TIAA Institute

Trends and Issues
January 2025

Do households have a good sense of their long-term care risks?

Introduction

Many older adults will require some long-term care (LTC) later in life, with over half needing intensive support, often for an extended period. The resources required to meet such high-intensity, long-duration needs—either informal support from family members or paid formal care—can be substantial. The questions are whether older adults understand their risks and whether the accuracy of their perceptions varies by socioeconomic characteristics.

Anqi Chen
Center for Retirement Research at Boston College

Alicia H. Munnell
Center for Retirement Research at Boston College, TIAA Institute Fellow

Nilufer Gok
Center for Retirement Research at Boston College

Despite the large literature on LTC risks and insurance, little research has focused on whether people have a good sense of how much help they may need with daily activities as they age. Those who overestimate their risk could hold on to their nest egg and unnecessarily restrict their consumption in retirement, while those who underestimate their risk could experience unmet needs or need to spend down to qualify for Medicaid. This brief, based on a recent paper, compares two measures of self-assessed LTC risks with objective probabilities of ending up with high-intensity care needs.[1]

The first section of the discussion provides some background on LTC risks overall, how care is provided, and the limited research on self-assessed LTC risks. The second section defines how we measure objective and subjective risks. The third section assesses whether the available measures of subjective risks capture the same concept as the objective risks. The final section concludes that neither of the subjective measures are good proxies for comparing to the objective measures. But examining how the subjective responses vary by demographics does provide some useful insights, specifically that Blacks and Hispanics appear optimistic about their future needs relative to other groups. And while women seem to be aware of average LTC risks, they may not realize that they face higher-than-average risks of needing care. These findings are concerning because these groups have the highest objective risks of needing high-intensity care and also have fewer resources to provide for this care.

1 Chen, Munnell and Gok (2025).

Background

As people age, most eventually need help with housework or other instrumental activities of daily living (IADLs) like shopping or preparing meals, and sometimes with more essential tasks, or activities of daily living (ADLs) like bathing, eating, and toileting. While some can get by with assistance a few times a week (low intensity), over half of older adults will have high-intensity needs—that is, require help with two or more ADLs, or have an Alzheimer's or dementia diagnosis—often for an extended period (see Table 1).[2]

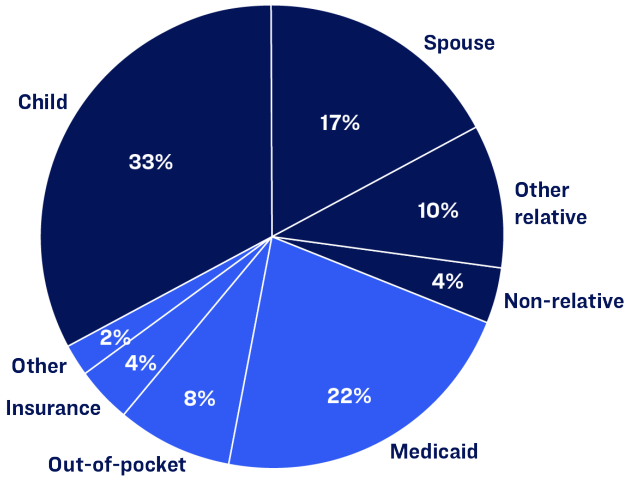
TABLE 1. LIFETIME PROBABILITY OF A 65-YEAR-OLD NEEDING LTC, BY DURATION AND INTENSITY

Duration	None	Intensity		
		Low	Moderate	High
0 to 1 year	18%	10%	5%	14%
1 to 3 years		5	3	20
3+ years		5	2	18

Source: Authors' update of Belbase, Chen and Munnell (2021a).

Households cover these long-term care needs in two ways. The more common way is unpaid, informal care provided by family members (see Figure 1). The less common way is paid formal care, financed primarily out-of-pocket or through Medicaid. Currently, less than 5% of adults have long-term care insurance, and qualifying for Medicaid requires households to impoverish themselves.[3]

FIGURE 1. PERCENTAGE OF TOTAL CAREGIVING HOURS PROVIDED TO INDIVIDUALS AGES 65+, BY SOURCE



Source: Belbase, Chen and Munnell (2021b).

