Special Article

Research progress from the SCI Model Systems (SCIMS): An interactive discussion on future directions

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Context/Objective: To describe current and future directions in spinal cord injury (SCI) research.

Design: The SCI Model Systems (SCIMS) programs funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) during the 2011 to 2016 cycle provided abstracts describing findings from current research projects. Discussion among session participants generated ideas for research opportunities.

Setting/Participants: Pre-conference workshop before the 2016 American Spinal Injury Association (ASIA) annual meeting. A steering committee selected by the SCIMS directors that included the moderators of the sessions at the ASIA pre-conference workshop, researchers presenting abstracts during the session, and the audience of over 100 attending participants in the pre-conference workshop.

Methods/Results: Group discussion followed presentations in 5 thematic areas of (1) Demographics and Measurement; (2) Functional Training; (3) Psychosocial Considerations; (4) Assistive Technology; and (5) Secondary Conditions. The steering committee reviewed and summarized discussion points on future directions for research and made recommendations for research based on the discussion in each of the five areas.

Conclusion: Significant areas in need of research in SCI remain, the goal of which is continued improvement in the quality of life of individuals with SCI.

Keywords: Spinal cord injury, Future directions, Model systems, Research, Progress

Spinal cord injury (SCI) can result in impairments that lead to life-long disability. While the incidence of SCI is relatively low, the lifetime costs associated with this injury (which often occurs early in life) are significant. In recognition of the need for better care and research in SCI, SCI Model System (SCIMS) program was

initiated in 1972 by the Rehabilitation Services Administration and has been continuously funded since, with 14 regional centers currently administered by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).^{1,2} Each center included in this program is responsible for collecting demographic and long-term outcome data on individuals with SCI. In addition, centers are required to conduct both site-specific and collaborative

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research. At the end of each 5 year cycle the centers traditionally hold a conference and produce a document that summarizes the state of the science and areas of need for research in SCI rehabilitation. The goal of the 2016 conference was to use research from the SCIMS centers as a springboard for an interactive discussion on future directions for SCI research. The objective of this report is to describe the process by which the symposium for dissemination was developed, describe the research presented, and summarize the discussion and directions as set forth at the meeting and by the symposium steering committee.

Methods

We formed a steering committee of SCIMS project directors and scheduled the event as a preconference associated with the American Spinal Injury Association (ASIA) annual meeting in April 2016. Abstracts were solicited by the committee from the 14 model SCI systems grantees and we received 16 submissions. These abstracts were then grouped into five themes: (1) Demographics and Measurement; (2) Functional Training; (3) Psychosocial Considerations; (4) Assistive Technology; and (5) Secondary Conditions. The steering committee developed guidelines for presenters, and moderators were recruited. The moderators were charged with maximizing discussion time and drafting a summary of the discussion for inclusion in this paper.

Presenters were asked to address directions for research and to participate in the moderator-led discussion. To obtain as much input as possible, individuals who pre-registered for the course were emailed the agenda and presentation titles in advance of the meeting; they were asked to provide input on specific directions for research they would like to discuss and encouraged to participate in the discussion. This paper summarizes the presentations and highlights discussion topics and research directions as discussed during the preconference workshop. The recommendations in this manuscript were formulated by the moderators based on the discussion. The steering committee members, who participated in the meeting, reviewed the recommendations and the discussion.

Results

Over 100 people registered for the conference. There was significant audience participation throughout the day for each session.

Demographics and measurement

The Demographics and Measurement Session included a variety of topics. The first presentation focused on changes in demographic characteristics of persons with

recent onset SCI over the five decades of the National SCI Model Systems database operations.³ Participating sites enrolled a total of 30,881 participants in the database from 1972–2014. Yuying Chen reported increases in the percentages of motor incomplete injuries, age-specific single/never married status, and greater education. Some previously reported trends continued including increasing age at injury and increasing percentages of racial minorities, fall etiology, and higher cervical injuries for various age, sex, race, and etiology groups.

