

Secondary health conditions in individuals aging with SCI: Terminology, concepts and analytic approaches

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Running Head: Secondary health conditions in SCI

Abstract

Study design: Literature review.

Objectives: Utilizing those with spinal cord injury (SCI) as a representative population for physical disability, this paper: (1) reviews the history of the concept of *secondary conditions* as it applies to the health of individuals aging with long-term disabilities; (2) proposes a definition of *secondary health conditions* and a conceptual model for understanding the factors that are related to secondary health conditions as individuals age with a disability; and (3) discusses the implications of the model for the assessment of secondary health conditions and for developing interventions that minimize their frequency, severity, and negative effects on the quality of life of individuals aging with SCI and other disabilities.

Methods: Brief review and summary of key findings from original research articles, reviews, and book chapters addressing the concept of secondary health conditions in individuals with SCI and other disabilities.

Conclusions: Terms used to describe SCI-related health conditions are inconsistent throughout the literature. This inconsistency represents a barrier to strengthening the evidence base and effectively translating findings into improved rehabilitation and health-care policy and practice. A working definition of the term *secondary health conditions* is proposed for use in research with individuals aging with SCI, with the long-term goal of facilitating stronger evidence and increased knowledge upon which policy and practice can improve the health and well-being of individuals aging with a disability.

Keywords: Spinal cord injury, secondary conditions, secondary health conditions, comorbidities, aging with disability, accelerated aging

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Introduction

The importance of studying the acute and chronic health conditions that can develop as a result of having a long-term disability was first emphasized in the late 1980s,¹ perhaps due in part to increases in survivorship and longevity of the disabled population. Much of the research on this topic has relied on the term “secondary conditions” to describe these health conditions, without clear consensus on the definition of the term, or agreement on which health conditions are truly “secondary” to disability. This lack of consistency, in conjunction with the absence of a model or framework for organizing the assessment and subsequent treatment of these health conditions, has impeded research in this area. The purpose of this paper is to facilitate progress in this area by: (1) reviewing a history of the “secondary conditions” concept; (2) proposing a new label (“secondary health conditions”) for and definition of the concept; (3) presenting a model for understanding the relationships between these conditions and their precursors and sequelae; and (4) discussing the implications of the proposed model for future research.

Background and History of the Secondary Conditions Concept

It is now well-documented that in individuals with long-standing physical disabilities, a number of significant acute and/or chronic health conditions may develop or be influenced by the presence of disability.²⁻³ The first conceptual paper to highlight the importance of systematic research into the nature, scope, and impact of these health conditions was published in 1988 by Michael Marge.¹ He used the term *secondary disabilities* to describe health conditions that develop after the onset of a *primary disability*. This definition was quite broad, and included *all* health conditions that emerged after the onset of the primary disability, whether or not they were related to the primary disability. One year later, Houk and Thacker⁶ used the term *secondary complications* to describe this same construct. Additional terms that have been used to label

health conditions in individuals with disabilities include *comorbid conditions* or *comorbidities*,⁷ *medical complications*,⁸⁻⁹ and *associated conditions*.¹⁰

In 1991, the Institute of Medicine (IOM) defined the term *secondary conditions* as “...any additional physical or mental health condition that *occurs as a result of having a primary disabling condition*” [italics added] and recommended more research studying their development and prevention.¹¹ A number of researchers responded to this call and initiated research programs to study the nature and scope of physical and psychological conditions that were thought to be the result of or influenced by a primary disability.¹²⁻¹³

Since the 1991 IOM report, research focusing on the concept of health conditions following disability has significantly influenced our field by enhancing our understanding of the associations between aging and important health outcomes in individuals with SCI and other disabilities. Key findings from this research include the following.

