

# End of Life: Hospice and Palliative Care, Clinician Perspective

*National Academy of Sciences Workshop on Nursing Home, Hospice and Palliative Care for Individuals with Later Stage Dementia*

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# Outline



Case Presentation



Caregiving Challenges



Limitations in Home-based Hospice and Palliative Care in dementia

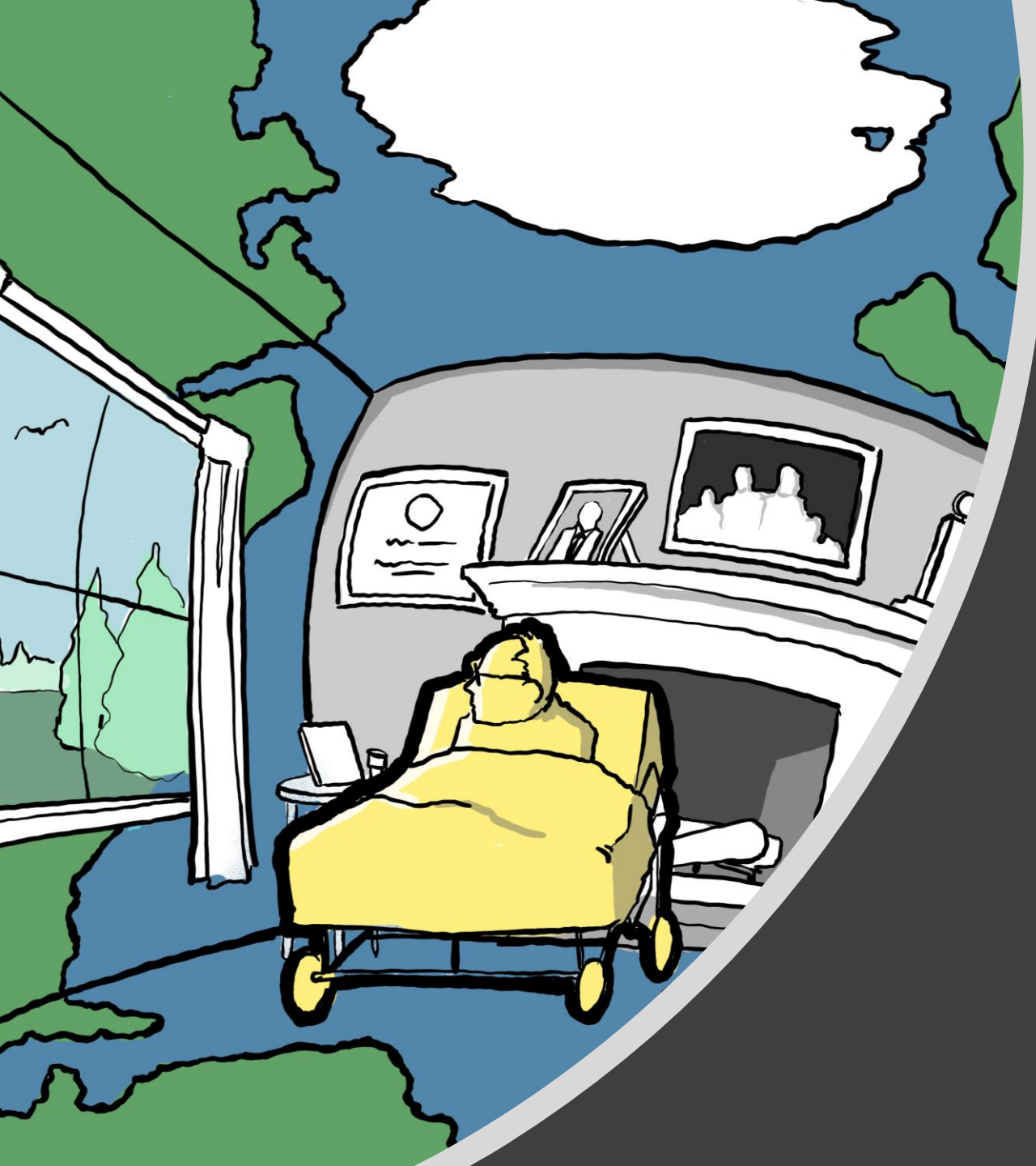


Directions for Research

# Disclosure

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*I have no potential conflicts of interest to report.*



