examining technology for mobility and identifying barriers and opportunities that may have a great impact on individuals with SCI. However, there were a few areas that participants felt were not fully covered. One area was technology that improved mass transit. As energy resources become scarcer, it is likely that mass transit will improve. Improvements in technology that facilitate access to mass transit are likely to facilitate easier travel for individuals who use wheelchairs. Meeting participants believed that communication technology would allow for extension of rehabilitation after discharge. Through telerehabilitation, 'online' exercise and medical consultation could be extended past an initial inpatient rehabilitation hospitalization or could complement and extend outpatient therapy sessions. The advent of motion tracking video games that link through the internet highlights the reality of this type of intervention.

Technology to expand social interactions for the SCI community is another type of virtual reality communication technology with great promise. Although not typically thought of as technology for mobility, the ability to interact online with the SCI community while remaining at home has been and can continue to be transformative. As technology improves, this communication medium will improve by allowing greater social interaction. The ability to see the person you are talking to is now a reality; more meaningful interactions, including gaming, and the potential for long-distance touching through haptic feedback, are likely to develop. Advances in communications together with social media have great potential to expand and bring together the SCI community.

Gaps preventing advances

Group discussions identified three main gaps that prevent substantial advances in assistive technologies.

Gaps between technology and products. The perception from consumers, individuals with SCI, on the panel can be summed up by, 'we can put a man on the moon but we can't (fill in the blank)'. Technological advances surround us; but consumers and clinicians believe that the products they rely on every day have not changed. Further, individuals living with SCI hear researchers talk about their ideas, but rarely see a tangible output, even after years of experiments and hype. Technologies are often perceived as not existing, being cumbersome, unreliable, or not meeting consumer needs. These perceptions persist in the backdrop of amazing advances in technology for entertainment and computing.

Gaps between researchers and individuals with disabilities. Another gap is between what consumers and researchers believe are the important areas of focus and approach. This gap can be best summarized by a consumer who said that too often researchers focus on technology that tried to fix her partially paralyzed hand, rather than making daily activities easier with the hand she has (that is, compensatory activities). Individuals with SCI cited specific areas that they believed needed additional technology-based research: mobility, including transfers in the home, the ability to get out in the community and movement that enable activities, such as dressing, and exercise technologies that allow for safe improvements in fitness. Although not necessarily under the rubric of movement, the panel believed technology research should focus on bowel, bladder and sexual function. The perceptions of consumers on the panel were that researchers often focus on available technology, not the needs of individuals with SCI. The perception of engineers was that the consumers need to learn what technology can do for them. This difference in perspectives highlights a large communication gap. What is needed is a comprehensive rethinking of the engineering approach to clinical problems in SCI. This approach must comprehensively take into consideration the needs and desires of the consumers.

Gaps in translation. Both consumers and researchers agreed that translation of technology to usable products takes too long and often does not occur. Their shared perception was that funding mechanisms do not foster product development from the start of an idea, through to finding or founding a company, to regulatory approval and sales. In addition, regulatory hurdles are high, more so when considering the size of the population. FDA device approval requirements, insurance coverage procedures and compensation levels for purchasing advanced technologies hinder translation.

Policy and research recommendations

Below is a list of recommendations that came from the working groups. We purposefully decided to avoid making technology-specific recommendations. Therefore, the following recommendations are focused on policies that would facilitate research and translation of technology into clinical products.

(1) Increase funding to provide technologies to consumers.

No amount of funding for research into assistive technologies will be translated if there is no funding for the development of technology. Technology has the potential to transform lives, and, in the long run, save costs. However, a narrow view on funding for technology will stifle research and prevent meaningful changes. The fact that individuals with SCI have to battle to get a good wheelchair makes is seem unlikely that insurance will cover a functional electrical stimulation system controlled by a brain computer.

(2) Increase research related to assistive technologies.

Technological advances not related to SCI can have a great impact on SCI.[4] However, these advances will not occur unless there is funding that promotes the adoption of these technologies to meet the needs of individuals with SCI.

(3) Set priorities based on an assessment that includes an understanding of costs, benefits, consumer needs and available technology.

Priorities related to specific technologies must take into account major factors such as the available technology, the functional outcome gains the technology will allow, the goals of the consumer and the economic benefit to society. Decisions on which technology areas to fund and pursue cannot be driven just by researchers or advances in science. These decisions must be driven by funding agencies who could include the stakeholders.

