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REVIEW & ANALYSIS

Spinal Cord Injury and Aging

Challenges and Recommendations for Future Research

ABSTRACT

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Population aging, caused by reductions in fertility and increasing longevity, varies by country and is anticipated to continue and to reach global proportions during the 21st century. Although the effects of population aging have been well documented for decades, the impact of aging on people with spinal cord injury (SCI) has not received similar attention. It is reasonable to expect that population aging features such as the increasing mean age of the population, share of the population in the oldest age groups, and life expectancy would be reflected in SCI population demographics. Although the mean age and share of the SCI population older than 65 yrs are increasing, data from the National Spinal Cord Injury Statistical Center suggest that life expectancy increases in the SCI population have not kept the same pace as those without SCI in the last 15 yrs. The reasons for this disparity are likely multifactorial and include the changing demographics of the SCI population with more older people being injured; susceptibility of people with SCI to numerous medical conditions that impart a health hazard; risky behaviors leading to a disproportionate percentage of deaths as a result of preventable causes, including septicemia; changes in the delivery of health services during the first year after injury when the greatest resources are available; and other unknown factors. The purposes of this paper are (1) to define and differentiate general population aging and aging in people with SCI, (2) to briefly present the state of the science on health conditions in those aging with SCI, and finally, (3) to present recommendations for future research in the area of aging with SCI.

Key Words: Spinal Cord Injury, Aging, Health Conditions

Industrialized countries are seeing an increase in the average age of their populations because of decreasing fertility and increasing longevity. In the past century, life expectancy has nearly doubled and the proportion of the population older than 65 yrs has increased 10-fold. Today, there are approximately 35 million Americans 65 yrs and older, and this number is expected to double in the next 25 yrs.[1] This trend is anticipated to continue and reach global proportions. Key features of population aging include an increase in the mean age of the population, a larger share of the population in the oldest age groups, and an increase in life expectancy. The tracking of these features in the spinal cord injury (SCI) population provides preliminary insight into aging trends after SCI.

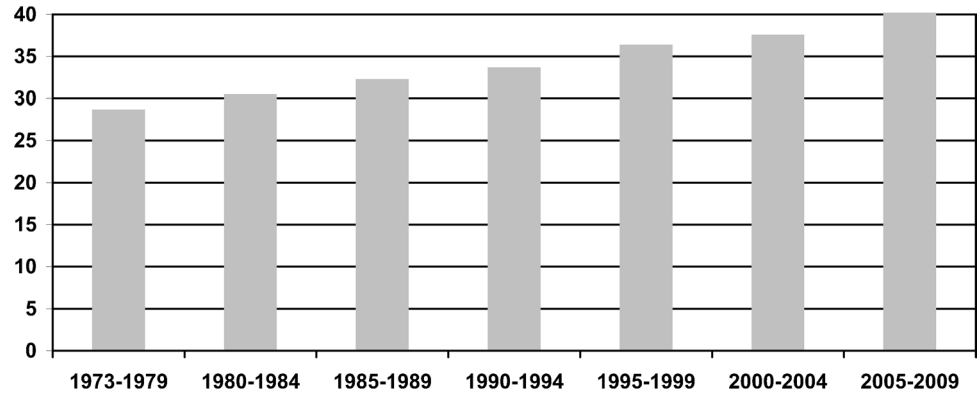

FIGURE 1 *Trends in distribution of age at injury.*

The National Spinal Cord Injury Statistical Center's (NSCISC) longitudinal database, supported through the National Institute of Disability and Rehabilitation Research's (NIDRR) SCI Model Systems (SCIMS), provides a source of comparison with the general population (The NSCISC database captures data from an estimated 13% of the US population with traumatic SCI. Other databases, such as those derived from the Veterans Administration system, are available and may comprise a different sector of the SCI population with different aging issues).

Effects of General Population Aging on Subpopulation with Spinal Cord Injury

As the mean age of the US population has increased in the last century, we have likewise observed an increase in the mean age of the SCI population. According to the NSCISC, the mean age at time of injury in the United States has increased from 28.7 yrs in the 1970s (1973–1979) to 38.0 yrs in 2000[2] and was approximately 40 yrs during the 2005–2009[2,3] period (Fig. 1). Although data from multiple sources and other industrialized countries confirm the increase in mean age for people with new SCI,[2,4–6] changes in referral patterns and in the SCIMS centers contributing to the longitudinal database along with changes in injury prevention strategies may also affect this trend.[3,7]

This increasing age at injury potentially results from older individuals being injured and/or increasing survivorship and longevity among those with early onset SCI. In a recent review of the literature, the emergence of a bimodal age distribution[5,6,8–12] of SCI has been observed in some countries, with a peak in age of onset among young adults caused by motor vehicle crashes, violence, and sports and another peak in onset among people 65 yrs and older primarily caused by falls.[13] It appears that, with the aging of the population, a greater number of people are surviving and active at older ages and are therefore contributing to the changing age distribution of people with new SCI. The implications of an emerging bimodal distribution of SCI involve addressing the characteristics and needs of very different populations in clinical care and research: those with younger onset SCI who advance to old age with SCI (or who are aging with SCI) and those who have aged (including frail older persons) and incur SCI. Figure 1 shows the mean age at injury over time.

