

End-of-Life Care for People Living with Dementia

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July 7, 2020

Outline

Context for dementia and end-of-life care

Key policy challenges

Key gaps in our knowledge

Context for Dementia Care

Almost 6 million PLWD in the United States

- Most are older and live at home or in other community-based settings
- Many with more advanced dementia live in NHs
- Most have limitations in self-care, mobility, and other ADLs

Health care costs very high for PLWD in last years of life

- Sizeable portion for LTSS and unpaid care

Medicare and Medicaid programs central

- Medicare covers 95% of all people with dementia
- Medicaid covers 25% of PLWD in community and 70% of PLWD in NH

Context for End-of-Life Care

EOL care for PLWD often poor quality and misaligned with preferences

Excessive hospitalizations and burdensome transitions at EOL

- Many hospitalizations unnecessary and inconsistent with patient and family wishes
- Increase chances for discontinuity in care and poor symptom management

Limited financing for palliative care outside of hospice

Hospice use has increased

- 1-in-5 enrollees now have primary Dx of dementia

Decrease in NH and hospital deaths and increase in home and hospice deaths over last decade

- Still, around 2/3 with advanced dementia die in NHs

New Context: COVID and EOL Care

Estimated 15,000 excess deaths among those with ADRD in US, Feb-May '20

NHs account for around 40% of all COVID deaths in the US

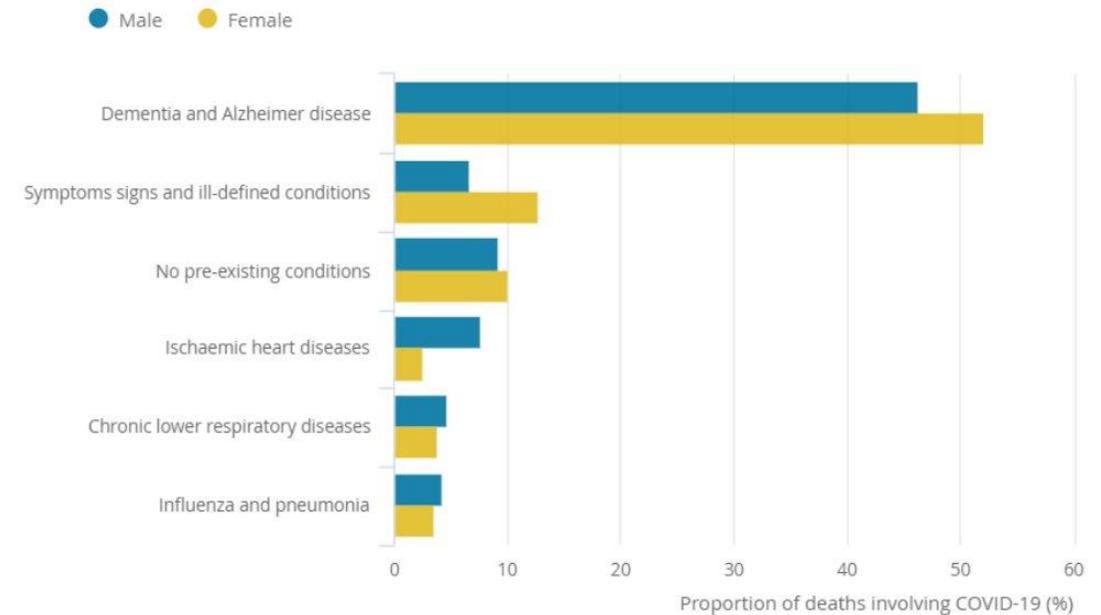
- Uncertain ability to provide adequate EOL care in context of lockdown
- Limited access for hospice agencies

Limited data on impact for PLWD in ALFs and at home

Collateral and longer-term impact is unclear

Dementia and Alzheimer disease was the most common pre-existing health condition in deaths involving COVID-19 among care home residents

Proportion of deaths of care home residents involving COVID-19 by main pre-existing condition, occurring from 2 March to 12 June 2020, registered up to 20 June 2020, England and Wales



Source: Deaths involving COVID-19 in the care sector, England and Wales: deaths occurring up to 12 June 2020 and registered up to 20 June 2020 (provisional)

Office for National Statistics

Key Policy Challenges

Medicare Hospice Benefit Limitations

Inadequate Coverage of Long-Term Services and Supports

Fragmented Service Delivery at End-of-Life

Medicare Hospice Benefit Limitations

Benefit structure a poor fit for PLWD

- Not available initially to NH residents

Prognosis requirement a barrier to hospice access

- PLWD have longer LOS and higher rates of live discharge

Hospice enrollment doesn't address other systemic challenges

- Not a LTSS substitute
- Doesn't address broader NH quality challenges
- Substantial racial/ethnic disparities in hospice enrollment

Artificial division between Medicare SNF and hospice benefits

- Forces choice between rehabilitation and comfort care
- SNF care incentivized for patients and providers

Inadequate Long-Term Services and Supports Coverage

Almost all PLWD need LTSS in years leading up to EOL

- Yet, no universal coverage

Few purchase private insurance

- Less than 10% among people 65+ (few new policies purchased)

