WHAT LEVEL OF LONG-TERM SERVICES AND SUPPORTS DO RETIREES NEED?

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Introduction

For late-career workers and retirees, the possibility of needing care later in life is a real concern. This concern may reflect media reports of the high likelihood of infirmity and the high cost of care – particularly in nursing homes. It is easy for people to jump to the conclusion that most retirees will either need to trade in their nest egg and independence to get support in a nursing home or languish in their homes with unmet needs. Fear of dependency may make retirees reluctant to spend their 401(k) balances, depriving themselves of necessities as they age. The narrative that emerges from the academic literature, however, is more nuanced. Many people will experience only brief periods of needing care, and the burden in terms of the money spent on formal caregivers or the time spent by informal caregivers will be minimal.

The goal of this three-part series of *briefs* is to help retirees, their families, and policymakers better understand the likelihood that 65-year-olds – over the course of their retirement – will experience disability that seems manageable, catastrophic, or somewhere in-between. This initial *brief* begins by describing the risk of needing different levels of support during retirement. The second *brief* will examine the caregivers and financial resources available to provide such assistance, and the final *brief* will consider both the risk of needing support and the resources available, in order to identify people who are most at risk of facing unmet needs.

The discussion in this *brief* proceeds as follows. The first section introduces the analysis. The second section explains the methodology, including how we measure and classify support needs. The third section describes the results: about one-fifth of retirees will need no support and one-quarter are likely to experience the type of severe needs that most people dread. In between these two extremes, 22 percent will have low needs and 38 percent will have moderate needs. As one would expect, needs vary by marital status, education, race, and self-reported health. The final section looks ahead to the next two *briefs*.

Background

As we age, our bodies, minds, and senses weaken, making us more susceptible to diseases and eroding our functional capacity. As a result of this natural process, most people eventually need help – first with housework, or other instrumental activities of daily

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living (IADLs) like shopping or preparing meals, and then with more essential tasks, or activities of daily living (ADLs) like bathing, eating, and toileting.

In fact, a recent study estimated that a 65-year-old has a 7-in-10 chance of developing a "severe" need for long-term services and supports (LTSS), which sounds quite alarming.¹ But this overall risk of needing LTSS masks tremendous variation in the duration and intensity of the required support. While some might require years of around-the-clock care in an institution to cope with dementia, others might just need occasional help from relatives to recover from illnesses and injuries. And, in most cases, getting support will not require spending years in a care facility – according to the study cited above, only 12 percent of retirees will spend 4 or more years in a nursing home. Instead, a majority who need support will likely get it from relatives, and even those who rely on paid support will often get it in a residential setting or stay at an institution for only a short period.

Still, retirees have reason for concern. Getting LTSS can be costly, whether the cost is measured as the money spent on formal caregivers or the time spent by informal caregivers, and access to these resources is unevenly distributed. To concerned retirees, their families, and policymakers, an important question is: considering both expected needs and available resources, who is likely to face a manageable burden, and who is not? The following analysis takes the first step by describing the risks of 65-year-olds needing various levels of LTSS over the course of their retirement.

Methodology

To meaningfully characterize the risk posed by a need for LTSS in retirement, one must jointly consider the severity and the duration of support needed. Existing studies, however, typically consider each dimension separately – by either examining support intensity at a specific point in time or support duration exceeding a specified intensity level. This *brief* considers both dimensions by developing a system to sort LTSS needs of varying intensity and duration into three categories: minimal, moderate, and severe. Each category presents individuals and their caregivers with different types of challenges. This sorting system is applied to over two decades of data on actual LTSS experience by *Health and Retirement Study* (HRS) participants and used to estimate the lifetime odds of a 65-year-old developing each type of need.

The sorting process itself involves three steps: first, support needs are defined as low, medium, or high in intensity; second, needs are classified as short, medium, or long in duration; and third, a two-dimensional matrix with intensity and duration is used to classify the nine possible types of LTSS needs as minimal, moderate, or severe. Because the assumptions made at each step of the sorting process could affect how the results might be interpreted, the next section describes the process in more detail.