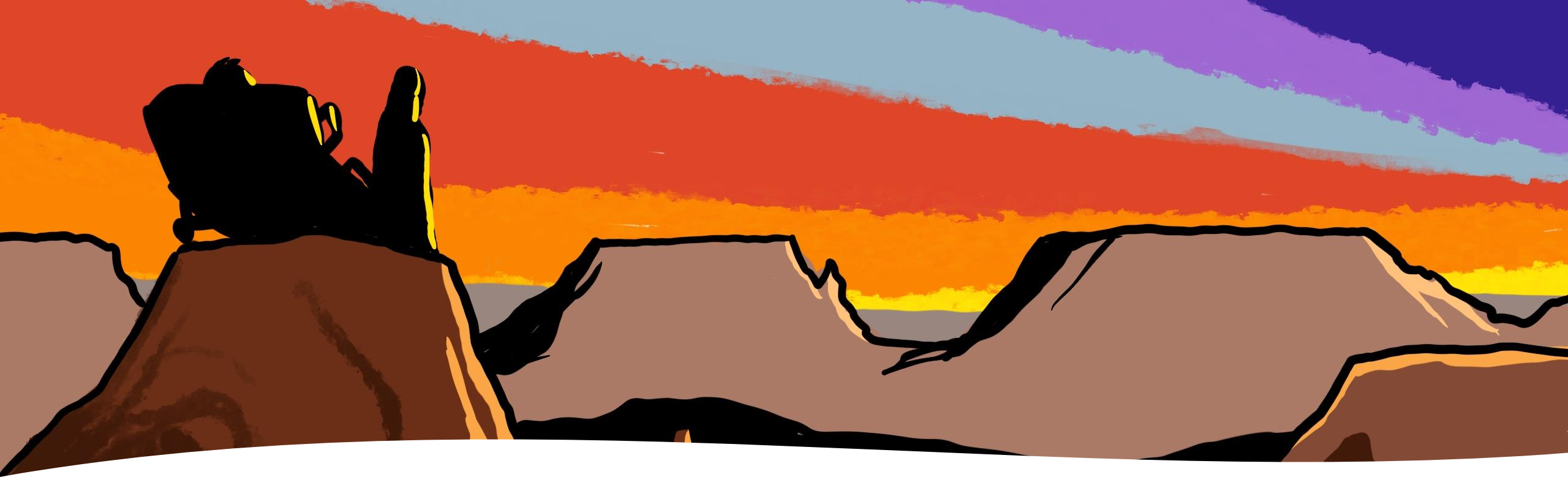
# Case Presentation

Mr. R

# Challenges in Caregiving

- Caregiver demands
  - From time of diagnosis, lifetime cost of dementia care \$322K (Jutkowitz, et al. *J Amer Geri Society* 2017.)
    - 70% born by family
  - Isolation, lost sleep, lost sense of identity
  - Neglect of caregiver's own health needs and wellness





