





**NATIONAL ALZHEIMER'S PROJECT ACT COMMITTEE
REPORT ON 2014-15 RECOMMENDATIONS**

OCTOBER 24, 2022
SUSAN L MITCHELL MD, MPH

 Marcus Institute
for Aging Research
Hebrew SeniorLife

 HARVARD MEDICAL SCHOOL
AFFILIATE

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2014-15 Advanced Dementia Expert Panel

Objectives:

- To convene experts to review current research, innovative practices, and health policy pertinent to the care of persons with advanced dementia and their families
- To make recommendations to HHS and the NAPA Advisory Council about priority initiatives to improve that care.

Meetings

Research: January 28, 2014

Clinical Practice: September 28, 2014

Policy: January 21, 2015

Organization

Co-Chairs: Susan Mitchell MD MPH, Laurel Coleman MD

Facilitator: Katie Maslow, "IOM"

Core Group: Attend all meetings, formulate final recommendations

Experts: Specific meetings

Observers: public, professional and provider organizations, advocates, and staff from many federal agencies (AoA/ACL, AHRQ, ASPE, CDC, CMS, HRSA, NIA, NINR, SAMHSA, and VA)

Research: Main Conclusions

Design: Descriptive >>> intervention

Methodology: Database = primary

Setting: nursing home > hospital > community

Focus: Feeding tubes > infections > hospice > decision-making > prognosis > family > costs

Knowledge: Delineated problems and main targets to improve care

Research: Main Conclusions

Clinical Course: Terminal condition, prognostication difficult

Sources of Distress: Treatable symptoms, measurement challenges

Treatment of clinical complications

- Feeding and infections most common

- Tube-feeding has no benefit, overuse of antibiotics

Health services

- Hospice helps but under-utilized

- Hospital: common, costly, burdensome, avoidable

- Misuse of Skilled Nursing Facility (post acute care)

- Disparities

Strategies to improve care

- Mostly observational: Advance care planning, hospice,

- Two RCTs: decision support tools

Research: Main Conclusions

- Clearly delineated opportunities to improve care
- Research priority: determine how to address opportunities
 - Design and test clinical interventions and models of care to improve advanced dementia care
 - Design and evaluate health policy initiatives that incentivize high quality goal-directed care

Clinical Practice: Main Conclusions

- Promising programs are slow to “scale up” and replicate
- Programs merit broader evaluation
- Successful programs need good leaders and culture change
- Are there policy incentives/ and regulatory “levers” that could hasten implementation of these models?

Policy: Main Conclusions

- Complex policy issues with high risk for unintended consequences
- Lack of access to palliative care
- Long-term care: complex fiscal and regulatory policies create misaligned incentives that promote poor care
- Hospice: problems with access for persons with dementia, documentation of dementia diagnosis, and coordination with the Medicare SNF benefit
- Home and community care: Large number of persons with advanced dementia but little information about specific needs
- Acute and sub-acute care settings and services: High use but care is often not beneficial
- Quality metrics: many unique issues for advanced dementia

Final Recommendations

- **Overarching Goal**
 - To ensure the quality of life and quality of care for persons living with advanced dementia and their families across care settings
- **Formulated by Core Group**
- **Principles**
 - Focus on advanced dementia
 - Build from and fill gaps in the existing National Plan
 - Not iterative of other federal initiatives
 - Focus on priorities
 - Feasible

Strategy 1

To ensure access to high quality palliative care for persons with advanced dementia and their families across all settings via...

