Improving Timely Diagnosis of Dementia in Diverse Communities: Barriers and Facilitators in Primary Care

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CHIIS
Center for Health Innovation & Implementation Science

Conflict of Interest

- I have no potential conflicts of interest

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Primary Care

- 40-50% of dementia is unrecognized
- Impact of unrecognized or delayed dementia identification
  - Higher rates of hospitalization
  - Longer length of inpatient stays
  - Lower quality of co-morbidity management
  - Increase in unsafe activities
  - Low likelihood of receiving dementia care for patient and family
  - Higher career stress, burden, and isolation

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Research on Early Detection

- 50% agree to dementia detection research enrollment
- 80-90% accept screening for dementia
- 7-13% screen positive
- 33-52% accept diagnostic evaluation following positive screen
  - ➢50% are diagnosed with Dementia
  - ➢30% are diagnosed with MCI

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Who Screens Positive for Dementia in Primary Care?

- Individuals aged ≥ 80: OR 2.5; $P < 0.05$
- Individuals with less than high school education: OR 3.6; $P < 0.05$
- Individuals with self-reported forgetfulness: OR 4.7; $P < 0.05$
- Screening at urban vs. suburban and rural setting: OR 2.4; $P < 0.1$
- Patients screened face-to-face vs. phone: OR 2.2; $P < 0.1$

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Boustani et al. JGIM 2005; Fowler et al. JCIA 2010

Momentum for Early Detection

- Rapidly growing population
- Pharmacological treatments
- Evidence of suffering
- Potential to improve the journey

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National Alzheimer's Project Act

(NAPA)

GOAL 1: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025

Strategy 1.C. Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias

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1996, 2003, 2013, and 2020

Evidence is insufficient to recommend routine screening in Primary Care

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Proponents of early detection

- Identify reversible causes
- Reduce cognitive burden
- Initiate interventions
- Evaluate safety
- Validate concerns
- Planning for care
- Health promotion activities
- Target treatment

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Critics of early detection

- Harms > Benefits
- Depression
- Anxiety
- Over burden health system
- Labeling
- Patients don't want to know
- No cure

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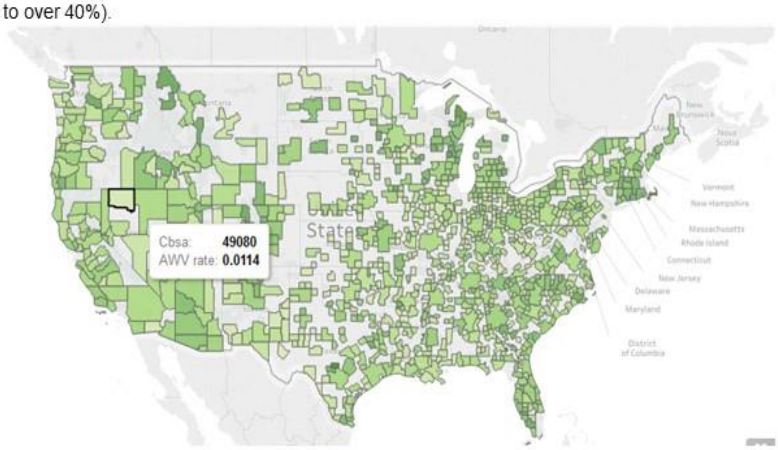
Medicare Annual Wellness Visit

Rates of Annual Wellness Visit

- **11.8%** (0% to over 40%).



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Fowler et al, JAGS 2018

Receipt of Subsequent Cognitive Care in the Year after Index

	AWV Cohort	Control Cohort	Standard difference
	N = 66,399	N = 66,399	
Neuropsychological testing	0.75%	0.55%	0.02
Imaging of the head and neck, brain, or skull	10.68%	11.78%	-0.04
Laboratory tests (TSH, B12, Folate, Syphilis)	7.50%	5.11%	0.10
Diagnosis of MCI or ADRD	6.16%	6.86%	-0.03
Initiation of any medication indicative of ADRD	1.00%	1.08%	-0.01

CHOICE Trial

- Three site, two-arm RCT
- Primary Care patients ≥65yo w/o dementia
- Outcomes
  - ➢Health-related quality of life
  - ➢Depression and Anxiety
  - ➢Health care utilization
  - ➢Advance care planning