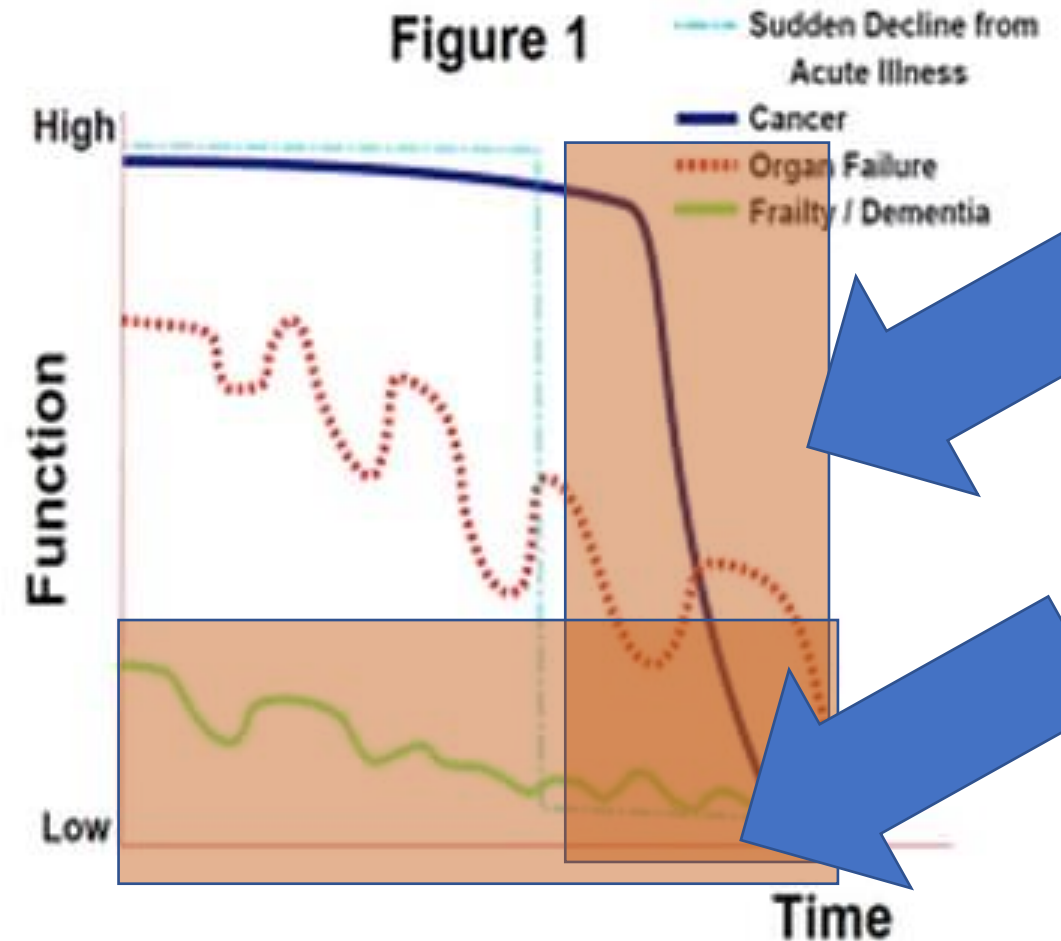
## Challenges in Caregiving

- End of life
  - Usual supports more difficult to access
  - Adult daycare, clinic-based primary care, specialty geriatrics support
  - Escalating physical needs, symptom burden, behavioral disturbances make in-home care particularly challenging



# Limitations in Hospice and Palliative Care

- Hospice eligibility guidelines in use do not reliably predict prognosis (Brown MA, et al. *Palliat Med.* 2013;27(5):389-400.)
- Dementia is the hospice diagnosis with the greatest variability in length of survival (Am J Hosp Palliat Care. 2003; 20(2):105-13.)
- Enrollments often either very short (<1 week) or very long (>165 days) (De Vleminck, et al. J Am Dir Assoc. 2018; 19(6):633-38.)



# Limits in Hospice and Palliative Care

- Hospice
  - Limited caregiver support at home
  - Limited ability to access inpatient hospice services
  - No routine caregiving hours, respite can be difficult to obtain
  - Wide variation in hospice access in nursing homes