(4) Provide funding mechanisms that encourage a better innovation pathway that supports technology development and transfer. The process should include a multidisciplinary approach from start to finish and encouragement of industry university partnerships.

The ideal process to support development of technologies should be encouraged by funding agencies, and each step along the way should be funded (see Figure 1). Funding should encourage a multidisciplinary approach including involvement of individuals with SCI. Government agencies should work to encourage industry and university collaborations. These collaborations should include not only small business but also larger ones capable of making the investment needed to bring technologies to market.

(5) Continued work on better outcome measures capable of providing insight and detecting differences in items that are meaningful to consumers and are medically relevant.

Better outcome measures will help all areas of SCI research. The outcome measures developed must help make the arguments that will lead to funding of new technologies, including cost effectiveness of interventions.

(6) Lower the regulatory bar for approval of certain assistive technologies.

The costs of bringing technologies to market must be addressed. Technologies that are specific to SCI address the needs of a small population. With a limited research and development budget, companies are likely to avoid projects that appeal to such a small market.

AGING WITH SPINAL CORD INJURY

Individuals with SCI are at elevated risk for a number of significant acute and chronic medical complications or emerging health challenges that may develop or be influenced by SCI, aging or a combination of both. These health challenges are termed 'secondary health conditions'. Although the track leaders recognized that aging with SCI has significant reciprocal effects on psychosocial function, participation and employment, they decided *a priori* that these topics were beyond the scope of the aging track, and that the psychosocial track would assume responsibility for these topics.

Three manuscripts on aging with SCI issues were drafted in preparation for the conference. Groah *et al*.[6] wrote a research recommendation paper that is designed to provide a broad overview of research gaps and recommendations to promote research in aging with SCI. This was followed by a paper targeting conceptual issues of aging with SCI, specifically secondary health conditions,[7] and by a manuscript tracking progress and gaps in SCI care, along with anticipated changes in the SCI population over the next 10 to 20 years.[8] These preparatory manuscripts provided a point of departure for presentations and discussions at the conference.

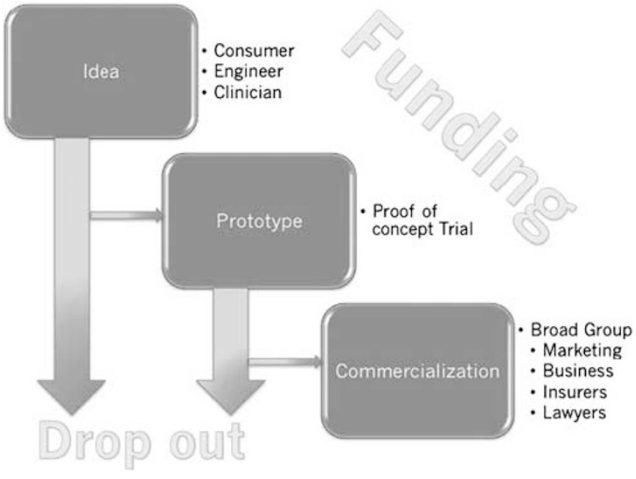

Figure 1 Steps in product development. Each step needs funding and the funding should require that a multidisciplinary team be included to increase the likelihood of a relevant outcome. Not all ideas will make it through the entire process. A full color version of this figure is available at the *Spinal Cord* journal online.

Presentations

Dr Michael DeVivo provided an overview of recent and anticipated population changes that will affect aging issues, as outlined in his paper.[7] Dr Luigi Ferrucci of the National Institute on Aging at the National Institutes of Health provided a geriatrician's perspective of aging with SCI that emphasized key components of the aging phenotype: changes in body composition, imbalance in energy production and utilization, homeostatic dysregulation and neurodegeneration. In this model, these factors affect physical and cognitive frailty through increased disease susceptibility, reduced functional reserve, reduced healing capacity and stress resistance, unstable health and failure to thrive. He proposed that changes in body composition, energy imbalance, homeostatic dysregulation and neurodegeneration can independently or in combination lead to accelerated aging.

