The Medical University of South Carolina (MUSC) held the 2013 State of the Science conference in Chicago, IL (MedStar National Rehabilitation Hospital co-hosted). This comprehensive report describes MUSC’s research and interim results as well as presentations related to psychological, socio-environmental, and behavioral risk and protective factors of secondary health conditions and mortality related to Spinal Cord Injury (SCI). MUSC’s SCI research endeavors support “Longevity after Injury ®.”

Prevention and Management of Secondary Health Conditions in People after Spinal Cord Injury

Report of the State of the Science 2013

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Executive Summary

In May 2013, the Medical University of South Carolina (MUSC) held the 39th Annual Pre-Course titled, “The State of Science of Prevention and Management of Secondary Health Conditions in People after Spinal Cord Injury” (Medstar National Rehabilitation Hospital co-hosted). The pre-course commenced the American Spinal Injury Association’s 2013 Annual Meeting. The state of the science conference presented interim results as well as presentations related to the prevention and management of secondary health conditions (SHCs) in the Spinal Cord Injury (SCI) population.

Spinal Cord Injury, whether acquired as an adult or child, is a severe disabling condition that results in permanent sensory and motor loss. According to the National Spinal Cord Injury Statistical Center (NSCISC, 2013), there are approximately 12,000 new cases of SCI each year which do not include those who die on site of accident. The long-term effects of SCI are profound, as SCI typically requires an extended inpatient hospitalization which varies depending on the type and severity of injury and there is a lifelong increased risk of the development of secondary health conditions.

Secondary health conditions include psychological as well as physical conditions that affect one’s quality of life and influence increased rates of morbidity and mortality. These SHCs are indirectly related to the SCI and are associated with a wide array of precipitating factors. SHCs include, but are not limited to, urinary tract infections (UTIs), pressure ulcers (PU), depression, respiratory issues, and chronic pain. Although preventable, SHCs significantly contribute to increased Emergency Department (ED) visits, re-hospitalizations, and/or death in the SCI community (Guilcher et al., 2013). Furthermore, SHCs are also associated with reduced participation in society, unemployment, lower quality of life (QOL) (Hammell, Miller, Forwell, Forman, & Jacobsen, 2009; Leduc & Lepage, 2002; Lidal, Veenstra, Hjeltnes, & Biering-Sorensen, 2008), and even diminished life expectancy (Krause, DeVivo, & Jackson, 2004). Researchers continue to investigate factors affecting SHCs and share findings with those in the SCI community, including clinicians and rehabilitation professionals treating SCI patients.

The state of the science conference provided a forum where researchers presented informative results from their respective research studies. The conference addressed the following topics: Risk and Prevention of Secondary Conditions after Adult and Pediatric SCI; Depression, Measurement, Participation, and Subjective Well-Being; Secondary Conditions and Mortality; Disparities, Surveillance, and Community. Below we present a summary of key recommendations from the state of science conference.

Summary of Recommendations

1. Establish conceptualized schemes that differentiate SHCs from chronic health conditions and conduct research on those conditions with greatest impact on health, QOL, and longevity.
2. Develop, disseminate, and promote best practice prevention and screening tools better inform clinicians, rehabilitation specialists, and SCI population about risk, prevention, and management of SHCs.
3. Enhance life expectancy of SCI population by identifying risk factors for preventable causes of death and actively focusing on effective prevention techniques.
4. Expand population-based studies, which provide an all-inclusive view of disparities and diversity related minorities, limited access to care, and low income.
5. Conduct more intensive investigations of the relationship between aging factors, SHCs, and longevity, including biomarker assessment of stress-based disorders.
Preface

In 2009, the Medical University of South Carolina (MUSC) and MedStar National Rehabilitation Hospital (NRH) both received a Rehabilitation Research and Training Centers (RRTC) grant from the National Institute on Disability Rehabilitation Research (NIDRR) to study secondary conditions in individuals with Spinal Cord Injury (SCI). One central component of each grant is to host a state-of-the-science conference, presenting findings of grant research and illustrating needs for further research.

On May 5, 2013, MUSC and NRH co-hosted the 39th Annual Pre-Course titled, “The State of Science of Prevention and Management of Secondary Health Conditions in People after Spinal Cord Injury.” The pre-course was one of several educational sessions to commence the American Spinal Injury Association’s 2013 Annual Meeting in Chicago, IL.

Medical University of South Carolina (MUSC)

Dr. James Krause is the Principal Investigator and Dr. Lee Saunders is the Co-Principal Investigator of the RRTC on Secondary Conditions in Individuals with Spinal Cord Injury. Together, they have utilized federal funding to launch and sustain the Longevity after Injury Project (LAIP) which conducts research focused on promoting health, longevity, and quality of life after injury or paralysis. MUSC’s LAIP focuses on psychological, socio-environmental, and behavioral risk and protective factors of secondary health conditions (SHCs) and mortality.

The research project combines an integrated program of research to identify risk and protective factors for secondary conditions with a systematic program of education, training, dissemination, and technical assistance that allows the new knowledge to be directly translated into prevention strategies at the policy, rehabilitative, clinical, community, and individual stakeholder level.

Our philosophy is the key to prevention of secondary conditions is to first identify to whom they occur to and why, then to widely educate and disseminate the new knowledge to professionals and stakeholders in a format they can directly use in the prevention of secondary conditions. Our research program identifies the risk and protective factors putting the greatest number of individuals at risk for the greatest number of conditions. Currently, we have three research studies integrated around two theoretical models of risk of secondary conditions. We have enrolled over 2,500 participants to date. To learn more about MUSC’s RRTC on Secondary Conditions in Individuals with SCI, including the research studies and instrument used, please click on the following link: MUSC RRTC information.

MedStar National Rehabilitation Hospital (NRH)

Project Director Suzanne Groah, MD, MSPH oversees the Medstar National Rehabilitation Hospital RRTC on Secondary Conditions in the Rehabilitation of Individuals with SCI which focuses on cardiometabolic syndrome and pressure ulcers in the SCI population. To read more about the NRH RRTC grant and its research studies, please visit http://sci-health.org/introduction.

