Alzheimer's and Dementia Care:
The Need and Solutions

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ADC Alzheimer's and Dementia Care PROGRAM

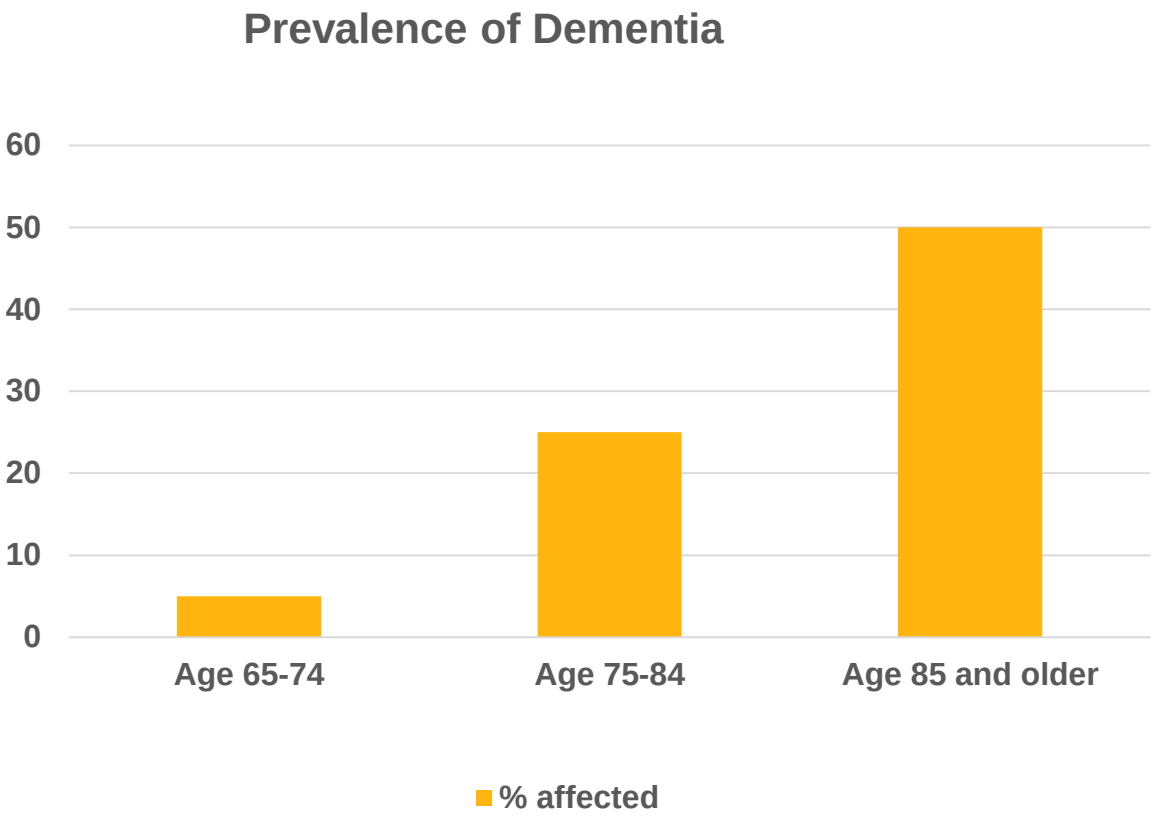
UCLA Health

The John A. Hartford Foundation

What we will cover

- Dementia and Alzheimer's disease
  - Definitions and causes
  - Complications
  - Management
    - Caregiver support
    - Comprehensive Dementia Care Management
    - ADC-Local and national
  - ADC ECHO
  - Dementia Care Aware

The Gray Plague



6.5 million Americans have Alzheimer's

By 2025, it will be **7.2 million**

Higher prevalence in African Americans (much higher) and Latinos

Dementia-2011 NIA Definition

- A chronic acquired decline not explained by delirium or psychiatric disorder in two or more of the following domains:
  - Memory
  - Reasoning and complex tasks
  - Visuospatial
  - Language
  - Personality
- Sufficient to affect daily life

Causes of Dementia

• Alzheimer's Disease	60-80%
• Vascular dementia	10-20%
• Dementia with Lewy bodies	15%
• Frontotemporal dementia	5%
• Toxic-metabolic disorders	4%
• Other movement disorders	6%