Four panelists followed with complimentary perspectives in a panel discussion chaired by Drs Ivan Molton and Suzanne Groah. Dr Mark Nash detailed the impact of body composition changes and energy imbalances that are common after SCI with a discussion on cardiometabolic disease risks. Dr David Berlowitz presented for Dr Sonia Ancoli-Israel on sleep disorders in people with aging and with SCI. Dr Michael Boninger followed with a vision for the next 10 years of aging-related care and research, with a focus on the musculoskeletal system and on assistive technology. Dr Gary An continued this discussion with a focus on inflammation.

Gazing into the crystal ball of aging with SCI rehabilitation research: outcomes

Recommendations from the plenary speakers, panelists and workshops were synthesized by the conference leaders to develop major goals stemming from this track. The recommendations are listed below.

Nomenclature and conceptual issues. (1) Clarifications of pertinent nomenclature.

The term 'secondary conditions' has been utilized throughout the disability literature without a clear definition of what constitutes a secondary condition and without clear differentiation from 'associated condition.' Further, this terminology is used more in disability-related research and as such, may detract from clear communication with scientists outside of the disability and rehabilitation community. This point is addressed in detail in Jensen *et al*.'s manuscript in this focus issue.

(2) There are complex interactions between aging before the onset of a disability and aging with a disability.

Historically, people with SCI sustained injury during their teens or early adult years and had not experienced significant aging at the onset

of SCI. Much of their aging occurs with the SCI. With population aging and changing demographics, older individuals are sustaining more injuries resulting in SCI or are developing medical conditions resulting in spinal cord disease. As a result, there is wide variability in the degree to which aging has occurred before injury, which in turn affects aging with SCI. Also, we are just beginning to observe SCI in the frail elderly. These factors have significant implications for rehabilitation research and care.

Secondary health conditions. (3) The impact of health conditions for people with SCI was a common point of discussion in the plenary and panel presentations as well as the discussion groups.

Major areas of concern included cardiovascular and cardiometabolic disease, respiratory dysfunction, musculoskeletal overuse and injury. Common threads linking these conditions and relevant to SCI rehabilitation include changes in body composition, obesity and inflammation. As an example, body composition changes are nearly universal after SCI and are characterized by an increase in fat mass and reduction in muscle mass. People with SCI, then, have a propensity for obesity, which in turn influences systemic inflammation. As enumerated by Drs An and Nash, inflammation is a result of these changes and also a progenitor to other secondary conditions, such as skin breakdown and cardiovascular disease.

(4) Awareness and identification of risk clusters (risk factors that tend to cluster together, for example, obesity and hypertension) can aid SCI consumers and clinicians to diagnose secondary conditions earlier and before they have progressed significantly or caused functional decline.

With a better understanding of risk clusters, preventive therapeutic options can be initiated before disease onset or earlier in the course of disease.

(5) Personalized medicine is an emerging area for future research.

As stated above, specific possibilities for research include identifying and examining biomarkers, genetic and epigenetic influences, including proteomics and metagenomics, which can lead to more effective therapeutic strategies such as pharmacogenomics. These newer technologies are advancing rapidly and offer great promise in clinical care in the near future. These assessments may prove exceedingly useful for people with SCI, as they offer new diagnostic options when clinical diagnosis is often impeded by a lack of clinical signs or symptoms. Banking of biological specimens was discussed as an option and could facilitate longitudinal examinations of research questions.

(6) Participants made a strong recommendation for increased research and clinical care attention to the application of treatment guidelines, such as use of National Cholesterol Education Program Adult Treatment Panel (NCEP-ATP)[9] guidelines for the treatment of high blood cholesterol in people with SCI.

This attention could range from studies of existing guidelines to better understand the applicability of guidelines to people with SCI, modification of existing guidelines for the SCI population, developing new guidelines based on evidence and expert recommendation and studies of how guidelines are utilized in practice.

Methods and analyses. (7) Given that SCI is a relatively low prevalence condition and that aging research often requires large samples over a greater amount of time, greater attention needs to be given to statistical methods that are designed for human studies with a small number of participants.

Use of quantitative and qualitative methods and analyses will offer greater information output from studies with relatively small samples.

(8) One group spent a significant amount of time discussing the use of the 0.05 level of statistical significance.

SCI rehabilitation research is hampered by low subject numbers and outcomes often have ceiling and floor effects. The 0.05 level of significance is arbitrary; rather than rigidly apply this criterion, greater attention should be paid to clinically meaningful findings and analyses that overcome limitations imposed by small sample size. Areas of research that may diverge from the 0.05 level of significance include education, high-risk high-reward conditions, proof-of-principle and preliminary studies in a themed area.