Trials

The Indiana University Cognitive Health Outcomes Investigation of the Comparative Effectiveness of dementia screening (CHOICE) study: study protocol for a randomized controlled trial

Nicole R Fowler[1*], Amanda Hartswood[2,3], Amie Frame[2,3], Anthony J Perkins[2,3], Sujuan Gao[4], Christopher M Callahan[2,3,4], Greg A Sachs[3,5,6], Dustin D French[5] and Malaz A Boustani[2,3,6]

Cite this article as: Fowler *et al.*: **The Indiana University Cognitive Health Outcomes Investigation of the Comparative Effectiveness of dementia screening (CHOICE) study: study protocol for a randomized controlled trial.** *Trials* 2014 **15**:209.

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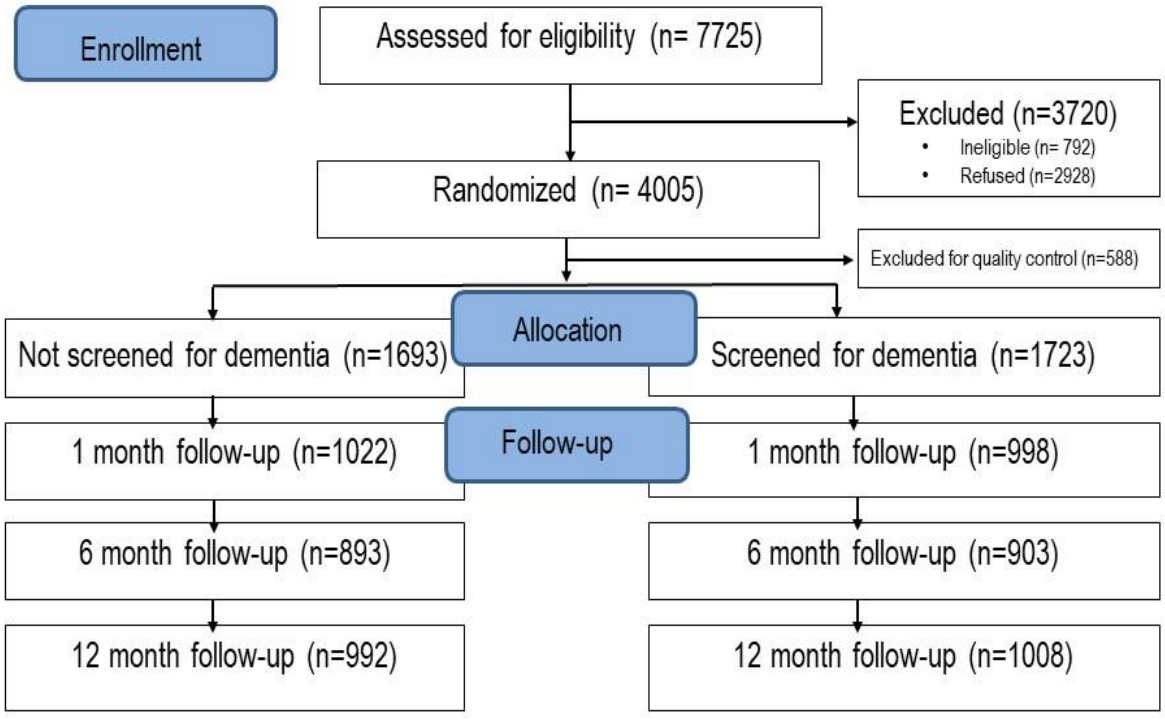

Characteristics of Study Patients

	Screen	No Screen
	N = 1723	N = 1693
Age, mean ± SD	74.2±7.0	74.1±6.5
White, n (%)	1164 (67.6%)	1137 (67.2%)
Female, n (%)	1167 (67.7%)	1089 (64.3.%)
Education level, n (%)		
Less than high school	363 (21.2%)	357 (21.2%)
High school	571 (33.4%)	556 (33.1%)
Some college or college degree	778 (45.4%)	769 (45.7%)
Charlson Comorbidity Index, mean ± SD	2.7±2.8	2.8±3.0
Screened positive on MIS-T or Mini-Cog, n (%)	87 (5%)	NA