Alzheimer's Disease: 2011

- 3 stages
  - Preclinical: normal cognition; defined by changes in biomarkers
  - MCI: impaired cognition, intact function; positive biomarkers; may help determine progression to dementia
  - Dementia: impaired cognition; impaired function; biomarkers may be helpful in excluding AD as cause

Stages of Dementia

Mild

Difficulty with:

- Finances
- Driving
- Medications
- ↓ insight & judgement
- Short term memory
- Social withdrawal
- Mood changes

Moderate

Difficulty with:

- Instrumental ADLs
- Some ADLs
- Gait and balance
- Disorientation
- Worsening memory
- Getting lost
- Repeating questions
- Delusions/Agitation

Severe

Difficulty with:

- ADLs
- Mobility
- Swallowing
- ↓ verbal output
- Remote memory
- Recognizing family
- Apathy/depression
- Sundowning

Alzheimer's Disease Behavioral Symptoms

- NPI-Q symptoms at any point during their disease
  - Apathy 70%
  - Anxiety 68%
  - Irritability 66%
  - Agitation/aggression 64%
  - Dysphoria/depression 62%
  - Sleep/nighttime behaviors 62%
  - Delusions 36%
  - Hallucinations 26%

Management

- This is a lifelong disease
- Play the ball where it lies
  - If disease is early, include person living with dementia
  - If late, rely on family and caregiver
- Aim for the highest level of independence that works for everyone

- Treat the disease
- Manage hot-button issues (e.g., driving)
- Manage other diseases
- Manage symptoms
- Advance Care Planning

Caregiver Support

- Caregivers are the most important resource
- Over 50% of caregivers develop depression
- The more knowledgeable and empowered the caregiver is, the better the care
- Caregiver training/support programs work
  - REACH II (12 individual and 5 telephone support groups over 6 months)
  - NYU CI (2 individual counseling sessions, 4 family counseling sessions, weekly support groups, ad-hoc counseling)
  - Alzheimer's Association and other community resources

Caregiver Support (Cont.)

- Barriers and limitations
  - Focus only on the caregiver
  - Tested using traditional research not pragmatic designs
  - Cost ($2.50-$5/day for 6 months) and reimbursement
  - Poor integration with health care systems

Comprehensive Dementia Care

- Focuses on patient and caregiver and includes:
  - Continuous monitoring and assessment
  - Ongoing care plans
  - Psychosocial interventions
    - Aimed at person living with dementia
    - Aimed at caregivers
  - Self-management
  - Medication management (some community-based don’t)
  - Treatment of related conditions
  - Coordination of care

New Models of Comprehensive Care for Dementia

- Community-based-Implemented at CBOs or home by SWs, RNs, MFTs
  - BRI Care Consultation
  - MIND at Home (Hopkins)
  - The Care Ecosystem (UCSF)
- Health System-based-Implemented in health systems by NP or MD-led staff
  - Indiana University Healthy Aging Brain Center (HABC)
  - The UCLA Alzheimer's and Dementia Care Program (UCLA ADC)
  - Integrated Memory Care Clinic (Emory)

How Comprehensive Care Models Differ

- Staffing
- Base of operations
- Scope of services
- Intensity
- Cost
- Efficacy/Effectiveness (pragmatism)
- Potential ROI
- Level of evidence

Comparison of Some Dementia Care Models

Structure and Process	BRI CC	Care Ecosystem	MIND	HABC	UCLA ADC	IMCC
Key personnel	SW, RN, MFT	Non-licensed APN, SW, Pharmacist	Non-licensed RN, MD	Non-licensed MD, SW, RN, Psychologist	NP, PA, MD	APN
Key personnel base	CBO	Community	Community	Health system	Health system	Health system
Face-to-face visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	No	No	No	Yes	Yes	Yes
Communication w/ PCP	Mail, fax	Fax, phone	Phone, mail, fax	EHR, phone, mail	EHR, phone	N/A
Order writing	No	No	No	Yes	Yes	Yes
Benefits						
High quality of care	N/A	N/A	N/A	Yes	Yes	Yes
Patient benefit	Yes	Yes	Yes	Yes	Yes	NS
Caregiver benefit	Yes	Yes	Yes	Yes	Yes	NS
Costs of program	++	++	+++	+++	++++	++++
Cost savings, gross	++	++	None	++	++++	++++

The UCLA Alzheimer's and Dementia Care Program

Mission: To partner with families, physicians, and community organizations to:

- maximize person living with dementia function, independence, and dignity,
- while minimizing caregiver strain and burnout.