1. There is evidence for premature or accelerated aging in those with SCI compared to same-aged cohorts in the general population.¹⁴ This is particularly evident for the musculoskeletal, endocrine and cardiovascular systems.¹⁵⁻¹⁷
2. The frequency of certain health conditions increases with duration of SCI. For example, individuals who are 10 or more years post-SCI are more likely to develop kidney stones, non-urinary related infections, and musculoskeletal problems.¹⁸
3. Individual secondary health conditions can be clustered into higher-order secondary health condition constructs that may be useful for classifying and measuring these conditions in individuals with SCI, as well as other disabilities.¹⁹

Despite the acknowledged importance of the secondary conditions concept as it relates to the lives of individuals living with disabilities, there is no clear agreed-upon definition of the

concept to guide research. Thus, it is not surprising that there is a lack of consistency in the way that these conditions are conceptualized and measured in the scientific literature. Some scientists have expanded their definition of secondary conditions from the IOM's conceptualization to include disability-related social and activity limitations.^{7, 10, 20} In 2000, the *Healthy People 2010* public health initiative was released²¹ and expanded the types of conditions included under the term *secondary conditions* even further to include "... medical, social, emotional, mental, family, or community problems that a person with a primary disabling condition likely experiences." Clearly, a more consistent and limited definition is necessary to help organize and direct research efforts in rehabilitation, and to improve communication with other related fields, such as geriatrics and public health.

Since March of 2009, under the auspices of the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, a SCI Model Systems Special Interest Group on Aging* has been meeting regularly to discuss issues related to aging with SCI, to improve our scientific understanding of these issues and processes. The group recently developed a list of recommendations for future research on aging with SCI²² that includes the need for new information that would improve rehabilitation interventions aimed at reducing secondary conditions as people age with SCI. A necessary step in this process is to propose a clear definition of the secondary conditions concept that could facilitate the development of relevant measures as well as a working model for understanding the associations between secondary health condition and other important quality of life domains.

Proposed Definition and Conceptual Model

* The SCI Model Systems Special Interest Group on Aging members include, in alphabetical order, Margaret Campbell (NIDRR liaison), Susan Charlifue, Anthony Chiodo, Martin Forchheimer, Suzanne L. Groah, Mark P. Jensen, James S. Krause, Dan Lammertse, Ivan R. Molton, Laszlo Nagy, Denise Tate, and Jeanne Zanca.

Proposed definition

We agree with the IOM's 1991 view that the secondary conditions concept should be limited to physical and psychological health conditions, and not include other domains that are also known to be influenced by the presence of a disability, such as social or activity limitations. To help make this distinction clearer, we believe that it would be useful to include the word "health" (i.e., secondary *health* conditions) when referring to the concept. As pointed out in the 2007 IOM report, *The Future of Disability in America*, distinguishing secondary physical and psychological health conditions from the other social and activity consequences that can result from a primary disability does not diminish the importance of the latter.²³ Making this distinction allows us to develop models in which these individual domains can be viewed as mutually interactive, rather than separate independent dimensions within the same overarching construct of secondary conditions. For purposes of this paper, we have chosen the International Classification of Functioning, Disability and Health's (ICF) language and framework for describing and classifying health and health-related states because it provides a useful distinction between physical and psychological health conditions ("body functions and structures") and day-to-day functioning ("activities and participation").²⁴

Any definition of secondary health conditions should also acknowledge that these conditions can arise secondarily to a disability via at least two pathways. First, having a disability may increase the risk of having a health condition directly resulting from the disability, (such as having neurogenic bladder or spasticity, as evidenced among individuals with SCI), or indirectly via an increase in sedentary behaviors that contribute to the development of conditions, such as obesity and diabetes. Through these pathways, living with SCI places individuals at higher risk of experiencing age-related chronic health conditions or comorbidities, such as osteoarthritis,

hypertension, and coronary artery disease, with greater severity and at a younger age than their non-disabled counterparts. This process contributes to what has been described as “accelerated aging.”¹⁴ Any definition of secondary health conditions should acknowledge these two types of influences on the health status of individuals with SCI in order to facilitate their measurement and study.

Based on the above considerations, we define *secondary health conditions* as “physical or psychological health conditions for which their development or course is influenced directly or indirectly by the presence of a disability or impairment.” While this definition implies causality, it would be too limiting to restrict it to simply linear causal relationships. Rather, one must take a multi-dimensional view of disability and health, such that a change in one health condition may well influence the presence or severity of other conditions.

It is also useful to examine and apply some previously established criteria for causation to help determine whether or not a condition is influenced by a disability.^{25, 26} Three of these criteria are particularly relevant for determining whether disability influences a health condition. They are (1) temporality – the causal agent (in our case, disability onset) precedes the secondary health condition or worsening of the condition; (2) biological gradient – more of a potentially causal agent (in our case, greater disability or longer disability duration) leads to an increase in the frequency or severity of the condition; and (3) plausibility/coherence – a causal relationship is biologically or psychologically reasonable given the state of our scientific knowledge.