American Spinal Injury Association (ASIA)

Physicians, medical professionals, and researchers established the American Spinal Injury Association (ASIA) in 1973 to give stakeholders a forum to align SCI research, exchange ideas, and educate new and upcoming medical professionals about SCI and its effects. Since its inception, ASIA has supported those engaged in
treatment of SCI by establishing standards of excellence, educating the public, fostering research, and facilitating communication among SCI stakeholders.

In May 2013, ASIA celebrated its 40th anniversary and sponsored the 39th Annual Meeting where medical professionals were invited to share research and new information concerning the treatment of SCI. Visit http://www.asia-spinalinjury.org/index.php to learn more about ASIA and its upcoming conferences.
**Morning Session Overview**

The morning session provided a well-rounded perspective on SCI and its complications. Keynote speaker Ed Eckenhoff, MHA, has lived with SCI for over 30 years. He gave a compelling talk about his injury and the challenges he overcame as young adult with SCI. Eckenhoff addressed the importance of support from family, peers, and rehabilitation institutions.

Additionally, the MUSC panel composed of James Krause, PhD, Glen White, PhD, and David Gray, PhD, explained the need for education, training, and awareness related to SCI and secondary health conditions (SHCs). The panel discussed several items researchers should focus on—aging, continuation of healthiness and quality of life, cost of SCI and complications, and SHCs. Keynote speakers reiterated the overall mission of the conference and subsequent presentations was to improve the quality of life for those living with SCI and better educate clinicians about SCI-related complications, which many of them are preventable.

To hear more about keynote speakers’ presentations, please click on the following link: [http://vimeopro.com/muscchp/longevity-after-injury/video/69625238](http://vimeopro.com/muscchp/longevity-after-injury/video/69625238)

Jim Rimmer, PhD, served as the plenary speaker and informed the audience about the importance of fitness centers promoting exercises targeted towards those with disabilities since the number of disabled individuals will increase significantly in the near future. One particular concern is environmental factors that contribute to a decline in physical activity among those with SCI, which ultimately negatively impacts their health status. These environmental factors include inaccessible facilities, lack of adequate physical equipment, poorly designed communities, and policies that do not promote physical activity.

To learn more about Dr. Rimmer’s presentation, please click on the following link: [http://vimeopro.com/muscchp/longevity-after-injury/video/69481777](http://vimeopro.com/muscchp/longevity-after-injury/video/69481777)

Researchers from both MUSC and NRH provided an overview of their respective RRTC grant. MUSC’s Dr. Lee Saunders provided an overview on MUSC’s RRTC on Secondary Conditions in Individuals with Spinal Cord Injury (SCI) which consist of the following studies: (1) 15-year longitudinal study used to predict secondary conditions, (2) population-based study investigating access to services and relationship to secondary services, and (3) 17-year longitudinal study examining changes in METS and consequences for other secondary conditions. The goal of these studies is to identify the broad spectrum of factors influencing the development of secondary conditions related to SCI. Dr. Saunders spoke about the importance of educational training and capacity building activities for future researchers in addition to performing SCI research.

NRH’s Inger Ljungberg and Manon Schladen gave an overview of the NRH RRTC on Secondary Conditions in the Rehabilitation of Individuals with SCI which focuses on cardiometabolic syndrome and pressure ulcers in the SCI population. Ljunberg and Schladen also mentioned the significance of training focused on consumers from underserved populations and health care professionals.

To view the RRTC overviews from NRH and MUSC, please click on the following link: [http://vimeopro.com/muscchp/longevity-after-injury/video/69627734](http://vimeopro.com/muscchp/longevity-after-injury/video/69627734)

The morning session prepared attendees for a vast amount of research and knowledge related to SCI and SHCs. Speakers set the precedence for following presentations and encouraged learning, inquiry, and dissemination.
The long-term effects of SCI include a lifelong increased risk of the development of secondary health conditions (SHCs). These SHCs are indirectly related to the SCI and include, but are not limited to, urinary tract infections or UTI, pressure ulcers, depression, respiratory issues, and chronic pain. Many SHCs are preventable; however, more education and training in risk and prevention measures are needed to reduce the prevalence of SHCs in both adult and pediatric SCI.

Due to varying growth and developmental stages associated with adolescence, those with pediatric onset SCI face different challenges and SHCs than those with adult onset SCI. Children who sustain a SCI have a relatively long life span, and they are susceptible to SHCs over a longer period of time compared to adult onset SCI. Children with SCI suffer from several musculoskeletal issues; the two most prevalent are scoliosis and hip subluxation. According to Dr. Vogel, UTIs (70%) were reported the most among pediatric SCI.

Dr. James Krause identifies pressure ulcers, UTIs, depression, loss of bone density, and chronic conditions as several of the most prominent secondary health conditions in the adult SCI population. In order to prevent these SHCs, Dr. Krause explains his Theoretical Risk and Prevention Model (TRPM) which identifies risk factors for developing SHCs. These risk factors include income/poverty, prescription medication abuse, binge drinking, repeat hospitalizations, and fractures/amputations.

In an effort to educate clinicians and prevent SHCs in people with SCI, MUSC partners with Shepherd Center in Atlanta, GA to provide educational training and mentoring programs for trauma centers in South Carolina. Community clinicians are unaware of the occurrence and varying number of SHCs affecting those living with SCI. The National Council on Disability (National Council on Disability, 2009) reports, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care.” When SHCs are not properly prevented or managed, individuals with SCI experience frequent ED visits and re-hospitalizations, increased medical costs, and, in worst case scenarios, untimely death. Shepherd Center has developed several fact sheets pertaining to SHCs. The following fact sheets are distributed to clinicians to better assist them prevent and/or effectively manage SHCs: Recommendations for Bladder and Bowel Management in People with Acute SCI, High Risk Factors for Pressure Ulcer Development, and Minimal Acute Care Documentation for Patients with SCI. By providing quality training and education, clinicians will be able to better prevent and/or manage SHCs which often leads to an increased QOL and life expectancy after SCI.