Although the mean age at injury increased steadily between 1973–1979 and 2005–2009 and there is a trend toward a bimodal distribution of new injuries by age, SCI still occurs predominantly among young men. According to 2009 data from the NSCISC,[3] the most common age at SCI was 19 yrs, with one-fourth of all injuries occurring to persons between the ages of 17 and 23 yrs (25.3%) and half of all injuries occurring between the ages of 16 and 30 yrs (50.9%). Sixty percent of the population surviving with SCI is currently younger than 45 yrs.[2] Hence, although population aging has affected the demographic distribution of SCI such that we may observe the emergence of a bimodal distribution, most people still incur their injuries as young adults and before experiencing significant aging. The result is that most people with new SCI have the potential to live most of their lives with SCI and have the potential for significant aging with SCI.

The second feature of population aging is the increasing share of the US population who is 65 yrs and older. US Census Bureau data reflect this change, reporting that the population 65 yrs and older has increased 10-fold in the past century and by 12.0% from 1990 to 2000. Furthermore, during the 1990s, the highest rate of growth (38%) of the older population occurred among the oldest (those 85 yrs and older), with the number of those from 75 to 84 yrs increasing by 23%, and the number of those from 65 to 74 yrs increasing by less than 2%.[14] Similarly, the US SCI population also has seen a steadily increasing share among older age groups with the proportion of those 65 yrs or older

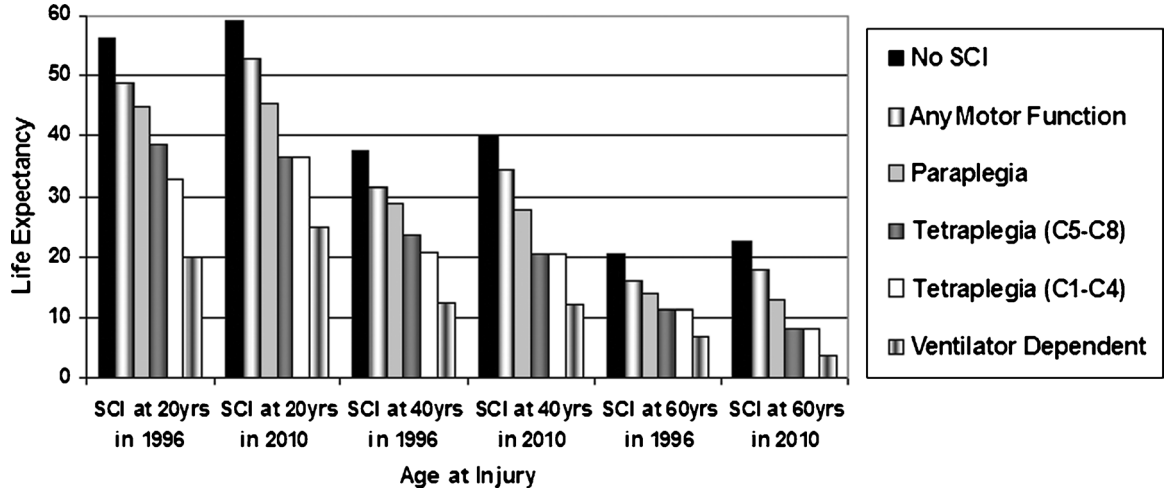

FIGURE 2 *Trends in life expectancy for those surviving the first year after SCI. SCI indicates spinal cord injury.*

increasing from 3.1% in 1973–1979 to 10.1% in 2005–2010.[14] However, once again, this comparison may be affected by population variability in participating SCIMS over the 27-yr span because the data are derived from a longitudinal database that was developed in the early 1970s when it is anticipated that relatively few older adults would have been enrolled in the early years of the database.

Increasing life expectancy is a third feature of population aging.[15] This feature is reflected in US population dynamics with longevity nearly doubling during the 20th century.[1,16] Data on life expectancy in the SCI population derived from the NSCISC database are shown in Figure 2, which compares life expectancies among people with SCI by (1) injury severity (motor incomplete, paraplegia, low tetraplegia, high tetraplegia, or ventilator-dependent), (2) age at injury (20, 40, or 60 yrs old), and (3) year of injury (1996 *vs.* 2010), as well as with the life expectancy of the general US population.

As seen in Figure 2, life expectancy for the population with SCI has been and continues to be lower than that observed for the US population without SCI. However, within the SCI population, life expectancy varies significantly according to the level and severity of SCI, as well as the prevalence of risky behaviors and socioeconomic status.[3] In general, those with motor incomplete injuries have seen absolute increases in life expectancy since 1996, although less than that observed in the US general population over the same time period. However, even these modest improvements were not observed in most of the other groups with motor complete paraplegia or tetraplegia.