2 ADLs include: bathing, eating, walking, toileting, getting in/out of bed, and getting dressed. Studies on the intensity of LTC needs among the elderly have found three types of people: 1) those who need support with only IADLs (e.g., shopping or preparing meals) are considered to have low-intensity needs; 2) those with one ADL have medium-intensity needs; and 3) those with two or more ADLs or dementia have high-intensity needs. These definitions are consistent with Health Insurance Portability and Accountability Act (HIPAA) requirements and prior literature. See Spillman et al. (2014) and Johnson (2019).

3 LIMRA (2022) estimates that only 3% of Americans have long-term care insurance.

The resources required to meet high-intensity LTC needs, either from family members or paid formal care, can be substantial. To plan effectively, older adults need a realistic assessment of their risks. Unfortunately, the extent to which older adults have a good understanding of their own LTC risks is largely unknown.[4]

One of the few studies that examines the likelihood of individuals ages 72+ needing nursing home care in the next five years.[5] The results show that, in aggregate, respondents had a reasonably good sense of their future nursing home needs. However, respondents who say they will likely need a nursing home in the next five years are likely to be in poor health already. It's unclear whether younger, healthier retirees or near-retirees will have similar predictions about their future LTC needs.

The analysis below looks at two measures of self-assessed LTC needs and whether these measures can offer useful comparisons to predicted objective probabilities of having such needs.

Measuring objective and subjective risks

The data for the analysis come from the Health and Retirement Study (HRS), a nationally representative biennial longitudinal survey of U.S. adults ages 51 and older and their partners.

Objective risks of high-intensity care

The objective measure focuses on older individuals' risk of needing 90+ days of high-intensity care.[6] For roughly 60% of the sample, it's possible to observe the entire lifespan of the individual and their LTC needs; for the other 40%, who are still alive, their lifetime needs are projected based on the experience of current and older cohorts from earlier surveys.[7] Lifetime risks are based on the individual's most severe experience. That is, a person who needs help cleaning and cooking in her 60s, then in her 70s has a bout of cancer that requires some support a few times a week, and in her 80s develops dementia that requires around-the-clock care would be counted once and classified as having high-intensity LTC needs.

Subjective risks of high-intensity care

Older adults' self-assessed risk of needing high-intensity care comes from two HRS questions: 1) "What is the percent chance that you will *ever* have to move to a nursing home?" and 2) "Assuming that you are still living at age 85, what are the chances that you will be free of serious problems in thinking, reasoning, or remembering things that would interfere with your ability to manage your own affairs?"[8] For both questions, participants answer with a number between 0 and 100, where 0 means they see no chance that the event will happen and 100 means they think the event will occur with certainty. In the case of the cognition question, the inverse of the response represents the respondent's perceived risks of having serious cognitive limitations.[9]

Neither question is an ideal measure of the need for high-intensity LTC. For the first question, people are likely to rate their prospects of moving to a nursing home lower than their perceived LTC needs, both because nursing homes are unpopular and because people can increasingly get some high-intensity care in their own homes.[10] For the second question, the wording is broad enough to cover milder forms of cognitive decline (e.g., sometimes forgetting to pay bills), which makes it likely to generate "higher" measures of perceived risk compared to a metric focused solely on dementia diagnosis.[11] But these two questions are the only ones available in the HRS to serve as proxies for expected LTC.

4 Much of the work on subjective LTC risks is from the perspective of whether individuals' perceptions influence decisions on buying LTC insurance (Pauly, 1990; Brown, Goda & McGarry, 2012; and Finkelstein & McGarry, 2006). The limitation is that very few people buy LTC insurance. Others, such as Henning-Smith and Shippee (2015), have examined characteristics associated with LTC risks, but they don't compare self-assessments with objective measures of risk. While some surveys ask respondents if they think they'll ever need LTC, few distinguish between the different levels of care, and almost none are able to compare self-assessed risks with actual risks. See Associated Press-NORC Center for Public Affairs Research (2015), Robison et al. (2013), and Khatutsky et al. (2017).