Session Questions and Comments
Q: How are we to help bridge the gap between pediatric SCI program/services and adult SCI program/services?

A: Start the transitioning process early, as early as age 14. More success is seen when pediatric SCI patients are seen in both the pediatric and adult SCI programs providing an overlap of services and programs; however, there is a struggle with this when seeing if their health insurance will cover such an overlap of services. This overlap promotes communication between the pediatric facility and adult care providers. Lastly, medical homes may provide substantial assistance in transitioning care and facilitate communication between pediatric and adult care. To learn more about medical homes and their significance, please visit the following website:


Limitations and Further Research Needs
While research has advanced the understanding of SCI and determined risk factors of SHCs, there are several limitations to risk and prevention efforts. One significant component is most SCI research examines
demographic information from SCI Model Systems of Care and does not look at the general population with SCI. Thus, there is a need for more population-based SCI studies to better document SHCs in the general population. Investigating SHCs in the SCI general population, as well as in the SCI Model Systems of Care, can help better educate clinicians regarding preventable SHCs and complications of SCI.

According to Dr. Vogel, more longitudinal studies on pediatric patients with SCI (e.g. those 0-12 years of age) are needed to better document progress, setbacks, and secondary health conditions in the pediatric population.

**Key Points**
1. In contrast to the adult SCI population, pediatric SCI patients, have varying growth and developmental stages which impact their physiological and psychological health, longevity, and quality of life.
2. Utilize Theoretical Risk and Prevention Model (TRPM) to identify primary types of risk factors for secondary conditions and prevent secondary health conditions.
3. Healthcare providers and clinicians can significantly support prevention and/or management of SHCs with continuous education on best practices of prevention strategies and encourage SCI program development in trauma centers as well as acute care hospitals.

**Video Presentation**

Please click on the following link to see an archived video of the presentation: [http://vimeopro.com/muscchp/longevity-after-injury/video/69627735](http://vimeopro.com/muscchp/longevity-after-injury/video/69627735)

**Afternoon Session 2: Depression, Measurement, Participation, Subjective Well Being (SWB)**
David Gray, PhD; Allen Heinneman, PhD; Charles Bombardier, PhD

Depression is a serious illness that has a huge effect on daily life. As noted by Dr. Bombardier, when compared to the general population, depression is even more prevalent in those with SCI, with rates ranging from 20-38% of inpatient populations. Since there are an elevated number of individuals who have co-occurring SCI and depression, it is often viewed that depression is a secondary condition resulting from the injury. Research, however, has revealed that depression may be a risk factor for traumatic injuries, such as SCI, due to the fact that many individuals had depression prior to their traumatic injury.

With the potential of depression being a risk factor for SCI, it is imperative that proper tools are in place for screening and prevention. As revealed in a longitudinal study, depression is not being treated effectively in those with an SCI (Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011). Even when compared to other conditions, rehabilitation in these individuals is less efficient and takes longer. Dr. Gray revealed that in addition to less efficient rehabilitation, depression affects other components of the individual’s life. Despite the benefits of being active in one’s community, those who have depression are significantly less likely to be involved in community activities, even when compared to SCI persons who have other secondary conditions. The individuals who are less involved in community activities also have a lower life satisfaction (Tasiemski, Kennedy, Gardner, & Taylor, 2005). With knowing the negative effects of depression on an SCI patient, it is important to understand how this population can be treated more effectively.

As described by Dr. Heinneman, before the focus can be on treatment, healthcare providers need to understand the normal patterns of recovery for persons with an SCI and their level of functioning. Longitudinal studies that use a measure such as the Functional Independence Model (FIM) can educate healthcare providers about the changes over time a patient has with their functioning. Understanding the complete process of recovery first is necessary in order to successfully evaluate and treat future patients.
To target the correct individuals for treatment, screening for depression during the inpatient stay is the first step (utilizing PHQ-9 and DSM-IV for depression). Once screened, healthcare providers can pursue those in need of intervention and utilize an interdisciplinary and comprehensive model to treat the patient. According to Dr. Bombardier, adopting an evidence-based collaborative care model would cause at least a 50% improvement in the rate of response to treatment in primary care. This multifaceted treatment approach would involve a team of psychiatrists, psychologists, and care managers all working together to motivate the patient, monitor progress, and conduct behavior and/or cognitive modification therapy to assist the patient in staying compliant with treatment. Having such treatment would increase facilitators for participation in rehabilitation and community activities and help to decrease any potential barriers. It is essential to have such treatment regularly in place to decrease the total cost of care (depression currently has a 14.9% increase in total cost) and to improve overall quality of life in this population.

**Significant Questions and Comments**

**Q:** How will a collaborative care model decrease the total cost of care for this population?

**A:** Implementing a collaborative care model would cause treatment to be more effective and efficient. This would result in less total time a patient is in rehabilitation which would decrease the cost of care.

**Limitations and Further Research Needs**

It should be noted that much of SCI research participant information is collected through the SCI Model Systems of Care and is not truly a cross-section of the overall SCI population. Additionally, self-report was a primary method used in the collection of this data, which is limited to the participant’s subjective viewpoint.

Although some research has indicated that depression may be a risk factor for SCI, more conclusive research needs to be conducted in order to have more effective prevention techniques.

**Key Points**

1. Depression is even more prevalent in those with a spinal cord injury (20-38% of inpatient populations) compared to the general population.
2. Longitudinal studies, documenting the normal patterns of recovery and normal levels of functioning for persons with an SCI is useful to educate healthcare providers on what to expect during treatment and how to best treat their patients.
3. An evidence-based collaborative care model would improve the rate of response to treatment by at least 50% within primary care, thus improving outcomes.

