

Aging with and into Disability: Current Status and Future Directions

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Abstract

Background: In North America and Western Europe, recent advancements in medical care and rehabilitation have contributed to longer life expectancies for persons with physical disabilities acquired early in life. At the same time, the increasing proportion of older adults in the general population has resulted in higher prevalence of new-onset disabilities in older adulthood.

Recognizing the need for evidence-based research in aging with and aging into disabilities across disciplines and sub-disciplines, a State of the Science (SOS) meeting was held in April 2011 in Washington, D.C. This conference, sponsored by the University of Washington's Aging with a Physical Disability Rehabilitation Research and Training Center (UW Aging RRTC), focused on reviewing research findings and identifying a research agenda in key areas at the intersection of aging and disability. This paper summarizes findings and recommendations resulting from this SOS conference.

Introduction

The disconnect between aging and disability research as well as clinical care networks is becoming increasingly evident in the context of a rapidly aging population and longer lifespans of those with disabilities. In the United States, approximately 37.3 million (or 12.4%) of the population is over 65. By 2030, this rate is projected to rise to 20.4%, making older adults the fastest growing age demographic.¹ Similarly, research from the UK suggests that the number of older adults is expected to increase by 50% by 2036 (UK Government Actuary's Department, 1999). This "graying" of the population will result in an increase of disabling conditions as these individuals age "into" disability.

Moreover, individuals with long-standing disabilities have benefited from medical and technological advances and are living longer. For example, individuals with spinal cord injury (SCI) are now expected to live about 85% of a typical lifespan.² Similar increases in longevity are observed in persons with degenerative neurological disabilities such as Multiple Sclerosis.³ Those living into old age with long-standing disabilities acquired in early adulthood are said to age *with* disability⁴, and represent a growing population with specialized healthcare needs.

Unfortunately, despite the considerable overlap of needs between those aging "with" and those aging "into" disability, the service, research, and policy networks for these individuals are poorly organized.⁵ This problem of separation between aging and disability represents a missed opportunity for scientific understanding and clinical care, because age and disability are trajectories that interact across time.⁴

In April of 2011, the University of Washington's Aging with a Physical Disability Rehabilitation Research and Training Center (UW Aging RRTC) organized a national state of the science (SOS) conference to help bridge the gap and stimulate discussion among "aging" and "disability" researchers. Experts in the fields of aging and disability research were asked to review the current status of research, particularly as it relates to 1. the definition of the "secondary health conditions" concept, and self-management strategies for such conditions; 2. the barriers to community participation; 3. recent attempts to develop and implement effective strategies for measuring key outcomes; and 4. ways to more effectively link research efforts to public policy.

Below are key areas highlighted at the meeting:

Secondary Health Conditions in Persons Aging with Disability.

Definition and Timing. "Secondary" health conditions are defined as "physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment".⁶ In general, aging with disability is associated with a greater incidence of certain secondary health conditions and symptoms; some of which include under use/overuse conditions, system changes (e.g., cardiovascular disease), infection (e.g., greater wound healing time), mood changes (depression and anxiety), and chronic pain. This, and evidence of earlier onset of chronic diseases, suggests accelerated aging after disability.^{7,8} It was emphasized that conditions and symptoms change across the lifespan in response to time factors such as time with disability, age at disability onset, chronological age, and birth cohort.⁹ Future work in this area would ideally focus on identifying which conditions most negatively

impact community participation and quality of life, how these conditions causally interrelate, standardization of terminology, and collection of longitudinal data.

Self-Management of Secondary Health Conditions. Behaviorally and medically determined disability, deconditioning, and physical and mental symptoms become more interdependent with increased age. Further, examination of the efficacy of self-management interventions targeting age-related secondary conditions will be important. Such programs include psycho-education on health behaviors, problem-solving, behavioral activation, coping enhancement, cognitive restructuring, and relaxation techniques. During the meeting, researchers discussed a need for new multi-target interventions that could result in synergetic benefits effects (e.g., pain and sleep). It was also suggested that such interventions could be more widely available within collaborative or stepped care models by means of the Internet and bibliotherapy, group interventions, brief interventions in primary care, and/or delivery of interventions via consumer groups.

Barriers to Community Participation & Employment.

Three common barriers to community participation in persons aging with disability were emphasized: falls, employment, and difficulties in communication. It was concluded that there is a strong literature base on falls and aging in the general population though there is very little research in the area off falls and aging adults with disabilities.¹⁰ Existing data suggests that falls are more prevalent among individuals with disability. It was agreed that fear of falling, fall self-efficacy, and falls history are particularly important fall variables to consider in future research.

Examining such variables in disability samples could lead to customized programs to prevent falls based on evident risk factors.¹⁰

Next, employment has been a growing area of focus in the context of individuals aging with a disability. Approximately 60-80% of individuals with disabilities are not in the workforce.¹¹

Available data suggest that primary barriers to employment include a lack of a national health scheme, functional limitations associated with primary disability, functional limitations with secondary conditions, social and environmental access issues, and a lack of vocational rehabilitation and related services.¹¹ Despite this lack of knowledge, recent efforts in the US have emphasized employment and aging with a disability (e.g., CDC initiatives on working well with a disability and dealing with secondary conditions). An important next step will be to shift focus to ways to overcome specific barriers to employment.

Discussants at the conference emphasized the role of interpersonal communication in the receipt of quality health. Effective communication is necessary to a range of health behaviors, including scheduling appointments, communicating with healthcare providers in the contexts of assessment and treatment, and getting prescriptions. Improving communicative participation could include treating underlying speech or language deficits but also treating contributory factors such as depression and fatigue. Future research should include refining measurement of communicative participation and the development and testing of participation-based interventions.