The second presentation illustrated the value of linking data from the National SCI Model Systems Database with economic and spatial data in small geographic areas.⁴ Amanda Botticello described the variations that were identified in outcomes following SCI by geographic region and proximity to urban areas. This work helps expand our understanding of how features of residential neighborhoods and communities are related to the long-term health and disability experienced by persons with traumatic SCI.

In the third presentation, Alan Jette described advances in patient-reported outcome (PRO) measurement conducted by SCIMS collaborators.⁵ The Spinal Cord Injury Functional Index/Assistive Technology (SCI-FI/AT) short forms (SF) measure basic mobility, self-care, fine motor function, and ambulation and demonstrate good internal consistency, group-level reliability, excellent correlations between SFs and scores based on the computer adaptive testing (CAT) version and the total item bank.

The fourth presentation by Dan Graves summarized a collaborative project addressing a limitation of the American Spinal Injury Association (ASIA) Impairment Scale,⁶ which has limited representation of myotomes for thoracic segments of the spinal cord, levels T1–L1. The Trunk Scale was designed to address this deficiency by measuring voluntary control over trunk musculature. The unpublished results demonstrate high reliability and evidence of construct validity.

Several themes emerged from these presentations, as well as opportunities for future research. The enormous value of NIDILRR's investment in the SCIMS Database is evident in how investigators can identify and explore trends in demographic and injury characteristics, and in how advances in medical and surgical management result in improved survival of persons with high cervical injuries. Findings demonstrate the need to focus on issues related to aging and the cultural competency of clinical teams during acute and rehabilitation care. Future studies should focus on fall prevention among older adults as a means to prevent SCI, cultural

competency of providers, and changing needs for vocational rehabilitation, among other topics. Advances in measurement of trunk musculature control has immediate application during rehabilitation, in tracking benefits of interventions, and monitoring rehabilitation progress. Future studies should focus on methods to measure trunk function that can be performed at bedside.

Discussion following the presentations focused on the critical influence of environmental factors on the health status, employment, and participation of persons with SCI. Not only does the built and natural environment influence opportunities for participation, but so does assistive technology, support, relationships, attitudes, systems, services, and policies.⁷ NIDILRR's Long-Range Plan⁸ identifies environmental factors as a focus of research. Studies focused on describing the mechanisms through which environments shape the experience of disability are needed.⁹ Factors such as length of community exposure and residential instability deserve investigation as do supports such as caregivers, transportation, and state-level policy and service variations.

Discussion also focused on the utility of PROs to monitor and track persons with SCI through an episode of care and monitoring their status in the community. Future studies should promote person-centered care by evaluating linkages between PROs, such as the SCI-FI/AT CATs and short forms, and instruments required for payment by the Centers for Medicare and Medicaid Services (CMS).

Functional training

The Functional Training presentations included three studies relevant to improving functional performance in persons with SCI. First, Lisa Haubert presented findings from a study of joint forces generated during car transfers.¹⁰ Key factors influencing transfer-related forces were identified based on electromyographic and kinematic data. Higher shoulder joint forces were associated with higher neurologic levels of injury and transfers to higher-profile vehicles (i.e. SUVs). Placing the lead hand on the steering wheel was associated with higher levels of shoulder pain, compared with placing the lead hand on the driver's seat or overhead. Education about transfer-related risks to shoulder joint health, and training in techniques to minimize forces are critical for preserving shoulder joint integrity.

In the second presentation, Lynn Worobey presented results from a multi-center randomized clinical trial on group wheelchair skills training being conducted at four SCIMS centers. Participants who received wheelchair skills training were compared to participants

who attended classes on aging and weight management/nutrition.¹¹ No between-groups differences in wheelchair skill capacity and performance were identified, perhaps because high baseline scores resulted in ceiling effects. However, greater improvement among participants with tetraplegia and those who attended more classes indicated the capacity for meaningful functional improvements in wheelchair skill level even many years post-SCI.

In the final presentation, Kristin Leech described outcomes from a study that examined the effects of high intensity (fast) walking in participants with incomplete SCI.¹² In addition to treadmill walking kinematics and muscle activation patterns, the investigators assessed serum levels of brain-derived neurotrophic factors (BDNF). During treadmill walking, measures of limb coordination and muscle activity indicated a trend toward more normal patterns with higher walking speeds. Single-session assays of serum BDNF concentrations increased only with fast walking, and were significantly correlated to increased heart rate and oxygen consumption.