**Video Presentation**


**Afternoon Session 3: Secondary Conditions and Mortality**

Michael DeVivo, DrPH; Yue Cao, PhD; Eric Garshick, MD

Over the past few decades, life expectancy has been gradually increasing in the general population. However, Dr. DeVivo noted that for individuals with SCI post their one-year mark, there has been no change in life expectancy. Despite the improvements in medicine and technology, many health conditions that affect those with spinal cord injuries are remaining stagnant or have just recently started providing better outcomes with regards to longevity. Respiratory conditions (such as pneumonia) are the primary cause of death in individuals with an SCI and contribute to over one quarter of all deaths. Other leading causes of death within this
population include external causes (such as accidental drug overdoses, homicide, or suicide), effective and parasitic diseases (e.g. septicemia, AIDS, or TB), ischemic heart disease, and cancer.

According to Dr. DeVivo, many of the leading causes of death in those with an SCI are uncommon causes of death among the general population. These conditions, such as septicemia, are secondary health conditions that have a higher likelihood of developing in those with an SCI. While higher mortality is seen among those who have higher levels of injury, are male, or are African American, there are many risk factors for mortality that are preventable. As stated by Dr. Cao, some treatable risk factors and behaviors that contribute to the static mortality rate include smoking status, pressure ulcers, pneumonia, kidney calculus, and poor self-perceived health.

In the primary cause of death for this population, which is respiratory conditions, smoking status and lung function were the biggest predictors of death. A longitudinal decline in lung function is associated with factors that are not directly related to SCI, including body mass index (BMI), age, and smoking status. According to Dr. Garshick, those with an SCI who quit smoking three years ago or less were 3.37 times more likely to die compared to those who never smoked. As he acknowledges, many of the factors that play into mortality are preventable and/or treatable. Since much of the mortality among the SCI population can be attributed to preventable risk factors, it is imperative that prevention strategies be in place to target individuals who may be more susceptible to developing the risky factors that are associated with secondary conditions. With prevention techniques in place, healthcare providers can help decrease the alarming rates of mortality for certain conditions and increase the overall life expectancy for individuals with spinal cord injuries.

**Significant Questions and Comments**

**Q:** How can we increase life expectancy for those in the SCI population?

**A:** Since much of mortality is associated with an individual’s risky behaviors, it is important to have prevention and treatment in place directed at these behaviors. Additionally, improving respiratory muscle strength may slow the decline in lung function (Jain, Brown, Tun, Gagnon, & Garshick, 2006).

**Q:** Some previous research has shown that being underweight is a greater risk factor for mortality than being overweight. How will that affect future research?

**A:** Future research needs to look specifically at the lower than normal BMIs as opposed to looking at any outliers from the normal range, regardless if they are below or above. Specifically looking at those with the lower BMIs will help researchers and healthcare providers to know the mortality risks associated with being underweight.

**Limitations and Further Research Needs**

A primary method for collecting mortality information is through the Social Security Death Index (SSDI), which only has 92% reliability, leaving room for error. Additionally, participants in these mortality studies were gathered from the SCI Model Systems of Care, and are not truly representative of the overall SCI population.

According to Dr. Cao, future research needs to be focused on effective prevention techniques of risk factors to help to bridge the gap between life expectancies in the general population and the SCI population.

**Key Points**

1. Although life expectancy has been increasing in the general population, it has remained static for the SCI population over the past three decades
2. Increased mortality in the SCI population can be attributed to secondary conditions that don’t primarily affect the general population, such as pressure ulcers, septicemia, kidney calculus, and pneumonia.

3. To increase longevity in this population, there needs to be a focus on prevention of developing secondary conditions.

**Video Presentation**


**Afternoon Session 4: Disparities, Surveillance, Community**

Glen White, PhD; Lee Saunders, PhD; Vanessa Noonan, PhD, PT; Yaga Szlachcic, MD

While studying secondary health conditions (SHCs), researchers have identified noteworthy disparities in the SCI general population. As stated earlier, increased number of studies aimed at the SCI general population would potentially shed light on various disparities, SHCs, and varying issues affecting those who do not have access to the SCI Model Systems of care. As studies progress, researchers develop approaches to move SCI research forward. These approaches include promoting more population-based studies, developing comprehensive research, and monitoring disparities in the SCI community.

Dr. Lee Saunders oversees a population-based study which looks at the association of health services (e.g. access to care) with secondary conditions. The population-based cohort includes people with SCI in South Carolina. Interim results have identified significant differences in the population-based study versus a model SCI center. For example, in regards to demographics, the population-based cohort consisted of more minority participants, higher number of ambulatory status, and more participants with an annual household income of less than $25,000/year than Shepherd Center’s cohort. After adjusting for age at survey, years after injury, level of injury, general health, and household income, the population based cohort had increase odds of hospitalization in the previous year. Thus, those in population-based cohort are more likely to have more hospitalizations, days in hospital, ER visits, and surgeries than those in clinical rehab settings.

Many researchers promote research studies using surveillance data and cohorts from diverse groups with SCI. Under the direction of RRTC on Aging with SCI funding, researchers at Rancho Los Amigos in Downey, CA investigate disparities related to cardiometabolic risk. These researchers have included diverse groups of participants of predominately lower socioeconomic status from large urban areas to determine the impact of racial/ethnic and sex disparities on cardiometabolic abnormalities in individuals living with SCI. They have found significant findings point to several different factors which increase the odds of developing cardiometabolic diseases. Factors influencing disparities in cardiac and metabolic risk include: (1) genetic predisposition, education, access to care, cultural beliefs and socioeconomic status, (2) higher prevalence of Chronic Vascular Disease (CVD) in African Americans, and (3) higher prevalence of diabetes in Hispanics and Pacific Islanders. African Americans and men, with the exception of Hispanic women, were more likely to develop Metabolic Syndrome (METS). This study highlighted the importance of early intervention with life style modifications to reverse possible damage and prevent CVD.

