



University of Pittsburgh

Caregiving for the Seriously Ill: Overview and Impacts

Richard Schulz, PhD

**Distinguished Service Professor of Psychiatry
School of Medicine
University of Pittsburgh**



Family Caregiving is an Important Public Health Issue

- 18 million caregivers of older adults
- Economic value of family caregivers' unpaid contributions was at least \$234 billion in 2011
- Growing gap between need/desire for family care and availability
- Adverse impacts on caregiver: economic, psychiatric and physical morbidity, quality of life

Caregiver Role is Complex and Demanding

- Family caregivers have always been the primary providers of older adults' long-term services and supports such as:
 - Household tasks and self-care (getting in and out of bed, bathing, dressing, eating, or toileting)
- Tasked with managing difficult medical procedures and equipment in older adults' homes, overseeing medications, and monitoring symptoms and side effects, and navigating complex health and LTSS systems
 - Including health care services that, in the past, were delivered only by licensed health care personnel (injections, IVs)
 - And, often, without training, needed information, or supportive services

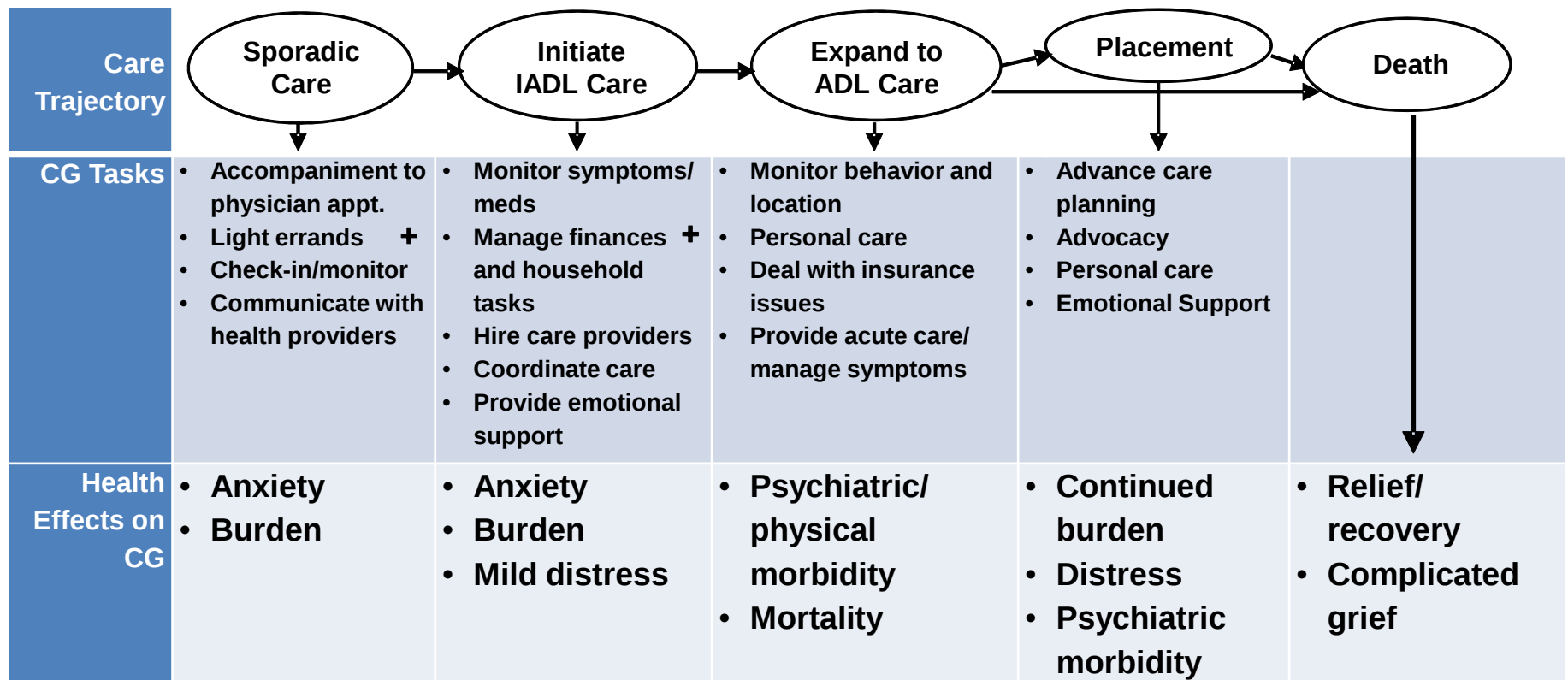
Impact of Caregiving is Highly Individual and Dependent on Personal and Family Circumstances