Several discussion themes arose related to areas for future study. Most importantly, the need to understand characteristics that indicate responsiveness to training is critical. In studies intended to answer questions about responsiveness to training, results are likely to be skewed by inclusion of individuals who demonstrate a high level of function. It may be important for studies to stratify treatment groups based on baseline function or to have high baseline function be an exclusion criterion.

Another discussion topic focused on identifying predictors of responsiveness to skill training, with questions such as: How are age and time post-injury related to responsiveness to training? Does optimal skill-acquisition time vary for different types of skills? How do factors such as level of self-efficacy influence responsiveness to training? Short lengths of stay in rehabilitation centers results in discharge before maximum restoration of function. Understanding what factors influence responsiveness will maximize rehabilitation outcomes and allow training to be directed toward the most appropriate goals. When clinical presentation indicates high likelihood that motor function will be restored, training should be directed toward that goal. When motor function is less likely to be restored, training should focus on promoting optimal compensation and access to necessary assistive technology.

Discussion also focused on the variability of therapy delivery and outcomes among rehabilitation programs. Beyond the conventional individual format of training,

some skills may be best acquired in group training. Peer trainers may be an effective training approach for some types of skills. Moreover, some skills can be safely and effectively practiced in home settings. It is important that the measured skill acquisition outcomes be meaningful for persons with SCI. For example, there is limited value in improving treadmill walking speed if this improvement does not carry over to improved over ground walking ability.

Research focused on understanding dose-response relationships is critical. Under-dosed rehabilitation results in under estimation of the value of rehabilitation, and a higher dose than necessary represents a poor use of resources. For some skills, rate of acquisition is influenced by intensity of training (e.g., speed, number of repetitions, heart rate elevation). Alternatively, high intensity is not beneficial or is even detrimental for some skills (e.g. high repetitions of transfers can have a detrimental effect on shoulder joint health).

Discussion also focused on development of biomarkers to characterize injury severity and responsiveness to training. Biomarkers can be low-tech like gait speed or motor score or higher tech like genomics. For biomarkers to be of value, they must be validated with the best available clinical prediction rules. The time and expense related to acquiring, processing, and analyzing biomarker-derived measurement is justified only if they prove to be of greater value than the best clinical predictors.

Psychosocial considerations

Three presentations highlighted the topic areas of self-efficacy, longitudinal changes in vocational interests, and barriers to accessing health and wellness activities in persons with SCI. Susan Charlifue and Jennifer Coker presented results of a randomized controlled trial of a psychologically based group education intervention designed to improve self-efficacy.¹³ Self-efficacy, defined as individuals' beliefs in their ability to succeed in accomplishing specific goals and meeting life challenges, was measured using the Moorong Self-Efficacy Scale.¹⁴ Their study included subjects who were at least 4 weeks post-discharge from inpatient SCI rehabilitation. Preliminary results from 81 participants, 41 in the Treatment group and 40 in the Control group, indicated a significant effect of the treatment, as those participants had an increase in self-efficacy (the primary outcome) over the 6- week treatment period. This increase was maintained in the 24 weeks after the treatment.

Yue Cao presented results of an observational study lead by James Krause that analyzed changing patterns

of vocational interest.¹⁵ Data were available from 250 persons living with chronic SCI over a 10-year period based on the 6 General Occupational Themes (Realistic, Investigative, Artistic, Social, Enterprising, and Conventional) in the Strong Interest Inventory. The study presented significant differences in patterns of vocational interest after SCI between men and women and between Whites and Blacks. At the follow-up time point, all males (Whites and Blacks) had higher interests related to realistic occupational theme than females, while all Blacks (males and females) had higher interests related to conventional occupational theme compared to Whites.

The session concluded with a presentation by Stephanie Bughi describing a study that assessed quality of life outcomes associated with a 3-month, community-based care approach that integrated wellness interventions into clinical practice.¹⁶ While there was a decline in attendance over the follow-up period, comparison of pre- and post-participation questionnaire results generally showed improved quality of life indicators in those who adhered to the program.

