Early Detection of Dementia: Clues in the EMR (Electronic Medical Record) & Strategies to Maximize Quality of Life

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Early Detection of Dementia: Are There Clues in the Electronic Medical Record (EMR)?

Sascha Dublin, MD, PhD
Research Team

- Dr. Deborah Barnes, UC San Francisco and San Francisco VA
- Dr. Sei Lee, UC San Francisco and San Francisco VA
- Dr. Eric Larson, KP Washington, PI of ACT study
- Dr. Zachary Marcum, University of Washington
- Kaiser Permanente Washington Health Research Institute team: Katie Rose Richmire, Eric Baldwin, Rod Walker, Barbara Harding
## Outline

<table>
<thead>
<tr>
<th>Section</th>
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<td>Background and Importance</td>
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<td>Results</td>
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<tr>
<td>Discussion and Next Steps</td>
</tr>
</tbody>
</table>
Patient Stories

- Ms. E
- Mr. J
Patient Stories

- Ms. E

- Mr. J

Were there clues in their earlier interactions with the healthcare system that could have helped us recognize their dementia earlier?
Background

- 5 million people in US living with Alzheimer’s Disease
- Expected to grow dramatically in coming years
- Half of them have not been diagnosed
- Many have comorbid conditions that require self-management
  - E.g., diabetes
Consequences of Undiagnosed Dementia

- Difficulties with self-management such as remembering medications
- Preventable Emergency Department visits and hospitalizations
- Risky behaviors
  - Driving, managing finances
- Missed opportunities to plan for the future and express preferences
- Stress for patients and families who do not understand what is happening
“We think our mom had dementia for four or five years before she was finally diagnosed. She spent those years living in a confused and scary world that she handled with anger and sometimes rage. It would have been very helpful for us to know what was wrong from the beginning.”

— Family member of patient from Kaiser Permanente Washington
Goals and Objectives

- Long term goal: To develop and test an automated tool using EMR data to identify patients likely to have undiagnosed dementia

- Goal of current project: to develop preliminary data to support this work, including
  - To identify a cohort of patients with undiagnosed dementia and validate this concept
  - To extract EMR variables that may predict dementia, including novel variables such as no-shows for clinic visits

- Funding sources: HMORN OAIC pilot grant (R24AG045050) and Tideswell at UCSF
Objectives of Pilot Project

- **Aim 1:** To determine the feasibility of obtaining novel EMR data revealing *chaotic patterns of care*, such as missed clinic visits.
- **Aim 2:** To describe *patterns of health care utilization* in patients with undiagnosed dementia.
- **Aim 3:** To describe *adherence to chronic cardiovascular medications* in patients with undiagnosed dementia.
Conceptual Model

**Figure 1. Conceptual Model of EMR ‘Fingerprint’ of Undiagnosed Dementia**

- **Difficulty Managing Comorbid Conditions**
  - More ‘outlier’ values for chronic conditions (e.g., blood pressure, HbA1c)
  - More unfilled medications

- **Chaotic Healthcare Utilization**
  - Fewer preventive and primary care visits
  - More ED visits and hospitalizations
  - More missed visits (“no shows”)

- **Other Presenting Symptoms Related to Dementia**
  - Depression
  - Weight change
  - Sleep problems
Methods: Overview

- Unique resources: data from a prospective cohort study of dementia linked with electronic medical records (EMR) data
- “Gold standard” data on dementia diagnoses made as part of a research study
- EMR data reveal participants’ interactions with healthcare system
  - Allow us to determine when healthcare team recognized that a patient had dementia: before or after ACT study diagnosis?
Adult Changes in Thought (ACT) Study

- Prospective cohort study begun in 1994
- Set within an integrated healthcare delivery system, Kaiser Permanente Washington (formerly Group Health)
- Recruits health plan members age 65+, living in the community, without dementia
- Participants are seen every 2 yrs to detect incident dementia and collect data about risk factors and exposures
- Over 5,000 people enrolled to date; over 1,000 dementia cases
- Enrollment and follow up are ongoing

U01AG006781 (PIs: Larson and Crane)
ACT Methods: Dementia Diagnoses

- Participants screened every 2 years with the Cognitive Abilities Screening Instrument
- Low scores prompt detailed evaluation
  - Neuropsychological testing
  - Examination by study physician
  - Review of records and imaging
- Consensus committee assigns dementia diagnoses based on DSM-IV criteria
Linked EMR data

- ACT study data are linked with EMR data from Kaiser including:
  - Diagnoses
  - Pharmacy data on medication fills
  - Vital signs (weight, blood pressure, etc.)