Defining Low, Medium, and High Intensity

Studies examining the intensity of LTSS needs among the elderly have found three types of individuals: those who need support with only IADLs (low intensity), with 1 ADL (medium intensity), or with 2+ ADLs or dementia (high intensity).² For example, Spillman et al. (2014) report that, on average, informal caregivers spend almost 30-percent more time caring for someone with 1-2 ADLs compared to a person with only IADLs.

To see whether this type of relationship between severity of disability and hours holds for slightly different categories and more recent data, we merged the National Health and Aging Trends (NHATS) dataset - which has information on functional limitations and unmet needs - with the National Survey of Caregivers (NSOC) - which has data on the amount of support received. The results from these merged data validate the earlier findings regarding the hours of support by functional limitations. Those who need help with 2+ ADLs or dementia require about 2.5 times the support of those who need help with only IADLs (see Figure 1 on the next page). Note that these numbers pertain only to informal care, which in some instances will be supplemented by more formal arrangements.

Figure 1. Monthly Hours of Support from Informal Caregivers Received by Individuals with Varying Activity Limitations



Sources: Authors' calculations from *National Health and Aging Trends* (NHATS) and *National Survey of Caregivers* (NSOC).

Defining Short, Medium, and Long Spells

Unlike care intensity, studies that analyze the duration of LTSS needs do not distinguish between short and long spells in a consistent manner.³ One reason for the discrepancy might be that the definition of a short or long spell depends on the severity of the need. For example, studies that measure the use of nursing homes – where people with the most intense needs go – typically consider a short spell to be less than a year, while studies that measure the presence of any ADLs – which can often be supported at home – often define a short spell as lasting up to 2 years (see Table 1). Somewhat arbitrarily, we adopt the spells

TABLE 1. Alternative Definitions of Short,Medium, and Long Duration

Duration	Nursing home use (Friedberg et al. 2014)	Having 2+ ADLs or dementia (Johnson 2017)
Short	Up to 1 year	Up to 2 years
Medium	1-3 years	2-4 years
Long	More than 3 years	More than 4 years

Sources: Friedberg et al. (2014) and Johnson (2017).

from the nursing home literature for categorization: short = up to 1 year; medium = 1-3 years; and long = more than 3 years. Fortunately, a robustness test shows that the results are not very sensitive to a oneyear variation in the definition of spell.

Measuring Risk Considering Both Intensity and Duration

The next step in the sorting process involves classifying LTSS needs into three qualitatively different categories – minimal, moderate, or severe – based on a joint consideration of the intensity and duration of a need. To do so, we create a three-by-three matrix outlined in Table 2, with intensity on one axis and duration on the other.⁴

TABLE 2. CLASSIFICATION OF LTSS SEVERITY BASED ON THE INTENSITY AND DURATION OF NEED

	Intensity				
Duration	Low	Medium	High		
Up to 1 year	Minimal	Minimal	Moderate		
1-3 years	Minimal	Moderate	Moderate		
More than 3 years	Minimal	Severe	Severe		

Source: Authors' assessment.

Finally, we use 20 years of data from the HRS, a biennial longitudinal survey of Americans over age 50, to determine the lifetime LTSS care needs for individuals starting at age 65. For roughly 60 percent of the sample, it is possible to observe the entire lifespan of the individual and their LTSS needs; for the other 40 percent, who are still alive, their lifetime needs are projected based on the experience of current and older cohorts from earlier surveys (see Appendix for more details).⁵ Lifetime needs are based on each individual's most severe experience. That is, an individual who breaks her leg requiring minimal care in her 60s, then has a bout of cancer in her 70s requiring more than a year of support, and then develops dementia in her 80s requiring more than three years of care would be counted once and classified as having "severe" LTSS needs.

Results

The results show that roughly one-fifth of 65-yearolds will die without ever requiring LTSS and about one-quarter will have severe needs (see white and red shading in Table 3). In between these two extremes, 22 percent will experience minimal needs (gray shading) and 38 percent will experience moderate needs (pink shading). These results are consistent with prior studies, which found that 26 percent of adults over 65 would have severe LTSS needs for over 4 vears.⁶ A number of other studies have estimated that 35-59 percent of households will need some form of nursing home care, either short or long term.⁷ Many of those individuals have high-intensity needs, even if for only a short period, and our estimates (in the last column in Table 3) show that about 50 percent of individuals will fall in that category.