5 Finkelstein and McGarry (2006).

6 The focus is on those with high-intensity needs that last more than 90 days for two reasons. First, many people who will need high-intensity care for short periods of time—e.g., after a knee or hip replacement—aren't counted because those instances don't impact their long-term quality of life. Second, from a financing perspective, Medicare covers skilled nursing home stays after an acute event (such as surgery), limiting the out-of-pocket costs for families.

7 For more details, see the full paper (Chen, Munnell & Gok, 2025).

8 Between ages 75 and 79, respondents are told to assume they're still alive at age 90. Between ages 80 and 84, they're told to assume they're still alive at age 95. And between 85 and 90, they're told to assume they are still alive at 100.

9 A limitation of this approach is that the two expectation questions aren't asked of respondents of the same age. The average age at which respondents are asked about their perception of ever needing nursing home care is around 55 compared to 67 for the question regarding severe cognitive limitations. Thus, it's not really possible to compare the subjective questions with each other, but they are the best questions for determining how pre-retirees and young retirees assess their own risks for needing high-intensity LTC as they age.

10 An AP-NORC survey on long-term care found that 76% of Americans prefer to receive care in their home and 66% are moderately or very concerned about losing their independence as they get older (Associated Press-NORC Center for Public Affairs Research, 2021).

11 Recent studies have found that dementia can occur up to nine years before an official diagnosis (Swaddiwudhipong et al., 2023), and Alzheimer's and dementia diagnoses are more likely to be missed or delayed among Blacks and Hispanics, so they may be underdiagnosed (Hinton et al., 2024; Lin et al., 2022).

Results

This section begins with the results for objective risks and then compares them to respondents' self-assessed risks.

Objective risks

The results show that 52% of those 65+ will need high-intensity care for more than 90 days at some point over their remaining lifetime (see Table 2). Roughly half of those needs are generated by physical ailments and half from cognitive decline. The percentage of risk varies by education, race and gender. Specifically, those with less education, Blacks and Hispanics, and women have higher-than-average likelihood of needing high-intensity LTC.

TABLE 2. LIFETIME PROBABILITY OF A 65-YEAR-OLD OF NEEDING HIGH-INTENSITY CARE BY TYPE AND BY EDUCATION, RACE, AND GENDER

	Total	Cognitive (Alzheimer's/ dementia)	Physical (2+ADLs only)
All	52%	29%	25%
Education			
HS or less	53%	29%	27%
Some college	48%	26%	25%
College or more	46%	28%	20%
Race			
White	50%	28%	25%
Black	57%	34%	26%
Hispanic	57%	31%	31%
Gender			
Men	46%	25%	23%
Women	56%	31%	27%

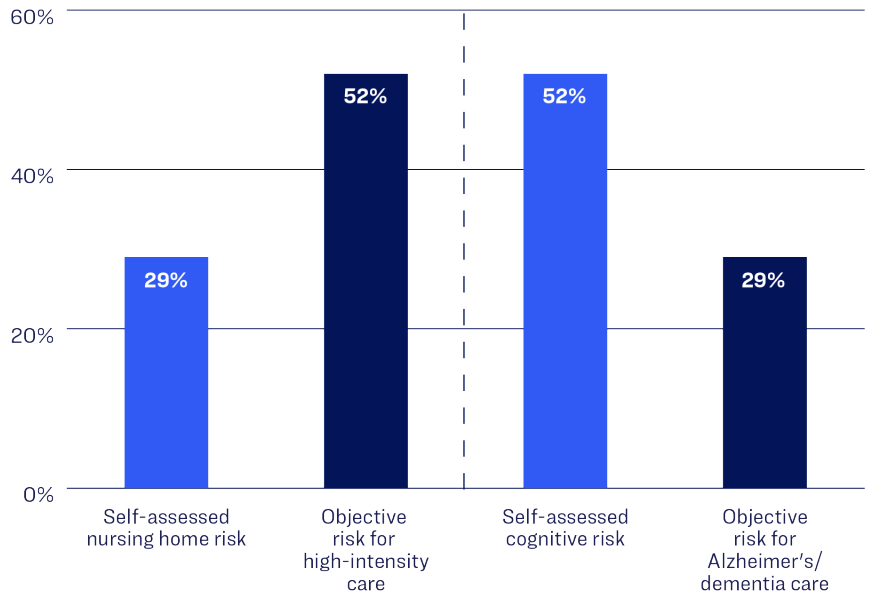
Note: Estimated risks for cognitive and physical ailments don't add up to the total risks because they involve separate models that have different transition probabilities and error terms.