- Primary palliative care
- Palliative care consultation
- Hospice
 - Beneficial but major access concerns

Strategy 2

Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families

- Healthcare workers (nurses, physicians, direct care workers, social workers) and long-term services and supports (e.g., transportation, meals)
- Culturally competent
- Across all settings
- New and existing workers

Strategy 3

Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia

- Harmonize documentation across settings
- Critical to care, research, program evaluation, and policy

Strategy 4

Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families

- Across care settings
- Align payment and delivery
- Unique considerations that merit focus on advanced dementia

Strategy 5

Leverage existing policy mechanisms to ensure access to high quality care for persons with advanced dementia and their families

- Examples: payment, regulatory, and public reporting
- Consider existing infrastructure, e.g. state coalitions to improve dementia care, QIOs (Quality Improvement Organizations), HHS Partnership for Patients

Strategy 6

Support quality metrics that ensure transparency and accountability for the care of persons with advanced dementia and their families

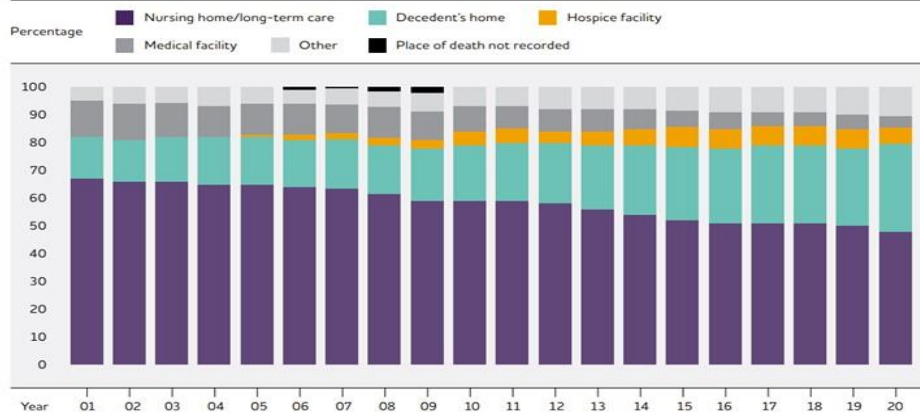
- Include proxy reporting (e.g. family, nurse)
- Examples of unique metrics
 - Effective symptom assessment and management
 - Burdensome, non-beneficial treatments (e.g., tube feeding, transitions)
 - Care concordant with values and preferences
- Critical for clinical care accountability and research and policy evaluation

Pivotal Events 2015-2022

- Huge influx of AD/ABDR research \$\$ to NIA
- Hospice policies to reduce long-stays
- Maturation and uptake of electronic health records
- National Partnership
- Huge increase in Medicare Advantage (~45%)
- AHRQ and NASEM reports on dementia interventions
- COVID pandemic

Strategy 1: Palliative Care Access

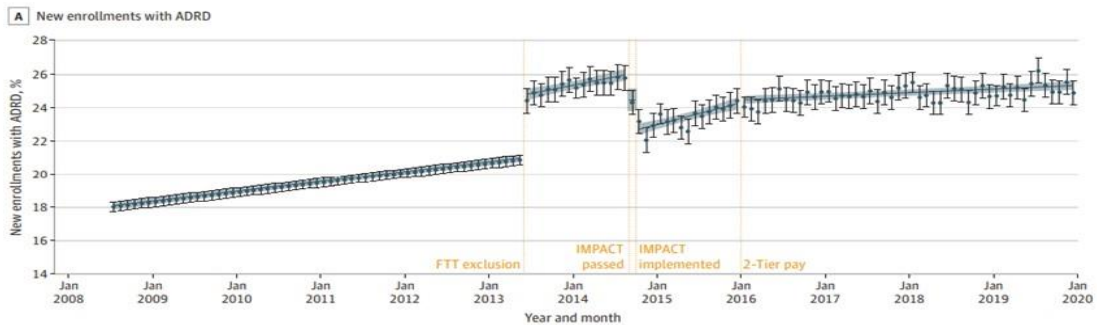
Place of Death Due to Alzheimer's Disease, 2001 to 2020



Strategy 1: Palliative Care Access

- Hospice
 - Benefits patients with dementia
 - % hospice patients increases in 2010's
 - dementia patients increasing, have longer-stays
 - 2 CMS polices long-stay “crack down”
 - audit hospice providers with ++ long-stays (2014)
 - reduced payment after 60 days (2016)