Temporality may be established through diagnostic interview. One strategy that may be used to meet the *biological gradient* criterion is to administer measures of potential secondary health conditions to samples of individuals with disabilities, and then compare the rates of those conditions between (1) participants who have had the disability for a relatively long time and (2)

a similarly-aged subgroup with relatively recent onset disability. This design controls for age at onset and chronological age effects, so differences in the frequency of conditions between the two groups potentially could be due to disability duration – with the caveat that the inception era cohort effect (i.e., the health care available at the time of disability onset) is a potential confounder. Two such studies support non-urinary tract infections, kidney stones, fractures, contractures, curvature of the spine, and pressure sores as meeting the biological gradient criterion for being secondary health conditions in individuals with SCI.^{18, 27}

The *plausibility/coherence* criterion is also addressed in our working definition. It makes sense, based on what is known about biology, that health conditions associated with a sedentary lifestyle (e.g., higher fat mass levels, diabetes, cardiovascular conditions, and bone density loss) would be influenced by having a disability. This plausibility, when combined with evidence that these conditions occur more frequently in individuals with SCI than in non-disabled individuals, supports them as secondary health conditions.²⁸⁻³¹ Although a systematic review of the research literature to identify all health conditions that meet our proposed criteria is beyond the scope of this paper, some common examples of these are listed in Table 1.

[Insert Table 1 about here]

Moving Forward: Models for Assessing and Understanding Secondary Health Conditions

Although there is much that we have learned about secondary health conditions, our scientific understanding of them, and our ability to reduce their negative effects, will be further facilitated by (1) a measurement model for assessing secondary health conditions and (2) a conceptual framework both for formulating hypotheses regarding the causes and effects of these conditions and for developing interventions that will reduce their frequency, severity, and negative impact.

Measurement models of secondary health conditions. As mentioned above, the potential pool of possible secondary health conditions in our definition consists of the ICF's list of body functions and structures.²⁴ We anticipate that the conditions that meet the criteria for being “secondary” to a disability (i.e., temporality, biological gradient, and plausibility criteria) very likely cluster into subdomains. A recent study using a factor analysis of selected health outcome measures yielded six health outcome factors, supporting this possibility.¹⁹ Although some of the measures included in the analysis assessed complications that do not meet the definition of secondary health conditions presented here (e.g., they included measures assessing activities and participation), a number of other measures did. Moreover, three clear health-condition factors emerged from the analyses reflecting (1) pressure sores, (2) illness/infections, and (3) orthopedic conditions. In addition, a measure of emotional functioning (depression) was associated with a separate factor, providing support for a distinction between psychological and physical secondary health conditions.

Conceptual models of secondary health conditions. We propose a framework that could be used as a point of departure for understanding the predictors and effects of secondary health conditions in Figure 1. This model hypothesizes that both disability-related factors, such as severity of disability, and demographic factors, such as age, can have direct effects on the development and trajectory of secondary health conditions. “Age” in our model reflects four age-related variables, each of which potentially could have distinct effects on secondary health conditions: (1) chronological age; (2) age at disability onset; (3) disability inception era; and (4) duration of disability. The model also hypothesizes that disability and age can interact to influence the development of secondary health conditions (i.e., via the “accelerated aging” pathway noted to occur in individuals with physical disabilities^{7,32,33}). Secondary health conditions, in turn, are

hypothesized to have a negative effect on activity and participation, which in our model are important factors, distinct from secondary health conditions. Activity and participation levels can also influence the development of secondary health conditions. Finally, the model explicitly notes that interventions and adaptive coping responses can influence both the development of secondary health conditions and their negative effects on activity and participation.

[Insert Figure 1 about here]

Implications and Next Steps in Research Agenda

Need for improved measurement. Our understanding of the specific conditions that meet criteria as secondary health conditions, as well as the factor structure of measures of these conditions, is limited at this point. Based on a review of the literature, we have formed a preliminary list of such conditions for people with SCI (Table 1). Further work should focus on developing, testing and refining validated measures of these conditions, for use in SCI and ultimately in other disabilities.

