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Discrimination Risks of Alzheimer's as Support for Social Insurance for Long-Term Care

Allison K. Hoffman

University of Pennsylvania Law School

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Private insurance for long-term care has all but collapsed. Major private insurers have dropped their long-term care lines, or watched them fail.¹ Existing policies have been subject to shocking premium rate increases.² Insureds face two- or three-fold premium increases, just to keep policies active that they have funded for decades. Even active, coverage often pays for only a slice of the care that they need.

Scholars have acknowledged that turning the private market around would be a heavy lift.³ The recent study in this issue by Jalayne J. Arias, Ana M. Tyler, Benjamin J. Oster, and Jason Karlawish provides more evidence on shortcomings of private long-term care insurance,⁴ and reinforces the need to focus on social insurance solutions.

The Arias study highlights a great irony: with 5.5 million people currently living with Alzheimer's and an expected 14 million by 2050, getting private long-term care insurance to cover their care needs is only becoming harder. As the authors describe, most people with Alzheimer's and other diseases that cause dementia are intensive users of long-term services and supports—assistance with non-medical needs necessary for daily life, such as help bathing, eating, or paying bills. Yet, medical researchers increasing ability to identify who is at the most risk of developing symptomatic Alzheimer's, by identifying biomarkers of the disease, will make it impossible for those very people to insure privately for future care needs.

The study illuminates that state law—based on a model act developed by the National Association of Insurance Commissioners—allows private insurers to use biomarker data in underwriting decisions, including a decision not to offer coverage at all.⁵ This means that an insurer can consider someone's elevated risk for Alzheimer's in an application for a long-term care policy, which will undoubtedly lead to rejection.

Their findings illuminate critical flaws in the private market for long-term care insurance. First, private insurers profit by excluding those people most in need of coverage, unless regulation prohibits it. Their profit motive is contrary to larger social goals of financial and health security for people at risk of Alzheimer's. Second, insurance is primarily regulated at the state level, which means a state could prohibit insurers from using biomarkers in underwriting (this is the primary solution the study's authors recommend). Yet, to make such protections

¹ Leslie Scism, "Collapse of Long-Term Care Insurer Reflects Deep Industry Woes," Wall Street Journal, Dec. 4, 2016.

² Howard Gleckman, "Another Big Long-Term Care Insurance Premium Hike," Forbes, Aug. 1, 2016.

³ J.R. Brown & A. Finkelstein, "Insuring Long-Term Care in the U.S." Journal of Economic Perspectives 25, no. 4 (2011), 119-142.

⁴ J. J. Arias, A. M. Tyler, B. J. Oster, and J. Karlawish, "The Proactive Patient: Long-term Care Insurance Discrimination Risk of Alzheimer's Disease Biomarkers," Journal of Law, Medicine & Ethics __, no. __ (2018): #-#, at #.

⁵ See Arias, supra note 4.

universal would require *every* state to regulate, or for Congress to step in and pass a law that applies to all states. If the law prohibited insurers from considering biomarkers, but people knew their own, those people who are most likely to need insurance will disproportionately buy it (adverse selection), and prices would increase beyond their currently unaffordable levels. Third, these types of consumer protections laws are a moving target. Today, it's biomarkers. Tomorrow, it's new medical advances that the current law did not imagine. As medicine innovates, so will insurance underwriting practices to exclude risky applicants in any way possible.

It has become abundantly clear that the only way to create adequate insurance for long-term care is through a universal social insurance program. Some point to the repeal of the Patient Protection and Affordable Care Act's social insurance program for long-term care, the CLASS Act, as evidence that social insurance cannot work. To the contrary, its failure, based on actuarial flaws and the ability of people to opt out, highlights the importance of *mandatory, universal coverage*, like the coverage most peer nations have embraced in developing long-term care social policy.⁶

The reasons for the lack of social insurance for long-term care in the United States are multifaceted, but at least one reason is a failure to consider the full social impact of the problem. Social policies and private insurance for long-term care have conceived of risk of long-term care too narrowly, from the perspective of those people needing care.⁷

The problem become more acute if we consider risk from the perspective of family members and friends who may become responsible for someone in need of long-term care—what I elsewhere call “next-friend” risk.⁸ By one estimate, the financial losses alone—including forgone income, pensions, benefits, and retirement savings—sustained by the average informal caregiver who leaves the workforce to care for her parent are \$300,000.⁹ Two-thirds of informal caregivers are women and over one-third leave the workforce or reduce working hours.¹⁰ Informal caregivers also face significant physical and mental health risks.¹¹

This level of financial and health risk can destroy a family's long-term security. It looks like the level and type of risk that historically has motivated popular and political support for social insurance. The risks are random, unevenly distributed, and potentially devastating and are passed from one generation to the next, creating intergenerational insecurity.

⁶ T. Muir, Measuring Social Protection for Long-Term Care, OECD Health Working Paper No. 93 (April 12, 2017): at 11.

⁷ A. Hoffman, “Reimagining the Risk of Long-Term Care,” Yale Journal of Health Policy, Law, and Ethics 16, no. 2 (2016), 239-315.

⁸ A. Hoffman, *supra* note 7.

⁹ MetLife Mature Market Institute, The MetLife Study of Caregiving Costs to Working Caregivers (June 2011).

¹⁰ MetLife, *supra* note 9.

¹¹ N.B. Coe and C.H. Van Houtven, “Caring for Mom and Neglecting Yourself? The Health Effects of Caring for an Elderly Parent.” 9 Health Econ (2009): 991-1010.

Instead of seeing these costs as risks that could be managed collectively, long-term care has been cast as something families can and should manage—in part because they do, in homes and out of the public eye. Yet long-term care as a private obligation is increasingly untenable. The actual care needs of people with chronic illness and disability are becoming more intensive, as the Arias study shows. At the same time, families and friends are less able to address these needs. Single-parent families and two wage-earner households are the new normal, leaving little cushion to absorb caregiving.¹² Families have dispersed geographically.¹³ And the ratio of people needing care to those who can provide it is increasing as people live longer and have fewer kids.¹⁴

Families will face increasing insecurity from next-friend risk with the rise in Alzheimer's and related diseases that demand intensive care for many years. By seeing the costs friends and family have borne as evidence of an insurable risk and pursuing policies that are more sensitive to this risk, we can protect people from severe insecurity that arises out of the tragic misfortune of having a loved one become ill or disabled.

¹² U.S. Census Bureau, *Statistical Abstract of the U.S.: 2012* (2012): at 840; H. N. Fullerton, Jr., "Labor Force Participation: 75 Years of Change, 1950-98 and 1998-2025," *Monthly Labor Review* (Dec. 1999): at 4.

¹³ P. Ren, U.S. Census Bureau, *Lifetime Mobility in the United States: 2010* (2011): at 1, 3.

¹⁴ E. Brandon, "65-and-Older Population Soars," *U.S. News and World Report*, Jan. 9, 2012, at <http://money.usnews.com/money/retirement/articles/2012/01/09/65-and-older-population-soars>.