Implications of coverage gap especially severe for PLWD

- Reliance on family and unpaid care, out-of-pocket payments, and Medicaid

Some bipartisan discussions of national coverage, in addition to being included in some Medicare-for-All plans

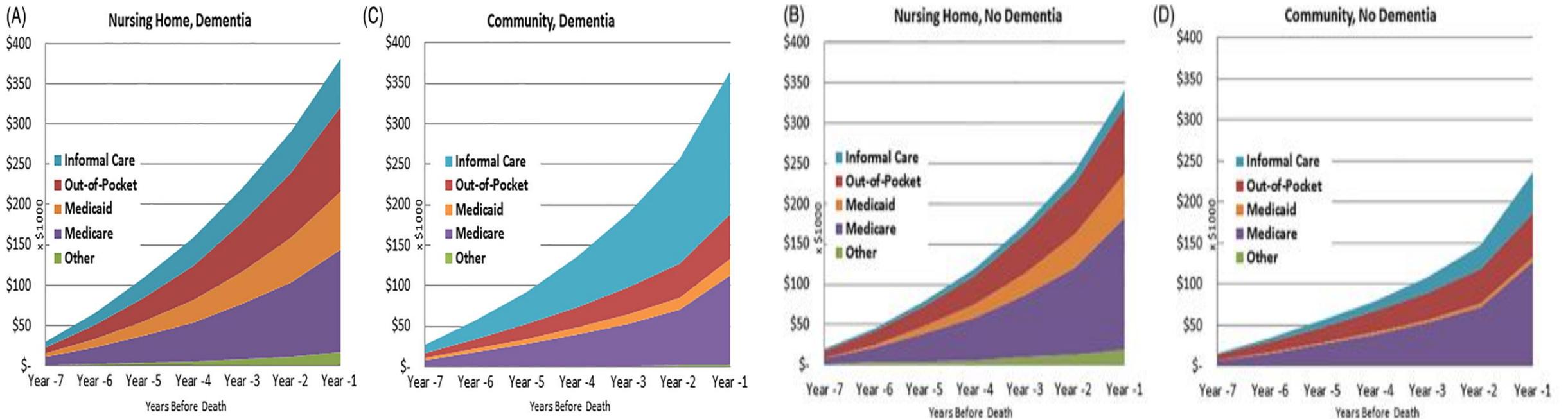
State efforts may hold greater promise for now

- Washington is most notable example - just underway
 - Payroll-tax funded, \$100/day up to 100 days (starting in 2025)

Large Role for Unpaid Care and OOP Costs

Over last 7 years of life, total costs considerably higher for PLWD (\$372k vs. \$243k)

- o OOP + unpaid care especially prominent for those living in the community (64%)
- o Larger role for PLWD, on average: \$203k (Dementia) vs. \$103k (No Dementia)



Source: Kelly et al. Residential Setting and the Cumulative Financial Burden of Dementia in the 7 Years Before Death. 2020. *JAGS* 68 (6): 1319-1324.

Payment Silos Highlight Need for System Redesign

Service needs of PLWD currently fragmented by:

- Payer type and benefit
 - inpatient and outpatient (Medicare Parts A and B)
 - post-acute rehabilitation (Medicare SNF and home health)
 - end-of-life (Medicare hospice)
 - long-term services and supports (Medicaid/out-of-pocket)
- Provider type/setting
 - MDs, hospitals, nursing homes, home health, and hospice

Implications can be higher costs and worse outcomes:

- Few incentives to coordinate care across settings
- Perverse incentives within settings
 - hospitalization of NH residents

The Need for Integrated Care

PLWD have interconnected medical, social, and supportive service needs

In context of policy, we often talk about these needs separately

- Reflects Medicare's fragmented approach and exclusions

Dying in America → piecemeal reforms won't be effective

- Committee argued for different mix of medical and social services
 - Caregiver training and support, home modifications, meals/nutrition, and transportation

Policy context moving in this direction via role of managed care and value-based care

Research Gaps

Interaction between Medicare and Medicaid services for PLWD who are dually eligible

- Little known about how Medicaid LTSS and Medicare acute/post-acute services interact (not to mention unpaid supports from family)

End-of-life care quality in nursing homes

- Lack of NH Compare measures and regulatory focus inhibits quality improvement

Expanded access to palliative care outside of the hospice benefit

- Opportunities through MA plans and value-based approaches
- Still unclear how to deliver these services effectively for PLWD

Impact of enrollment in MA Special Needs Plans and other integrated financing and delivery models

- Yet, hindered by lack of quality measures specific to PLWD and to EOL

Concluding Thoughts

General EOL policy challenges have more severe consequences for PLWD

- Gaps in financial coverage
- Care fragmentation
- Care that is misaligned with individuals' preferences

Hospice can help but with challenges

- Do we need a reconceptualization of hospice?

Quality measurement will need to keep pace with policy context

- Increased flexibility for Medicare Advantage plans to reimburse palliative care

COVID further exposes considerable gaps in system

Thank you!

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