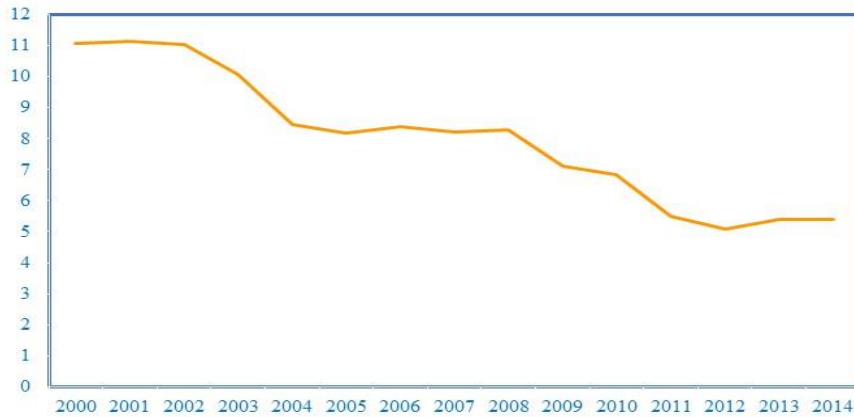
Strategy 1: Palliative Care Access



Gianattasio, JAMA 2022

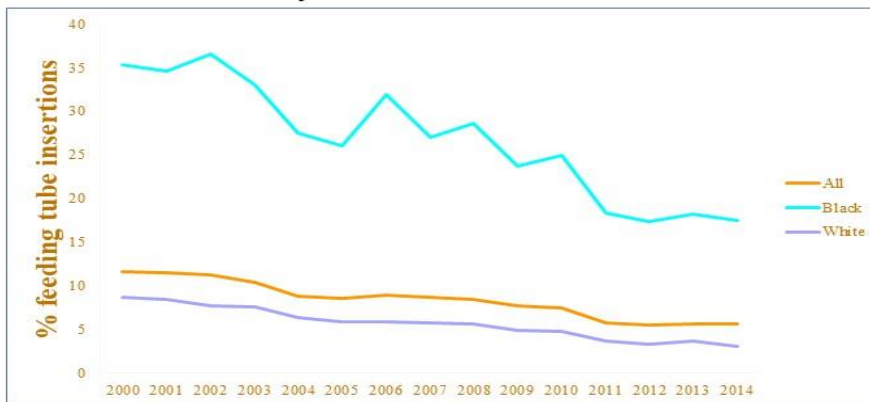
Strategy 1: Palliative Care Access

Feeding insertions in nursing home residents with advanced dementia 2000-2014

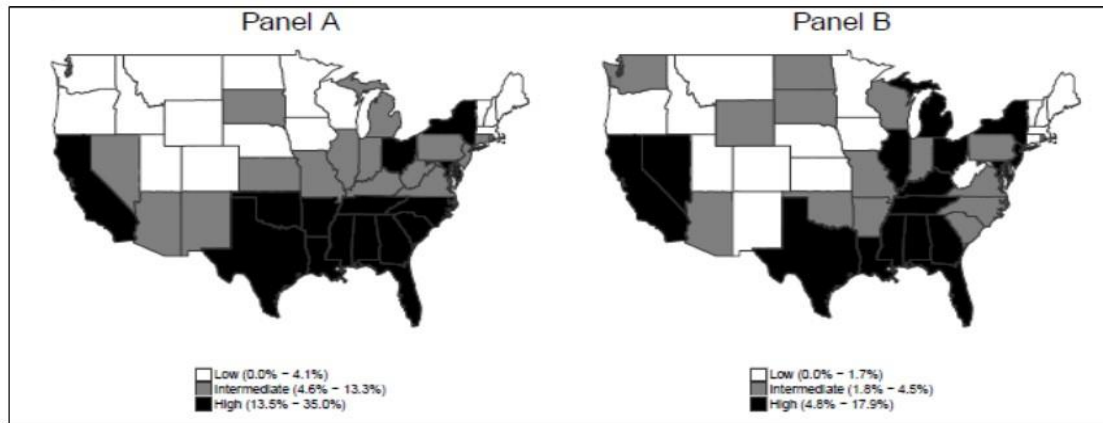


Strategy 1: Palliative Care Access

Feeding insertions in nursing home residents with advanced dementia 2000-2014 by Race