- We can identify from these EMR data whether a person received dementia-related diagnosis codes or medications before or after their ACT diagnosis
Defining “Undiagnosed Dementia”

- For ACT participants found to have dementia, we identify the ACT study visit where they had abnormal cognitive test results leading to their diagnosis
  - This is the “index visit”

- Require 2 years of prior Kaiser enrollment, to ensure adequate EMR data

- Consider them “undiagnosed” if:
  - No prior diagnosis codes for dementia in EMR data
  - No prior prescription fills for dementia medication
  - No diagnosis code for subjective memory complaints in the past 2 years
Undiagnosed Dementia

- We found that 44% of those who developed dementia were “undiagnosed” based on EMR data (automated)
- Reviewed medical records for a small sample
  - Confirmed that 90% truly were not recognized prior to ACT diagnosis
Comparison Group

- ACT participants without dementia
- Selected 3 controls for each “undiagnosed dementia” case
  - With an ACT visit around the time of the case’s index date
  - This defines their “index date”
- Required 2 years of Kaiser enrollment as of the index date
Covariates: Potential Predictors

- Focused on characteristics well captured in the EMR (and thus feasible for use in an automated score)
- We developed a covariate list a priori, based on clinical plausibility, review of literature, and existing prediction scores
  - Known dementia risk factors
  - Evidence of difficulty managing comorbid conditions (e.g. ‘outlier’ values for blood pressure)
  - Chaotic healthcare utilization (more ED visits, fewer preventive visits)
  - Other dementia-related symptoms (e.g. depression, sleep problems)
Trying to Measure Difficulty Managing Chronic Conditions

- Concept: may have inadequate control or labile control (sometimes remember medications, sometimes forget)

- For hypertension, we identified the lowest and the highest BPs in the prior 2 years

- Calculated the difference between maximum and minimum as a measure of lability

- Same approach for hemoglobin A1c for patients with diabetes
  - Measure of level of control of blood sugar

- Also examined missingness: how often missing the measure of hemoglobin A1c
“No Shows” for Clinic Visits

- Available from EPIC (Clarity) starting in 2005, but ACT study goes back to 1994
- Older scheduling system: LastWord, 1995-2009
- Finding these data was like looking for something in a crowded and dusty attic
- Ultimately, our programmer was able to find information
Results
## Results: Demographics and Comorbid Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Undiagnosed Dementia (N=436)</th>
<th>No Dementia (N=1308)</th>
<th>Age-adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (years)</td>
<td>85.2</td>
<td>78.8</td>
<td>NA</td>
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<tr>
<td>Female</td>
<td>61%</td>
<td>59%</td>
<td>0.16</td>
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<tr>
<td>Non-Hispanic White</td>
<td>92%</td>
<td>90%</td>
<td>0.75</td>
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<tr>
<td>Congestive heart failure</td>
<td>28%</td>
<td>13%</td>
<td>&lt;0.01</td>
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<tr>
<td>Cerebrovascular disease</td>
<td>22%</td>
<td>10%</td>
<td>&lt;0.01</td>
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# Difficulty Managing Comorbid Conditions: Hypertension

<table>
<thead>
<tr>
<th></th>
<th>Undiagnosed Dementia (N=252)</th>
<th>No Dementia (N=662)</th>
<th>Age-adjusted p-value</th>
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</thead>
<tbody>
<tr>
<td>Highest systolic BP in past 2 years, mean*</td>
<td>154.6</td>
<td>154.1</td>
<td>0.10</td>
</tr>
<tr>
<td>Lowest systolic BP in past 2 years, mean*</td>
<td>126.2</td>
<td>127.2</td>
<td>0.75</td>
</tr>
<tr>
<td>Lability (max – min)</td>
<td>31.9</td>
<td>29.6</td>
<td>0.47</td>
</tr>
</tbody>
</table>