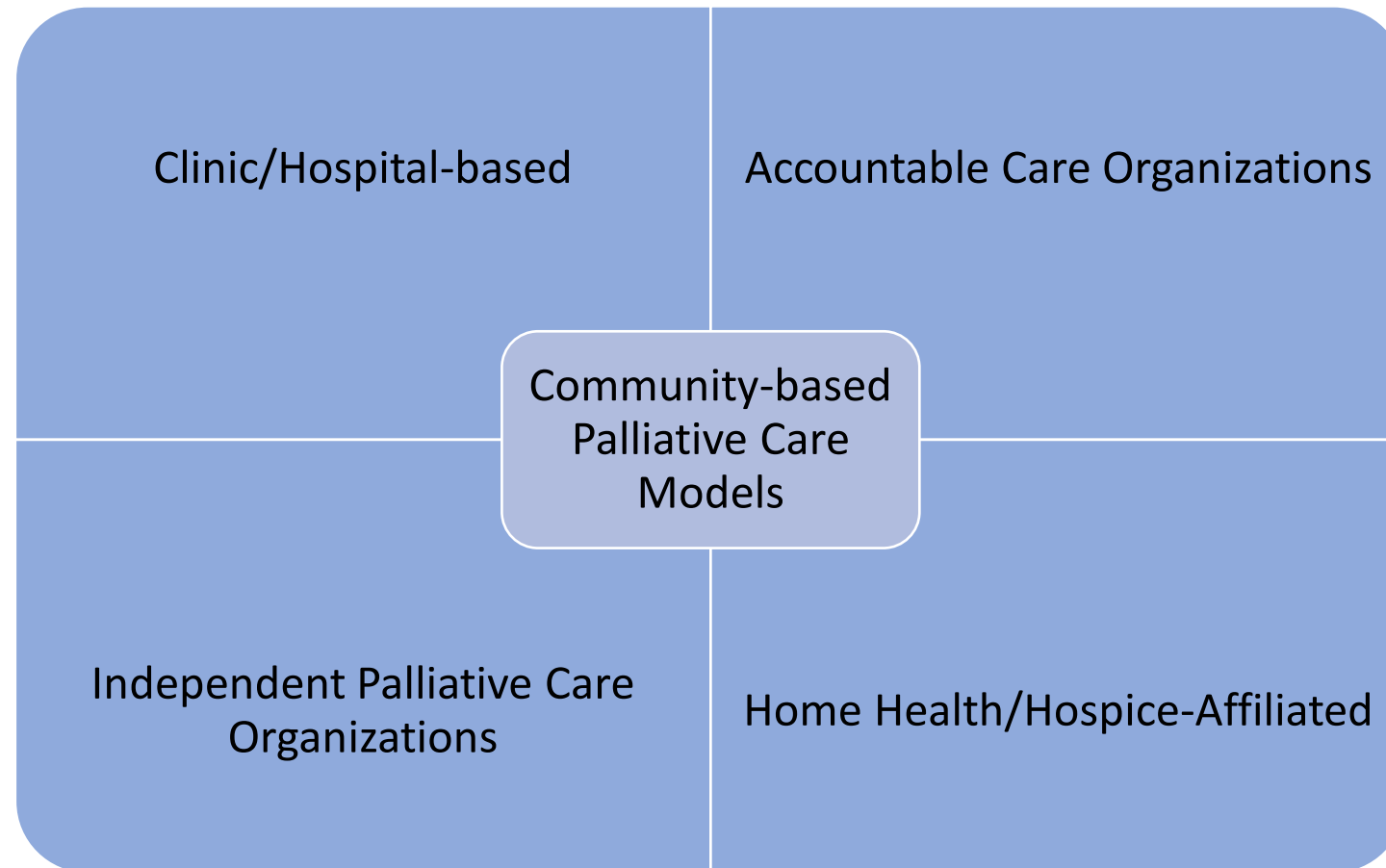


# Case Presentation

- Mr. R



# Limits in Palliative Care Infrastructure

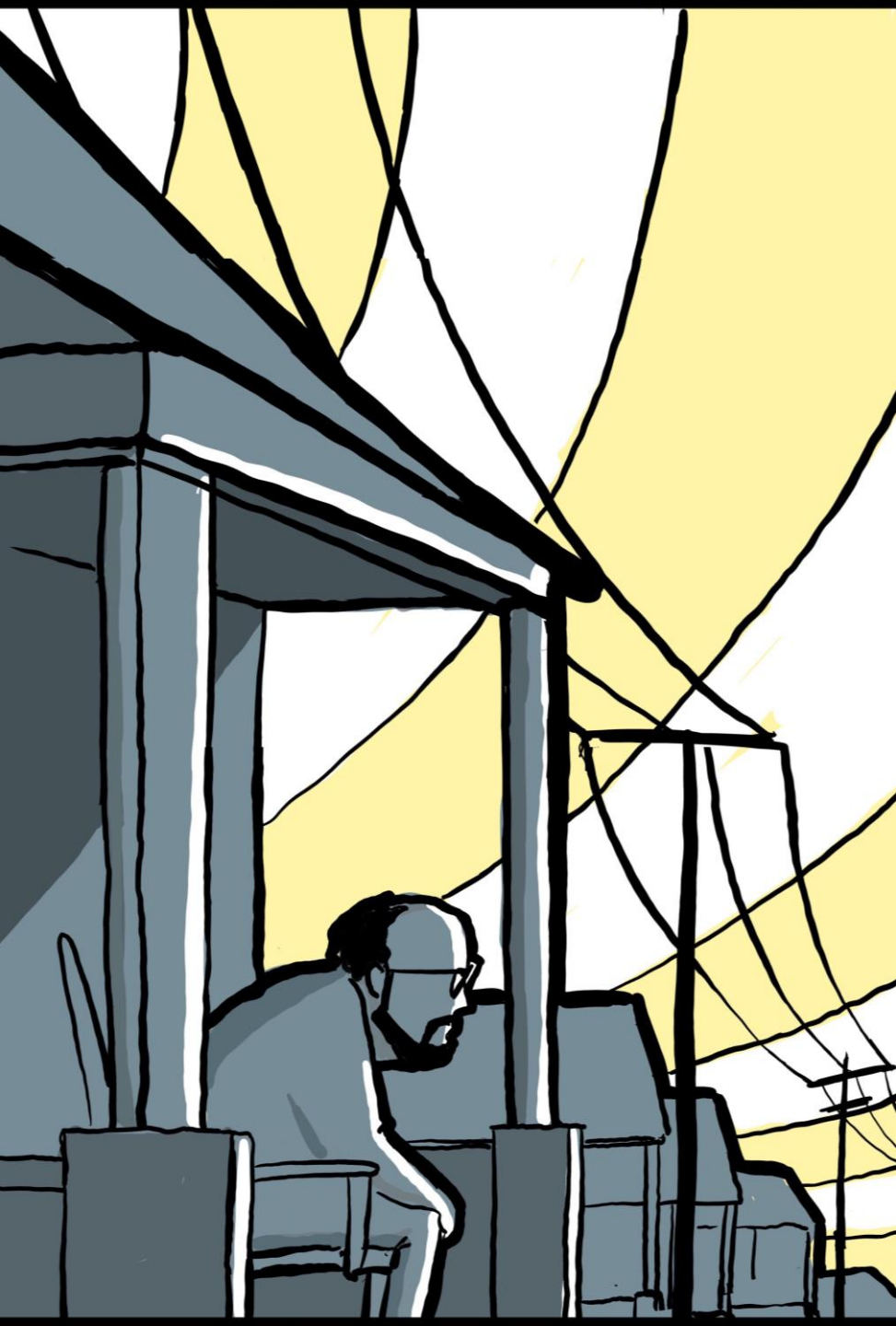




# Limits in Palliative Care Infrastructure

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- Limitations in models
  - Lack of personal care services
  - Lack of home skilled medical services such as PT/OT/RN (outside of post-acute) reimbursement model
  - Lack of uniformity
  - Partnerships with ACO's and risk-sharing may shift focus away from patient goals
  - No regulatory oversight, wide variability