UCLA Health

ADC Alzheimer's and Dementia Care PROGRAM

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The UCLA Alzheimer's and Dementia Care Program

- Began in 2011 with philanthropic funds
  - Planned 250 patients
- Round 1 CMMI Award July 2012—Dec 2015
  - To expand the program to 1,000 patients
- As of August 25, 2022, over 3500 patients have been enrolled; >760 active plus 338 on wait list

The Program

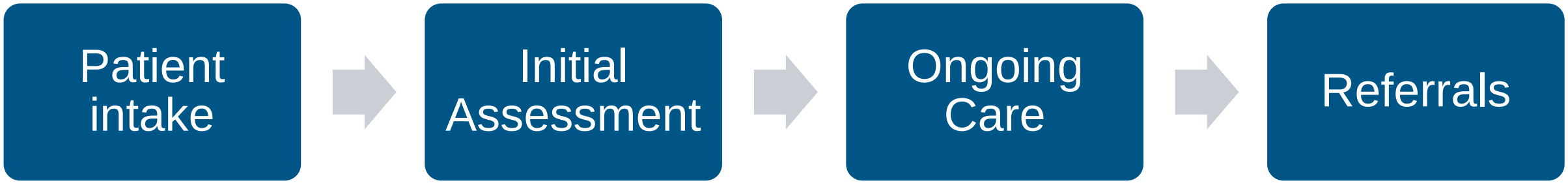
Approaches the patient and caregiver as a dyad; both need support

Provides comprehensive care based in the health system that reaches into the community

Recognizes that this care is a long journey.

Uses a co-management model with Nurse Practitioner Dementia Care Specialist (DCS) who does not assume primary care of patient

ADC Process


Patient intake
Initial Assessment
Ongoing Care
Referrals

The UCLA Alzheimer's and Dementia Care Program

- Works with primary care and specialty physicians to care for patients by
  - Conducting in-person needs assessments
  - Developing and implementing individualized dementia care plans
  - Monitoring response and revising as needed
  - Providing access 24 hours/day, 365 days a year
- Partners with community-based organizations (CBOs) to provide direct services (e.g., adult day care) and caregiver training

Services Provided by Partner CBOs

- Services for patients:
  - Adult day services
  - Programs for enhancing brain health (for early stage memory loss)
- Services for families/caregivers:
  - Education (workshops, classes, informational sessions, handouts)
  - Counseling and peer-to-peer support
  - Case management
  - Legal and financial counseling
  - Support groups

Dementia Care Specialist

- Advance Practice Provider
  - Nurse Practitioner, Clinical Nurse Specialist (with prescribing authority), Physician Assistant
- Healthcare system-based, outpatient clinic setting
- Dementia Care Co-Management along with the individual's medical team (e.g., Primary Care, Neurologist, Psychiatrist)
- Each DCS follows roughly 250 patients

Dementia Care Specialist Training

- On-line curriculum (GAPNA distribution)
  - 22 on-line modules + 4 asynchronous videos
- Zoom training
  - 1:1 weekly trainings with a DCS expert
    - Brings together information learned in the on-line training to the real world environment
    - Case based scenarios
    - Networking
  - Available office hours each week

DCS Training vs The Model

- Completion of DCS training (both on-line and one-on-one)
  - Document of Completion
- Completion of skills training alone is not sufficient for implementation of the ADC Program; additional training about the model of care is necessary

Dementia Care Assistants

- Dementia Care Assistants (DCA)
  - Licensed (RN, SW) or Non-licensed, trained staff
  - Reach out to lower acuity PWD-caregiver dyads
  - Offer resources (i.e. CBO, non-pharm behavioral modifications)
  - Help to schedule appointments
  - Identify dyads in crisis
  - Allow DCSs to work at the top of their license