Source: Authors' calculations using RAND Health and Retirement Study (HRS) longitudinal file (1992–2020v2) and University of Michigan HRS (1998–2020).

Comparing objective and subjective risks

Figure 2 compares: 1) HRS respondents' subjective risk of ever ending up in a nursing home with the objective risk of needing any high-intensity care; and 2) respondents' subjective risk of needing help with cognitive decline with the objective diagnosis of Alzheimer's disease or other dementia. Unfortunately, these results match our expectations. Self-assessed nursing home risk—at 29%—is substantially lower than the objective measure of high-intensity LTC needs, as people generally dislike the idea of entering a nursing home and home care may be a viable alternative. And self-assessed cognitive risk—at 52%—is much higher than objective risk of Alzheimer's or dementia because the HRS cognitive question is so broad.

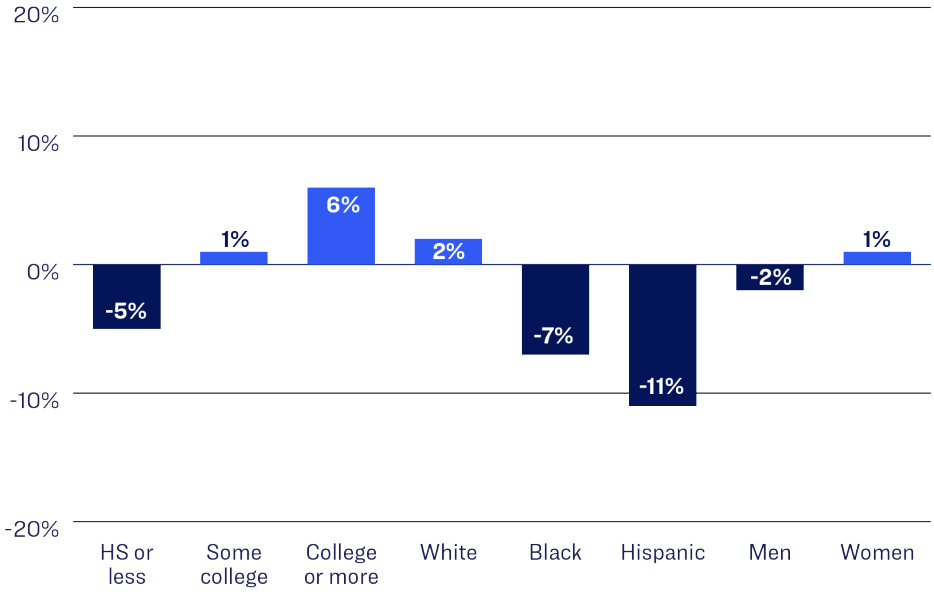
FIGURE 2. OBJECTIVE AND SUBJECTIVE RISK MEASURES, OVERALL AVERAGES



Source: Authors' calculations using RAND HRS longitudinal file (1992–2020v2) and HRS (1998–2020).

While the HRS questions are likely not good measures of older households' perceived high-intensity future needs, the variation in responses by demographics provides some useful insights. In terms of ever moving into a nursing home, Blacks, Hispanics, and those with a high school degree or less perceive their risks to be substantially below average (see Figure 3). As noted earlier, these groups face a higher likelihood of needing high-intensity LTC.