An example of the type of applicable measure as relates to SCI is the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS), which is based on the Secondary Conditions scale,¹³ and assesses 16 conditions in terms of how they limit activity.³⁴ As we learn more about specific conditions that are influenced by certain disabilities, measures such as the SCISCS will become increasingly useful. Furthermore, the recently developed International SCI Standards and Datasets includes several of these conditions, and provides a framework for the development of new, standardized measures that best capture the concept of secondary health conditions.³⁵⁻⁴¹

Need for improved analytic strategies. Research is still needed to thoroughly identify and evaluate the factors that influence and contribute to the development of secondary health conditions. For example, although we know that aging influences the musculoskeletal system in

individuals with SCI differently than it does in individuals who are not disabled,¹⁵ we do not know yet how neuromuscular aging affects respiratory complications in older adults with SCI. Similarly, the lack of evidence on natural aging processes of the gastrointestinal and genitourinary systems after SCI indicates there is not enough evidence to conclude that aging itself influences these body systems differently in individuals with SCI than in individuals without SCI.¹⁵ Also, there are a large number of behavioral and life-style factors that influence the development and course of secondary health conditions. For instance, although the risk of pressure ulcers clearly increases dramatically at SCI onset, behavioral factors play a role in their development and course.⁴² These behavioral factors can, in turn, be influenced by treatments that buffer the potential negative effects that other factors (such as age) have on secondary conditions (via intervention/prevention strategies, as indicated in Figure 1).

While a measurement model will help guide the selection of variables to assess, and ultimately may help us determine how best to combine these variables into composite factors, a conceptual model provides guidance regarding both (1) hypotheses to test and (2) analytic approaches needed to better understand the factors that impact the development and effects of secondary health conditions. As such, our proposed model (see Figure 1) indicates that, in order to design a cross-sectional study to determine what factors may predict pressure sores, it would be important to assess chronological age, duration of SCI, age at SCI onset, date of SCI (as a measure of inception era), the prevention strategies used to influence skin health (e.g., frequency of position or weight shifts, type of seating surface), and both the frequency and severity of pressure sores. Our conceptual model predicts that one or more of the age-related variables (chronological age, age at injury, inception era cohort, duration of injury⁴³) as well as prevention strategies could interact with the disability to predict the frequency and development of pressure sores.

Importantly, the model also predicts that the effects of disability and age-related variables on activities and participation are mediated, at least in part, by their effects on secondary health conditions.

Understanding the importance of age-related variables in the development of secondary health conditions could also be furthered by more longitudinal research. Such research could track the trajectories of secondary health conditions in people aging with SCI, relative to matched individuals without SCI. Finally, the importance of prevention strategies for enhancing health in the general population has been examined in multiple studies, but such research in SCI is limited. Identifying and studying the effects of these prevention strategies represents a critical area of research focus.

Some Limitations of the Secondary Health Conditions Concept

Despite the clear importance of clarifying and understanding the concept of secondary health conditions, as well as their precursors, consequences, and potential interventions, the study and terminology of *secondary health conditions* does have a number of limitations that should be acknowledged. First, although many of these conditions are pertinent across disabilities, others are disability-specific. Because of this, any definition that stipulates a standardized set of conditions will not likely be useful in cross-disability research. Moreover, exclusive reliance of the label *secondary health conditions* by rehabilitation researchers and practitioners has the potential to create unnecessary divisions in the study of chronic health conditions among disabled, non-disabled and aging populations. For example, urinary tract infections (UTIs) are a significant and common secondary condition for many individuals with SCI. But interventions developed by SCI researchers to better manage this secondary health condition may also be useful for clinicians who serve non-disabled individuals with neurogenic bladder needs, among

whom UTIs are not referred to as “secondary health conditions.” Similarly, general research on UTIs in non-SCI and aging populations would likely be of interest to SCI clinicians and researchers. Rigid terminological differences can potentially serve as a barrier to the widespread exchange of this information. Thinking exclusively in terms of *secondary* health conditions, as opposed to the more general concept of chronic health conditions, has the potential to restrict important cross-fertilization among researchers from different fields, thereby limiting the benefits that would occur from shared terminology and more active communication. The solution to this limitation may be to not discard the concept of secondary health conditions altogether, but rather to ensure that disability researchers do not focus exclusively on the disability and rehabilitation literature.

