

# Pragmatic Trials involving People Living with Dementia and their Care Partners: Lessons from the STAR Caregivers Virtual Training and Follow-up Protocol

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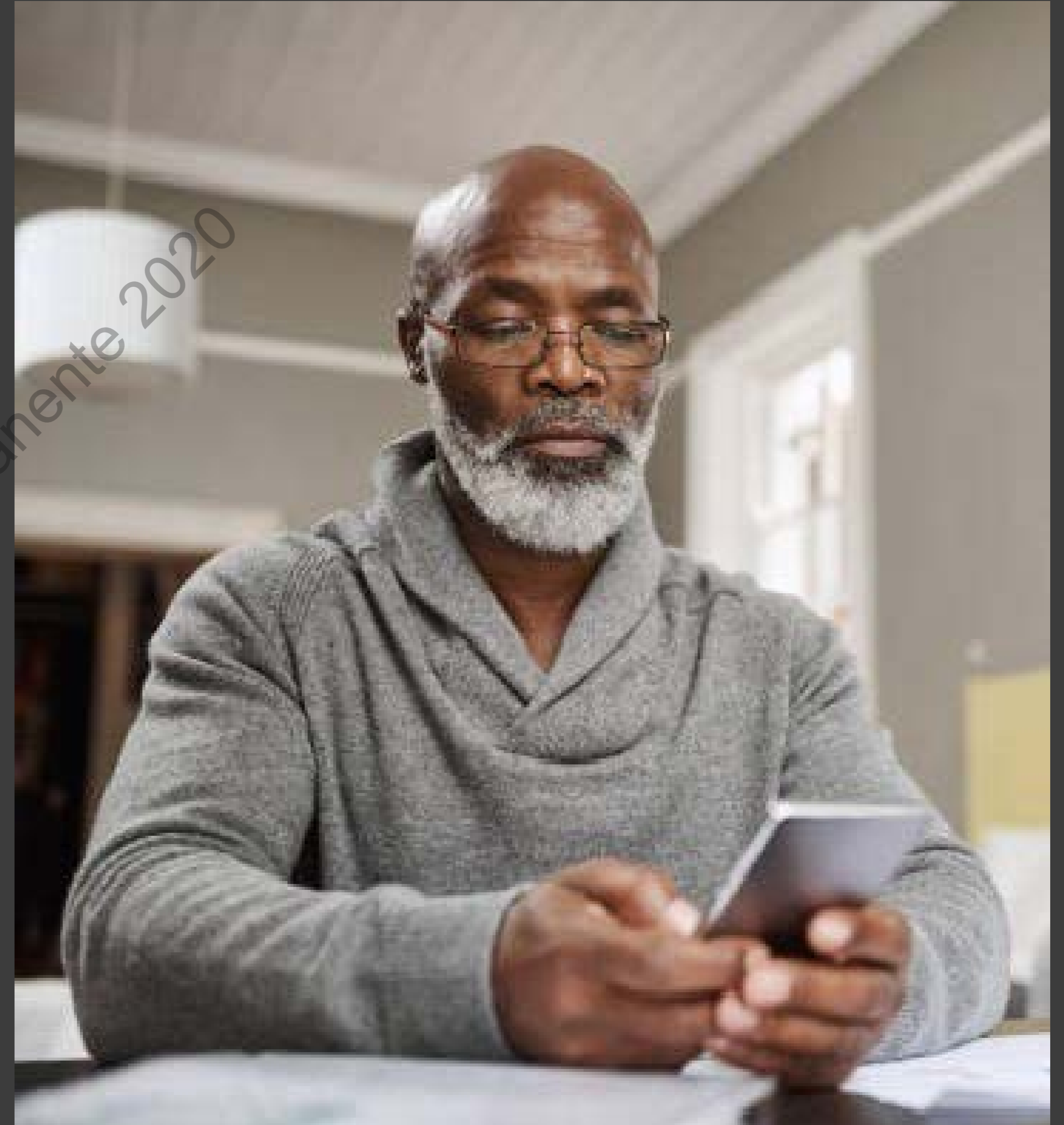
# Introduction

- Brief background on behavioral and psychological symptoms of dementia
- Review of original STAR-Caregivers trials
- Overview of our intervention and protocol
- Issues
  - Assessing eligibility
  - Consent
  - Pragmatic collection of measures and outcomes



# Motivation for the STAR-VTF study

- Alzheimer's Disease and related dementias (ADRD) are associated with behavioral and psychological symptoms
- Persons living with dementia (PWLD) are often prescribed antipsychotic medications for these symptoms



**Choosing Wisely<sup>®</sup>**

*An initiative of the ABIM Foundation*

American Geriatrics Society



Leading Change. Improving Care for Older Adults.