Table 3. Lifetime Probability of 65-year-old Developing Minimal, Moderate, or Severe LTSS Needs

	Intensity				
Duration	None	Low	Medium	High	
0-1 years		8%	4%	12%	
1-3 years	17%	6	4	22	
3+ years		4	2	22	

Note: Numbers do not add to 100 due to rounding. *Source:* Authors' calculations.

The patterns of LTSS needs across different sociodemographic measures are also as expected. Married individuals, who tend to be wealthier and enjoy the support of a spouse, are more likely to experience no or minimal LTSS needs and less likely to experience severe needs than unmarried individuals (see Figure 2).⁸

The distinction by educational attainment is more dramatic (see Figure 3). Among individuals with some college or more, 22 percent experience no LTSS needs compared to 9 percent for those without a high





school diploma. A measurable difference also occurs in severe needs: 20 percent for people with some college or more compared to 28 percent for those without a high school diploma.





At first, the results by race looked surprising, because the life expectancy of the three groups is so different; Hispanics live much longer than whites or Blacks, which might suggest that they are healthier and have less need for LTSS. But the results indicate that Hispanics and Blacks look similar in their LTSS requirements, and both groups fare much less well than whites (see Figure 4).

FIGURE 4. PROBABILITY A 65-YEAR-OLD WILL DEVELOP MINIMAL, MODERATE, OR SEVERE LTSS NEEDS, BY RACE



Perhaps the most interesting finding is the very strong relationship between self-reported health at ages 65-70 and subsequent LTSS needs.⁹ Thirty percent of individuals who report their health as "excellent" or "very good" appear to escape any need for LTSS (see Figure 5). That share drops to 18 percent for those who describe their health as "good" and to 5 percent for those who say their health is "fair" or "poor." Conversely, the share of individuals whose needs are severe increases from 18 percent for those with excellent/very good health, to 23 percent for those with fair/poor health. This finding suggests that, as they retire, individuals have some basis for assessing their likely need for future LTSS.¹⁰

Figure 5. Probability a 65-Year-Old Will Develop Minimal, Moderate, or Severe LTSS Needs, by Self-Reported Health Status at Retirement



Source: Authors' calculations.

Conclusion

This *brief* – the first in a three-part series – describes the risks for 65-year-olds of needing various levels of LTSS over the course of their retirement. The classification into minimal, moderate, and severe needs takes into account both the intensity of the need and the length of time the services are required. Lifetime experiences from 65-year-olds observed in the Health and Retirement Study indicate that about one-fifth will need no support as they age, and one-quarter are likely to experience the type of severe needs that most people dread. The patterns across sociodemographic groups are as one would expect. Married individuals, those with some college or more, whites, and those who report excellent/very good health will need relatively little in terms of support, while single individuals, those without a high school diploma, Blacks and Hispanics, and those who report poor health will need a lot.

The big question is whether those who need help will have the resources available either in terms of family or friends to receive informal support or sufficient finances to pay for formal support. To answer that question, the next *brief* will examine the caregivers and financial resources that are typically available for assistance, and the final *brief* will consider both the risk of needing support and the resources available to identify people who are particularly at risk of experiencing needs they do not have the resources to meet.

Endnotes

1 Johnson (2017) categorizes individuals who need help with two or more ADLs or have dementia (following HIPAA's requirements for a disability that qualifies for long-term care insurance payments) as having a severe LTSS need.

2 As noted, the assumption for a "high intensity" need is in line with Johnson (2017) and with HIPAA's requirements.

3 See, for example, Kemper et al. (1997); Friedberg et al. (2014); and Johnson (2017).

4 The current categorization implies a nonlinear increase in care needs when LTSS care intensity or duration increases, with needs increasing more rapidly if individuals need care for longer durations. Another way to group duration and intensity is to assume a linear relationship. That is, moving from low to medium intensity is just as bad as moving from medium to high intensity, and similarly for duration. The results of the two different approaches are similar.