*In past 2 years.
# Difficulty Managing Comorbid Conditions: Diabetes

<table>
<thead>
<tr>
<th></th>
<th>Undiagnosed Dementia (N=88)</th>
<th>No Dementia (N=175)</th>
<th>Age-adjusted p-value</th>
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<tbody>
<tr>
<td>Highest HgbA1c in past 2 years (mean)</td>
<td>7.9</td>
<td>7.7</td>
<td>0.08</td>
</tr>
<tr>
<td>Lowest HgbA1c in past 2 years (mean)</td>
<td>7.1</td>
<td>6.8</td>
<td>0.02</td>
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<tr>
<td>Lability (max – min)</td>
<td>1.1</td>
<td>1.1</td>
<td>0.62</td>
</tr>
<tr>
<td>Missing A1c</td>
<td>6%</td>
<td>9%</td>
<td>0.25</td>
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</table>
# Healthcare Utilization in Past 2 Years

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<tr>
<th></th>
<th>Undiagnosed Dementia (N=436)</th>
<th>No Dementia (N=1308)</th>
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</thead>
<tbody>
<tr>
<td><strong>Ambulatory visits, mean</strong></td>
<td>11.8</td>
<td>9.8</td>
<td>0.08</td>
</tr>
<tr>
<td><strong>≥ 1 ED visit</strong></td>
<td>48%</td>
<td>25%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td><strong>≥ Hospitalization</strong></td>
<td>31%</td>
<td>21%</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>≥ “No-show”</strong></td>
<td>43%</td>
<td>29%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td><strong>≥ 1 visit for accident or injury</strong></td>
<td>14%</td>
<td>6%</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>
## Healthcare Utilization in Past 2 Years, cont.

<table>
<thead>
<tr>
<th></th>
<th>Diagnosed Dementia (N=544)</th>
<th>Undiagnosed Dementia (N=436)</th>
<th>No Dementia (N=1308)</th>
<th>Age-adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulatory visits, mean</td>
<td>14.5</td>
<td>11.8</td>
<td>9.8</td>
<td>0.08</td>
</tr>
<tr>
<td>≥ 1 ED visit</td>
<td>53%</td>
<td>48%</td>
<td>25%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>≥ Hospitalization</td>
<td>46%</td>
<td>31%</td>
<td>21%</td>
<td>0.02</td>
</tr>
<tr>
<td>≥ “No-show”</td>
<td>53%</td>
<td>43%</td>
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<td>≥ 1 visit for accident or injury</td>
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<td>6%</td>
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## Other Presenting Symptoms of Dementia

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<tr>
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</thead>
<tbody>
<tr>
<td>Weight change (max – min), mean (lbs)</td>
<td>11.7</td>
<td>9.6</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Missing weight</td>
<td>37%</td>
<td>29%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Depression</td>
<td>25%</td>
<td>14%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Sedative/hypnotic use</td>
<td>25%</td>
<td>23%</td>
<td>0.16</td>
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</table>
## Other Presenting Symptoms of Dementia, cont.

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<tr>
<th>Weight change (max – min), mean (lbs)</th>
<th>Diagnosed Dementia (N=544)</th>
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<th>Age-adjusted p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight change (max – min), mean (lbs)</td>
<td>13.3</td>
<td>11.7</td>
<td>9.6</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Missing weight</td>
<td>28%</td>
<td>37%</td>
<td>29%</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Depression</td>
<td>38%</td>
<td>25%</td>
<td>14%</td>
<td>&lt;0.01</td>
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<tr>
<td>Sedative/hypnotic use</td>
<td>33%</td>
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<td>23%</td>
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Conclusions

- We were able to identify a cohort with “undiagnosed dementia” and compare them to people without dementia

- We extracted or created some novel measures from the EMR
  - Measures of difficulty managing chronic conditions, such as lability measures for BP and HgbA1c
  - “No shows” for clinic visits
Conclusions, cont.

- Many individual variables were associated with undiagnosed dementia, after adjustment for age:
  - Illnesses such as CHF, stroke, diabetes, and depression
  - ED visits, hospitalizations, and visits for accidents or injuries
  - No shows for clinic visits

- It remains to be seen whether incorporating these variables into a predictive model yields a model with strong ability to predict undiagnosed dementia
Patient Story

- Mr. J: missed labs, no-showed for visits with me
- Team could have reached out more proactively to remind him and family
- With an earlier diagnosis, we could have provided a clearer answer about why he was doing poorly living alone
- Maybe could have identified cancer sooner
Next Steps

- Seek funding to develop the full predictive model and validate it prospectively
  - Want to apply model to data from our EMR, identify patients who may have undiagnosed dementia, and bring them in for detailed evaluation

- Seek input from stakeholders about how to best implement the risk score in a clinical setting
  - Patients, caregivers, clinicians and healthcare system leaders
  - What resources does each group need to make this feasible?
Next Steps, cont.