Furthermore, despite promising advances in life expectancy for those with functional motor preservation (motor incomplete SCI), life expectancy estimates still do not match those observed in the general population and are, in fact, reduced on the order of 9%–78%, depending on the severity of injury and the age at onset.[3] The data also exclude ventilator-dependent individuals, which would be expected to reduce the survival estimates even further. Specifically, those with less severe injuries tend to have life expectancies that more closely approximate, yet still do not quite match, those of the general population. Disturbing, however, is that, within severity of injury groups, life expectancy has an increasing proportional decline by age. For example, an individual with C5–C8 tetraplegia who is injured at age 20 yrs and survives the first year has a 31% reduction in the remaining life expectancy (from 58.8 yrs to 40.3 yrs), whereas a similar patient injured at age 65 yrs would experience a 59% reduction (from 18.7 to 7.6 yrs), and a similar patient injured at age 75 yrs would have a 69% reduction (from 11.9 to 3.7 yrs). Hence, life expectancies are significantly reduced for those with SCI, and there is an interaction between the severity of injury and age at injury that affects these estimates (Fig. 3).

The comparison of temporal trends in life expectancy is another method to track how successfully people with SCI are aging. Comparing 1996 with 2010, life expectancy in the US general population increased 4.1% for 20-yr-olds (from 56.3 to 58.6 yrs), 5.6% for 40-yr-olds (from 37.6 to 39.7 yrs), and 9.3% for 60-yr-olds (from 20.5 to 22.4 yrs),[17] whereas comparable data from the NSCISC of persons surviving the first year of SCI between 1996 and 2010 yielded mixed results. Temporal improvements in life expectancy between 1996 and 2010 for the least severely injured are promising in that they exceed those observed for the general population. For example, the increase in life expectancy for a 20-yr-old with functionally motor incomplete SCI is 7.5%, from a mean of 49 to 52.7 yrs; 40-yr-olds have seen a 7.9% increase,

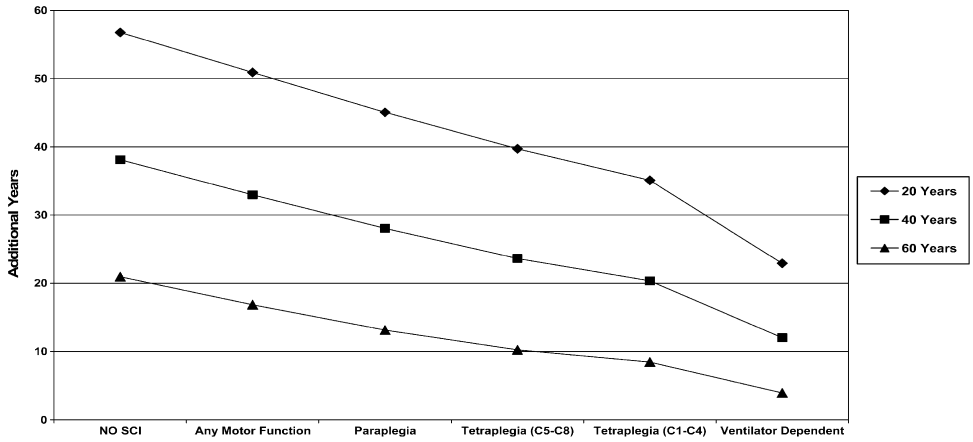

FIGURE 3 *Summary of effects of age at injury and severity of injury on life expectancy. SCI indicates spinal cord injury.*

from a mean of 31.7 to 34.2 yrs, and the increase was 11.9% for 60-yr-olds, from a mean of 15.9 to 17.8 yrs. Alarming, however, are the life expectancy reductions occurring during this 14-yr period for the following groups:

- people with paraplegia injured at ages 40 and 60 yrs,
- people with low tetraplegia injured at age 60 yrs,
- people with high tetraplegia injured at ages 40 and 60 yrs, and
- ventilator-dependent individuals injured at ages 40 and 60 yrs.

Figure 4 shows the gaps in life expectancy for the SCI and non-SCI populations by age and severity of injury.

In summary, the mean age at injury and mean age of the SCI population have increased, likely a result of overall population aging. However, SCI has clear detrimental effects on longevity, with life expectancy increasing for the least severely injured and for those injured at younger ages. In 2006, Strauss et al.[18] noted that most improvements in mortality over the past 30 yrs of data collection of the SCIMS had been realized in the first 2 yrs after injury (40%), whereas the improvement in mortality in 2 yrs after injury had been small and not statistically significant. As stated by DeVivo and Chen,[19]

The percentage of elderly persons in the prevalent [SCI] population will not increase meaningfully until significant progress is made in reducing the high annual mortality rates currently observed among older persons with SCI. Those who reach older ages will typically have incomplete and/or lower level injuries and will have relatively high degrees of physical independence and overall good health and community participation.