According to DeJong & Batavia ([DeJong & Batavia, 1991](#)) “Persons with SCI have a specific constellation of ongoing health problems that are not being addressed by the mainstream of the American health care system, and that demand the attention of the HSR [Health Services Research] community.” Consequently, researchers are pushing for awareness and a more comprehensive research capacity on SCI and its complications. With funding from the Christopher & Dana Reeves Foundation, since 2004, Dr. Glen White has provided training, equipment, and resources for SCI care to those in physical medicine &rehabilitation (PM&R) and SCI.
community in Peru. He utilized Quality of Life grant funding to host “train the trainer” workshops, conduct pre- and post-testing, and create a manuscript to describe the trainings and results.

In moving forward, researchers urge and support the development of more clinical/consumer tools (e.g. Canadian Best Practice Guidelines for the Prevention and Management of PU in people with SCI), implementation, and standardization of best practices for SCI care.

Session Questions and Comments
Q: What are the expectations of C1-C4 injuries, those ambulatory SCI patients walking who probably shouldn’t be walking?

A: We have several studies which focus solely on ambulation, and our data report those who are in between walking and using a wheelchair far the worst in outcomes related to fatigue, depression, and chronic pain.

Limitations and Further Research Needs
As researchers utilize surveillance data to identify disparities in various SCI communities, there is a need for more comprehensive research capacity on SCI that focuses on cost analysis, SHCs, quality of life, and other issues related to SCI complications. In order to wholly address SCI and its complications, researchers and clinicians must look at psychological and socio-environmental as well as physical health. Additionally, once identifying factors of increased risk in the SCI population, there must be a concerted effort to create and report more clinical/consumer tools on best practices for SCI and SHCs.

Key Points
1. Current state of science (SOS) is lacking information from individuals who did not receive rehabilitation in a research facility. Those in population-based cohort more likely to have more hospitalizations, days in hospital, ER visits, and surgeries than those in clinical rehab settings.
2. Factors influencing Disparities in Cardiac and Metabolic Risk include: (1) genetic predisposition, education, access to care, cultural beliefs and socioeconomic status, (2) higher prevalence of CVD in African Americans, and (3) higher prevalence of Diabetes in Hispanics and Pacific Islanders
3. There are limited resources pertaining to SCI care for clinicians and those with SCI, especially in rural areas and less developed countries. In moving forward, there needs to be more clinical/consumer tools (e.g. Canadian Best Practice Guidelines for the Prevention and Management of PU in people with SCI), implementation, standardization of best practices, and "train the trainer" approaches to SCI care education.

Video Presentation

Please click on the following link to see an archived video of the presentation:
Conference Assessment

In an effort to assess the overall pre-course and presentations, MUSC developed an evaluation for attendees. The evaluations were disseminated before the pre-course, and attendees were asked to return completed evaluations at the conclusion of the pre-course. Attendees were asked to use a numeric rating scale of 1-5 where 1 = strongly disagree and 5 = strongly agree to rate the overall conference and presentations¹.

A total of 26 evaluations were collected and used to perform analysis. The evaluations were entered into SPSS (Statistical Product and Service Solutions) to provide statistical analysis of demographics, overall conference, and presentations.

Demographics

The evaluation included several demographic questions to identify the types of professionals in attendance and where they were from. Each participant was asked to provide their profession, city and state (locale), and how they learned about the pre-course.

Profession

Many participants listed their profession as physical medicine and research (PM&R). Those in physical therapy and occupational therapy were also several of who attended the pre-course. Seven, or approximately 27%, of attendees listed their profession as “Other” and specified their profession; those were described as nurse practitioners, psychologists, and a pulmonary neurologist. One evaluation did not list a profession.

¹ The following numeric rating scale was used to evaluate the overall conference and speakers’ presentations: 1=strongly disagree; 2=disagree; 3=neither agree nor disagree; 4=agree; 5=strongly agree.
Locale

Comparable to the various professionals in attendance, the diverse locales represented were a testament to the demand and need for rehabilitation research throughout the country. As anticipated, professionals from all over the United States attended the pre-course—from Seattle, Washington to Boston, Massachusetts. Below is an illustration of where attendees traveled from to attend the conference in Chicago, IL which is marked with a red star.

Learned about pre-course

We asked attendees how they learned about the conference to see which marketing tool was the most effective. A significant number (approximately 44%) responded they learned about the pre-course from a website. When asked to specify the name of the website, nearly 31% stated the ASIA website. Twenty-seven percent (27%) learned about it from a colleague. Thus, the more successful recruitment medium was the ASIA website which had detailed information about the pre-course, including speakers’ names, conference agenda, and program descriptions.

Overall Conference

There was compelling evidence the conference achieved its intended goal—to effectively educate medical professionals and SCI stakeholders about secondary health conditions impacting the SCI community. Aforementioned, attendees were asked to use a numeric rating scale of 1-5 where 1 = strongly disagree and 5 = strongly agree to rate the overall conference.

Attendees were asked to rate the overall conference using the following questions and/or statements:

- What is your overall rating of the conference?
- The program achieved its stated objectives.
- The content was relevant to my educational needs.
- The time allotted to each session was appropriate.
- There was adequate time for discussion.

2 The following numeric rating scale was used to evaluate the overall conference and speakers’ presentations: 1=strongly disagree; 2=disagree; 3=neither agree nor disagree; 4=agree; 5=strongly agree.
I learned something new/helpful/useful.

Over half of the respondents, approximately 70%, marked “strongly agree” or “agree” when asked if they learned something new. Similarly, 70% of respondents stated that the conference achieved its stated objectives and marked “strongly agree” or “agree.” Below is a breakdown of the general overall impression of the conference.

![Overall Conference Graph]

Presentations

A complete agenda of presentations is located in the appendix of this report. There was ample, constructive feedback from attendees regarding presentations. Attendees were asked to using the same 1-5 rating scale to evaluate presentations which were based on the following criteria3:

- Useful content
- Effective presentation
- Organized presentation
- Questions addressed
- Audio/visual quality

Morning Session

The morning session included keynote speakers, the plenary speaker, and an overview of both MUSC and NRH’s RRTC grants. Speakers are listed below.