- Submitted an R01 in 10/2016
- Application was discussed and scored but score not in fundable range
- Criticisms: concern about unintended consequences, potential harms, and lack of a “cultural lens”
- Very important that we have something to offer patients and families after a dementia diagnosis
  - Information and support
  - Planning for the future
  - Local resources
Questions? Suggestions? Advice?

- How can we move this work forward?
Research Team

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Questions?
Early Detection of Dementia: Strategies to Slow Decline

Deborah E. Barnes, PhD, MPH
Associate Professor of Psychiatry and Epidemiology & Biostatistics, UCSF
Research Health Science Specialist, SFVAMC
Senior Investigator, Tideswell at UCSF
Disclosure

- Dr. Barnes is Co-Founder of Together Senior Health, which is dedicated to improving function and quality of life in people living with dementia.
Overview

- Drugs for Dementia
- Non-Drug Treatments
  - Physical Activity
  - Cognitive/Social Engagement
  - Music
  - Caregiver Education
  - Multicomponent Interventions
- The PLIÉ Program
Evidence Pyramid

- Systematic Reviews - Meta-analysis
- RCTs
- Cohort studies
- Case-Control
- Cross-sectional studies
- Case series, Case reports
- Ideas, opinions, editorials, anecdotal
Drugs for Dementia
Dementia Medications

• Two classes of drugs, small improvements

• Cholinesterase inhibitors
  • Cognitive function: 0.28*
  • Physical function: 0.29*

• Memantine
  • Cognitive function: 0.33*
  • Behaviors: 0.22*
  • Physical function: 0.11*


* Standardized effect sizes
Visualizing Effect Size: Small
Visualizing Effect Size: Medium

Visualizing Effect Sizes (Cohen's $d = 0.5; U3 = 0.69$) -- "medium effect"
Visualizing Effect Size: Large
Dementia Medications cont.

- Minimal impact on quality of life in people with dementia or caregivers
- Often discontinued due to side effects
- Do not change disease course
- New drugs being tested - mainly for prevention

Hansen et al, Drug & Aging 2007; Birks, Cochrane Review, 2006; Smith et al., Alz Dis Assoc Disord 2006; Doody et al, NEJM 2014; Salloway et al., NEJM 2014
Non-Drug Treatments
Physical Activity

- 16 RCTs (n=937)
  - Mostly walking, balance, strength
  - Mostly institutional settings
  - Improved physical function
  - Improved cognitive function?

Forbes et al, Cochrane Review 2013
## Treatment Effect Sizes

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Values are standardized effect sizes: 0.2=small; 0.5=medium; 0.8=large

Cognitive Activity

Cognitive training
- structured activities to improve targeted ability
- 11 trials (N=476) - no effect on cognition, mood, ADLs

Cognitive/social stimulation
- group activities to promote cognitive/social function
- 15 trials (N=718) - improved cognitive function, QOL

Bahar-Fuchs et al., Cochrane Review 2013; Aguirre et al., Cochrane Review 2013.
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Music

• 20 studies (N=651)
• Reduced anxiety, behavioral symptoms
• Alive Inside: https://www.youtube.com/watch?v=IaB5Egej0TQ

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<td>0.44</td>
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</table>

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Caregiver Education

- 33 RCTs
  - Improved dementia-related behaviors
  - Improved CG mood (community)
  - Improved CG well-being (institutional)

Olazarán et al, Dement Geriatr Cogn Disord 2010.
<table>
<thead>
<tr>
<th>Treatment</th>
<th>Physical Function</th>
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</table>

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Multicomponent Interventions

- 19 RCTs
  - Delayed institutionalization
  - Improved physical function
  - Improved cognitive function
  - Improved behaviors
  - Improved mood
  - Improved QOL
  - Improved CG mood, well-being & QOL

Olazarán et al, Dement Geriatr Cogn Disord 2010.
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<td>0.41</td>
<td>0.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td></td>
<td></td>
<td></td>
<td>0.49, 0.64</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td>0.22, 0.56</td>
<td>0.27</td>
</tr>
<tr>
<td>Combined</td>
<td>0.37</td>
<td>0.31</td>
<td>0.56</td>
<td>0.60</td>
<td>0.68</td>
</tr>
</tbody>
</table>

