Disability onset before late life: Implications for supportive services

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Relatively little is known about the number and characteristics of persons who enter retirement ages already experiencing disabilities, although there is widespread belief that improved medical treatments and survival may be contributing to a higher proportion of older persons who have longstanding limitations that began in midlife or earlier. Recent studies also have found small increases in the rate of activity limitation among persons nearing retirement ages, suggesting that the number with early onset limitations may increase.[1,2]

The implications for supportive services in late life are not clear. Onset of disability before late life may lead to early adaptations so that living arrangements and other supports may already be in place to maximize functioning in old age. On the other hand, early onset of disability may be either a cause or consequence of disadvantage, leading to impaired educational attainment and employment opportunities, lower income, and lower resource accumulations for retirement. Research has shown, for example, that those who have ever applied for Social Security Disability Insurance (SSDI), whether or not they are successful, have poorer outcomes with respect to income, wealth, and health in late life.[3]

In this study, we exploit data from the National Health and Aging Trends Study (NHATS), a new resource for studying old-age health and functioning, to identify those who experienced early onset limitations and explore whether and how they differ from persons with the onset of limitations in later life. We examine demographic and socioeconomic characteristics; health and functioning; social and family support networks; assistive technology and environmental accommodations; and use of supportive services. In this abstract, we focus primarily on describing the characteristics of those who experience early onset limitations, and briefly discuss preliminary findings with respect to disability, unmet needs, and family support networks.

Data and measures

Data are from the first round of the NHATS, which was fielded in 2011 and released in May 2012. The NHATS, a longitudinal study with annual re-interviews, has been designed to better measure both trends and trajectories in functional limitation, with self-report data from an innovative protocol and as well as performance tests. It provides a platform for research to better understand both causes and consequences of declining function for individuals, families, and society.

The NHATS sample is drawn from Medicare enrollment. The baseline sample consists of 8,077 with complete interviews, 468 of whom reside in nursing homes and are not interviewed, although basic demographic information is collected, and functional and health information will be available from assessment and other public program data to be linked to the survey data. We therefore focus primarily on the 7,609 respondents living outside nursing homes in all types of residential situation, including traditional housing, retirement communities with minimal services, and those in residential care settings providing supportive services. Depending on the outcome measure we further subset the population to those with some level of limitation, or those receiving help. All estimates are weighted using analytic weights that adjust for unequal probability of selection and nonresponse.

Early onset disability

To identify persons with early onset limitations, we combine an indicator of Medicare coverage prior to age 65 from the sample frame with self-report data on the duration of use of assistive devices or help for mobility or personal care activities (e.g. bathing, toileting). This measure does not capture all with functional problems beginning before age 65 for several reasons. First, others who applied for but did not receive SSDI and Medicare, will not be identified in the administrative data. Second, limitations in activities other than mobility or personal care, such as managing household tasks independently, or cognitive impairment may have started before age 65. Finally, only the frame information on early entry into Medicare coverage is available for nursing home residents.[4] Nevertheless, we believe analysis of those we are able to identify provides important insights into late life effects of earlier onset limitations.

Functional limitations

We start with a broad definition of limitation that draws on the richness of the data yielded by the new protocol before narrowing the focus to compare use of supportive services by those with early and later onset limitations. The activities included are household activities (doing laundry, shopping, getting meals, managing money, and managing medications), mobility (getting around outside, getting around inside, getting out of bed), and personal care (bathing, dressing, toileting, eating), and the definition ranges from receiving help to receiving no help and having no difficulty with any activity. The intermediate categories are those who use devices to perform one or more activities but report no difficulty when using their accommodations, who are considered to be successfully accommodating a limitation, and those who report doing an activity by themselves at least some of the time but having difficulty, are considered to have a limitation and to be at risk for adverse consequences. Residents of nursing homes are considered to have limitations by definition.

Prevalence and characteristics

We are able to identify about 3.5 million persons, or 10 percent of the Medicare population age 65+ who had limitations prior to age 65, identified by early entry into Medicare, use of devices or help with mobility or personal care, or both (Table 1). Another 22 million, or 61% have some limitation using the broad definition including those who have successfully accommodated their limitations, those who have difficulty but receive no help, and those who receive help. The remaining 29% report no difficulty or help. Those with onset before age 65 are markedly younger than those with later onset, with an age distribution similar to that for those with no disability or limitation.