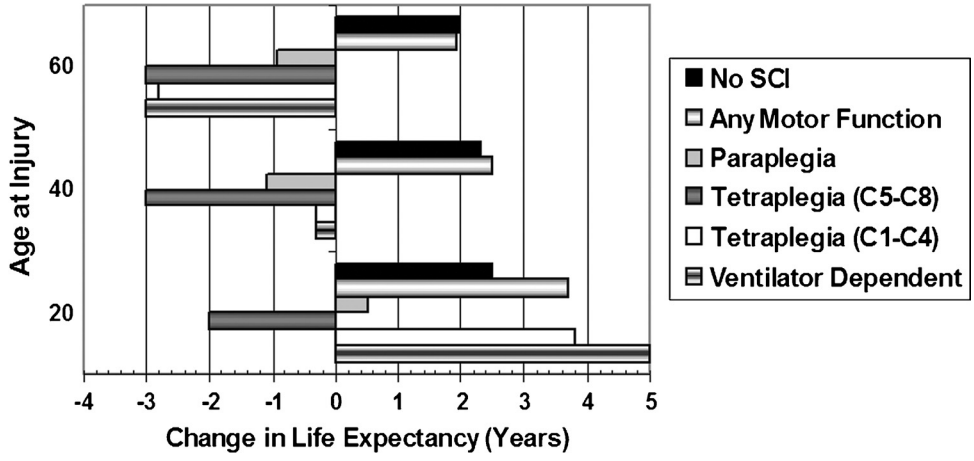

FIGURE 4 *Life expectancy gaps of the population with SCI by severity of injury compared with the US general population during the time period from 1996 to 2010. SCI indicates spinal cord injury.*

In a recent workshop on aging with SCI,[4] during which consumers with SCI discussed pertinent aging issues alongside medical experts, it was similarly concluded that "…although there have no doubt been improvements in long-term rehabilitative care, their effect in enhancing the life span of persons with SCI appears to have been overstated." In summary, although medical and rehabilitative care have significantly improved longevity for people with SCI compared with that observed 50–70 yrs ago,[20–22] recent data indicate a relative plateauing of life expectancies for many people with SCI. Therefore, significant disparities exist in life expectancy within and between those with SCI and the general population, and this gap appears to be widening.

Aging Trajectory After SCI: An Argument for Accelerated Aging

The previously mentioned data suggest that SCI alters the trajectory of aging such that both the rate and characteristics of aging are affected. The term "accelerated aging" has been used to describe this altered aging trajectory in people with physical disability in the context of health conditions occurring earlier and/or more frequently than would otherwise be observed, leading to a narrow margin of health.[23] This accelerated aging for people with SCI are likely caused, in large part, by a cadre of physiologic changes associated with the neurologic injury and impairment that lead to immediate and long-term effects on body systems.[20,24] These body system–based phenomena have been confirmed in several studies describing health complications associated with aging and SCI,[25–27] and there have been several reviews summarizing the impact of aging with SCI by organ system.[28–30] Individuals with SCI report more health problems, and they do so at a younger age, than do nondisabled individuals.[31,32] The consequences of this altered aging trajectory are cumulative and far-reaching and include impacts on physical function, psychosocial function, and quality-of-life.

Factors Influencing Altered Aging Trajectory in People with SCI

A comprehensive review of the health conditions that are impacted by SCI is beyond the scope of this article. However, the following briefly demonstrates the impact of the SCI on body systems as they age with SCI.

- Lack of standing, ambulation, muscle activity, and weight bearing all contribute to rapid and marked changes in body composition such that muscle mass declines and adipose increases. Most recent evidence suggests that up to three-fourths of those with chronic SCI are overweight or obese.[33] Body mass index only identifies approximately only one-third to one-half of persons with SCI as overweight or obese, leading to the conclusion that BMI is not accurate in people with SCI.[34–37] An adjusted BMI tool for SCI has been suggested,[38] although further refinement is needed. The increased risk for obesity in persons with SCI is present despite normal to slightly lower caloric intake than is observed in the general population,[37] emphasizing the need for physical activity and prudent diet as preventive countermeasures.
- This same inactivity and lack of muscle activity contributes to profound and nearly universal reductions in bone mineral density in individuals with SCI,[39,40] putting people with SCI at a higher risk of fractures and accompanying reductions in function and independence. Diagnosis of osteoporosis requires dual x-ray absorptiometry; however, the optimal screening method and frequency for people with SCI have not been resolved.
- With a propensity toward overweight and obesity,[37] adipose tends to be preferentially located around the abdomen among people with SCI. Recent evidence implicates abdominal adiposity as an accurate predictor of cardiovascular disease.[41,42] Abdominal or visceral obesity is now used as a marker of cardiometabolic syndrome and correlates with an increase in fasting triglycerides,[41] increased inflammation—specifically C-reactive protein,[43,44] depressed high-density lipoprotein cholesterol, and elevated low-density lipoprotein cholesterol in persons with SCI.[45] Fat should be considered an endocrine organ, as it is known to be associated with the production of inflammatory mediators and puts people with SCI at risk of health conditions associated with being overweight and obese.
- People with SCI have recently been shown to be at a greater risk of systemic inflammation (likely because of the heightened fat stores, pressure ulcers, and frequent infections).[46,47] Because atherosclerosis has been identified as having an inflammatory basis, this may put people with SCI at an even greater risk of cardiovascular and, possibly, other chronic health conditions. A recent analysis of causes of mortality by DeVivo and Chen[19] indicates that deaths caused by "ischemic heart disease" and "other heart disease" were the third