- For some, caregiving instills confidence, provides meaning and purpose, enhances skills, and brings the caregiver closer to the older adult
- For many, it leads to emotional distress, depression, anxiety, and impaired physical well-being
- Intensity and duration of caregiving and the older adult's level of impairment are consistent predictors of depression or anxiety
- Other risk factors for adverse effects:
 - low socioeconomic status
 - high levels of perceived suffering of the care recipient
 - living with the care recipient
 - lack of choice in taking on the caregiving role, poor physical health of the caregiver
 - lack of social support
 - physical home environment that makes care tasks difficult

Financial Risks of Caregiving

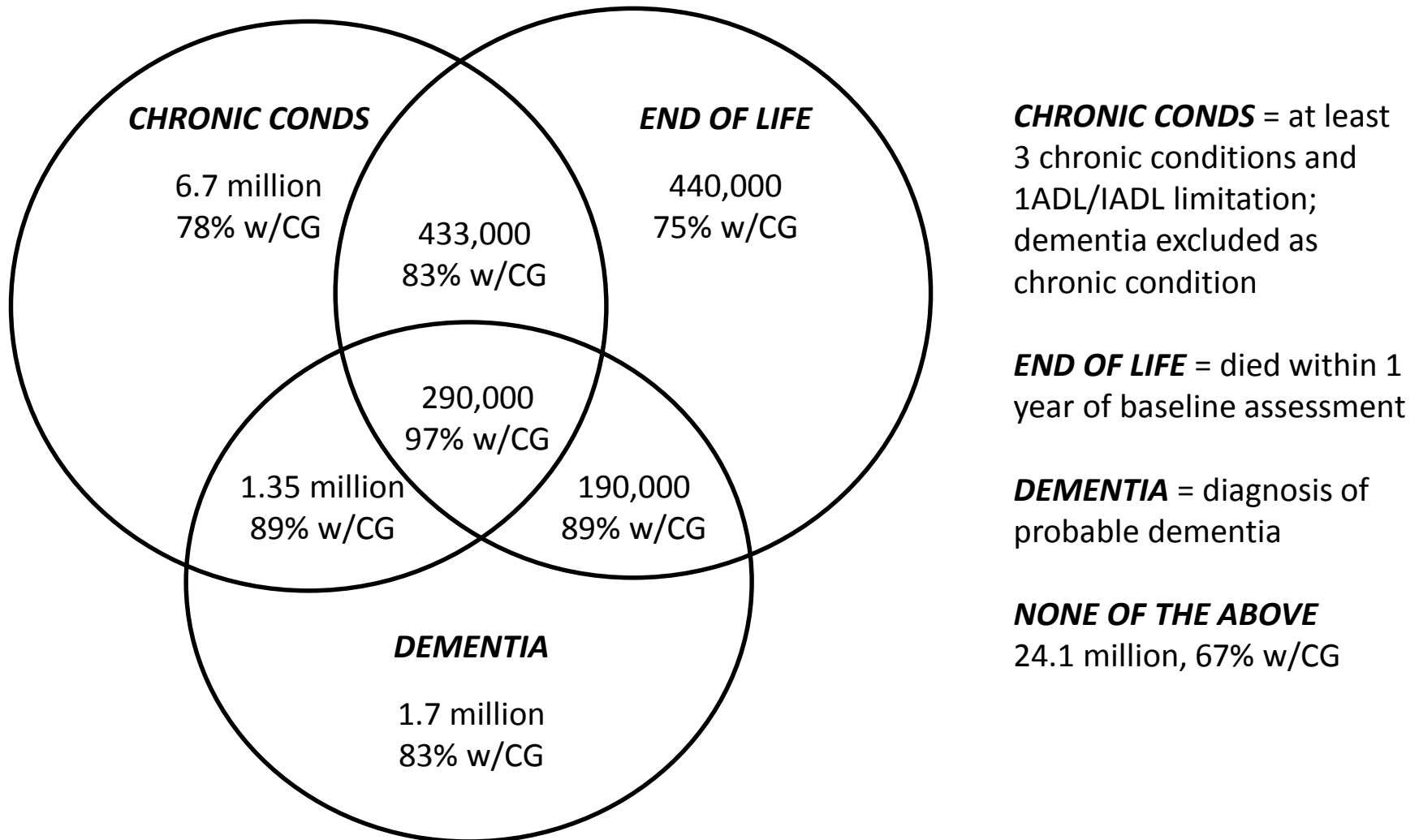
- Loss of income, Social Security and other retirement benefits, and career opportunities if they have to cut back on work hours or leave the workforce
- Substantial out-of-pocket expenses that undermine their own future financial security
- Most vulnerable are women, those with low income, persons who live with or far from care recipient, those with limited work flexibility