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3 The following numeric rating scale was used to evaluate the overall conference and speakers’ presentations: 1=strongly disagree; 2=disagree; 3=neither agree nor disagree; 4=agree; 5=strongly agree.
Keynote Speakers:

NRH: Ed Eckenhoff
MUSC: James Krause, PhD; Glen White, PhD; David Gray, PhD

Plenary Speaker: Jim Rimmer, PhD

RRTC Overviews:

NRH: Inger Ljungberg, MPH and Manon Schladen, MS
MUSC: Lee Saunders, PhD

MUSC Session 1: Risk and Prevention of Secondary Conditions after Adult & Pediatric SCI

Moderator: Larry Vogel, MD

Panelists: Debbie Backus, PhD, PT; James Krause, PhD; Larry Vogel, MD
MUSC Session 2: Depression, Measurement, Participation, and Subjective Well Being (SWB)

Moderator: David Gray, PhD

Panelists: Allen Heinneman, PhD; Chuck Bombardier, PhD; David Gray, PhD

MUSC Session 3: Secondary Conditions and Mortality

Moderator: Mike DeVivo, PhD

Panelists: Yue Cao, PhD; Eric Garshick, MD; Mike DeVivo, PhD
Additional Observations

In addition to numeric ratings, we encouraged and welcomed observations, recommendations, and concerns about the overall conference and presentations. Ratings and independent observations aid our research team in presenting future research findings to various audiences in a more effective manner. Below are a few additional commendations, concerns, and recommendations:
Commendations

- The MUSC Panel was “very interesting” and an “outstanding group.”
- “Today’s offering were excellent & well integrated.”
- All ratings of 5 “as expected”

Recommendations and Concerns

- Please partner with other facilities, including Kennedy Krieger Institute or KKI
- Introduce topic of each session to focus the audience
- Increase diversity (e.g. women and minorities)
- Limited time for Q&A with one session
- Too much info and too fast
- Too much use of pointer

Summary

The assessment provided valued insight for both MUSC and its partners. The ratings and additional feedback will benefit MUSC considerably when presenting research to various audiences in the future. The diverse professions and locales represented in the audience were evident to the need for rehabilitation research pertaining to SCI and secondary health conditions. In summary, as shown by the ratings, the overall conference and presentations achieved the intended goal of effectively educating SCI stakeholders about the prevalence of secondary health conditions and prevention and management tools.
Speaker Biographies

Keynote Speakers (listed in alphabetical order)

Ed Eckenhoff

Edward A. Eckenhoff is the Founder, and former President and Chief Executive Officer of the National Rehabilitation Hospital. He currently serves as President Emeritus of NRH. Eckenhoff received his Bachelor of Arts degree from Transylvania University in Kentucky. He completed a master’s degree in education at the University of Kentucky and subsequently a master’s degree in healthcare administration at the Washington University School of Medicine in St. Louis. Before coming to Washington, D.C., he was Vice President and Administrator at the Rehabilitation Institute of Chicago.

While in college, Eckenhoff suffered a spinal cord injury that left him paralyzed – a personal experience that fueled his desire to improve healthcare for all persons with disabilities. The accident left then 20-year-old Eckenhoff with paraplegia. Over the years, Eckenhoff’s leadership in the healthcare field has been recognized by various organizations. The American Medical Association awarded him the Citation of a Layman for Distinguished Service, the highest honor it bestows on a non-physician. He received the 1995 Meritorious Award from the American Occupational Therapy Foundation and the Brent England Exceptional Leadership Award from the American Hospital Association. In 1989, he was named “Washingtonian of the Year” by Washingtonian magazine. In 2001, Eckenhoff received the Regent’s Award from the American College of Healthcare Executives and was named “Alumnus of the Year” by Washington University School of Medicine, Hospital Administration Program. Transylvania University has bestowed an Honorary Doctorate in Humane Letters upon him along with their Distinguished Alumnus Award. In 2003, Eckenhoff received the B’nai B’rith National Healthcare Award. And in 2009, the NRH Board of Directors presented him their annual award.

David Gray

Dr. Gray is a community based rehabilitation scientist working in the Occupational Therapy program at Washington University School of Medicine in St. Louis, MO. He lectures in courses including: disability and social policy; therapeutic used of assistive technology and research project development. He has developed three measures of subjective reports of participation and environmental facilitators and barriers to participation for those with mobility, visual and hearing limitations. His research involves understanding the various factors that influence community participation by people with disabilities. He was active in developing the Participation and Environment components of the International Classification of Functioning, Disability and Health (ICF).

Jim Krause

James S. Krause, PhD, serves as Director and Principal Investigator of the Rehabilitation Research and Training Center on Secondary Conditions in Individuals with SCI at the Medical University of South Carolina (MUSC) and holds the rank of Professor and Associate Dean for Research in the College of Health Professions at MUSC. He is also the Director of the Center for Rehabilitation Research in Neurologic Conditions at MUSC and Principal Investigator for the Center on Health Outcomes Research and Capacity Building for Underserved Populations with SCI and TBI and a Disability Rehabilitation Research Project entitled Successful Employment and Quality work Life after Severe Disability due to SCI.
Dr. Krause has published extensively in the areas of employment, health and secondary conditions, health disparities, and risk for early mortality after neurologic injury. He has authored 150 articles in peer-reviewed journals. He has also been a presenter or co-presenter at over 200 presentations at national and international professional conferences. Additionally, Dr. Krause serves as Editor-in-Chief of Topics in Spinal Cord Injury Rehabilitation, the official journal of the American Spinal Injury Association.

Glenn White

Glen W. White, PhD, has been involved in the rehabilitation and independent living field for over 33 years. He currently directs the Research and Training Center on Independent Living at the University of Kansas and serves as Principal Investigator of the NIDRR-funded Research and Training Center on Community Living. Dr. White is a Professor in the Department of Applied Behavioral Science and directs the Research Group on Rehabilitation and Independent Living at the University of Kansas, where he teaches in the areas of applied behavioral science, community psychology, and disability studies.