and fourth leading causes of death in people with SCI, being responsible (either as a primary or a secondary cause of death) for 12.8% and 14.6% of deaths, respectively. When compared with the US general population, standardized mortality ratios tended to be highest for people with SCI who were younger. It is recommended to use US general population guidelines in the screening of cardiometabolic risk after SCI.

- There is greater cumulative "wear and tear" on the musculoskeletal system in individuals using manual wheelchairs, caused by upper limb overuse and leading to a propensity to develop rotator cuff and biceps tendinitis, as well as nerve impingement and other upper limb syndromes.[48–50] The prevention, assessment, and management of these conditions is summarized in the Paralyzed Veterans of America Consortium Guideline "Preservation of Upper Limb Function Following Spinal Cord Injury" and includes a regular assessment of function, ergonomics, equipment and pain, and prescription of lightweight customizable wheelchairs.[48]
- Skin breakdown and pressure ulcers continue to be disturbingly prevalent in people with SCI. During acute medical and rehabilitation hospitalization, 27%–40% of individuals with SCI will experience a pressure ulcer.[51–53] Data from the NSCISC's 1998 annual report indicated that another 15% had a pressure ulcer during their first year after rehabilitation[54] and that, by year 20, 29% had had at least one pressure ulcer.[55,56] Prevention includes regular monitoring for skin breakdown and pressure reliefs, although the frequency with which pressure reliefs are recommended varies.
- Repeated infections (particularly of the bladder) are common and related to the need for urinary catheterization.[57,58] Striking is DeVivo and Chen's[19] recent report on the magnitude of the risk of septicemia as the most significant cause of death compared with that expected compared with the general population (standardized mortality ratio, 35.5).
- Dysmotility of the bowel occurs immediately after injury and can continue throughout the life span.[59] Especially with aging, poor bowel management may be associated with reduced quality or satisfaction with life caused by lengthy bowel emptying programs and/or incontinence.[60]
- Pulmonary insufficiency is directly related to the level of SCI. People with tetraplegia and high paraplegia tend to have ineffective cough, leading to mucous retention, atelectasis, and infection risk, necessitating increased surveillance for pulmonary decline and infection prevention.[61] DeVivo and Chen[19] have recently shown that pulmonary emboli (standardized mortality ratio, 24.4) and pneumonia and influenza (standardized mortality ratio, 16.6) are the second and third leading causes of death, respectively. Obstructive sleep apnea and sleep-disordered breathing are also prevalent[62] but may be underrecognized. Important preventive practices include regular vaccinations for people with SCI who have pulmonary insufficiency and a high index of suspicion for sleep apnea.
- Further neurologic impairment and deterioration can occur over time (caused by either syringomyelia or other etiologies).[63] Surveillance with periodic neurologic assessment allows early detection.
- Depression rates for persons with SCI are higher than for the general population but they vary with age and time since injury. Based on the Patient Health Questionnaire to diagnose depressive symptoms, Bombardier et al.[64] found that individuals between the ages of 25 and 49 yrs reported the highest rates of probable major depression (15% *vs.* 8.7% in younger adults and 6.5% in older adults). Among individuals who have had SCI for at least 10 yrs, the rates of depression range from 17%–33%, being significantly higher than that of the general population of the same age cohort.[65] However, these rates are significantly lower (reaching a low of 8.7%) in those 21 yrs or more after injury. Therefore, for older individuals with SCI, the risk of depression is highest during the first two decades after injury. In general, the risk of depression in the older population increases when other illnesses are present, and the ability to function becomes limited. For SCI survivors 65 yrs and older, the consequences of becoming depressed are potentially greater than they are for the nondisabled for the reasons stated previously, such as the loss of function, loss of social roles, increased dependency on caregivers, and increased risk of co-morbid conditions such as diabetes.[66]

The prevention of, surveillance for, and management of these and other health conditions in people with SCI are challenged further by the fragmented nature of the US healthcare system. Primary care physicians may not have familiarity

or comfort in the needs of people with SCI. Medical office accessibility may also hinder access to care. Physiatrists more often have knowledge of the needs of people with SCI but may lack primary care expertise. Consultations with other medical specialists may be common because of the propensity to develop health conditions. Lack of a coordinated approach to the complex care required for people aging with SCI likely contributes to the continued development of the medical and psychosocial health conditions that negatively affect health, function, quality-of-life, and participation.

