

Long-Term Care: More common and costly than imagined



Robert Pokorski, MD, MBA

Agenda

1

Most studies underestimate likelihood and cost of LTC

2

Adult children, not spouses, provide most LTC

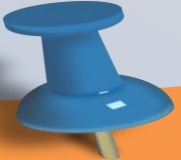
3

Cost of LTC

4

Conclusions

Studies underestimate likelihood and cost of LTC



“Generally, only people with the most severe disabilities qualify [for Medicaid]. Large amounts of formal and unpaid care—possibly the majority—are now delivered to people with less severe disabilities.”¹

– Melissa Favreault, PhD, Senior Fellow at the Urban Institute and principal author of many government-sponsored reports about LTC

Points of engagement

- Most estimates of the likelihood and cost of LTC are too low because they are based on strict HIPAA criteria
- **One in four people** who pay for care and almost **three in four** who receive only unpaid care are not counted in most statistics because their disability does not meet HIPAA criteria²

¹ Favreault MM. Incorporating long-term services and supports in health care proposals: Cost and distributional considerations. Urban Institute. May 2020., p.33.

² Pokorski R. InvestmentNewsNet. In Press.

2 ways to estimate likelihood and cost of LTC

Likelihood and cost of LTC vary with criteria

HIPAA criteria

- Includes severe disability only
- Official criteria used in most studies of likelihood & cost of LTC

Advantage: Generally used to determine eligibility for LTC benefits

Disadvantage: Underestimates true likelihood and cost of LTC because people who need care at pre-HIPAA levels of disability are not counted

Consumer criteria

- Includes all levels of disability
- Unofficial consumer perspective based on when care is first needed & costs first incurred

Advantage: Represents likelihood and cost of LTC from perspective of care recipients & family caregivers

Disadvantage: Not all care and costs are considered LTC for purposes of benefit eligibility

HIPAA* criteria: Official, strict, requiring certification by a health care provider

A person requires LTC if he/she has been **certified by a licensed health care provider** as:

1. Unable to perform (without substantial assistance) at least 2 of the 6 Activities of Daily Living (ADLs), including bathing, continence, dressing, eating, toileting, and transferring in or out of a bed or a chair, **for a period of at least 90 days,**
or
2. Requiring substantial supervision for protection from threats to health and safety due to severe cognitive impairment

* Health Insurance Portability and Accountability Act (HIPAA) of 1996. A version of this definition is used by Medicaid and many financial service products that provide a benefit for LTC

Points of engagement

- People who meet HIPAA criteria have severe disability
- Care provided and costs incurred prior to reaching HIPAA-level disability are **not included** in most statistics
- Result? Likelihood and costs of LTC are higher than expected

Consumer criteria: Unofficial consumer idea of when care is first needed and costs first incurred

Progressive disability requiring more care and increasing costs¹

Stage 1 IADL care

- Difficulty with instrumental activities of daily living²
- Help may be needed, especially if living alone, but costs usually minimal
- Not counted as LTC by HIPAA criteria

Stage 2 Standby care

- Disability increases, paid caregivers may be hired
- Health care provider does not certify that LTC is needed
- Not counted as LTC by HIPAA criteria

Stage 3 Hands-on care

- More care needed, more expenses incurred
- Health care provider does not certify that LTC is needed
- Not counted as LTC by HIPAA criteria

Stage 4 HIPAA-level care

- Severe disability, self-care is no longer possible
- Health care provider certifies that LTC is needed
- Only care counted as LTC by HIPAA criteria

¹ These four stages were created by the presenter solely for this discussion.

² Cooking, housework, laundry, managing finances and medical care, phone and computer use, shopping, and transportation.

Agenda

A couple is seen from behind, sitting on a wooden bench on a grassy bank overlooking a large body of water. The sky is filled with dramatic, orange and yellow clouds from a sunset. Two bicycles are parked on the grass in front of the couple. The overall mood is peaceful and contemplative.