Table 1. Population Characteristics, Medicare beneficiaries age 65+

	Onset before age 65	Onset after age 65	No difficulty or help
Number (000s)	3,593	22,340	10,453
Percent of population	9.9%	61.4%	28.7%
		Distribution	
Age			
65-74	72.4%	39.6%	70.7%
75-84	22.7%	39.2%	25.8%
85+	4.9%	21.2%	3.5%
Residential setting			
Community	87.7%	88.7%	99.4%
Residential care	8.2%	7.1%	0.6%
Nursing home	4.1%	4.2%	0.0%
Gender			
Male	49.3%	36.4%	54.5%
Female	50.7%	63.6%	45.5%
Race/ethnicity			
White, nonhispanic	71.6%	81.2%	81.1%
Black, nonhispanic	15.4%	7.5%	7.0%
Other nonhispanic	3.1%	3.9%	4.2%
Hispanic	8.7%	6.3%	6.3%
Refused	1.1%	1.0%	1.3%

Despite their younger age, those with early onset of limitations are no more likely than those with later onset to be in nursing homes. They are less likely than those with earlier onset and slightly more likely than those with no limitation to be female. They are more likely to be black or Hispanic than either those with later onset or no limitations, for which the race/ethnicity distributions are similar.

Community residents

Disability in late life is well known to be associated with lower education and income. The socioeconomic disadvantage of those with early onset limitation is even greater, both in early life and later (Table 2). Those with early onset are nearly twice as likely as those with later onset to have less than a high school education and more than twice as likely than those with no limitations, despite the fact that they are similar in age distribution. They also are far more likely to report having been poor in childhood than either group, and their income disadvantage

Table 2. Socioeconomic characteristics, community residents age 65+

	Onset before age 65	Onset after age 65	No difficulty or help
Number (000s)	3,445	21,408	10,453
Percent	9.8%	60.6%	29.6%
	Distribution		
Education			
Less than HS graduate	37.9%	21.8%	15.5%
Economic status in early life			
Average or above	52.7%	62.6%	66.7%
Below average	19.8%	18.8%	17.0%
Poor in childhood	25.2%	16.9%	14.8%
Current income relative to poverty			
Less than 200% of poverty	63.2%	44.4%	31.1%
> 2X pov-3X pov	16.9%	20.0%	17.8%
> 3X pov	19.9%	35.6%	51.0%
Homeowner	57.8%	70.8%	81.5%
Section 8 housing	8.9%	3.1%	1.5%
Medicaid	26.5%	12.0%	7.1%
Respondent or spouse receives SSI	14.5%	7.7%	5.2%

at time of interview is even more dramatic. Consistent with reported income, those with early onset are far more likely to be in subsidized Section 8 housing, to be receiving Medicaid assistance, and to be receiving Supplemental Security Income (SSI).

Similar disadvantages are seen for health, with 56% of those with early onset reporting fair or poor health, twice the proportion for those with later onset. They also report markedly higher rates of common chronic diseases, including heart disease, diabetes, lung disease, stroke, and arthritis. They also have a similar rate of Alzheimer's disease (6%) to those with later onset, despite the fact that they are far younger.

In the remainder of the abstract, we briefly describe preliminary results for disability and support characteristics among those with early and late onset limitations. As the work progresses, we will be adding analyses of use of support services, such as meals on wheels and transportation services, and hours of informal help and unpaid care among those receiving help. Our preliminary estimates indicate that 55% of those with early onset limitations receive help, compared with 36% of those with later onset, and only 11% are successfully accommodating their limitations, compared with 34% of those with later onset. Among those report either help or difficulty performing activities on their own, those with early onset limitations were far more likely to report having experienced adverse consequences when help was not available, such as being able to dress, bathe, or get to the toilet in time to avoid an accident, or having to go without clean laundry, a hot meal, or groceries. We found no differences in the type of residential setting between those with early and late onset disability,

and only modest differences in living arrangement, with those with early onset limitation being more likely to live with relatives other than a spouse or child or with nonrelatives. We also found no differences in the availability of potential support in the form of household members and children available to serve as informal caregivers.

References

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