Impact of Accelerated Aging on Function, Quality-of-Life, and Participation

It is critical to note that many of the health conditions that are affected by SCI may not manifest typical signs and symptoms of those conditions. The propensity for "silent" disease increases the likelihood of delayed diagnosis, thereby increasing the risk of more advanced disease and subsequent functional decline, reduced participation, loss of employment, and reduced quality-of-life. Consistent with these observations, there is now an increasing body of research documenting that, with increasing age after SCI, there are declines in important health dimensions including health status and functional independence, and a corresponding increase in medical systems utilization.[66–70]

The impact of these health-related changes on quality-of-life in persons living with SCI is interactive and complex, yielding inconclusive findings. For example, it is well established in nondisabled persons that increasing age is associated with increases in subjective well-being.[71] It is also clear from several studies that most individuals with SCI report levels of quality-of-life that are not significantly different than those in nondisabled persons.[72] However, approximately 20% of individuals with SCI report declines in subjective well-being with aging.[73] In these individuals, coexistent depressed mood can be associated with a variety of negative outcomes including poorer perceived health and community integration,[74] factors associated with life satisfaction in persons with SCI.[70] In a study of British individuals aging with SCI, it was found that, although increasing depressive symptoms and reported health problems were noted with increasing duration of injury, stress levels decreased, life satisfaction improved, and the reported quality-of-life remained stable and relatively good.[75] Other research has indicated that, whereas age at injury has been associated with lower subjective well-being in a number of life areas, increasing years lived since injury has been associated with more favorable subjective evaluations of life.[66]

Lastly, nonmedical, environmental, and lifestyle factors interact with these health conditions to impact participation, aging, and longevity. Lifestyle factors include high-risk behaviors such as alcohol misuse, smoking, and overuse of psychotropic medications, all of which have been linked to an elevated risk of mortality after SCI.[76] These lifestyle factors could explain some of the variance observed in longevity in people with SCI. Furthermore, the SCI population as a whole also lags behind the general population in terms of employment and income, whereas, at the same time, low income is a primary predictor of early mortality in both the general population[77,78] and among those with SCI.[18,79,80]

Interactions Relevant to Aging with Spinal Cord Injury

The complexities of aging and SCI are in part caused by the interaction and overlap between various age-related factors.[81,82] There are at least four key age-related factors that are salient to SCI outcomes (1) current chronologic age, (2) age at injury, (3) duration of injury, and (4) age cohort (that is, the "generation effect," or the social, economic, and medical context around an individual's SCI). Three of these (current age, age at injury, and duration of injury) can easily be quantified numerically or statistically, whereas the fourth (age cohort) is more complex, reflecting multiple environmental parameters.

These age-related variables can have both independent effects on an outcome or health condition and interact with each other to affect an outcome. Consider chronologic age as an example: because organ systems function less well as people age, the older a person is, the greater the risk for significant health conditions such as diabetes, heart disease, and osteoporosis. These vulnerabilities are likely reflected in the observed greater rate of organ system decline in individuals aging with SCI, which contribute to poorer health and greater disability. Age at injury is important when one considers the fact that younger adults are generally healthier and have greater physiologic "reserve capacity" than do older individuals. As a result, with the same severity of SCI, older individuals would be expected to require a more lengthy recovery and rehabilitation after injury and may not be able to achieve as high a level of functioning as would their

younger peers. As has been noted previously, the duration of injury can have both positive effects (e.g., experience in coping with one's SCI and greater self-efficacy) and negative effects (such as a longer period of activity restriction and relative inactivity), contributing to negative health outcomes and greater rates of physical decline.[83]

Finally, although age "cohort" is a very difficult phenomenon to quantify, it is important to consider that the social, economic, and medical landscapes of SCI have changed dramatically over the past century. These changes range from significant medical advances in treating both SCI and associated medical problems (leading to increases in longevity from the mid-1900s to today, although note the decrease in longevity found over the past one to two decades) to sociopolitical factors such as a general increase in disability awareness, culminating in the passing of the Americans with Disabilities Act. Time-lagged designs are beneficial for evaluating the overall effects of broader environmental changes on outcomes but have rarely been used with SCI.[84] The social and medical experiences of being a person with SCI were considerably different in 1955 than at present, and this is important to keep in mind when working with individuals aging with SCI and other physical disabilities.