Outcomes Measurement in Disability Research

Recently there has been a focus on new and better measures in aging and disability research. Novel IRT-scored self-reported measures (e.g., PROMIS, NeuroQoL), IRT-scored proxy measures (e.g., PROMIS parent reports for pediatric domains), behavior monitors/sensors placed in home and community, and performance-based measures of motor, cognitive, sensory and emotional function (e.g., clinical tests and NIH Toolbox) are all being implemented and examined in aging and disability research contexts. At the conference, a multi-systemic assessment strategy was recommended. For example, when considering “falls”, performance-based measures such as balance testing or the NIH Toolbox balance task can tell us about balance. Self-report measures can provide additional information (e.g., fear of falls, number of self-reported falls). Proxy report can tell a researcher about the number of falls observed by caregiver. Embedded assessment could also tell a researcher about the number of falls detected by sensors at home.

Future research should examine how well the instruments can measure individuals aging with a particular disability or population, and adapt the instrument if needed. In addition, further work should develop cut-offs/categories that can be translated into clinical actions and significance, and decide on the appropriate comparison groups and develop corresponding norms.

Research and Public Policy.

The SOS conference discussions highlighted two primary issues in translation to policy: 1. the implications of research for policy as it can affect the lives of individuals with disability and 2.

implications of research as it affects future research funding. Linking research findings with the key issues facing individuals with disabilities can improve care and give researchers and practitioners more credibility. Likewise, it is important to advocate for research funding with proposals that are grounded in our understanding of the state of the science. Research findings do not speak for themselves; therefore, we need to give them a responsible voice by means of popular media outlets to reach and benefit the target populations. In other words, forming partners with various stakeholders (e.g., National Spinal Cord Injury Association (NSCIA), Muscular Dystrophy Association (MDA), Post-polio Health International (PHI), and the National MS Society, Center for Healthy Aging) both in “aging” and in “disability” will be most helpful in meeting goals of direct communication and influencing policy.

[Insert Table 1 here]

Summary and Conclusions

Table 1 summarizes the primary recommendations that resulted from the SOS conference. Primarily, it will be important to bridge the gap between aging and disability research and clinical practice networks. This will include standardizing and refining key terms, including the “secondary health conditions” concept. It will then be important to determine how these conditions might interact over time with physical disability, psychological function, and community participation. There is also a need to explore both risk and protective factors for these secondary conditions. Particularly important are well-designed, longitudinal, community-based studies that investigate the impact of interventions on secondary health conditions and quality of life. Research is also needed to refine or develop psychometrically sound measures that are also sensitive to a broad range of populations and levels and changes in function.

The future research agenda must appreciate and involve the many stakeholders who are involved in the aging with disabilities communities, including people living and aging with disabilities, health care providers, family members, and policy makers. Integrating the stakeholders' various perspectives into the research agenda will extend our current understanding of aging with disabilities and allow us to design better and more universally accessible and sustainable rehabilitation interventions.

Participants at the SOS Conference

Aging with a Physical Disability SOS, April 11-12, Washington, D.C.: Dagmar Amtmann, PhD; Charles Bombardier, PhD; Margaret Campbell, PhD; Gregory Carter, MD, MS; Susie Charlifue, PhD; Barbara Cochrane, PhD, RN, FAAN; Karon Cook, PhD; Rosaly Correa, MD, MSc, PhD; Gerben DeJong, PhD; Dawn Ehde, PhD; Marcia Finlayson, PhD, OTR/L; Mark Goetz, PhD; Suzanne Groah, MD; Mark Harniss, PhD; Allen Heinemann, PhD, ABPP (RP), FACRM; Robert Hornyak; Mark Jensen, PhD (Co-Chair); Kurt Johnson, PhD; Frank Keefe, PhD; Ivan Molton, PhD (Co-Chair); Robert Motl, PhD; Bruce Rybarczyk, PhD; Amanda Smith, BS; Lyssa Sorkin, MD; Michelle Stern, MD; Aimee Verrall, MPH; Kathryn Yorkston, PhD.

Table 1. Future research priorities based on the state of science conference

Bridge the Gap	<ul style="list-style-type: none"> • Improve communication and cross-citation among "aging" and "disability" research and clinical practice networks.
Secondary Health Conditions and Self-Management Strategies	<ul style="list-style-type: none"> • Further develop standard terminology of “secondary health conditions”. • Identify which conditions most negatively impact community participation and quality of life, and how these conditions causally interrelate. • Collect longitudinal data on secondary health conditions • Develop multi-target interventions with synergistic effects (e.g., pain and sleep) to lessen the impact and incidence of secondary health conditions. • Make interventions more widely available within collaborative or stepped care models (e.g., via internet and bibliotherapy, group interventions and brief primary care interventions).
Community Participation	<ul style="list-style-type: none"> • Develop and examine customized programs to prevent falls based on evident falls risk factors. • Identify ways to overcome specific barriers to employment.

	<ul style="list-style-type: none"> • Refine measurement of communicative participation and the development and testing of participation-based interventions.
<p>Outcomes Measurement in Disability Research</p>	<ul style="list-style-type: none"> • Further examine how well instruments can measure a population or individuals with a particular disability. • Further development of cut-offs/categories that can be translated into clinical actions and significance, and decide on appropriate comparison groups and develop corresponding norms.
<p>Research and Public Policy</p>	<ul style="list-style-type: none"> • Link research findings with key issues facing individuals with disabilities. • Advocate for research funding with proposal grounded in state of the science. • Give research findings a voice through popular media outlets to reach and benefit target populations. • Form partnerships with stakeholders.

1. Table 1: Annual Estimates of the Resident Population by Sex and Five-Year Age Groups for the United States: April 1, 2000 to July 1, 2008 (NC-EST2008-01). In: Division P, ed: U.S. Census Bureau; 2009:1.
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