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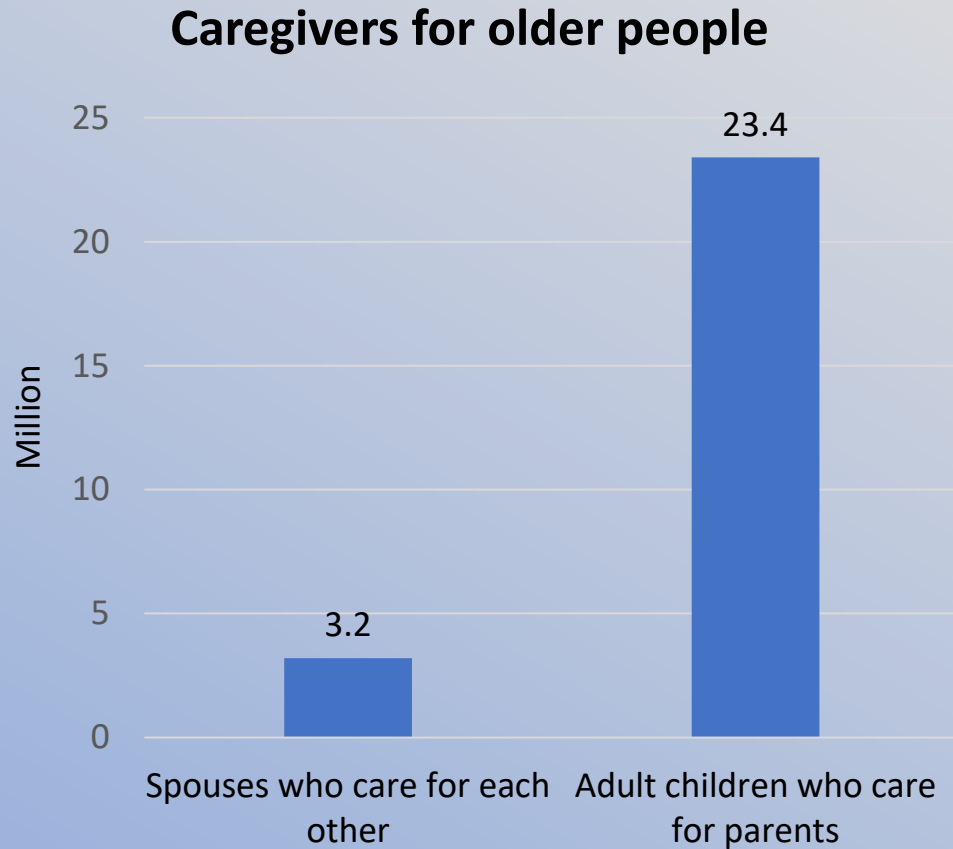
Conclusions



“A spouse who is an active caregiver provides substantially more hours of care than an adult child who is an active caregiver. However, the majority of adults with dementia do not have a spouse.”

Choi H, et al. Family care availability and implications for informal and formal care used by adults with dementia in the US. Health Affairs. September 2021, p.1363. 1366. 41% of men and 75% of women with dementia did not have a spouse.

Adult children, not spouses, provide most LTC (1)



- Not enough spouse caregivers
 - Some couples divorced, separated, widowed, too old or infirm to care for each other, and some people never married
 - Wives generally provide more care than husbands, daughters more care than sons¹
- Far more adult children caregivers
 - 7 times as many adult children care for parents (23.4 million) as spouses who care for each other (3.2 million)²
 - Children more likely to be caregivers if they live near parents¹

¹ Scommegna P. Family caregiving. Today's research on aging. Population Reference Bureau. February 2016.

² Jeszeck CA. Retirement security: Some parental and spousal caregivers face financial risks. GAO-19-382. May 1, 2019.

Adult children, not spouses, provide most LTC (2)

Number of spouses and adult children who provide LTC						
	Frequency			Duration		
	Daily	Several times a week	Less often	To 2 years	2-5 years	5+ years
Spouses	2,581,246	254,938	350,539	796,681	573,610	1,115,353
Adult children	4,911,928	6,549,237	11,695,065	6,081,434	3,976,322	8,654,348

Points of engagement

- Spouses are primary caregivers, but most LTC provided by adult children, who are secondary caregivers
- Ideally, financial plan includes funds for both spouses and adult children who provide care

Case example: Retired children caring for parents

Age 65, no plan

65-year-old couple sees no need to plan for LTC. They will care for each other. If something unexpected happens, their two children, ages 40 and 42, promise to care for them.

20 years later

Husband develops health problem at age 85. His wife, the primary caregiver, cares for her husband, who dies after a short illness. She lost her primary caregiver and she is alone.

5 years later

At age 90, wife develops Alzheimer's disease or another illness that will require care for remainder of her life.