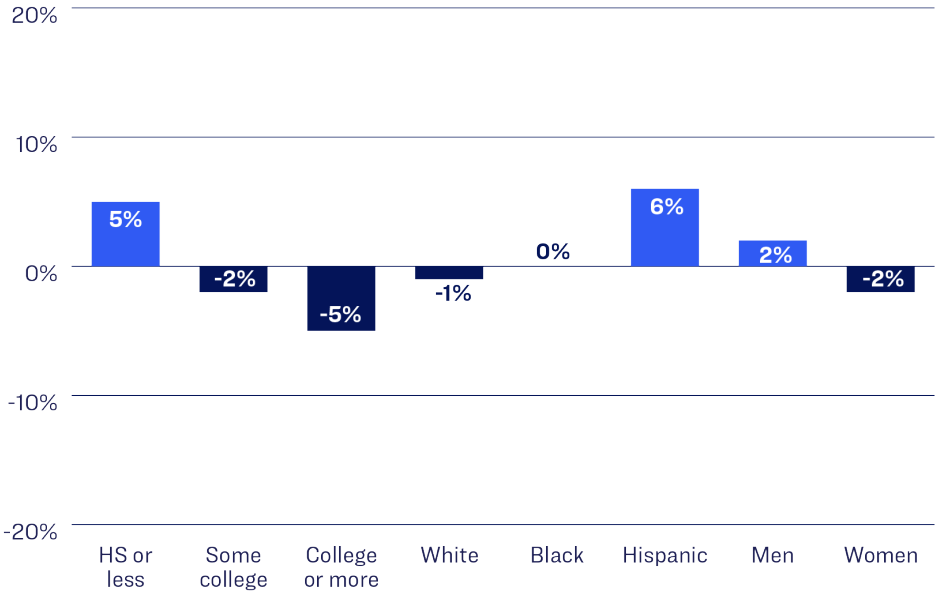
FIGURE 3. DEVIATION FROM AVERAGE OF SELF-ASSESSED RISK OF EVER MOVING INTO A NURSING HOME, BY EDUCATION, RACE AND GENDER



Source: Authors' calculations using RAND HRS longitudinal file (1992–2020v2) and HRS (1998-2020).

In terms of cognitive decline, assessments are generally more uniform across demographics, but here women and those with at least some college are more sanguine about needing help than other groups (see Figure 4). Women are slightly more optimistic despite the fact that they have a higher-than-average risk.

FIGURE 4. DEVIATION FROM AVERAGE OF SELF-ASSESSED RISK OF COGNITIVE DECLINE, BY EDUCATION, RACE AND GENDER



Sources: Authors' calculations using RAND HRS longitudinal file (1992-2020v2) and HRS (1998-2020).

Conclusion

This brief examines two measures of self-assessed LTC risks along with objective probabilities of ending up with high-intensity care needs. The results indicate that neither of the self-assessed measures are good proxies for capturing self-assessed high-intensity needs. However, looking at the demographic breakdowns for the self-assessments does provide some useful insights. Specifically, Blacks and Hispanics may be underestimating their risks of future LTC needs. And while women seem to be aware of average LTC risks, they may not realize that they face higher-than-average risks of needing care. In short, the groups that have a higher probability of high-intensity needs as they age also have fewer resources to provide for their care.

It's important to note that even being aware of LTC risks doesn't equate to being financially prepared to handle the costs of providing high levels of care. Nonetheless, a first step in being prepared is understanding the extent to which these risks exist. Future research could design questions that better capture older adults' perceived LTC risks.

References

Associated Press-NORC Center for Public Affairs Research (2015). Long-term care in America: Americans' outlook and planning for future care. http://surveys.associatedpress.com/data/NORC/AP-NORC%20LTC%202015%20Topline_US%20Trend%20FINAL.pdf

Associated Press-NORC Center for Public Affairs Research (2021). Long-term care in America: Americans want to age at home. https://apnorc.org/projects/long-term-care-in-america-americans-want-to-age-at-home/?doing_wp_cron=1719934263.4696496306945800781250

Belbase, A., Chen, A., and Munnell, A. H. (2021a). What level of long-term services and supports do retirees need? *Issue in Brief* 21-10. Center for Retirement Research at Boston College.

Belbase, A., Chen, A., and Munnell, A. H. (2021b). What resources do retirees have for long-term services and supports? *Issue in Brief* 21-16. Center for Retirement Research at Boston College.

Brown, J. R., Goda, G. S., and McGarry, K. (2012). Long-term care insurance demand limited by beliefs about needs, concerns about insurers, and care available from family. *Health Affairs 31*(6): 1294–1302.

Chen, A., Munnell, A. H., and Gok, N. (2024). Do households have a good sense of their long-term care risks? Working Paper 2025-5. Center for Retirement Research at Boston College.