5 Our sample includes people from the AHEAD, CODA, and HRS (1998-2018 waves) cohorts.

6 Johnson (2017) estimated that about 70 percent of individuals will ever need severe LTSS care, which is somewhat higher than our estimate of 56 percent for "high severity" care. This gap may be due to methodological differences. Johnson (2017) uses Kaplan-Meir survival functions to estimate the probability of developing severe LTSS needs. However, Kaplan-Meir survival functions are univariate and do not allow for controls or time-dependent variables. We used a multinomial logit that controls for various health, demographic, and socioeconomic characteristics (detailed in the Appendix). When using Kaplan-Meir survival functions with updated data, our estimates show similar results.

7 See Robinson (1999); Dick et al. (1994); Kemper and Murtaugh (1991); Murtaugh et al. (1997); Brown and Finkelstein 2007; and Hurd, Michaud, and Rohwedder (2014). 8 Brown and Finkelstein (2011) and Johnson (2017).

9 Due to small sample sizes in the NHATS/ NSOC, we used data from ages 65-70. We do not observe everyone at age 65 in the HRS; the results are for the 77 percent of individuals we do observe beginning at ages 65-70.

10 Hendren (2020).

11 Individuals in the AHEAD, CODA, and HRS cohorts are included.

12 About 20 percent of individuals who died in a nursing home had minimal or moderate care needs, consistent with Grando et al. (2002).

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APPENDIX

Appendix: Methodology

This *brief* examines the lifetime probability that an individual who has survived to age 65 will need minimal, moderate, and severe LTSS care. The level of care has two dimensions: intensity and duration.

Intensity

We use the HRS for years 1998-2018 to calculate the share of the population with various intensity of care needs.¹¹ Individuals who report only IADLs are considered to have low care needs, those with 1 ADL are considered to have moderate needs, and those with 2+ ADLs or dementia are considered to have high needs. For those who have died recently, the HRS also conducts exit interviews, which ask close family members about respondents' LTSS and care needs in their final months of life. Information on the respondents' IADLs and ADLs from the exit interviews are also included.¹²

Individuals' lifetime needs are based on their most severe experience. That is, an individual who breaks her leg requiring minimal care in her 60s, then has a bout of cancer in her 70s requiring more than a year of support, and then develops dementia in her 80s requiring more than three years of care would be counted once and identified as having "severe" LTSS needs.

We are interested in lifetime LTSS care needs. For those we observe from age 65 to death, we can easily calculate the share who require each level of care during their lifetime. However, limiting the analysis to just those observed from 65 to death would likely bias the results, by ignoring the LTSS needs of younger individuals in the sample who might develop care needs at older ages. To address this issue, we estimated a multinomial logit model to determine the lifetime probability of needing each level of care:

$$P(d_{ii+1} = j | x_{i}, a_{ii}, h_{ii}, d_{ii} = k) = \frac{\exp(x_{i}y_{i,j,k} + a_{ii}y_{a,j,k} + h_{ii}y_{a,j,k})}{\sum_{j,} \exp(x_{i}y_{i,j,k} + a_{ii}y_{a,j,k} + h_{ii}y_{a,j,k})}$$

The model includes four different states, denoted by d_{ii} , for classifying each individual in each wave: 1) individual is still alive and does not have care needs; 2) individual has died and did not experience care needs before death; 3) individual is alive and has care needs; and 4) individual has died and experienced care needs before death. The probability that an individual will enter into state j=1,...,4 at time t+1, given their current state k=1 is determined by a vector of socioeconomic characteristics x_{i} , five-year age groups a_{ii} , and self-reported health variables h_{ii} . The results of this model are used to project LTSS needs for those respondents who are still alive. The actual experience is used for those who have died.

Duration

We use NHATS and NSOC merged data to determine duration of care. This step involves calculating the average duration of care for people in each intensity group, by demographic and socioeconomic characteristic.

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