Care Trajectory: Tasks and Health Effects



High Need/High Cost Patients and Their Caregivers

Figure 1. Three Overlapping Patient Populations and Proportion w/at Least One Unpaid Caregiver (CG)*



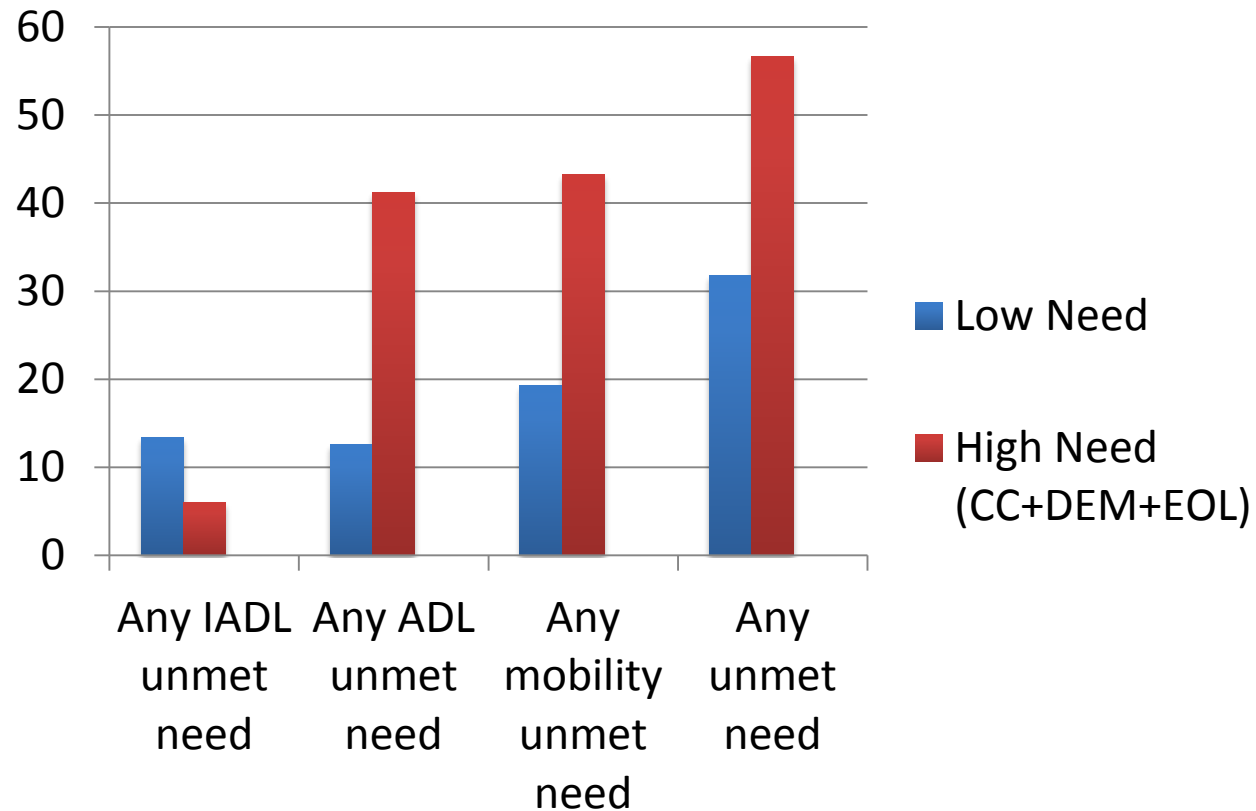
Source: National Health and Aging Trends Study (NHATS, 2011, N=7609); non-institutionalized U.S. older adults aged 65 and over, 35.3 million, weighted population estimates.

High Need/High Cost Patient Caregiver Impacts*

- More hours of care (1/3 report >100 hours per month)
- Provide help with more types of tasks
- Increased caregiver psychological and physical morbidity
- Increased financial strain (e.g., out-of-pocket expenditures, labor force participation)

*Compared to caregivers of low need patients; Schulz et al., *J. of Palliative Medicine*, 2018

Percent with Unmet Needs: Low and High Need Patients



High Need/High Cost Patient Unmet Needs

- Multiple Chronic Conditions (MCC):
 - Wet or soiled clothing; go without bathing, getting dressed, having to say in bed, stay inside, have limited mobility in home, and go without hot meals
- Persons with Dementia (DEM):
 - Wet or soiled clothing; bed bound, limited mobility in home
- End of Life (EOL):
 - Limited mobility in home; went without clean laundry

Contact: schulz@pitt.edu

Work supported by:

NIH (NIA, NINR)

Stern Family Foundation

Pittsburgh Foundation