Identifying Undiagnosed Dementia in Primary Care Using eRADAR

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Disclosures

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• Preliminary work funded by NIA R24 AG045050 and Tideswell at UCSF
• Dr. Dublin has had grant funding from GSK and Jazz Pharmaceuticals
• Dr. Barnes is co-founder and Chief Science Advisor for Together Senior Health, Inc., which offers online therapeutic programs for people living with cognitive impairment and is working to develop tools to support earlier detection of dementia
• Our institutions have determined that there are no conflicts of interest for this work
Background: Undiagnosed Dementia is Common

• 6 million people in U.S. living with dementia
  • About half are undiagnosed
• Earlier diagnosis may have benefits for patients and families
  • Opportunity to plan for the future, better support patient, and address safety risks
Recommendations for Early Detection Differ

- U.S. Preventive Services Task Force
  - Does not recommend for or against routine screening due to lack of evidence about benefits vs. harms
- Alzheimer’s Association, Gerontological Society of America
  - Advocate for early detection to provide patients and caregivers with support and education
- Medicare Annual Wellness Visit
  - Mandates “detection of cognitive impairment”
eRADAR Risk Score: Initial Development

• eRADAR stands for “Electronic health record (EHR) Risk of Alzheimer’s and Dementia Assessment Rule”

• We developed a statistical model to predict the likelihood a person has undiagnosed dementia using routinely available EHR data.

- Difficulty Managing Comorbid Conditions
  - More ‘outlier’ values for chronic conditions (e.g., high/low blood pressure, diabetes complications)
  - More unfilled medications

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

- Other Presenting Symptoms
  - Depression
  - Weight loss
  - Sleep problems
Methods for Developing eRADAR Algorithm

• Setting: ACT study, 1994-2014
• Linked ACT data with KP Washington EHR data
  ▪ Diagnoses, utilization, laboratory results, vital signs, medication data, and others
• “Undiagnosed dementia” = ACT dementia diagnosis WITHOUT recognition by the clinical system in the prior 2 years (based on ICD-9 diagnosis codes or dementia medications)
• Comparison group: no dementia
• Unit of analysis = ACT study visit (not person)
• Split the data into training set (70%) and test set (30%)
• Logistic regression modeling with LASSO

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Variables in the Final Model

- Demographic characteristics (e.g., age, sex)
- Chronic health conditions (e.g., diabetes, heart failure, cerebrovascular disease)
- Vital signs (e.g., high blood pressure, being underweight, weight loss)
- Medications (e.g., antidepressants, sedative-hypnotics)
- Healthcare utilization (e.g., primary care visits, Emergency Department visits, receiving Home Health care)
Results: Receiver Operating Characteristics (ROC) Curve

AUC - Area under the curve

Training: 0.782 (0.759, 0.805)
Test: 0.809 (0.777, 0.840)
Next Step: Further Validation

• Additional validation needed to address issues including:
  ▪ Research population (self-selected) vs. general clinical population
    • Racial and ethnic diversity (ACT population 90% white)
  ▪ Changes in coding over time, especially ICD-9 to ICD-10 transition
  ▪ Validation in a second healthcare system
Next Steps: Validation and Multisite Pragmatic Clinical Trial

• We obtained funding from the National Institute on Aging for additional work, culminating in a multisite embedded pragmatic clinical trial (ePCT)

• **Grant Aims:**
  - **Aim 1:** To evaluate eRADAR’s performance in different subgroups in 2 healthcare systems to inform selection of cutpoints for use in clinical settings
  - **Aim 2:** To determine whether implementing eRADAR through a supported outreach process increases dementia detection rates compared to usual care
  - **Aim 3:** To explore the impact of eRADAR implementation on healthcare utilization and experience of patients and family members

Funding: R01AG067427 and R01AG069734
External Validation Study

- Design: retrospective cohort study/validation study
- Data sources: electronic health records
- Identified individuals meeting eligibility criteria as of January 1 in each study year
- Looked back 2 years for baseline characteristics; calculated eRADAR score
- Followed individuals forward in time for 12 months for new diagnoses of dementia
  - Note: not able to identify “undiagnosed dementia” in this setting
- Evaluated performance measures such as sensitivity, positive predictive value, and AUC for eRADAR
- Examined performance in subgroups including by race and ethnicity

Funding: R01AG067427 and R01AG069734
Results: ROC Curves

Validation Set
- ACT testing set: 0.81 (0.78, 0.84)
- KPWA: 0.84 (0.84, 0.85)
- UCSF: 0.79 (0.76, 0.82)
Sensitivity for Subgroups by Race and Ethnicity
eRADAR showed strong external validity for detecting undiagnosed dementia in 2 healthcare systems with different patient populations and data sources.

Similar performance across larger racial and ethnic groups.

Variable definitions and programming code: [https://github.com/rycoley/eRADAR](https://github.com/rycoley/eRADAR)

Next step: test eRADAR as part of an intervention in primary care.

Coley et al., *JGIM* 2022

Funding: R01AG067427 and R01AG069734
Pragmatic Clinical Trial Design and Methods

- **Setting**: primary care clinics
  - Kaiser Permanente Washington
  - University of California, San Francisco

- **Population**: Patients age 65+ without dementia diagnosis or medications

- **Randomization**: Intervention or usual care (at PCP level)
  - PCPs roughly matched/grouped on number of eligible patients

Funding: R01AG067427 and R01AG069734
Intervention

- Eligible patients with high eRADAR scores (top 15-20%) invited for “brain health” visit with a research team member (licensed social worker)
  - In person, video or phone visit
  - Patients are encouraged to bring care partner
  - History, Instrumental Activities of Daily Living, depression screening, Montreal Cognitive Assessment (MoCA)
- Patients with results suggesting dementia are referred back to PCP for more evaluation and a final diagnosis

Funding: R01AG067427 and R01AG069734
Pragmatic Clinical Trial: Outcomes

• Primary outcome: New dementia diagnoses in following 12 months
  ▪ Secondary outcome: Diagnoses of dementia or mild cognitive impairment (MCI)

• Health care utilization
  ▪ Number of PCP visits
  ▪ Laboratory tests (e.g. thyroid, vitamin B12); brain imaging
  ▪ New starts of dementia medications
  ▪ Utilization such as ED visits, hospitalizations, etc.