Plenary Speaker

Jim Rimmer

James H. Rimmer, PhD, is a Professor in the School of Health Professions and the first Lakeshore Foundation Endowed Chair in Health Promotion and Rehabilitation Sciences at the University of Alabama at Birmingham. For over 30 years he has been developing and directing health promotion programs for people with disabilities aimed at reducing obesity, increasing physical activity and improving nutrition in youths, adults and seniors with disabilities. Since 1997 he has provided leadership in the development of interdisciplinary research programs in disability, physical activity and health promotion at the University of Illinois at Chicago and now at the University of Alabama at Birmingham (UAB). He currently serves as director of the UAB-Lakeshore Foundation Research Collaborative and is involved in a longitudinal study examining the health trajectories of people with disabilities. Dr. Rimmer directs two federally funded centers, the National Center on Health, Physical Activity and Disability (funded by CDC since 1999), and the Rehabilitation Engineering Research Center on Interactive Exercise Technologies and Exercise Physiology for People with Disabilities (funded by the National Institute on Disability and Rehabilitation Research since 2002).

Panel Speakers (listed in alphabetical order)

Debbie Backus

Deborah Backus, PT, PhD, is Director of Multiple Sclerosis Research at Shepherd Center in Atlanta, Georgia. Dr. Backus is an experienced physical therapist, educator, and researcher dedicated to facilitating interaction between basic scientists, clinical researchers, and clinicians interested in improving outcomes for people with multiple sclerosis (MS), as well as spinal cord injury (SCI). Dr. Backus’ research efforts focus on facilitating the translation of rehabilitation research into efficacious and cost-effective treatment interventions and programs to maximize positive outcomes in people with multiple MS and SCI.

Chuck Bombardier

Dr. Bombardier is a Professor and Head of the Division of Clinical and Neuropsychology in the Department of Rehabilitation Medicine at the University of Washington School of Medicine. He worked as the attending
psychologist on the inpatient rehabilitation unit at Harborview Medical Center in Seattle for almost 20 years. He specializes in the rehabilitation of persons with traumatic disabilities, especially spinal cord injury. He is the PI of one of the 14 NIDRR funded SCI model system centers and leads a multi-site trial of venlafaxine XR for major depression after SCI.

Yue Cao

Yue Cao, PhD, MSPH, holds the Faculty Research Associate position in the College of Health Professions at the Medical University of South Carolina (MUSC). He graduated from the joint program (PhD in Medical Sociology, and MSPH in Epidemiology) at the University of Alabama at Birmingham. Before moving to Charleston, he was a post-doctoral scholar at the National Spinal Cord Injury Statistical Center. In the past two years, he has authored or co-authored 11 publications in peer-reviewed journals. Dr. Cao’s research interests focus on health disparities, psychosocial perspectives of rehabilitation among people with traumatic spinal cord injury, and life course study.

Mike DeVivo

Michael J. DeVivo, DrPH, is a Professor in the Department of Physical Medicine and Rehabilitation at the University of Alabama at Birmingham. He has been affiliated with the National Spinal Cord Injury Statistical Center (NSCISC) since its inception in 1983, serving first as Manager of Analytic Services, then Project Co-Director, Project Director, and since July, 2005 as Director Emeritus. Dr. DeVivo has authored 133 peer-reviewed journal articles and 14 book chapters, mostly on the epidemiology and long-term outcomes of people with spinal cord injuries.

Erick Garshick

Eric Garshick, MD, MOH, is Associate Professor of Medicine at the Department of Veterans Affairs Medical Center at Harvard Medical School in Boston, and Associate Chief of the VA Boston Healthcare System Pulmonary and Critical Care Medicine Section. He is also affiliated with the Division of Network Medicine, Brigham and Women’s Hospital in Boston. He is Board Certified in Internal Medicine, Pulmonary Medicine, and Critical Care Medicine, Medical Director of the Pulmonary Function Laboratory at VA Boston, and an investigator in the Spaulding-Harvard SCI Model System Program. In addition to practicing pulmonary medicine and attending in the ICU at VA Boston, Dr. Garshick has been the principal investigator of a prospective study assessing respiratory health in chronic spinal cord injury.

Allen Heinneman

Allen W. Heinemann, PhD, completed his doctoral degree in clinical psychology at the University of Kansas with a specialty focus in rehabilitation. Since 1985, he has worked at the Rehabilitation Institute of Chicago where he directs the Center for Rehabilitation Outcomes Research, a rehabilitation-focused health services research unit. He is also a professor in the Department of Physical Medicine and Rehabilitation at the Feinberg School of Medicine, Northwestern University. His research interests focus on health services research, psychosocial aspects of rehabilitation including substance abuse, and measurement issues in rehabilitation. He serves as co-Editor-in-Chief for the Archives of Physical Medicine and Rehabilitation, and is on the editorial boards of NeuroRehabilitation, International Journal of Rehabilitation and Health, Journal of Applied Measurement, the Journal of Head Trauma Rehabilitation, and Rehabilitation Psychology.
Inger Ljungberg

Inger Ljungberg, MPH, is a Project Coordinator for the Medstar National Rehabilitation Hospital RRTC on Secondary Conditions in the Rehabilitation of Individuals with SCI. Her research interests include peer mentoring, public health multimedia, and database development related to Model Systems (traumatic) SCI, Spinal Cord Disease (SCD), and stroke.

Vanessa Noonan

Dr. Vanessa Noonan is currently is the Director of Research for the Rick Hansen Institute. The focus of her research and clinical practice has been in the area of spinal cord injury (SCI). Clinically, she has practiced as a physiotherapist in both the SCI acute and rehabilitation setting. Her research examines processes and outcomes of care following SCI rehabilitation, with the goal of moving research into practice and creating standards of care. Dr. Noonan obtained her PhD from the UBC School of Population and Public Health. Her doctoral thesis examined measures of participation in persons with SCI that are based on the International Classification of Functioning, Disability and Health (ICF) model. Dr. Noonan is currently a co-investigator on the Access to Care and Timing (ACT) project, which is examining the provision of care for persons with SCI in 12 Canadian centres, spanning 7 provinces, with the goal of identifying the attributes of ‘ideal care’ for SCI.