(9) Our knowledge about aging with SCI would benefit from the use of large existing databases. Ideally a number of these would follow cohorts longitudinally.

Examples of longitudinal databases include the Department of Veterans Affairs database, Centers for Medicare and Medicaid Services claims and assessment databases, the SCI Model System database and international databases, such as the European Multicenter study of SCI. Participants recommended that these data sets be made accessible to the scientific community to accelerate information return on investment.

(10) Key to growth in research on aging with SCI is greater collaborations, perhaps with the formation of aging-related translational research networks.

Participants should include rehabilitation scientists and clinicians, geriatricians, basic scientists, anthropologists and sociologists. This concept was reiterated throughout the conference.

Self-management. (11) Options for self-management and research on self-management of health conditions are an important component in future research.

Improving self-management promises greater freedom and independence in the community, which minimizes challenges associated with receipt of health care. Key areas for research include diet, nutrition and prevention of secondary conditions.

(12) Several participants suggested that we could learn much from healthy survivors with SCI.

Case series or a larger multi-center study could provide important information to determine characteristics associated with healthy and successful aging. The last 5 years of life could be specifically studied so that greater knowledge can be gained during the period of greatest health care demands.

PSYCHOSOCIAL, EMPLOYMENT AND QOL

The speakers, panelists, workshop and audience members discussed numerous research priorities spanning a diverse range of psychosocial, employment and QOL challenges after SCI that limit life satisfaction, economic self-sufficiency, independent living and full participation in society.

Presentations

Professors Marcel Post and Christel van Leeuwen[10] focused their plenary presentation on psychosocial issues, and Lex Frieden and Andy Winnegar[11] addressed employment issues; their contributions are published elsewhere in this special issue. Christine Griffin, JD, Deputy Director of the Office of Personnel Management, described the unique role of the US federal government as an exemplary employer of persons with disabilities, and federal law and policies that support the employment of veterans and civilians with disabilities. A total of four panelists in the psychosocial, employment and QOL track were asked to consider where we should focus our service efforts and research agenda. Dr Kathryn Boschen described the role rehabilitation serves in enhancing individuals' social well being. She identified important determinants of social well being, including

a sense of control and coherence; physical and mental health; financial, housing and employment issues; self-efficacy; family and relationships; friendships and social support; emotional life and sexuality; community life; and existential meaning. Professor David Gray from Washington University described opportunities for SCI research using community-based research paradigms. Professor Gregory Murphy from La Trobe University described psychosocial constructs influencing rehabilitation outcomes following SCI. Professor Luc Noreau from the Center for Interdisciplinary Research in Rehabilitation and Social Integration at Laval University noted the minimal employment gains over the last 40 years, worldwide. He emphasized a research focus on potentially modifiable factors such as policy disincentives that penalize employment by reducing disability support payments.

Discussion group recommendations

Conference participants developed several recommendations for future research.

Topical recommendations. (1) Interventions to enhance individuals' skills.

Participants agreed that there is a great need to evaluate interventions, which seek to promote self-management of secondary conditions across the lifespan. These studies should focus on mechanisms by which psychological characteristics, such as locus of control, skill competence and self-efficacy, affect self-management skills.

(2) Interventions to reduce environmental barriers.

Research is needed to describe person–environment interactions as a first step towards appreciating the nature and effects of accessibility barriers and supports on participation. Research on this topic will help expand a narrow focus on individual-level determinants of adaptation to a wider examination of social, built and natural, and other aspects of the environment on participation and QOL.

(3) Interventions to enhance employment.

Participants in the break-out sessions recognized that employment is affected by a multitude of factors, not only individual-level factors, such as skills, motivation and prior work history, but also the environmental context in which the built and natural environment imposes barriers. Other barriers that deserve attention include attitudinal, transportation, community mobility and other barriers. One of the themes described by Lex Frieden and Christine Griffin was the importance of studying flexible work options, including working at home, telecommuting and using flexible hours and technology to overcome barriers that limit people from work. The absence of large data sets that document employment outcomes was seen as a major research deterrent. What intermediate steps can increase the likelihood of success in vocational pursuits?

(4) Interventions to improve social support.