Aging with Spinal Cord Injury: Areas of Need for New Knowledge

Despite the growing evidence base in aging with SCI, many unanswered questions remain. Some of these questions are as follows:

1. What types of age-related health conditions and problems are most likely to emerge at an earlier age in individuals aging with SCI, relative to individuals who do not have an SCI or other disabilities?
   a. Are there differential rates of physical and cognitive decline for people with SCI compared with the general population that can be clearly linked to the presence of SCI itself?
   b. What types of health conditions that already exist in an individual as a result of aging are exacerbated by the presence of an SCI or a new SCI?
   c. Which of these health conditions play a role in limiting participation, community reintegration, life expectancy, and overall perceived life quality, and what interventions can be used to promote better outcomes in each area?
2. What is the time course or trajectory of these health conditions associated with aging with SCI?
   a. When do they emerge, and how does the trajectory vary by age of onset of SCI, etiology (traumatic *vs.* nontraumatic), level of injury, and other factors both related and unrelated to the injury such as the social and physical environment and lifestyle practices?
   b. Which of these health conditions have the greatest negative impact on psychologic functioning, physical functioning, and participation (including employment)?
3. How is aging with SCI differentiated from incurring an SCI during old age?
4. What are the most effective strategies for helping individuals with SCI prevent or delay the onset of health conditions associated with aging?
5. What role might health promotion and wellness interventions play in potentially mitigating the effects of aging on health and function in people with SCI?
6. What are the most effective strategies for decreasing the negative impact of aging-related health conditions that emerge on physical functioning, psychologic functioning, and participation, especially because the number of persons with SCI from underserved minorities continues to grow?
7. What type of health care delivery model for people with SCI would be effective in allowing access primary and specialty care, to reduce health conditions and cost of medical care, and to increase quality-of-life and longevity?

Recommendations to Advance the Field of Aging with Spinal Cord Injury

Based on this brief review of the evidence regarding aging with SCI, the SCIMS Aging Special Interest Group makes the following recommendations to advance research by focusing on the following:

1. Adequately powered longitudinal, cross-sequential, time-sequential, or other study designs to advance knowledge of the changing patterns of health conditions in samples of people aging with SCI.
2. Comparative databases related to aging with SCI and normative or typical human aging. The current lack of knowledge limits our ability to make a positive impact on the lives of people aging with SCI because it precludes the design and planning of effective treatments and

preventive approaches to delay the onset of age-related disability among individuals with SCI. Furthermore, without the evidence base to make recommendations that can enhance the lives of individuals aging with SCI, we cannot inform heathcare providers in the community of best practices and interventions.

3. New standardized measures to improve the assessment of changes in health and function and participation across the life span.
4. New knowledge regarding the full array of physiologic changes that occur with aging, with specific attention to physiologic function, functional independence, and quality-of-life. Examples of areas of research include
   a. causes of septicemia, which is a major contributor to mortality in this population;
   b. cardiovascular health and related problems including metabolic issues;
   c. changes in bone density that occur after SCI onset and the relationship of such changes to sex and other demographics;
   d. the constellation of pain problems (neuropathic, musculoskeletal, and visceral) and trends in pain over time, both as a function of age and duration of injury;
   e. fatigue and its effects on function and quality-of-life;
   f. cognitive decline and dementia, either as a function of increasing age, medication use, or other causes; and
   g. musculoskeletal decline and overuse because these have significant impacts on functional independence.
5. New knowledge regarding the effects of health and wellness interventions on those aging with SCI.
6. New knowledge about the long-term psychosocial consequences of aging with SCI and of being a family member or caregiver for a loved one aging with SCI. In addition, there is a need to examine caregivers who are aging and the effects on assisting the individual with SCI to maximize independence and functioning in the face of an increasing risk of chronic or acute health conditions.
7. Strengthening interdisciplinary collaborations among researchers and medical practitioners from geriatrics and other healthcare fields and specialties.
8. New knowledge regarding the benefits and use of interventions such as assistive technologies, robotics, wellness strategies, exercise, and medications for those aging with SCI.
9. New knowledge on healthcare delivery systems that would improve care and reduce cost.

Need for Additional Research Funding and Collaborations for Aging and Disability

To address these recommendations, it is essential to first assess the consistency and sufficiency of funding for research in the area of research and disability. Although research in the area of aging and SCI has been supported by several federal agencies, most notably NIDRR, these investments have lacked the magnitude of resources, scientific focus, and continued support necessary to result in both meaningful impacts on the field of rehabilitation and benefits to the target population. In fact, there are considerable limitations in the resources to conduct quality, longitudinal studies with large samples that explore aging with SCI.

Unfortunately, research into SCI and aging has not achieved a natural fit in any of the federal funding agencies and has not been a programmatic focus for any single agency. Several factors have likely contributed to this failure: (1) Most people with SCI incur their injury at a relatively young age and much earlier than the 65-yr cutoff used by federal agencies to define an older population; hence, a natural fit with federal research programs at the time of injury is currently not in existence. (2) As summarized previously, people with SCI have a unique aging experience with very diverse and complex needs. (3) There are differences in terminology, for example, with the term "secondary conditions" being used routinely in disability and rehabilitation research and other terms such as "chronic health conditions" or "multiple chronic conditions" being used more in aging and public health research. (4) With the aging of the population, the spinal cord disease population is growing and expected to grow further, leading to differences of opinion as to whether it is in the best interests of people with SCI to limit research solely to those with traumatic injuries *vs.* being inclusive of other forms of "nontraumatic" conditions.

