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Research Gaps in the Demography of Aging with Disability

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Abstract

The evidence base regarding the demography of aging with disabilities in the US is growing yet substantial gaps remain. This paper summarizes seven major research gaps identified during a conference held in May 2012: how many adults are aging with disabilities; has survival improved for individuals aging with disabilities; can the notion of active life expectancy help inform understanding of aging with disability; what is the pattern of onset of secondary conditions for individuals aging with disabilities and how might such conditions be prevented and/or their debilitating effects ameliorated; what role has obesity had in shaping the population of individuals aging with disability; how do individuals aging with disability differ from those who develop disability later in life; and what are the long-term consequences of developing disability before late life for subsequent health, functioning, and socioeconomic outcomes. Bridging these gaps is crucial for enhancing understanding of this understudied population.

Keywords

disability; aging; research

Background

Although not inevitable, aging is often accompanied by declines in physical, cognitive, and sensory capacity, which may lead to limitations in daily life. At the population level, the remarkable declines in the prevalence of activity limitations among older adults in the US during the 1980s and 1990s have paused and may soon reverse course as the baby boom generation enters late life. At the same time, clinicians have observed that individuals with debilitating early onset conditions are living longer than ever before. Taken together, these developments have called attention to the possibility that the number of adults aging with disabilities, and hence entering later life with limitations already in place, may also be increasing at a disproportionate rate in the US.

This paper summarizes major research gaps in the demography of aging with disability that were identified during a two-day conference in May 2012. The conference was undertaken with the dual aims of summarizing current knowledge about aging with disability and

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identifying major research and policy questions. Three agencies sponsored this conference: the newly formed Administration for Community Living within the U.S. Department of Health and Human Services, the National Institute on Aging, and the National Institute on Disability and Rehabilitation Research within the Department of Education. The federal Interagency Committee on Disability Research served as co-sponsor. The Center for Aging and Policy Studies at Syracuse University and the Center on the Demography of Aging at University of Michigan jointly organized the conference.

A companion paper to this research overview summarizes conference presentations about policy challenges relating to persons aging with disability.¹ This paper, which focuses on major research gaps, draws from 7 conference papers²⁻⁷ and the discussion generated among conference participants. For each topic area identified, one or two findings that were presented at the conference are provided, followed by a series of additional questions that reflect important gaps in the current state of knowledge.

Gaps in the Demography of Aging with Disability in the US 1. How many adults are currently aging with a disability?

Like estimates of the population with disability, the size of the population aging with disabilities is sensitive to data source and definition. Dr. LaPlante² reported that, applying age at onset distributions from the 2010 Harris Poll to the population estimates from the 2010 National Health Interview Survey, 13 million adults ages 18 and older in 2010 were living with an activity limitation because of a condition occurring before age 40. Previous estimates from the mid-1990s based on more severe definitions of disability put the figure at about 3 million.

Questions also exist about the composition of this group, whether it has been changing in size and composition, and if so, why. For instance, it is not known whether this group has been growing, and if so, whether the growth is the result of increases in survival among those with early-onset high-mortality conditions (such as traumatic brain injury, spinal cord injury, or traumatic burns, discussed by Dr. Groah⁴) or the result of increases in prevalence of non-fatal but debilitating conditions (such as obesity). Also unclear is the extent to which activity limitations reported by individuals aging with disabilities could be addressed through environmental interventions.

2. Has survival improved for individuals aging with disabilities?

Based on a review of the literature, Dr. Groah⁴ reported that survival rates have improved in recent decades for individuals with selected types of disabling conditions (traumatic brain injury, spinal cord injury, and traumatic burns) but still remain lower than the general population and may have recently leveled off. However, because of data limitations, the literature addressing trends in survival rates for individuals with disabilities compared to the general population remains thin. Most often, statistics from clinical, disease-specific registries or samples are compared to national rates, with little ability to adjust for possible differences in groups. Studies that focus on changes in age at death alone often do not take into consideration shifting age at onset and thus provide an incomplete picture. Also limited are studies that focus on the future: if survival trends among adults with disabilities continue, how many individuals aging with disability will survive to late life? What will be the effect on the mix of older adults with long-term and short term disability and on the mix of long-term care needs?

3. How can studies of active life expectancy help inform our understanding of aging with disability?

Disability measures are sometimes brought together with survival rates in the form of “healthy life expectancy” or “active life expectancy” calculations – that is the average number of years a population can be expected to live with and without disability. For instance, using data from the Health and Retirement Study, Drs. Montez and Hayward⁸ demonstrated that active life expectancy is strongly associated with early life measures of health and socioeconomic context, in part because disability onset, recovery, and mortality are linked to early life experiences. But comparisons of formal life expectancy calculations among groups who develop disability in childhood, adulthood, and late life have not been undertaken, nor is it known how much active life expectancy can be altered under different hypothetical intervention scenarios. Also missing are studies that explore questions about the near future: How many person years of “care” will today’s adults need in the future? Is there a gap between what will be needed and what is available based on the current long term care system? Finally, active life expectancy has almost exclusively been calculated using measures of limitations in self-care and household activities (activities of daily living and instrumental activities of daily living), but a natural extension of this work would be to use complementary concepts that reflect impairments in capacity—including physical, cognitive/intellectual and sensory capacity—and participation in daily life.

4. What is the pattern of onset of secondary conditions for individuals who are aging with disabilities and how might such conditions be prevented and/or their debilitating effects ameliorated?