Social support was recognized by the break-out group participants as being a critical factor in the long-term outcomes of individuals with SCI. Participants emphasized the need to improve measures of social support; they recognized that there are multiple QOL dimensions that should be linked to different types and kinds of social support. They emphasized that measurement should be multimodal and multidimensional. The use of quantitative and qualitative methods in the same study would enrich the results and the benefits of those studies.

(5) Aging and lifespan issues.

Break-out group participants identified the effects of aging on employment, psychosocial adaptation and QOL as being critical research topics. They recommended a research focus on health behaviors across the lifespan in terms of the impact on adjustment, types of interventions and risk stratification. Participants argued that investigators should recognize multiple dimensions of support systems and link these to social participation across the lifespan.

(6) Dual trauma diagnoses.

People with dual diagnose, such as traumatic brain injury in addition to SCI experience additional and unique needs. Needed are studies to determine what alternative or combined rehabilitation services help maximize health, participation and employment outcomes. The consequences of specific attentional, memory and other cognitive limitations were identified as critical concerns, as were the consequences of comorbid mental health and substance abuse on SCI outcomes.

(7) Community-based rehabilitation programs.

The participants recognized the importance of studying the effectiveness of community-based rehabilitation programs. Many services are provided not by medical providers, but by a variety of community organizations that provide services as well. The effectiveness and efficacy of these programs is rarely investigated.

(8) Peer mentoring.

Peers provide support, mentoring and promote community participation during and after rehabilitation. They are important adjuncts to rehabilitation across the continuum of care. Little is known about the receipt of peer mentoring and various outcomes across the lifespan. The extent to which credentialing, training and educational models are effective in preparing peer mentors is unknown. Needed are studies that evaluate components of peer mentoring programs in order to understand the benefits and limitations of peer support.

Methodological recommendations. (9) Instrumentation.

Participants emphasized the need for better research and clinical instruments that measure various aspects of psychosocial adaptation, employment and QOL. Participants recognized that these instruments should be tailored to various time periods of post-SCI and across the lifespan. Measures that describe economic costs and interventions are also needed. Constructs requiring better instrumentation include self-appraisal, pre- and post-injury self-management, self-efficacy, various skills and coping mechanisms, health-related QOL and environmental factors. Also needed are instruments measuring positive qualities across the lifespan, such as resilience, post-traumatic growth and cognitive appraisals. Participants described the need for an integrated assessment tool that examines disability as a function of the environment and the individual. Pediatric research and clinical practice, in particular, need high quality instruments that span early, middle and late childhood. Participants also emphasized the importance of high quality instruments to measure positive qualities affecting rehabilitation outcomes, such as resilience, post-traumatic growth and cognitive appraisals.

(10) Contemporary statistical models.

Participants emphasized the need to use sophisticated statistical models such as structural equation modeling and hierarchical linear modeling. Studies that define individual or subgroup outcome trajectories were of considerable interest. Wider adoptions of analytical models that can evaluate the complexities of SCI outcomes, such as structural equation modeling, require large samples. Multi-method approaches, such as those that incorporate qualitative and quantitative methods also are valuable, as they can yield complimentary results.

(11) Case-study designs.

Case-study designs are helpful in that they can document the paths by which individuals achieve successful adaptations in psychological, social or vocational aspects of their lives. Qualitative designs are useful in identifying what individuals did or their environments facilitated to

Table 1 Summary of Research and Procedural Issues from the SCI-SOS Conference

(For detailed discussion and description of these items, see text. Similar items in different tracks combined.)

General issues

- Active dialogue between all stakeholders.
- More effective networking.
- Better outcome measures, particularly functional outcomes, capable of providing insight and detecting differences in items that are meaningful to consumers and are medically relevant.
- Statistical methods that are designed for human studies with a small number of participants; consideration of the 0.05 level of significance.