Values are standardized effect sizes: 0.2=small; 0.5=medium; 0.8=large

The PLIÉ Program
Preventing Loss of Independence through Exercise (PLIÉ)

- Group movement + mindfulness program for people with memory loss or dementia
  - Physical + mental + social + music + caregivers
  - Focuses on abilities maintained, rather than lost
- **PLIÉ** = 10 affected individuals, 1 hour, 2-3 days/week, 18 weeks
- **Paired PLIÉ** = 5 pairs of affected individuals + care partners, 1 hour, 2 days/week, 12 weeks

Barnes et al., PLoS One, 2015; Wu et al., Aging & Mental Health, 2015
Key Elements of PLIÉ

‘Muscle’ Memory

• Repetition of movement sequences for basic daily movements (e.g., sit-to-stand)
• Increasing functional difficulty
• Slow pace, step-by-step instruction
• The body remembers even when the mind forgets
Key Elements of PLIÉ

Mindfulness

- In-the-moment, mindful body awareness
- Focus on breathing, awareness of bodily sensations
- Still the mind
- *People with memory loss are always ‘living in the present’*
Key Elements of PLIÉ

Music/Social Engagement

- Sit in a circle
- Connect with others through shared movement (e.g., reaching across circle, holding hands)
- Brief musical selections to enhance positive emotions and social connection
- People with memory loss often rely more on nonverbal and emotional cues
Key Elements of PLIÉ

Caregiver involvement

- Initial goals assessment to learn about each person’s background, motivators and goals
- Monthly home visit
- Illustrated booklet + video for home practice
- Motivation can be increased by tailoring programs to personal goals and interests
### Pilot Study: Quantitative Results

<table>
<thead>
<tr>
<th></th>
<th>Effect Size*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive function</td>
<td>0.76</td>
</tr>
<tr>
<td>Quality of life</td>
<td>0.83</td>
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<tr>
<td>Physical performance</td>
<td>0.34</td>
</tr>
<tr>
<td>Participant behaviors (distress)</td>
<td>0.21</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>0.49</td>
</tr>
</tbody>
</table>

Effect size: between-group differences in change from 0 to 18 weeks; small, 0.20; moderate, 0.50; large, 0.80.

*positive values favor PLIÉ

*Barnes et al., PLoS One, 2015*
Qualitative Results: Affected Individuals

- Physical changes
  - Increasing awareness of physical sensations
  - Increasing functional skill (sit-to-stand)
  - Movement memory

- Emotional changes
  - Acceptance of resting (“feel peaceful”)
  - Emotional memories (airplane)
  - Increasing appreciation of PLIÉ

- Social changes
  - Decline in anxiety (purse strap under chair)
  - Greater social connection (Italian song, “my friend”)

Wu et al., Aging & Mental Health, 2015
Qualitative Results: Caregivers

• Physical benefits: “I think Mom is benefitting physically. Straighter posture sometimes, easier to go from sit to stand, climb stairs.”

• Cognitive benefits: “[He] seemed more alert. Spoke a bit more. Followed instructions. I enjoyed more when he was more engaged.”

• Social/Emotional benefits: “Felt slimmer - calmer... no stress even when [she] asked 1 question several times over!”
Summary & Conclusions
Why Early Detection of Dementia Matters

- >5 million Americans have dementia
- Half undiagnosed
- EMR contains data elements that may help detect patients with undiagnosed dementia
  - ER visits/hospitalizations
  - Accidents/injuries
  - Missed clinic visits
  - Related symptoms/risk factors (weight loss, depression, TBI, stroke)
Why Early Detection of Dementia Matters cont.

- Dementia drugs may benefit some patients
- Non-drug treatments have many potential benefits and few risks
  - Multicomponent programs best (e.g., PLIÉ)
- Other potential benefits
  - Better management of comorbidities, fewer ER visits/hospitalizations, accidents, opportunity for advance care planning, reduced stress
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- Department of Defense
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- NARSAD
- Tideswell at UCSF
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Study Sites
Institute on Aging (San Francisco), Senior Access (San Rafael), Marin Adult Day Health Center (Novato), Catholic Charities (Santa Rosa), Kaiser (Oakland), Alzheimer’s Services of the East Bay (Berkeley), Primrose (Santa Rosa)

Study participants and caregivers
Questions?

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