The presentation by Drs. Molton and Jensen³ provided preliminary evidence that symptoms of sleep disturbance, depression, pain, fatigue and other secondary conditions among persons aging with a disability peak during middle age and contribute to declines in functioning. Findings were based on focus groups, a survey of 2000 individuals with physical disabilities, and a review of the published literature. However, most often information about secondary conditions among adults aging with disability is from cross sectional samples, stratified by age. What is less clear then is how secondary conditions unfold over time within individuals and whether their progression looks fundamentally different for individuals whose disabilities begin earlier vs. later in life. Also unknown is how secondary conditions interact with functioning; that is, at what point do conditions manifest and begin to necessitate changes in how activities are managed and/or influence other aspects of daily life and at what point do they begin to contribute to declines in functioning? Another important missing link relates to optimal treatment of symptoms and underlying functional loss among those aging with disabilities. In particular, a critical outstanding question is under what conditions the competing approaches of “use it or lose it” vs. “conserve it and preserve it” are appropriate.

5. What role has obesity had in shaping the population of individuals aging with a disability?

The literature has found that the onset of overweight and obesity in earlier life compounds the risk of developing mobility limitations in later life⁹ and that continued increases in obesity rates will lead to further increases in disability among those approaching late life.¹⁰ Building upon this literature, Drs. Martin and Schoeni⁵ have shown that on the national level, the prevalence of limitations has been increasing among non-elderly adults and this appears to be linked in part to upward shifts in the distribution of body mass index (BMI).

These findings are based upon repeated cross-sectional data from the National Health Interview Survey and thus it remains unclear whether disability is increasing among those approaching late life because of increases in onset, declines in recovery, shifts in mortality, or some combination of these phenomena. Another lingering question is how much of the increase is due to increased survival of individuals with lifelong or early onset disabilities versus those who are developing limitations (mostly in lower body mobility) in midlife? Also unclear is whether the types of disabilities that are increasing in prevalence necessarily impede participation in daily activities or if they are of the type that can be accommodated by adoption of assistive technology, changes in physical environments, or use of service-based assistance.

6. How do individuals aging with a disability differ from those who develop disability after entering later life?

Some of the earliest work on this question was undertaken by Dr. Verbrugge and colleagues in an article comparing individuals who developed disability before and after age 65.¹¹ At the conference, Drs. Martin and Schoeni⁵ presented updated evidence from the National Health Interview Survey showing that individuals who are younger than 65 still have fundamentally different chronic conditions underlying their disabilities than individuals 65 and older. Yet it remains unclear whether older individuals who reach late life after living with a disability for decades differ in their daily life experience from those who develop limitations later in life. Important outcomes yet to be studied, for instance, include symptoms and secondary conditions, use of accommodations, the rhythm of the day (time use), and evaluative and experienced wellbeing. Another important gap in our understanding is how the nature of limitations and ability of accommodations to bridge gaps between functioning and environmental demands differs for individuals who reach later life with disabilities and for those who develop them later in life. The role of expectations (of individuals and the people around them), motivation and related psychological factors and how they differ for the two groups has also not been explored.

7. What are the long-term consequences of developing a disability before late life for subsequent health, functioning, and socioeconomic outcomes?

Drs. Clarke and Latham⁶ demonstrated with national panel data from the Panel Study of Income Dynamics that adults aging with a work limitation are more vulnerable than those without disability to eroding health and loss of independence as they age. They attribute this finding in part to the different demographic and socioeconomic profiles and patterns of health behaviors over the life course of individuals who develop a work limitation. Dr. Latham⁷ also demonstrated using the Health and Retirement Study that adults aging with disability may be at an even greater risk of depression and poorer mental health in later life due to the potential synergistic nature of disability and depression over the life course. It is not known, however, whether these findings hold consistently for individuals who develop limitations at different points in the life course (e.g. childhood versus early or late adulthood) or whether they hold for different types of underlying causes or different levels of severity. Nor have studies to date been able to fully characterized the potentially synergistic relationship between underlying health conditions that give rise to limitations and secondary conditions that may develop subsequent to (or as a direct result of) limitations. Another important gap in the literature yet to be addressed is whether there are particular factors that might buffer the potentially negative consequences of experiencing disability early in life. Looking forward, it is important to understand how these differences in life experience will translate into projections of future late-life care needs.

Concluding Thoughts

Historically, the evidence base regarding aging with a disability straddles two substantially separate literatures, gerontology and rehabilitation/physical medicine. This approach has left substantial gaps in our understanding of the demography of aging with a disability. Bridging this divide is a crucial next step for enhancing the nation's understanding of aging with a disability, but the fields will continue to be challenged by disparate framing of questions and limited availability of data to address this topic.

With respect to framing of questions, most studies to date offer descriptions of subgroups of individuals with disabilities or comparisons between those who do and do not have particular types of limitations, rather than emphasizing cumulative differences in experiences over the life course. Some researchers continue to draw upon the more than two-decade-old disablement process framework advanced by the Institute of Medicine in the 1990s; others draw upon newer language and concepts from the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). Irrespective of the language, however, few researchers have questioned whether existing paradigms are adequate for understanding aging with a disability. Approaches that blend concepts and develop new frameworks¹² may be needed to further this research field.

In terms of available data, clearly there are now many examples in the literature of creative applications, but all the available data sets have weaknesses. Many are small, non-national, or disease-specific panels or registries focused on a single condition. Available national data resources are either cross-sectional, focused on particular age groups (e.g. older adults), or longer running panel studies with measures based on dated conceptualizations of disability. In short, there is no national disability surveillance system that would allow one to fully explore that nature of aging with a disability.¹³ New data sources or additions to existing sources will inevitably be needed to fill current gaps.

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