The discussion following the presentations highlighted the benefits of education-based interventions that have the potential to improve a range of psychosocial outcomes including self-efficacy, wellness, quality of life, and employment. The development of refined psychosocial outcome measures as well as categorization of key independent variables (e.g. vocational interests and other personal characteristics) should enable identification of significant elements of effective and individualized interventions. The discussion also highlighted the "real world" challenges of providing access to psychosocial interventions. With limited resources in our healthcare system, demonstrating the cost effectiveness of these approaches will be an important, if challenging, direction for future research. Participants recommended that future studies of psychosocial interventions should measure the durability of outcomes over longer time frames. For example, can a self-efficacy intervention lead not only to getting a job, but also to sustained employment? To the extent that health insurance does not adequately support psychosocial educational interventions, research on the creative use of community support mechanisms may identify sustainable alternatives.

Assistive technology

Assistive technology (AT) is of great value to people with SCI.¹⁷ This session included three presentations related to AT research completed at SCIMS centers. In the first talk, Dan Lammertse reported unpublished

findings regarding long-term experiences of implanted diaphragm pacing systems across six model systems. With an average of over three years since implantation, the majority (> 80%) were still using their pacers and while attendant care needs did not change in most, the overwhelming majority was satisfied with their decision to have implantation.

Next, Lynn Worobey presented data from four SCIMS centers on wheelchair failures, which are reported to occur in over 60% of wheelchair users with SCI in a six-month period. She reported unpublished results of a training course related to teaching maintenance skills as a means to prevent wheelchair breakdowns. Effectiveness of the training was evaluated using the Wheelchair Maintenance Training Questionnaire (WMT-Q) score, a measure of ability to complete maintenance tasks (capacity) and carry them out at an appropriate frequency (performance). At 6-month follow-up, WMT-Q scores of a cohort of power wheelchair users who received training improved in both capacity and performance, as compared to a wait list control group. Finally, Denise Fyffe presented unpublished data on racial and ethnic differences related to repairs from data collected across 8 SCIMS sites. While results were mixed, one notable finding was that non-Hispanic blacks were more likely to report adverse consequences as a result of a wheelchair breakdown than non-Hispanic whites.

Discussion following these presentations focused on funding of AT-related research and AT purchases by users. There was general agreement that it is easier to get funding for high-tech device research, even though individuals with SCI are more likely to benefit from low-tech devices. The need for low-tech device research was highlighted by the failure data presented by Lynn Worobey and the disparities work presented by Denise Fyffe. Research impacting AT quality and the service provision process could have immediate and meaningful impact on individuals with SCI. It was noted, however, that it may be easier to get research funding for high tech areas such as exoskeletons or neuroprosthetics, which offer hope for greater independence.

The other area of consensus was that research is needed to quantify the value of technology. The diaphragmatic pacing study provided an important example. The data presented indicate continued use and high satisfaction with diaphragmatic pacing. However, in the absence of a decrease in caregiver cost or burden, it is not clear if health insurance would cover the costs. Accounting for psychosocial benefits such as wellbeing, which do not present a clear cut return on investment, is essential to making the

argument for need. The discussion also focused on insurance coverage that limits clinicians' choice of AT. "If it is not covered, why even discuss it with the patient?" is a question many clinicians face. There was considerable discussion of this topic, reflecting payers' requirement that durable medical equipment be purchased only for home use,¹⁸ which makes little sense in the life of active wheelchair users with SCI. There was some cause for hope related to AT funding as the return on investment argument is more likely to be effective in the face of new payment or provider models. CMS is mandating bundling in post-acute care and in management of chronic complex conditions.¹⁹ If better technology can prevent pressure sores, pneumonia or depression, it might be easier to obtain insurance coverage for AT.