Overall Dementia Quality of Care (ACOVE-3 and PCPI QIs)*

- Community-based physicians 38%
- Community-based physicians & NP 60%
- UCLA Alzheimer's and Dementia Care 92%

- Based on medical record abstraction of first 797 patients

Physician Satisfaction

- Web-based, anonymous survey to physicians who had patients in the ADC program.
- Most physicians felt that the ADC Program helped them and their patients, also evidenced by continued high referral rates from physicians (currently 10-25 per week)

61%
Valuable medical recommendations

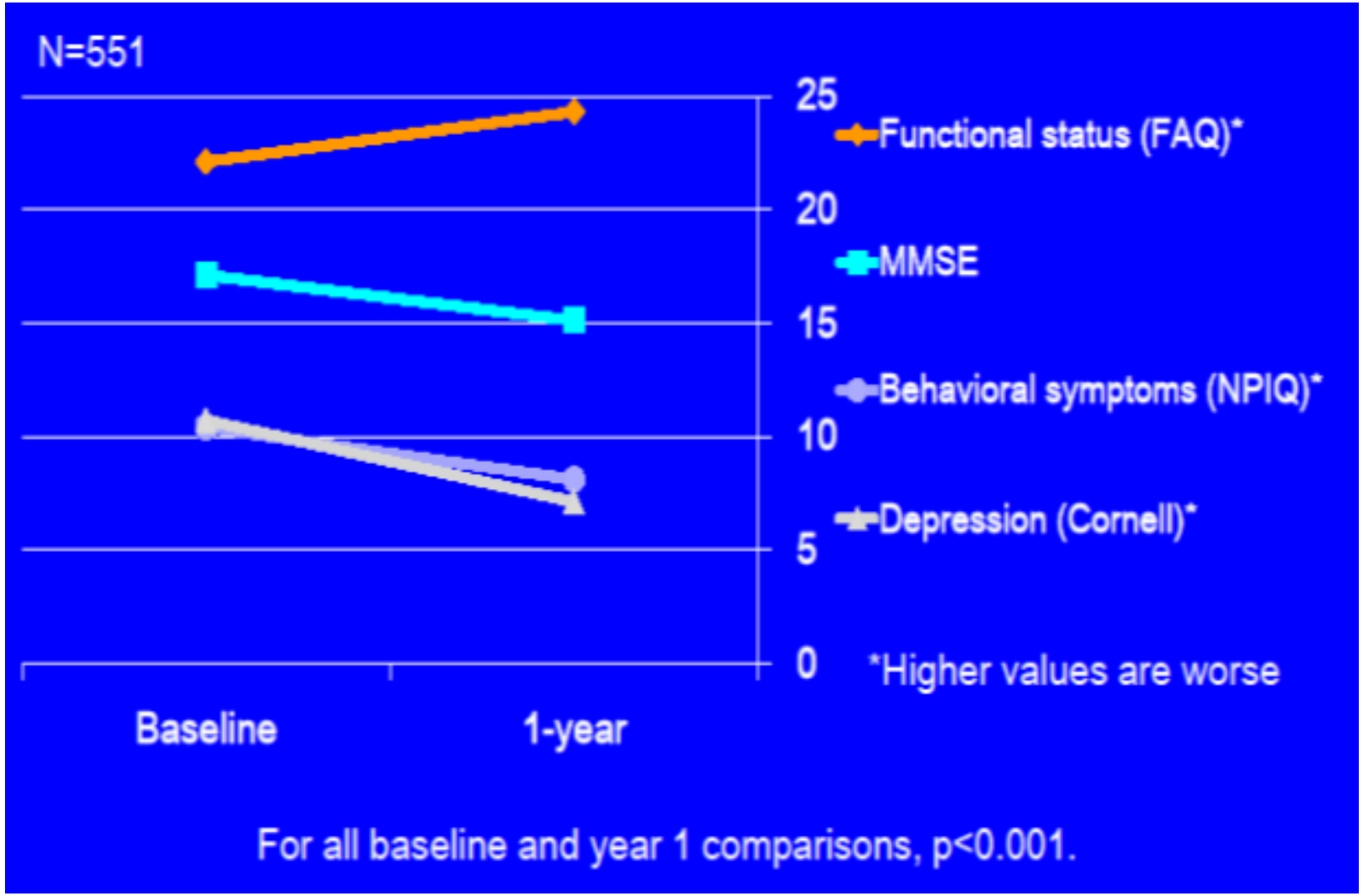
85%
Valuable behavioral recommendations

68%
Enhanced MD relationship with patient

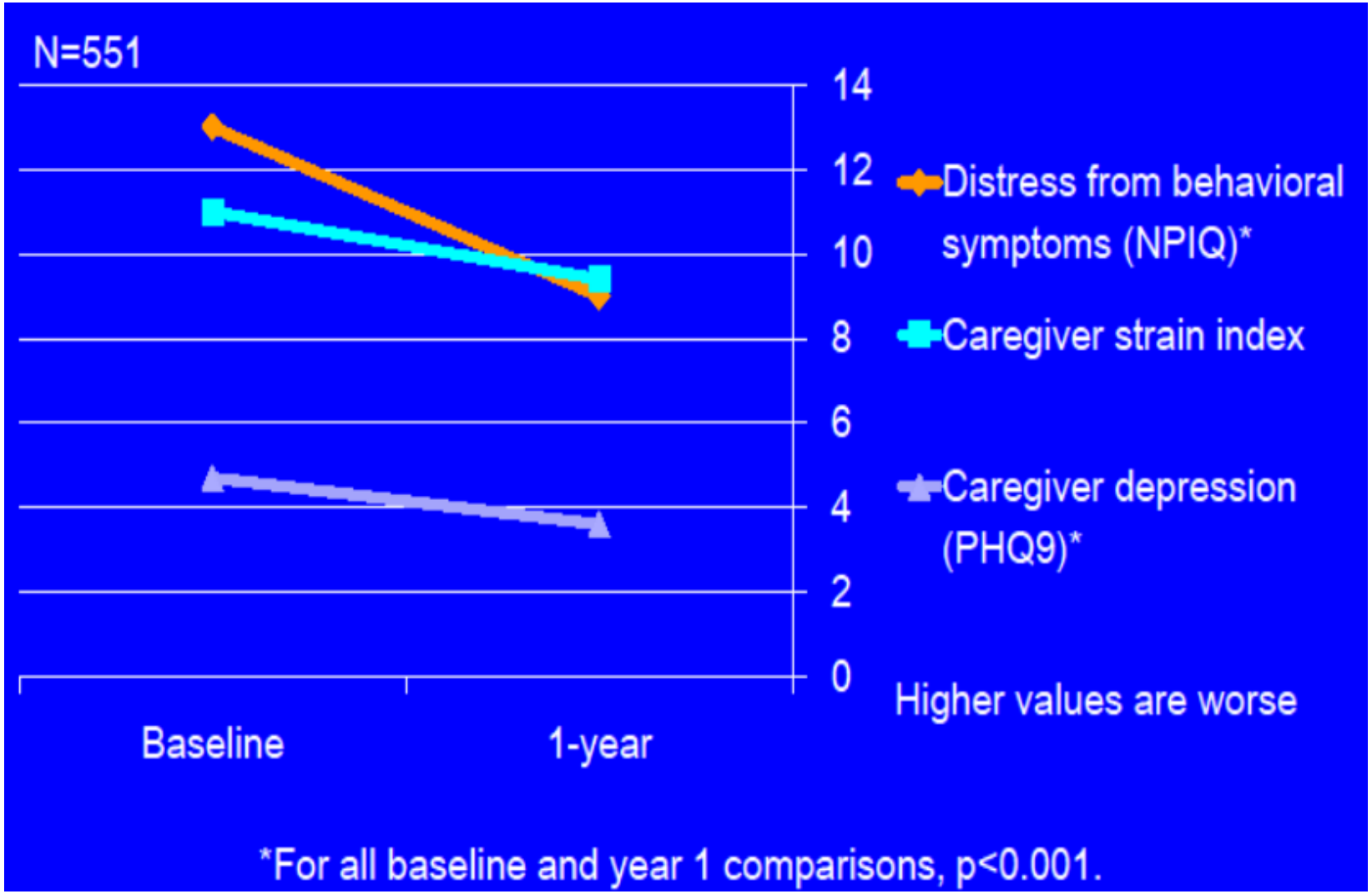
56%
Saved MD time

90%
Would recommend for other patients

1-year Outcomes: Patients



1-year Outcomes: Caregivers



Utilization and Costs

Type of Care	Impact
Hospitalizations	▼ 12%
ED visits	▼ 20%*
ICU stays	▼ 21%
Hospital days	▼ 26%*
Nursing home placement	▼ 40%*
Hospice in last 6 months	▲ 60%*