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Results

- No Evidence of Harm
- No Evidence of Benefit
- No difference in health care utilization or ACP
- Lower than anticipated +
- Higher than anticipated refusal for follow-up

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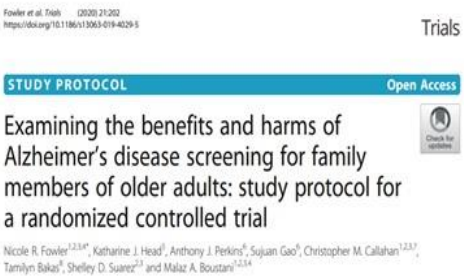

Fowler et al. Trials (2020) 21:202
https://doi.org/10.1186/s13063-019-4029-5

Trials

STUDY PROTOCOL Open Access

Examining the benefits and harms of Alzheimer's disease screening for family members of older adults: study protocol for a randomized controlled trial

Nicole R. Fowler[1,2,3,4*], Katharine J. Head[3], Anthony J. Perkins[4], Sujuan Gao[5], Christopher M. Callahan[1,2,3,7], Tamilyn Bakas[6], Shelley D. Suarez[2,3] and Malaz A. Boustani[1,2,3,4]

To test the impact of dementia screening on dyads (older adult + family member)

- Quality of life, depression, anxiety
- Caregiver preparedness, caregiving self efficacy
- Patient and family member reported cognition and PCP actions at 24 months
- Notification of – and + screening to patient, family member and PCP
- Multiple options for diagnostic follow-up

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ClinicalTrials.gov NCT03300180

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY

Effect of Patient Perceptions on Dementia Screening in Primary Care

Nicole R. Fowler, PhD, Malaz A. Boustani, MD, MPH,†‡§ Amie Frame, MPH,†§ Anthony J. Perkins, MS,†§ Patrick Monahan, PhD,‖ Sujuan Gao, PhD,‖ Greg A. Sachs, MD,†‡§ and Hugh C. Hendrie, MB, ChB, DSc†‡§¶*

Fowler, Nicole R., et al. "Effect of patient perceptions on dementia screening in primary care." Journal of the American Geriatrics Society 60.6 (2012): 1037-1043.

Hindawi
Journal of Aging Research

Older Primary Care Patients' Attitudes and Willingness to Screen for Dementia

Nicole R. Fowler,[1,2,3] Anthony J. Perkins,[1,2] Hilary A. Turchan,[1,2] Amie Frame,[1,2] Patrick Monahan,[3,4] Sujuan Gao,[3,4] and Malaz A. Boustani[1,2,3]

Fowler, Nicole R., et al. "Older primary care patients' attitudes and willingness to screen for dementia." Journal of aging research 2015 (2015).

Relationship between Perceptions and Screening Acceptance

	Odds Ratio	P Value
Perceive a Benefit of Knowing Early	0.80 to 0.85	.01
Has a relative with Alzheimer's disease	0.43 to 0.51	.014
Age, years		
65-69	[Reference]	
70-74	1.71 to 5.65	<.001
75-79	1.02 to 3.63	.01
≥80	0.9 to 2.44	.13

48% to 67% who screen positive refuse further diagnostic work-up for dementia

Those who live alone are less likely to seek treatment after a positive screen for dementia

Patients may not place value on tests that seem unrelated to cognitive functioning

- Live alone: OR 7.28; P < 0.01
- Pass temporal orientation (year, date, and day of the week): OR 1.37; P = 0.001
- Refuse screening for other conditions (colon, depression): OR 1.75; P < 0.01
- Concern of dementia-related stigma: OR 1.43; P < 0.05
- Race-Age interaction:
  - African-American ≥ 80 yrs: OR 3.1, P < 0.001
  - White-American ≥ 80 yrs: OR = 0.9, P = 0.728

Summary

- Early detection of ADRD and disclosure of the diagnosis are critical to optimal care for older adults and their family members.
- Reduce public stigma of ADRD in communities.
- Raise awareness of the benefits and increase access to evidence-based programs that reduce burden and improve outcomes that matter to patients and families.

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Thank you

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