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INTRODUCTION

Developing Epidemiologic Studies of People's Lived Experience

The Swiss Spinal Cord Injury Cohort Study as a Case in Point

ABSTRACT

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“*Non enim vivere bonum est sed bene vivere*” (What is good is not just living, but living well [Seneca, *Epistulae Morales* 70, 4]). This notion by Seneca describes the two main societal goals in relation to people's health.

The first goal is survival, the challenge to make it possible for everyone in society to live as long as humanly possible. There are two familiar health strategies that can be used to achieve this goal: prevention and cure.¹ Social progress and modern medicine have made it possible for more and more people in developed societies to enjoy a life span approaching the biologic limit of human nature.² The hope for the future is that this gift can be shared with low- and medium-resource countries. A telling example of this is the increase in survival among persons with spinal cord injury (SCI) in the last three decades.³

The second goal is that all people enjoy a good quality-of-life throughout their lifetime or, from the perspective of human rights, that all people are able to exercise the full range of opportunities throughout their life.⁴

A high level of functioning is instrumental to achieving the broader societal goals of population well-being or quality-of-life on the one hand, and each individual's highly valued autonomy on the other.^{5,6} The term *human functioning* points us toward the interrelatedness of body functions and structures, individual activity, and societal participation in the human lived experience.⁷ The World Health Organization conceptualization of functioning merges two distinct continua: first, a horizontal continuum of discrete categories of functioning arranged in three dimensions: body functions, body structures, and activities and participation; and second, a vertical continuum of degrees of functioning from a total lack to complete presence of functioning.^{8,9} This second continuum applies to each category of functioning and, in principle, across a range of categories as well.

The two principal health strategies that society relies on to achieve a high level of functioning across a range of categories are rehabilitation and support,

ideally provided in an integrative, person-centered approach across the continuum of care and across the health, social, labor, education, and other health-related sectors.¹ Beyond curative approaches, these rehabilitation strategies are essential to address the needs of people with chronic health conditions and major injuries such as SCI.

SCI is an event that totally reconfigures the realities of a person's daily life, across all dimensions of human functioning¹⁰: all organ systems and body functions below the level of the neurologic lesion can be affected, and living with SCI is associated with a range of complications such as pressure ulcers and genitor-urinary infections, spasticity, chronic pain, and changes in autonomic functions that continue to affect a person's functioning across their lifespan.^{11,12} These impairments do not, however, completely determine the lived experience of disability in persons with SCI because that depends on background contextual factors, both environmental and personal.¹³ Rehabilitation, including support and assistance, therefore, has to not only consider the medical and functional sequela of SCI but also consider central areas and aspects of modern social life, such as employment, transportation, social support, and accessibility in the community.

Comprehensively understood, rehabilitation builds on our fundamental knowledge of the biologic, psychologic, and social dimensions of health, as well as of determinants of human functioning and disability.⁷ Across this broad field of "human functioning and rehabilitation research," the "human functioning sciences" aim to understand human functioning and to identify targets for comprehensive interventions, with the goal of contributing to the optimization of functioning and the minimization of the experience of disability for each individual and across the population.^{14,15} Human functioning sciences build upon the development of theory and models that address the complex interplay of various factors from the physiologic to the societal.

The scientific foundation of epidemiologic studies explicitly grounded in the perspective of functioning or the lived experience is, however, not yet systematically developed.¹⁵ In the case of SCI, the scarcity of comprehensive studies contrasts with the huge volume of SCI literature from the biomedical perspective.¹⁶ Major challenges lie ahead, from modeling the bidirectional and complex interactions of the components and determinants of human functioning that cannot or do not exclusively rely on the well-established methods of public health, which are based on the biomedical or—as it is called in public health—the ecologic model of health, with

its generally unidirectional focus.¹⁷ The human functioning sciences are thus challenged to identify, apply, and possibly further develop suitable methods that can be applied in other scientific disciplines and fields. An example is the application of graphic models to the study of the complex associative structures of categories of functioning.^{18–20}

The development of the human functioning sciences, and more specifically, truly comprehensive epidemiologic studies, relies on research institutions that have made a commitment to meeting this challenge. An example is Swiss Paraplegic Research (SPF). Its mission is to contribute to the optimal functioning and social integration, health and, quality-of-life of people with SCI through clinical and community-oriented research.²¹ At Swiss Paraplegic Research, the Swiss Spinal Cord Injury Cohort Study (SwiSCI) is a research program committed to the understanding and improvement of the lived experience of people with SCI in Switzerland. SwiSCI follows the comprehensive perspective of functioning that is based on the biopsychosocial model of the lived experience, with a focus on comprehensive rehabilitation, from the injury to reintegration into society and in the long-term context including aging. The SwiSCI umbrella goals are to accumulate evidence in support of comprehensive interventions and community outcomes, particularly regarding the following: (1) health maintenance and successful aging with disability; (2) symptom and impairment control and capacity building; (3) empowerment, participation, and social integration; and 4) fair opportunity policies, effective services, and best care.

In this special supplement to the *American Journal of Physical Medicine and Rehabilitation*, we describe the development of SwiSCI, a large research program currently consisting of three interrelated studies: a retrospective study of medical records; a cross-sectional survey of persons with SCI living in the community, and a prospective cohort study including persons in the early rehabilitation phase, consisting of clinical tests, functional measures, and questionnaires that are being developed.²²

During the preparatory phase, a review of recent cohort studies in SCI has shown that only a few large cohort studies have been performed at all and that, after linking the measurement instruments used in these studies to the ICF Core Sets for SCI,²³ none of these studies encompassed all of the relevant aspects of health and functioning of persons with SCI.^{24,25} This finding underscores the relevance and significance of a new truly comprehensive cohort study in persons with SCI.

The first challenge in the development and execution of a truly comprehensive cohort study is to determine “what to measure” by way of a wide range of aspects of functioning, disability, and health that are relevant and significant to the lives of persons with SCI. Here, what might be scientifically optimal needs to be balanced against the need to focus and limit respondent burden. The article on “what to measure” in this special issue describes how the ICF Core Set approach can be used to offer an evidence-based approach to the selection of relevant ICF categories and its specifications to be measured in SwiSCI.²⁶

After the identification of the relevant ICF categories to be measured, the next challenge is to select appropriate measurement instruments. Besides sound psychometrical properties, measurement instruments must be feasible for use in a comprehensive study, without redundancy, with minimal burden for respondents, and with good comparability with other epidemiologic studies in SCI populations. Guidelines for psychometric evaluation of measures are well developed,²⁷ but there are no guidelines for criteria such as redundancy, efficiency, and comparability. The article on “how to measure” in this special issue is a first attempt to develop such guidelines.²⁸

The approach developed in the articles on “what to measure” and on “how to measure” is further exemplified in three articles in this special issue, which describe, in detail, the choices that need to be made of domains that need to be measured and the measurement instruments that need to be used, from the biomedical,²⁵ personal factor,²⁹ and participation and environmental factor perspectives.³⁰

We hope that this special issue inspires researchers worldwide to develop epidemiologic studies from the comprehensive perspective based on the ICF framework and using the methodologic approaches described here. In this respect, we hope that the SwiSCI study may serve as a model for similar studies for other health conditions, across countries and regions.

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