Total Medicare costs of care:
▼ $2,404/year *

* p<.05
Based on NORC external evaluation of CMMI Award using fee-for-service claims data and UCLA ACO data September 2015- September 2017

Going National

D-CARE Study (PCORI and NIA)

The John A. Hartford Foundation - Supported dissemination

Spread of the ADC Program 2019-2021

- Partnerships with:
  - Alzheimer's Association
  - American Geriatrics Society
  - Gerontological Advance Practice Nurses Association
- 4 sites as part of a randomized clinical trial, the D-CARE Study
- Dissemination sites supported by a The John A. Hartford Foundation grant

Dissemination Process

INQUIRY
- ADC Summary
- Initial Interest forms

EXPLORATION
- Phone call
- Qualitative fit

FEASABILITY / PLANNING
- Readiness Assessment Form
- Business case call
- ADC Team review

LETTER OF AGREEMENT

January 2019 to December 2021:

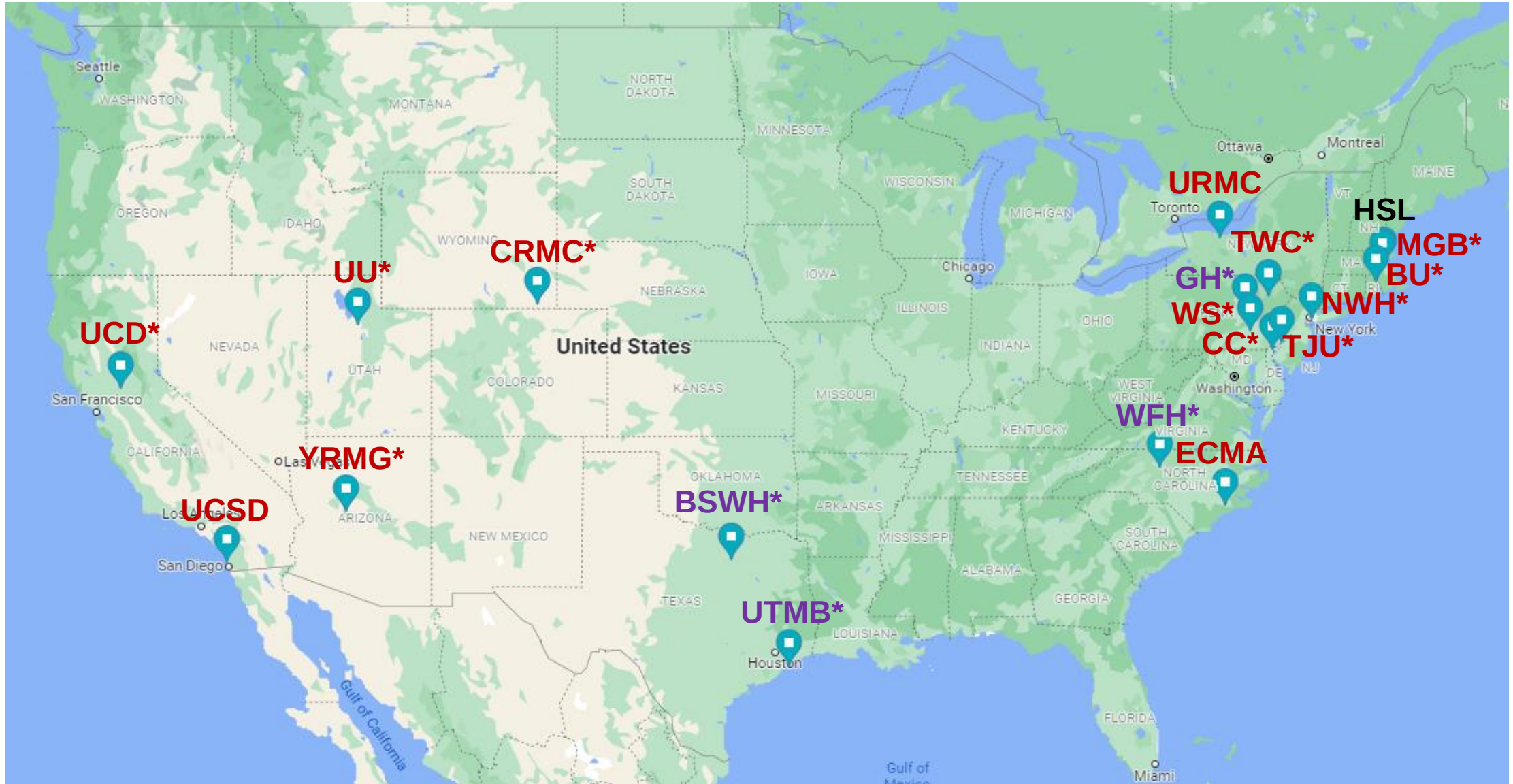
80 Sites expressed interest

58 Initial phone calls

23 Readiness assessment forms completed

14 Letters of Agreement signed; 10 sites actively seeing patients

Dissemination Sites



Lessons Learned in Early ADC Dissemination Efforts

- Identify and nurture a product champion
- The business case is critical
- Training is essential
- Local factors are important
- Be patient
- Don’t underestimate the time needed for program implementation

New in 2022

- ADC Dissemination Center
- National Dementia Care Learning Collaborative
- Partnership with IHI Age Friendly Health Systems
- ADC ECHO®
- Dementia Care Aware
- Training and technical assistance cost share

ADC Dissemination Center

- Create a menu of options for adopting sites including:
  - The core ADC Program, which can be adapted to fit the local environment of the adopting health system
  - Pre-adoption (ADC ECHO®)
  - Complementary Programs
    - Memory evaluations
    - Other comprehensive dementia care programs
- Additional geriatrics training

National Dementia Care Learning Collaborative

- Ongoing community of practice including both sites implementing the model and sites considering adoption
- Provides ongoing peer-to-peer feedback and group learning