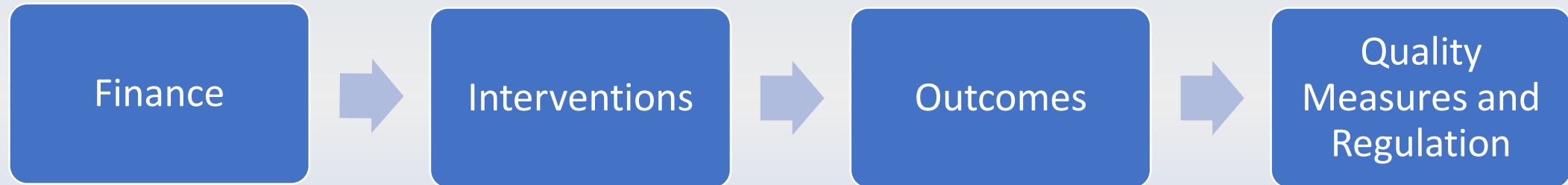
# Needs

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- Reimbursement structure for comprehensive palliative care services (physician, social work, nursing, chaplaincy)
- Home Health Aide hours
- 24/7 phone access for triage
- Accessible in-home primary care
- Family/caregiver counseling
- Transportation for specialty clinical services

# Future directions for research

- Quality investigation needed across the spectrum of community-based PC delivery
- Limited research into palliative care interventions in advanced dementia - *Cochrane Database of Systematic Reviews 2016, Issue 12. Art. No.: CD011513*
- Moving away from the “one-size fits all” hospice model, we should look toward need-based interventions rather than prognosis-based bundles



# Future directions for research

- Trials of in-home interventions for patients with dementia to determine best strategies and “doses” that will allow improved QOL, appropriate resource utilization, and goal concordant care





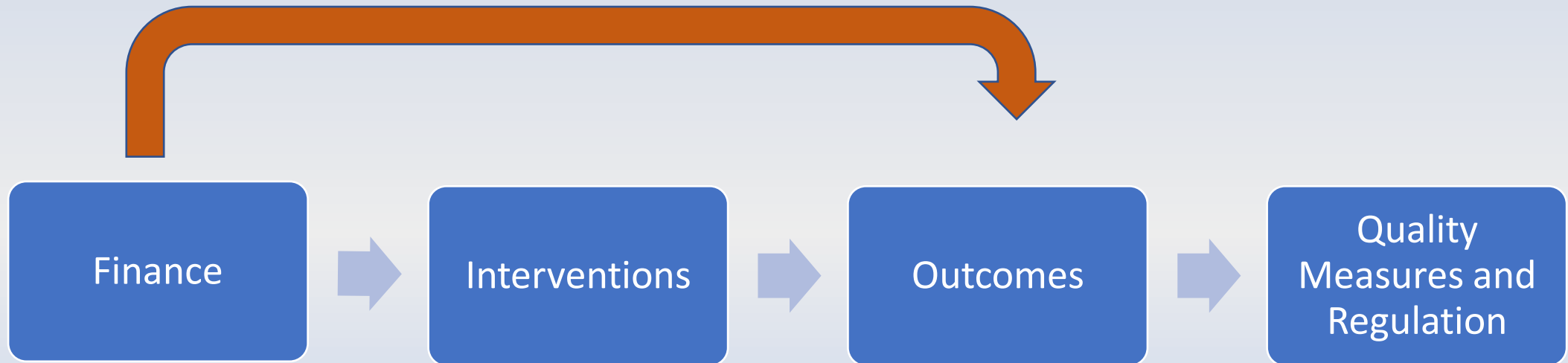
# Future directions for research

- Studies on the impact of various methods of financing palliative care services on access, quality, and cost of community-based services in dementia.



# Future directions for research

- Cost analyses of utilization and expenditures for in-home support that might bolster public policy arguments for expanded services for patients with advanced dementia.