It is also important to remember that individual consumers may not make clear distinctions regarding whether their current health conditions are or are not influenced by their disabilities. They may even find this issue irrelevant. For example, if they have heart disease, they require adequate evaluation and treatment of their heart disease, and may find the discussion of whether or not this chronic condition is disability-related to be invalidating. At the same time, it is also important to understand that many consumers may not be aware of the influence of their disability on a health problem or its treatment. It is critical that we understand these influences so we can provide guidance to our patients in order to improve health and longevity and prevent further disability or activity restrictions. From a point of view of costs and successful health care models, prevention plays a significant role in terms of identifying those at risk for developing such conditions and delivering early treatments to minimize negative effects.

Concluding Comments

Over the last 50 years, the field of medical rehabilitation has made incredible strides in identifying and treating injuries and illnesses that cause disability. With increases in longevity across disability groups, the field is necessarily shifting its focus to the management of health conditions that develop as individuals age with disability. Research efforts may have a significant impact in terms of understanding and treating these conditions, and disability researchers are presented with a unique opportunity to influence the quality of life of individuals living with disabilities such as SCI. Although quality research is not entirely dependent on a clear consensus on terms, such a consensus ensures better communication of results, maximizes efficiency by limiting unintentional replication of previous studies, allows for more effective meta-analysis, and generally moves the field forward. Although by no means definitive, we have proposed one definition for the term *secondary health conditions* as well as a conceptual model that we hope will help facilitate and guide research in this area.

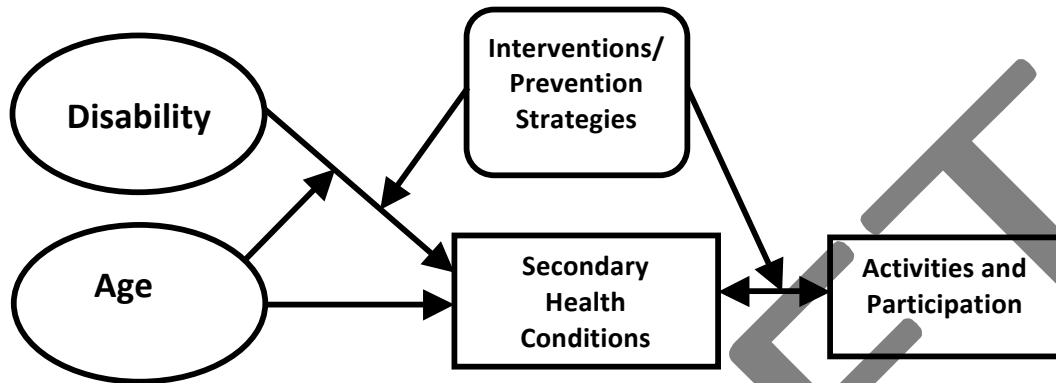
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Table 1. A list of secondary health conditions related to SCI and associated citations.

 Secondary Health Condition

Cardiovascular disease⁴⁴⁻⁴⁵
 Chronic pain⁴⁶
 Constipation⁴⁷⁻⁴⁸
 Contractures¹⁸
 Curvature of the spine¹⁸
 Deep vein thrombosis/pulmonary embolism⁴⁹
 Depression⁴⁹
 Fractures¹⁸
 Heterotopic ossification⁵⁰
 Immobilization hypercalcemia⁵¹
 Insomnia/sleep difficulties^{43,52}
 Kidney stones^{18,27}
 Neurogenic bladder⁵³
 Neurogenic bowel⁵⁴
 Non-urinary tract infections^{18,55}
 Obesity^{31,56}
 Osteoporosis/Bone density loss^{17,31,57}
 Pressure sores^{27,49}
 Restrictive lung disease⁵⁸
 Septicemia⁴⁹
 Sexual dysfunction⁵⁹⁻⁶²
 Sleep apnea⁶³⁻⁶⁵
 Spasticity⁶⁶⁻⁶⁷
 Urinary tract infection^{49,68}

Figure 1. Proposed model of the effects of disability and age on secondary health conditions, and relationship to activities and intervention/prevention strategies.



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