- Work with the Dissemination Center and collaborating entities (Alzheimer's Association, American Geriatrics Society, AARP, Age-Friendly Initiative, LEAD Coalition, GAPNA) to distribute educational materials
  - To learn more about The National Learning Collaborative, please contact ADCProgramNLC@edc.org

ADC Program and Project ECHO®

- 6-month tele-mentoring program with expert multidisciplinary specialist teams
- Strong emphasis on patient-centered care
- Connects health care teams from community-based settings in free continuing education series

Project ECHO®

Benefits include

- Case-based learning so that all participants teach and learn
- Brief didactic presentations from experts in the field
- Video conferencing for ease of access and to foster interactive learning

Project ECHO® Topics

- Diseases causing dementia
- Person-centered dementia care: Integration of family members
- Signs and symptoms of cognitive impairment
- Evaluation and diagnosis of dementia in the primary care office
- Advance Care Planning for persons living with dementia
- Dementia care management: behavioral and psychological symptoms of dementia (BPSD)
- And more…
  - To learn more about ECHO, please contact rbgoldberger@alz.org

Dementia Care Aware (DCA) Initiative

- California state-wide initiative led by UCSF
- Aims to improve care and quality of life for people living with dementia, especially those who are at higher risk and have experienced dementia care-related disparities
- Includes a new Cognitive Health Assessment benefit for Medi-Cal-only beneficiaries 65 and older
- Trains providers to improve the ability of primary care teams serving Medi-Cal beneficiaries to detect dementia and create care plans
- Funds practice support activities, including scholarships to implement the ADC program

The Future

Dissemination to 50 additional sites

Tens of thousands of persons with dementia receive the ADC Care

Medicare provides payment for ADC and other models of comprehensive dementia care

Q & A Session

For more information about implementation of the ADC model, please visit https://www.adcprogram.org/

Thank you!

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