Lee Saunders

Dr. Lee Saunders is a Research Assistant Professor in the Department of Health Sciences and Research at the Medical University of South Carolina (MUSC). She completed her doctoral degree in epidemiology at MUSC. Her research focuses on neurologic injuries, including traumatic spinal cord injury (SCI). Specifically, she works in the areas of health outcomes, employment, and mortality after neurologic injury. She has authored and co-authored 42 publications in peer-reviewed journals. Dr. Saunders has worked extensively with both the traumatic brain injury (TBI) and SCI Surveillance System Registries in South Carolina, including being Principal Investigator (PI) on a follow-up study of persons identified through the SCI Surveillance System Registry. Dr. Saunders is currently co-director of a Rehabilitation Research and Training Center on Secondary Conditions in Individuals with SCI and co-investigator on the Center on Health Outcomes Research and Capacity Building for Underserved Populations with SCI and TBI. Within these centers she serves as PI on two studies, the first of which is a study of access to care among a population-based cohort of persons with SCI. The second study investigates chronic health outcomes among underserved populations with neurologic injury. Dr. Saunders is interested in reducing health disparities in underserved populations and has been awarded several awards, including the Developing Scholar of the Year Award through MUSC’s College of Health Professions.

Manon Schladen

Manon Schladen, MSE, is the Co-Director of Training on both consumers (Project T1) and health professionals (Project T2) for the Medstar National Rehabilitation Hospital RRTC on Secondary Conditions in the Rehabilitation of Individuals with SCI. She is also the Assistant Director of Knowledge Translation and Educational Media for National Rehabilitation Hospital SCI Research Center.

Yaga Szlachcic

Dr. Yaga Szlachcic graduated from Warsaw Medical School in Warsaw, Poland and completed postgraduate training in Poland and Montreal Heart Institute in Montreal Canada. She completed research fellowship in
Clinical Pharmacology at University of California, San Francisco. She joined the medical staff and continued her academic track and became an Associate Professor of Clinical Medicine at the Keck School of Medicine at the University of Southern California. Dr. Szlachcic served as a chief of Cardiology Division of Rancho Los Amigos National Rehabilitation Center for 8 years before becoming the Chair of Department of Medicine and Director of Spinal Cord Injury Medical Home, the position she holds today. Dr. Szlachcic’s research is in management and prevention of secondary condition in SCI, particularly in women with SCI. Dr. Szlachcic is the Co-Director of the Southern California Spinal Cord Injury Model System at Rancho Los Amigos National Rehabilitation Center.

Larry Vogel

Lawrence C. Vogel, MD, has been the Medical Director of the Shriners Hospital for Children Pediatric Spinal Cord Injury program since 1983. He received his B.A. degree with distinction from Northwestern University in 1969 and his Medical Degree from the University of Illinois in 1973. He served as a pediatric resident at Yale-New Haven Hospital and subsequently completed a fellowship in pediatric infectious diseases at Michael Reese Hospital and the University of Chicago. Dr. Vogel is a diplomate of the American Board of Pediatrics and is certified in the Subspecialty of Spinal Cord Injury Medicine. Dr. Vogel is a Professor of Pediatrics at Rush Medical College. Over the past 30 years, Dr. Vogel has dedicated his time to the care of children and adolescents with spinal cord injuries. A major interest of Dr. Vogel's is long-term follow up of children and adolescents with spinal cord injuries as well as the psychological, educational, vocational and sexual adjustment of patients with spinal cord injuries and their families.
Conclusion

In an effort to share research studies concerning Spinal Cord Injury (SCI) and secondary health conditions (SHCs), the Medical University of South Carolina (MUSC) presented “The State of Science of Prevention and Management of Secondary Health Conditions in People after Spinal Cord Injury” (Medstar National Rehabilitation Hospital co-hosted). The state of the science conference set a forum for researchers to present interim results related to the prevention and management of SHCs in the SCI community.

With 12,000 new cases of SCI occurring every year and increasing long-term effects, such as secondary health conditions (SHCs), it is imperative that researchers inform clinicians, rehabilitation specialists, and those with SCI regarding risk and preventative measures to extend the life span of those affected by SCI. Secondary health conditions include Urinary Tract Infections (UTIs), pressure ulcers, depression, respiratory issues, chronic pain, and a host of other issues as discussed in this comprehensive report.

The state of the science conference provided an opportunity for researchers to present their research on SHCs and collaborate with others to educate SCI stakeholders about the prevention and management of SHCs and reduce the prevalence of SHCs in the SCI community. The conference addressed the following areas concerning SCI: Risk and Prevention of Secondary Conditions after Adult and Pediatric SCI; Depression, Measurement, Participation, and Subjective Well-Being; Secondary Conditions and Mortality; Disparities, Surveillance, and Community. Below is a list of recommendations to assist in the prevention and management efforts related to SHCs in the SCI population.

Summary of Recommendations

1. Establish conceptualized schemes that differentiate SHCs from chronic health conditions and conduct research on those conditions with greatest impact on health, QOL, and longevity.
2. Develop, disseminate, and promote best practice prevention and screening tools better inform clinicians, rehabilitation specialists, and SCI population about risk, prevention, and management of SHCs.
3. Enhance life expectancy of SCI population by identifying risk factors for preventable causes of death and actively focusing on effective prevention techniques.
4. Expand population-based studies, which provide an all-inclusive view of disparities and diversity related minorities, limited access to care, and low income.
5. Conduct more intensive investigations of the relationship between aging factors, SHCs, and longevity, including biomarker assessment of stress-based disorders.

Properly addressing and implementing these key recommendations has the likelihood to educate the SCI population as well as clinicians, promote better screening tools for SHCs, and significantly decrease the prevalence of SHCs. The face of disability is rapidly changing and the research and recommendations set forth in this report can provide great insight into better prevention and management strategies concerning SHCs related to SCI.
References