Neurological and functional recovery issues

- Improved electrophysiological methods, higher resolution imaging technologies and accurate biomarkers.
- Research goals include: upper and lower limb function; bladder and bowel function; pain, sexual health; autonomic function; peripheral nerve dysfunction; and musculoskeletal integrity.
- Active rehabilitation, including task-specific, active physical and occupational therapy; constraint-induced movement therapy; body-weight supported locomotor training; sensory stimulation; repetitive transcranial magnetic stimulation; and virtual-reality, robot-assisted movement therapy.
- Customized medical treatments based on personal genomic/proteomic profile.
- First generation neuroprotective interventions—limiting secondary neural tissue damage through biochemical and pharmacological actions.
- Augmentation of functions that are preserved after SCI, such as pharmacological and/or electrical/electromagnetic stimulation of residual hand function.
- Neural repair: first generation progenitor cell transplants to replace lost neural cells after SCI; biocompatible guidance channels to support the axonal outgrowth from transplanted or surviving cells as they bridge damaged CNS regions.
- First generation therapeutics that alter injured adult CNS tissue to establish an appropriate environment for neural repair.
- Neural circuit remodeling (neuroplasticity) involving axonal sprouting and changes in synaptic connectivity through directed activity-dependent training.
- Telerehabilitation and Telehealth for the early detection of medical challenges to facilitate rapid, cost-effective treatment without hospitalization, or telerehabilitation to maintain long-term functional capacities for social interaction and exercise promotion through video games that link through the internet.

Technology issues

- Improvements in technology that facilitate mass transit use.
- Virtual reality communication technology allowing greater social interaction.
- Gaps between: Technology and Products—existing technologies not meeting consumer needs; Researchers and Individuals with Disabilities—researchers' focus on needs rather than technology; Translation—reduction to practice takes too long and lacks adequate support.
- Increase research related to assistive technologies.

Aging with spinal cord injury

Nomenclature and conceptual issues

- Clarifications of pertinent nomenclature.
- There are complex interactions between aging before onset of a disability and aging with a disability.

Secondary health conditions

- The impact of health conditions for people with SCI.
- Awareness and identification of risk clusters.
- Personalized medicine is an emerging area for future research.
- Increased research and clinical care attention to the application of treatment guidelines.

Methods and analyses

- Knowledge about aging with SCI would benefit from the use of large existing databases, including longitudinal cohorts.
- Greater collaborations, perhaps with the formation of aging-related translational research networks.

Table 1 (Continued)

Self-management

- Options for self-management and research on self-management of health conditions are an important component in future research.
- Identify characteristics and skills of healthy survivors with SCI.

Psychosocial, employment and quality of life

Topical recommendations

- Interventions to enhance individuals' skills, reduce environmental barriers, enhance employment and improve social support.
- Aging and lifespan issues.
- Dual trauma diagnoses.
- Community-based rehabilitation programs.
- Peer mentoring.

Methodological recommendations

- Instrumentation.
- Contemporary statistical models.
- Case-study designs.
- Interventions implemented in multiple settings.

Theoretical considerations

- Need for conceptual frameworks.

achieve success in health, function, employment and education. This information can be used to design interventions and identify predictors of success that can be verified in larger samples.

(12) Interventions implemented in multiple settings.

Participants emphasized the need for research designs that evaluate interventions in multiple settings. Studies of treatment preferences and preferences for how treatment is delivered are needed, too. Opportunities to collaborate with managed care organizations for persons with disabilities were discussed. Public and private programs for Medicaid and dual-eligible (Medicaid and Medicare) beneficiaries provide a unique opportunity to implement naturalistic designs of health services. Insurers may be good partners for community-based research.

Theoretical considerations. (13) Need for conceptual frameworks.

Participants emphasized the importance of designing research studies within the context of a theoretical model; they particularly valued models that emphasize multiple aspects of the person-in-environment such as biopsychosocial models. Models provide a conceptual framework on which interventions and natural history studies can be designed. Wagner's chronic care management model[12] was identified as being particularly relevant for populations with SCI. Participants recognized the international adoption of the ICF, but noted that it is a taxonomy and not a causal model. Ecological mapping could be used to identify areas that offer accommodations for individuals with SCI in their community.

CONCLUSION

A number of themes emerged across the conference tracks, including the need for improved measures of process and outcome constructs, application of qualitative and quantitative research designs and use of contemporary statistical analytic approaches. Participants emphasized the importance of being attuned to the needs of consumers living with SCI, as were the consequences when consumers and investigators fail to appreciate each others' perspectives.

To help readers identify the multiple issues described in this paper, the authors prepared a table that highlights the issues and recommendations (Table 1).

The authors of this paper trust that readers will find the recommendations useful as the course for the future is planned. An overall

theme across all tracks is that more research is needed. That this research must use the latest techniques and information and most importantly, that this research must be collaborative. Although this paper is just a step in that process in the collaborative area, it was a large step as the recommendations above present the combined work of hundreds of volunteers.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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