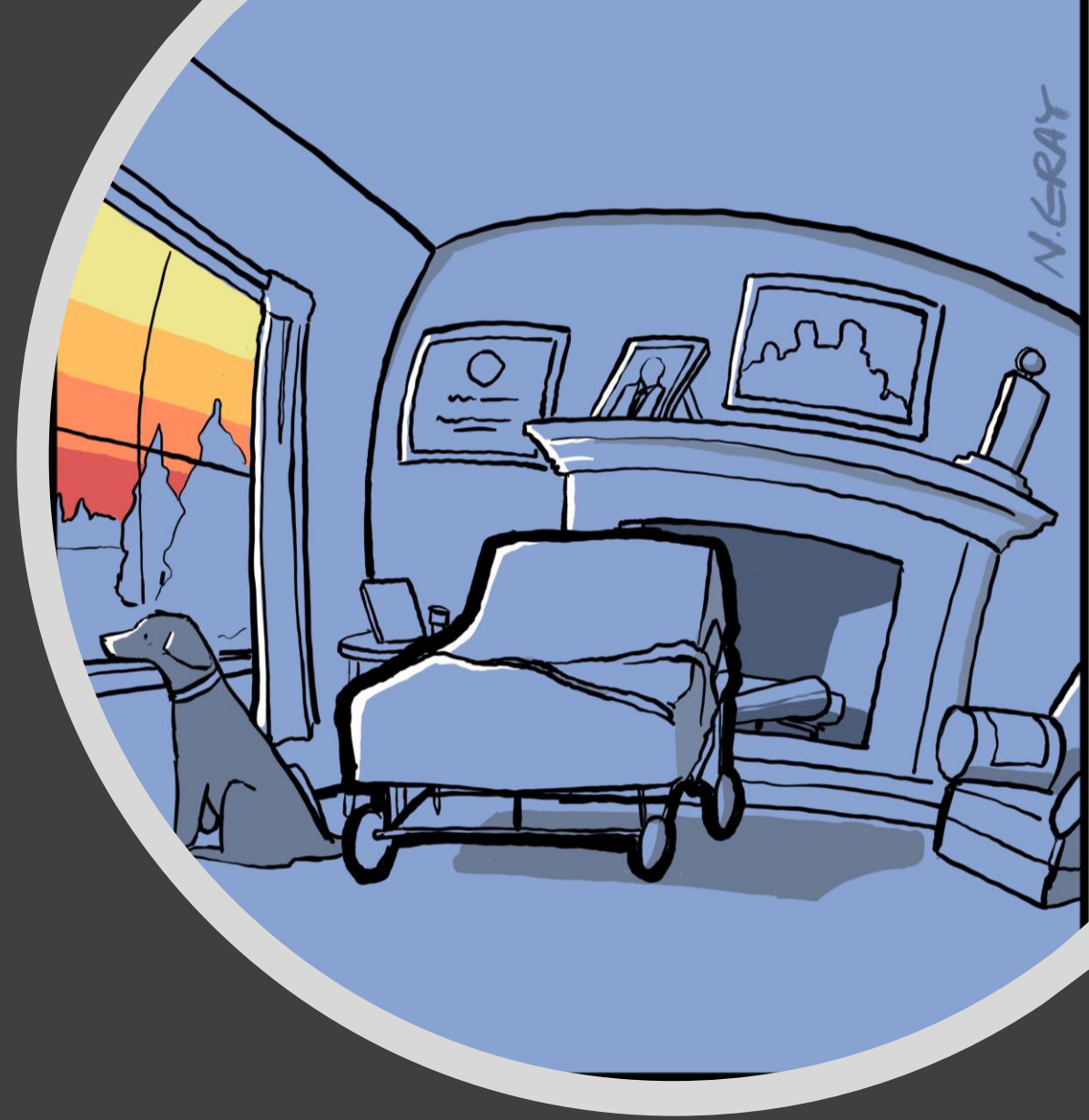
# Future directions for research

- Development of disease specific quality metrics to be used in oversight, accreditation, and care improvement for community-based palliative care.



# Thanks

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# Questions/Comments

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