• Patient, family, provider experience and satisfaction
  ▪ Post-visit surveys (participants)
  ▪ Semi-structured interviews with patients, care partners, PCPs (qualitative analyses)

Funding: R01AG067427 and R01AG069734
Stakeholder Engagement

- Patient advisory board at each healthcare system with about 4 members
  - Patient advisors do not have (known) cognitive impairment themselves but many have experiences with close family members
  - Reviewed study materials and processes and provided detailed feedback
  - Suggested language to decrease stigma
    - “Brain health” language in outreach letter and name of visit
    - Participated in many practice sessions to help train research interventionists
- Clinician input from:
  - Clinic chiefs
  - Physician champion/stakeholder at each clinic
- KPWA Geriatrics lead is a co-investigator

Funding: R01AG067427 and R01AG069734
Preliminary Results
Initial Results: Kaiser Permanente Washington

- We have completed study activities in our first Kaiser Permanente Washington clinic and are starting the study in our second clinic.
- As of 05/07/2023:

  - 2004 “high risk” by eRADAR score
  - 1056 in “usual care” arm
  - 948 in intervention arm
  - 887 received study outreach to date
  - 232 (26%) agreed to a study visit
  - 213 assessment visits completed

Overall, after accounting for cancellations and withdrawals, 24% are completing the study visit.
Characteristics of People Completing Visits

<table>
<thead>
<tr>
<th></th>
<th>Participants (N=213)</th>
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<tbody>
<tr>
<td>Age in years, mean ± SD</td>
<td>83.2 ± 5.2 years</td>
</tr>
<tr>
<td>Female</td>
<td>57%</td>
</tr>
<tr>
<td>Race: White</td>
<td>90%</td>
</tr>
<tr>
<td>Black</td>
<td>2%</td>
</tr>
<tr>
<td>Asian</td>
<td>4%</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>1%</td>
</tr>
<tr>
<td>Other or unknown</td>
<td>3%</td>
</tr>
<tr>
<td>Attended with care partner</td>
<td>64%</td>
</tr>
<tr>
<td>Visit mode*: In person</td>
<td>72%</td>
</tr>
<tr>
<td>Video</td>
<td>2%</td>
</tr>
<tr>
<td>Telephone</td>
<td>26%</td>
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*Visit mode not yet available for 10 participants.
## Assessment Visit Outcomes

<table>
<thead>
<tr>
<th>MoCA score*</th>
<th>Participants (N=213)</th>
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<tbody>
<tr>
<td>&lt;18</td>
<td>6%</td>
</tr>
<tr>
<td>18-25</td>
<td>39%</td>
</tr>
<tr>
<td>≥26</td>
<td>55%</td>
</tr>
<tr>
<td>Referred for follow-up for any reason</td>
<td>48%</td>
</tr>
<tr>
<td>Suspected dementia</td>
<td>15%</td>
</tr>
<tr>
<td>Suspected mild cognitive impairment</td>
<td>29%</td>
</tr>
<tr>
<td>Poorly controlled depression</td>
<td>4%</td>
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*MoCA score not yet available for 23 participants
Formative Evaluation

- Surveys sent to all participants after brain health visit
  - Closed- and open-ended questions
- Analysis performed after first 40 responses
  - Response rate: 53%
  - Average MoCA score lower in responders than non-responders
  - Of responders, 40% cognitively normal, 38% suspected MCI, 20% suspected dementia
  - For 30%, participant completed survey with help of care partner
Survey Results: % Agree

- Invitation letter was clear
- Wasn't sure what would happen during visit
- Felt comfortable talking about brain health
- Felt comfortable before completing exercises
- Felt upset or concerned
- Person doing visit put me at ease
- Found visit helpful

0 10 20 30 40 50 60 70 80 90 100
Open-Ended Feedback

• Positive
  ▪ “I was happy to find I was in the normal range for a woman of 85!! I’m a woman who had 3 older sisters and was concerned about my memory as 2 of these sisters died of Alzheimer’s disease.” (No cognitive impairment)
  ▪ [What went well]: “To learn that I should be aware of what I might be losing.” (Possible Dementia)

• Negative
  ▪ “The label ‘brain health research’ somewhat alarmed me, and prompted some negative thoughts about my well-being which I was afraid would influence the results.” (No cognitive impairment)
  ▪ “Unsatisfactory conclusion. What do I do now? Handout was very general.” (Possible MCI)
Challenges

• Low rate of people accepting a study assessment visit (24%)
  ▪ We are exploring alternative outreach approaches and referral strategies for those who decline a research visit
• Some participants with suspected dementia are choosing not to (or forgetting to) follow up for more evaluation
Conclusions

• eRADAR was developed using ACT data and externally validated using EHR data from KPWA and UCSF
• We are currently testing a pragmatic, primary-care based intervention to increase dementia detection using eRADAR
• Relatively low rate of participants agreeing to study assessment visit
• Higher than expected rate of cognitive impairment among those assessed
• Overall, the intervention has been feasible and well-accepted
• Next steps: initiate study in more clinics; collect quantitative and qualitative data about outcomes
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