The net result of the previously mentioned factors is that aging-with-SCI research has not "found a home" either within an individual funding agency or through an interagency collaboration. Although some agencies (National Institutes of Health, National Institute on Aging, Centers for Disease Control and Prevention, and the Agency for Healthcare Research and Quality) address aging in the general population, whereas others (NIDRR, National Center for Medical Rehabilitation Research in the National Institute of Child Health & Human

Development, and the US Department of Veterans Affairs) address disability issues, the linkages and collaborations necessary to support aging with SCI research are missing. Because of these challenges and a paucity of longitudinal investigations conducted within the United States, there remain significant knowledge gaps in this area, which subsequently limits our ability to effectively improve the aging experience of those with SCI, potentially widening the aging disparity gap.

Specific Recommendations for Spinal Cord Injury Model Systems Program

Given the notable disparities in aging and knowledge gaps regarding aging with SCI, the following recommendations are offered for consideration by the SCI Model Systems. Clearly, however, such recommendations could be implemented by others with an interest in furthering the field of knowledge regarding aging with SCI.

1. Funding and continued support for aging with SCI-specific research protocols within the SCIMS research portfolio and other NIDRR grant mechanisms.

With respect to the first recommendation, support of aging-specific research could be in the form of centers, individual studies, and/or modular studies focusing on the unique needs of those aging with SCI. An important consideration is that SCI alters the aging trajectory at the time of injury; hence, aging research need not be limited to the "aged."

2. Adding critical aging variables to the NSCISC database.

A second recommendation is for the NSCISC database to include additional variables to better capture basic knowledge regarding aging with SCI either in the form of core variables and/or specific variables obtained through a module or collaborative study. Variables to consider include those that are body system–specific (bowel, bladder, body composition, pain, fatigue, mental status, etc.), social, and/or related to participation.

3. Support for funding of larger collaborative aging-with-SCI studies across agencies.

A third recommendation would be to foster relationships among the various funding agencies that focus on aging and/or rehabilitation research (i.e., National Institute on Aging, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, NIDRR, US Department of Veterans Affairs, etc.) and to encourage carving out specific avenues for aging research applied to SCI. This type of approach could be undertaken in the areas of multiple sclerosis, neuromuscular disease, traumatic brain injury, burn, and other conditions as well.

4. Encouragement of collaborative and programmatic studies on aging with SCI across NIDRR grantees (e.g., Rehabilitation Research and Training Centers, Disability and Business Technical Assistance Centers, Rehabilitation Engineering Research Centers, etc.).

Approaches for facilitating a plan of action on the previously mentioned issues include:

1. Development of evidence-based treatment protocols and recommendations for health, function, and wellness promotion specific to people aging with SCI;
2. Targeted outreach to and education of persons with SCI in evidence-based recommendations for health, function, and wellness promotion so that these can be easily and readily used in their daily practice;
3. Targeted education of and outreach to healthcare professionals caring for people with SCI in a variety of settings to provide evidence-based recommendations for health, function, and wellness promotion;
4. Targeted education of funding agencies through liaising with the Centers for Disease Control and Prevention, primary care programs at universities with medical schools, the National Institute on Aging, National Center for Medical Rehabilitation Research, US Department of Veterans Affairs, Agency for Healthcare Research and Quality, and private foundations;
5. Development of collaborative networks potentially including any number of a variety of healthcare providers (primary care, rehabilitation, specialty services, etc..), health plans, healthcare organizations, state-based population registries, and researchers to conduct relevant research in the areas of SCI and aging; and
6. Developing collaborative relationships with consumer-based organizations representing persons with SCI such as the National SCI Association, Paralyzed Veterans of America and the network of organizations on aging.

CONCLUSIONS

Aging is a multidimensional process, and alterations in the aging trajectory caused by characteristics associated with SCI, such as severity of injury,

age at injury, duration of injury (corresponding to amount of time aging with and without SCI), era of injury, and others, make this process even more complex for people with SCI. Despite initial impressions and claims to the contrary, there has been remarkably little progress in improving longevity for people with SCI in recent years. As a result, there remains a great deal that is not yet known about the physiology of aging in individuals with SCI, the effects of aging, and the efficacy of interventions and possible preventative measures that might be used to buffer or mitigate these negative outcomes.

It is imperative that greater emphasis be placed on those aging with SCI and the aging-with-SCI experience to not only reduce but also eliminate the health and longevity disparities that have existed for years and continue to exist despite best efforts. The stubborn persistence of chronic medical conditions and early mortality, despite our advances in knowledge and training, suggests a high-priority need for aging research to improve the health and participation of people with SCI. Reversing this trend will require greater collaboration on the part of funding agencies, researchers, practitioners, advocates, policy makers, and others. Through a sustained focus on collaboration, research, coordinated clinical care, advocacy, and policy making, significant gains can be made toward not only "adding years to life" but also "adding life to years" for those aging with SCI.

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