Strategy 1: Palliative Care Access



Strategy 1: Palliative Care Access

- By every metric non-White, Black people living with advanced dementia receive poorer quality palliative care
- Systemic racism ingrained in health care delivery
- But...there are opportunities to target
 - Standardized training cultural competency
 - Standardized training in advanced dementia
 - Integration of goal directed care

Strategy 2: Workforce

JAMA Internal Medicine | Original Investigation

Association of Nursing Home Organizational Culture and Staff Perspectives With Variability in Advanced Dementia Care The ADVANCE Study

- Low-resourced NHs with relatively fewer staff and little in the way of staff training in dementia provide more aggressive care
- Staff in all NHs expressed assumptions that proxies for Black residents were reluctant to engage in advance care planning and favored more aggressive care.
- Many staff believed that feeding tubes prolonged life and had other clinical benefits.
- Improving advanced dementia care requires train staff in evidence based, shared decision-making, and cultural competency.
- **Impact of COVID**

Strategy 3: Data/Documentation

The image displays two screenshots. The left screenshot is from HealthIT.gov, showing the United States Core Data for Interoperability (USCDI) page. It includes a navigation menu, a search bar, and a main content area with a heading 'United States Core Data for Interoperability (USCDI)'. The right screenshot is from the HL7 FHIR Patient Reported Outcomes Implementation Guide, showing the title 'Patient Reported Outcomes FHIR Implementation Guide' and a table of contents.

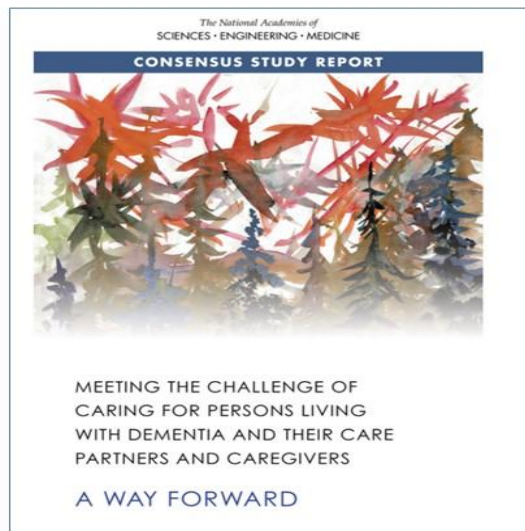
Desiderata for the development of next-generation electronic health record phenotype libraries

Martin Chapman ✉, Shahzad Mumtaz, Luke V Rasmussen, Andreas Karwath, Georgios V Gkoutos, Chuang Gao, Dan Thayer, Jennifer A Pacheco, Helen Parkinson, Rachel L Richesson ... Show more

Strategy 3: Leveraging Real World Data

- Challenges specific to dementia
 - Stage
 - Type
 - Caregiver
 - Health Equity

Strategy 4: Models of Care



Strategy 4: Models of Care

JAMA Internal Medicine | Original Investigation
The Trial to Reduce Antimicrobial Use in Nursing Home Residents With Alzheimer Disease and Other Dementias (TRAIN-AD): A Cluster Randomized Clinical Trial
 Susan L. Mitchell, MD, MSc, Daniel A. Habtemariam, Laura C. Hanson, MD, MPH, Andrea J. Loizeau, PhD, RN, PhD, Michele L. Shaffer, PhD

JAMA Internal Medicine | Original Investigation
Effect of the Goals of Care Intervention for Advanced Dementia: A Randomized Clinical Trial
 Laura C. Hanson, MD, MPH, Sheryl Zimmerman, PhD, Mi-Kyung Song, PhD, RN, Feng-Chang Lin, PhD, Cherie Rosemond, PhD, Timothy S. Carey, MD, MPH, Susan L. Mitchell, MD, MPH

The Hospice Advanced Dementia Symptom Management and Quality of Life Trial (HAS-QOL)
 Journal of pain and symptom management
 Author Manuscript HHS Public Access