65 and 67

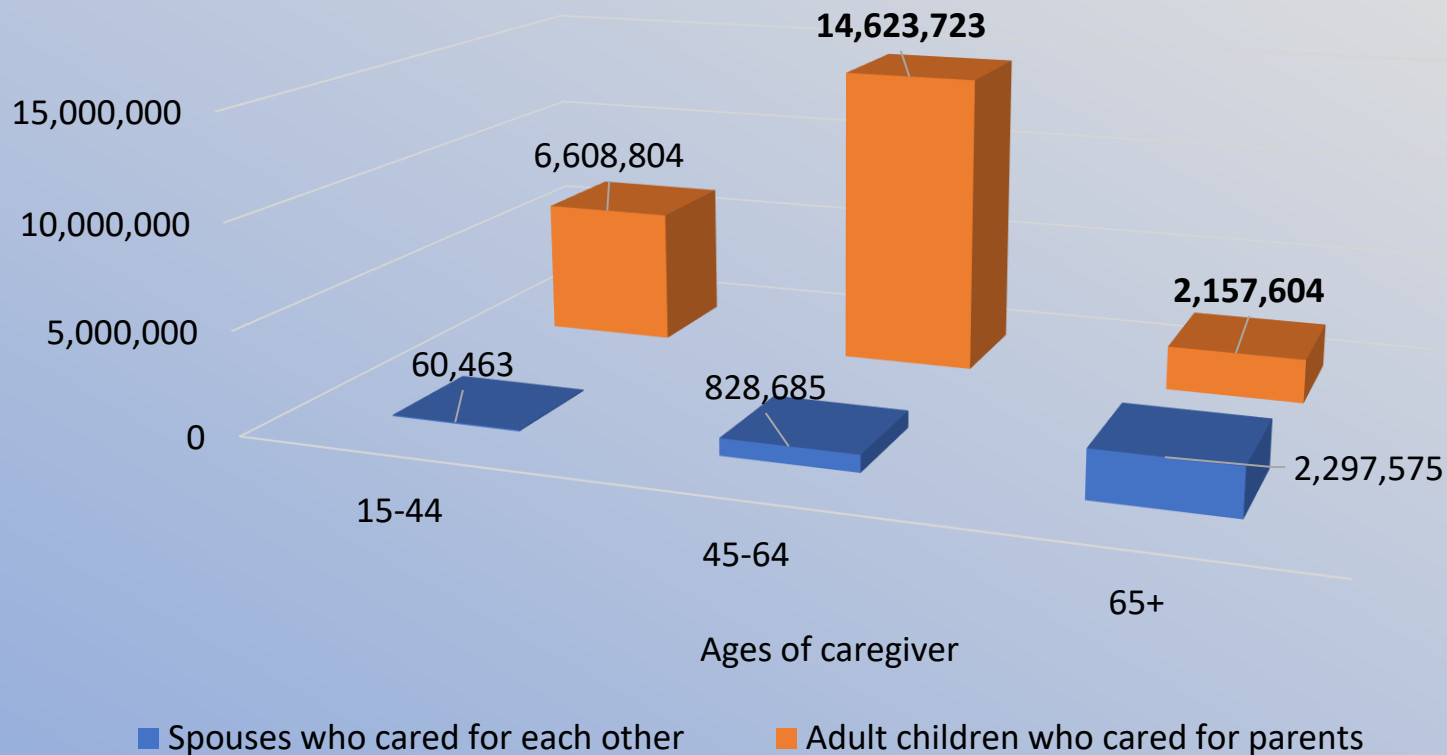
Her two children, the secondary caregivers, are retired at ages 65 and 67 when they get the call: mom needs help.

Is this possible?

Yes, and more often than people imagine.

Adult children retired, but still caring for parents

Number and ages of caregivers for spouses and parents each year, 2011-2017



Points of engagement

- 1 in 11 adult children who care for parents is 65 and older, ages when most people are retired
- 2 in 3 adult children who care for parents are 45 to 64, ages when most people are paying off home mortgages and saving for college and retirement

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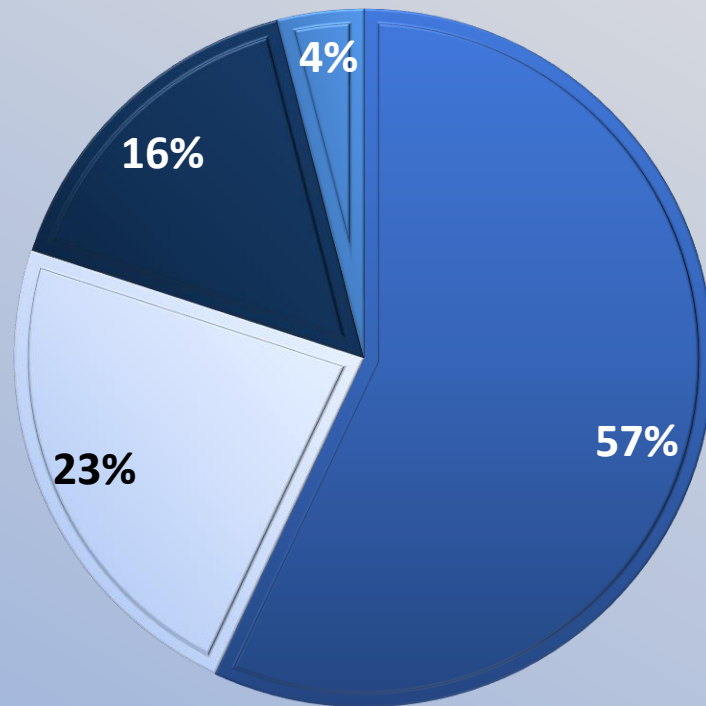
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Conclusions

Main payers of LTC: Medicaid and out-of-pocket

National spending for long-term care¹



■ Medicaid ■ Out-of-pocket ■ Other* ■ Private LTC insurance

- Medicaid is largest payer of LTC, followed by out-of-pocket
- Medicare does not pay for LTC.² Medicare pays for
 - Acute care (hospitalization)
 - Post-acute care after hospital discharge (up to 100 days in skilled nursing facility or home)

* “Other” includes private health insurance, veteran’s Benefits, Indian Health Service, state and local programs, and donations

¹ Hado E, et al. long-term services and supports. AARP Public Policy Institute, August 2019.