Finkelstein, A., and McGarry, K. (2006). Multiple dimensions of private information: Evidence from the long-term care insurance market. *American Economic Review* 96(4): 938–958.

Health and Retirement Study (HRS). RAND HRS longitudinal file, 1992–2020v2; and University of Michigan HRS, 1998–2020.

Henning-Smith, C. E., and Shippee, T. P. (2015). Expectations about future use of long-term services and supports vary by current living arrangement. *Health Affairs 34*(1): 39–47.

Hinton, L., Tran, D., Peak, K., Meyer, O. L., and Quiñones, A.R. (2024). Mapping racial and ethnic healthcare disparities for persons living with dementia: a scoping review. *Alzheimer's & Dementia 20* (4): 3000–3020.

Johnson, R. W. (2019). What is the lifetime risk of needing and receiving long-term services and supports? Research Brief. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. https://aspe.hhs.gov/reports/what-lifetime-risk-needing-receiving-long-term-services-supports

Khatutsky, G., Wiener, J. M., Greene, A. M., and Thach, N. T. (2017). Experience, knowledge, and concerns about long-term services and supports: Implications for financing reform. *Journal of Aging & Social Policy 29* (1): 51–69.

LIMRA. (2022, Nov. 15). Do consumers really understand long-term care insurance? News Release. Windsor, CT.

Lin, P., Daly, A. T., Olchanski, N., Cohen, J. T., Neumann, P. J., Faul, J. D., Fillit, H. M., and Freund, K. M. (2022). Dementia diagnosis disparities by race and ethnicity. *Medical Care* 59 (8): 679–686.

Pauly, M. V. (1990). The rational nonpurchase of long-term-care insurance. *Journal of Political Economy 98*(1): 132–168.

Robison, J., Shugrue, N., Fortinsky, R. H., and Gruman, C. (2013). Long-term supports and services planning for the future: Implications from a statewide survey of baby boomers and older adults. *Gerontologist 54*(2): 297–313.

Spillman, B. C., Wolff, J., Freedman, V. A., and Jasper, J. D. (2014). Informal caregiving for older Americans: An analysis of the 2011 National Study of Caregiving. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Swaddiwudhipong, N., Whiteside, D. J., Hezemans, F. H., Street, D., Rowe, J. B., and Rittman, T. (2023). Pre-diagnostic cognitive and functional impairment in multiple sporadic neurodegenerative diseases. *Alzheimer's & Dementia* 19 (5): 1752–1763.

About the authors

Anqi (Angie) Chen is associate director of savings and household finance at the Center for Retirement Research at Boston College. Her research interests include household finance, demographic changes, labor market outcomes and social insurance. Previously, she was a portfolio analyst at BofI Federal Bank, where she built models to test and identify risks in the bank's real estate portfolios.

Alicia H. Munnell is a senior advisor at the Center for Retirement Research at Boston College (CRR). She was the Peter F. Drucker Professor of Management Sciences at Boston College's Carroll School of Management from 1997–2024 and founded the CRR in 1998. Before joining Boston College in 1997, she was a member of the President's Council of Economic Advisers, served as assistant secretary of the Treasury for economic policy, and spent 20 years at the Federal Reserve Bank of Boston.

Nilufer Gok is a research manager at the Center for Retirement Research at Boston College. Nilufer completed four years of studies in pursuit of a PhD in economics from Pennsylvania State University before getting an MA in economics. She also earned a BA in economics from Bilkent University in Turkey.

About the TIAA Institute

The TIAA Institute helps advance the ways individuals and institutions plan for financial security and organizational effectiveness. The Institute conducts in-depth research, provides access to a network of thought leaders, and enables those it serves to anticipate trends, plan future strategies, and maximize opportunities for success.

To learn more, visit tiaainstitute.org.

Join the conversation online: @TIAAInstitute

The authors are all with the Center for Retirement Research at Boston College. Anqi Chen is associate director of savings and household finance. Alicia H. Munnell is a senior advisor. Nilufer Gok is a research manager.

This project received funding from the TIAA Institute and the Wharton School's Pension Research Council/Boettner Center. The content is solely the responsibility of the authors and does not necessarily represent official views of the above-named institutions.

4179538-0127

TIAA Institute

(01/25)