Triggered Palliative Care for Late-stage Dementia: a Pilot Randomized Trial
 Research Article
A Communication Intervention to Reduce Resistiveness in Dementia Care: A Cluster Randomized Controlled Trial
 Kristine N. Williams, RN, PhD, FGSA, FAAN,^{1,*} Yelena Perkhounkova, PhD,¹ Ruth Herman, PhD,² and Ann Bossen, RN, PhD¹

THE GERONTOLOGICAL SOCIETY OF AMERICA*
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 Advance Access publication April 5, 2016
 OXFORD

Strategy 4: Models of Care

Funding Opportunity Title

NIA AD/ADRD Health Care Systems Research Collaboratory (U54 Clinical Trial Required)

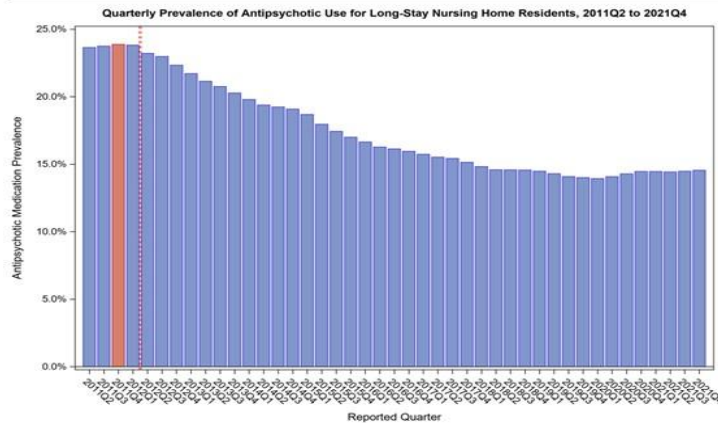


NIA IMPACT
COLLABORATORY
 TRANSFORMING DEMENTIA CARE

Mission

To build the nation's capacity to conduct ePCTs of non-pharmacological interventions within health care systems (HCS) for people living with dementia (PLWD) and their care partners (CPs)

Strategies 5/6: Leveraging Policies and Metrics



- National Partnership
- 2012
- CMS plus state/federal agencies
- Antipsychotic Use primary metric
- Good but also need alternative management strategies

Strategies 5/6: Leveraging Policies and Metrics

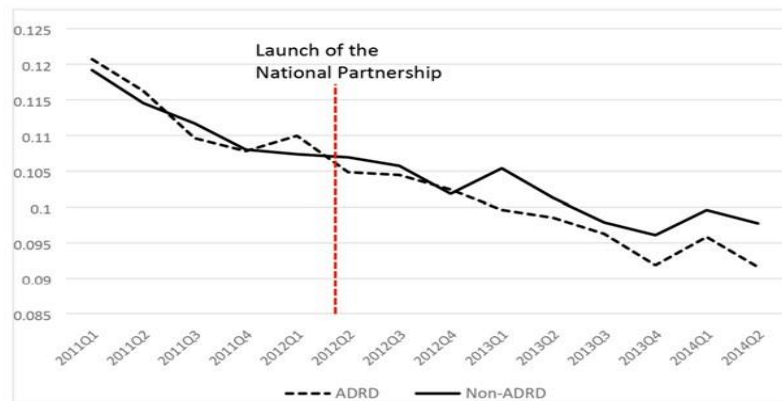


Figure 1. 30-day NH originated hospitalization readmission among residents with and without ADRD

Where are we strategies?

Strategy	Comment
Palliative Care Access	Increase hospice use, greater overall palliative care approach, huge <u>disparities</u>
Workforce	COVID impact NH workforce, knowledge about advance dementia suboptimal
Data/Documentation	Major advances and opportunities using real world data, but unique considerations with dementia
Models of Care	Few models with “efficacy” but research advancing
Leverage Policies	Can work, National Partnership, but need to be combined with alternative care strategies
Quality Metrics	Some limited initiatives; antipsychotics

Persistent and Emerging Priorities

- Disparities
- Knowledge of workforce (and PLWD and care partners)
- Evidence to support effective and scalable care programs
- Limitations of health care systems to evaluate and adapt new models of care