² Medicare and you 2022. U.S. Department of Health and Human Services, p.55.

Out-of-pocket costs for individuals needing LTC

Lifetime out-of-pocket LTC cost (2020 dollars) for 65-year-old individuals with HIPAA-level disability, by household income at age 65, and share who will have some costs paid by Medicaid. **Costs for pre-HIPAA-level care are not included.**¹

Income ²	Zero	Up to \$24,999	\$25,000-\$99,999	\$100,000-\$249,999	\$250,000+	Some Medicaid
\$53,504 to \$86,488	60%	12%	13%	9%	5%	22%
\$86,489 to \$142,501	58%	13%	13%	10%	6%	14%
\$142,502+	53%	12%	14%	11%	10%	8%

Point of engagement: Amounts underestimate cost of LTC. They don't include pre-HIPAA-level costs.

¹ Favreault MM, et al. Projections of risk of needing long-term services and supports at ages 65 and older. Urban Institute. January 2021, p.14, 17, 48, 49.

² Semega J, et al. Income and poverty in the United States: 2019. Current Population Reports. U.S. Census Bureau. September 2020, p.7.

Long-term care is expensive, especially at home

	Assisted living	Homemaker services	Home health aid	Nursing home, shared room	Nursing home, private room
Annual cost as usually reported¹	\$54,000 per year	\$59,488 per year for 44 hours of care per week (6.3 hours/day)	\$61,776 per year for 44 hours of care per week (6.3 hours/day)	\$94,900 per year	\$108,405 per year
Annual cost based on hours of care²					
6.3 hours/day	--	\$59,488	\$61,776	--	--
12 hours/day	--	\$113,568	\$117,936	--	--
18 hours/day	--	\$170,352	\$176,904	--	--
24 hours/day	\$54,000	\$227,136	\$235,872	\$94,900	\$108,405
Cost for 1 hour of care	\$6	\$26	\$27	\$11	\$12

¹ Genworth Cost of Care Survey 2021. Genworth Financial, Inc. February 16, 2022.

² Assisted living and nursing home care are 24 hours per day, 7 days per week. Home care varies in this example from 6.3 to 24 hours per day, 7 days per week.

Costs incurred by caregivers

Direct financial cost

Stop saving, borrow, more debt, delay bill payment, delay retirement

Points of engagement

- Retirement nest egg may be used to help parents.
- LTC plan ensures children don't face financial ruin if they need to provide care.

Whiting GC, et al. Caregiving in the U.S. 2020. The National Alliance for Caregiving (NAC) and AARP. May 20, 2020.

Work-related cost

Reduce hours, leave of absence, performance warning, retire early

Points of engagement

- Caregivers work less, disrupt careers, reduce savings, save less for college & retirement, reduce pension & social security credits.

Whiting GC, et al. Caregiving in the U.S. 2020. The National Alliance for Caregiving (NAC) and AARP. May 20, 2020.

Opportunity cost

Wages lost when time at work replaced by time for caregiving

Points of engagement

- Much of life is spent building career.
- If parents couldn't afford LTC, would you quit your job or work fewer hours to care for them?

Mudrazija S. work-related opportunity costs of providing unpaid family care in 2013 and 2050. Health Affairs. June 2019.

Physical & emotional cost

Less time for socialization, sleep, exercise, vacation

Points of engagement

- You were very busy raising your children. It could be like that again if you need to care for your parents, but you'd be much older.

Whiting GC, et al. Caregiving in the U.S. 2020. The National Alliance for Caregiving (NAC) and AARP. May 20, 2020.

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Goldilocks years

For many people, health, wealth, physical ability, and memory won't last forever



Likelihood and cost

LTC is both more common and more expensive than many people imagine



Adult children

Most LTC is provided by adult children. Some children will be retired, others middle-aged



Get help

Financial professionals can help plan for the uncertainties of LTC



Dr. Robert Pokorski is a consultant and public speaker with expertise in longevity, long-term care, and the decline of cognitive and financial ability at older ages. He specializes in educational meetings for financial professionals and consumers. To schedule a webinar or an in-person event, please contact Dr. Bob at:

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