Secondary conditions

Michael Boninger started this session by describing how repeated wheelchair transfers are an important contributing factor to upper limb pain and pathology frequently experienced by persons with chronic SCI.²⁰ Based upon this centers' work, skills training to improve transfer techniques could play a critical role in reducing shoulder pain.^{20, 21} Key recommendations included the importance of reducing and spreading the amount of transfers throughout the day and utilizing appropriate transfer techniques and equipment (e.g., transfer board).

Charles Bombardier presented results from a multi-site randomized controlled trial of venlafaxine XR (12 weeks) for major depressive disorder after SCI.²² Venlafaxine XR was well tolerated by most patients and was effective in decreasing core symptoms of depression as measured by the Hamilton Depression Rating Scale (HAM-D 17-item version and Maier subscale) and improving SCI-related disability as measured by the Sheehan Disability Scale.²³

The final presentation by Robert Boucher and Judith Salazar described their experience and results in utilizing formal guidelines to reduce opioid overuse and polypharmacy in their inpatient unit.²⁴ Utilizing their protocols of educating both patients and providers, they were able to significantly decrease the use of high dose opioid medications by more than 50% and polypharmacy by 35%.

Several themes and research priorities emerged from these presentations. Of key importance is that pain plays a prominent role in the life of individuals with SCI. The importance of professional and patient education regarding techniques to prevent or minimize pain and available treatments, is critical to success.

Discussion focused on research strategies to reduce risk for shoulder pain, including remote training via the web in proper transfer techniques to monitor patients' performance while reinforcing appropriate technique, and to monitor shoulder pathology perhaps with the use of diagnostic ultrasound or MRI, prior to functional decline. In addition, research could focus on automated transfer capabilities for candidates who are at greatest risk of decline. For major depressive disorder, an important focus of research is learning who benefits from treatment and whether early intervention or prophylaxis is beneficial given trends towards shorter lengths of rehabilitation stay. Lastly for pain management, future research projects should include focus on monitoring pain levels and evaluating alternative treatments such as marijuana.

Our goal as clinicians and researchers is to find methods that allow each individual with SCI to be as active as possible. With recent changes in healthcare, including shorter lengths of stay in rehabilitation after the SCI and less overall availability for hands-on education and training, research is needed to determine who, how and when treatment for secondary complications are beneficial. Methodology to predict who is at risk of developing secondary conditions may range from diagnostic tests including, radiological tests, to genetic markers. Other treatment options include the application of mindfulness approaches,²⁵ with a better understanding of how behavior and exercise can be incorporated into treatments for persons with SCI. It is important to recognize that low technology advances are available; while they are not as exciting as high tech developments, they are more readily available and should be evaluated if they improve patient activity and participation in a cost effective manner. Lastly, the importance of studying the socioeconomic aspects of care should be considered with identifying the barriers to treatment and finding solutions to overcome them.

Discussion and conclusions

The presentations and discussion highlight several areas for research that have the potential to improve the lives of individuals with SCI. While every effort was made to be inclusive, this paper does not represent a systematic review nor a comprehensive survey. It is likely that the specific areas of discussion were influenced by SCIMS funding priorities and the composition of the steering committee. Significant areas of research were omitted, including neural regeneration, biomedical, and pediatrics. The conference agenda did not use formal procedures to establish consensus due to time and fiscal constraints.

Several issues crossed the five thematic areas. A constant theme over the last few decades of SCI research has been the need for better outcome measures. While gains have been made as exhibited by the SCI-FI, the outcome metrics used to measure impact of interventions are critical to establishing effectiveness. The instruments must be easy to administer, psychometrically sound, sensitive, and clinically relevant. Along with outcome metrics is the need for high quality biomarkers. Both low and high tech biomarkers can indicate who benefits from specific interventions. A personalized approach to medicine offers a chance to maximize benefits while minimizing costs.

Much discussion focused on controlling costs in a resource-limited environment. While biomarkers have the potential to help with patient selection for interventions, patient and caregiver education and training are also important interventions. Smart phone applications, web group training, and social media have the potential to improve outcomes at a low cost and may allow clinicians to reach individuals in rural and low socioeconomic areas. Increasing the reach of interventions and targeting those who are most disadvantaged is an important goal for this research given that many individuals with SCI have limited resources.

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