**Five Things Physicians  
and Patients Should Question**

**Choosing Wisely<sup>®</sup>**

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American Psychiatric Association



**Five Things Physicians  
and Patients Should Question**



2

## Don't use antipsychotics as the first choice to treat behavioral and psychological symptoms of dementia.

People with dementia often exhibit aggression, resistance to care and other challenging or disruptive behaviors. In such instances, antipsychotic medicines are often prescribed, but they provide limited and inconsistent benefits, while posing risks, including over sedation, cognitive worsening and increased likelihood of falls, strokes and mortality. Use of these drugs in patients with dementia should be limited to cases where non-pharmacologic measures have failed and patients pose an imminent threat to themselves or others. Identifying and addressing causes of behavior change can make drug treatment unnecessary.

3

## Don't routinely use antipsychotics as first choice to treat behavioral and psychological symptoms of dementia.

Behavioral and psychological symptoms of dementia are defined as the non-cognitive symptoms and behaviors, including agitation or aggression, anxiety, irritability, depression, apathy and psychosis. Evidence shows that risks (e.g., cerebrovascular effects, mortality, parkinsonism or extrapyramidal signs, sedation, confusion and other cognitive disturbances, and increased body weight) tend to outweigh the potential benefits of antipsychotic medications in this population. Clinicians should generally limit the use of antipsychotic medications to cases where non-pharmacologic measures have failed and the patients' symptoms may create a threat to themselves or others. This item is also included in the American Geriatric Society's list of recommendations for "Choosing Wisely."

## STAR: A Dementia-Specific Training Program for Staff in Assisted Living Residences

Linda Teri, PhD,<sup>1</sup> Piruz Huda, MN, ARNP,<sup>1</sup> Laura Gibbons, PhD,<sup>1</sup>  
Heather Young, RN, PhD,<sup>2</sup> and June van Leynseele, MA<sup>1</sup>

## Adopting Evidence- Based Caregiver Training Programs in the Real World: Outcomes and Lessons Learned From the STAR-C Oregon Translation Study

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## *STAR-Caregivers*

### A Community-based Approach for Teaching Family Caregivers to Use Behavioral Strategies to Reduce Affective Disturbances in Persons With Dementia

By REBECCA G. LOGSDON, PhD, SUSAN M. MCCURRY, PhD, AND LINDA TERI, PhD

Compared to routine medical care, caregivers experienced reduced

- Depression
- Reactivity to PWD behaviors
- Frequency and severity of target behaviors

and improved quality of life.

# STAR Caregivers Components

- Realistic Expectations
- Practical, effective communication
- Activators, Behaviors, Consequences
  - ABCs
- Pleasant events
- Caregiver self-care



# STAR-VTF

## Virtual Training & Follow-up

- Scale-up:
- Intervention
  - Online self-learning – 6 modules
  - 6 x 30 min calls with a coach
  - Secure message support – 6 months
- Control
  - Mailed materials
  - Links to Alzheimer's Association video tutorials
  - No coach





- Restore
- Import
- Reset
- Question bank
- Repositories

- Switch role to...
- My profile settings

Get the STAR-C Handbook Here



Contact your counselor:

counselor@kp.org

555-555-5555

# STAR-C Caregiver Training

## Treatment of Mood and Behavior Challenges in Persons with Dementia



STAR-C Intervention Manual Handouts

Lesson 1



Lesson 2



Lesson 3



Lesson 4



Lesson 5



Section 6



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- ▼ 6. Challenging Behaviors

# Overview of Session 1

Improve quality of life for:

- Caregivers
- People living with dementia

Learn about:

- Problem-solving techniques
- Effective communication



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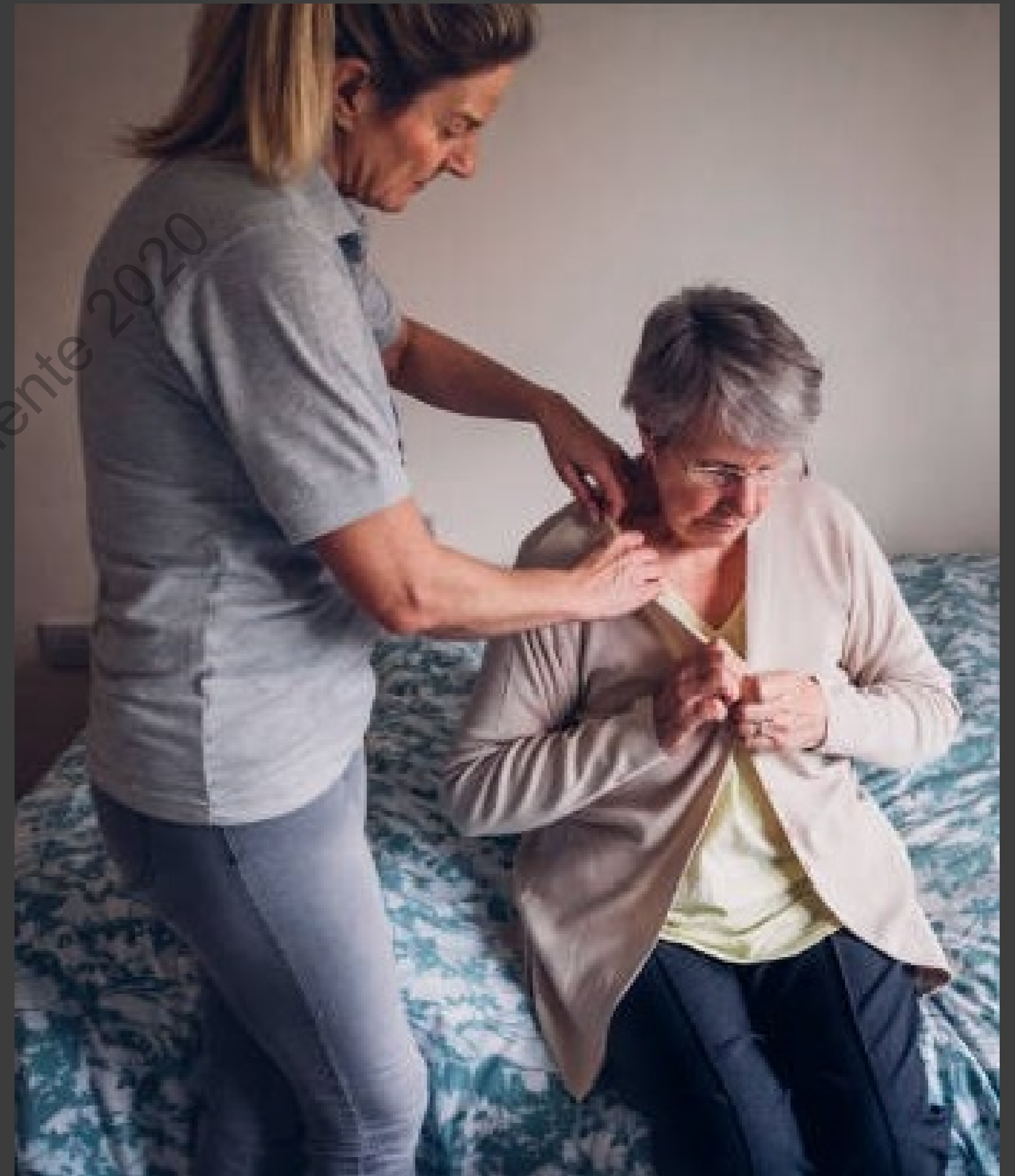


My Plan

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# Recruitment of 100 dyads

- Automatically PWD identification
  - Age  $\geq 65$
  - Diagnosis of ADRD
  - Prescribed incident antipsychotic
  - Enrolled for  $\geq 180$  days prior
  - Expected to live  $\geq 6$  months
  - No psychosis, bipolar disorder
  - Not living in SNF, AFH, MF
- Caregiver
  - Age  $\geq 21$
  - Lives with PWD or within 8 miles
  - Provides at least 8 hours of care
  - No ADRD diagnosis



# Outcomes

- Caregiver
  - Caregiver burden (RMPBC)
  - Kingston Caregiver Stress Scale
  - Caregiver Mastery Scale
  - Depression (PHQ-8)
- Person with Dementia
  - Antipsychotic medication refills
- Response rates to measure completion
- Training completion
- Time in motion for coaches (costs)



# Pragmatic Trial Issues: Recruitment

- Automated identification
  - What is the residential situation?
  - Who is the caregiver?
  - What was the antipsychotic prescribed for?



# Pragmatic Trial Issues: Physician outreach

- Screening questions
  - Was the Rx for BPSD?
  - Expected to live > 6 months?
  - Consent to participate
  - Any other reason to exclude?
- Must have MD's response to guide consent process



# Pragmatic Trial Issues: Caregiver Outreach

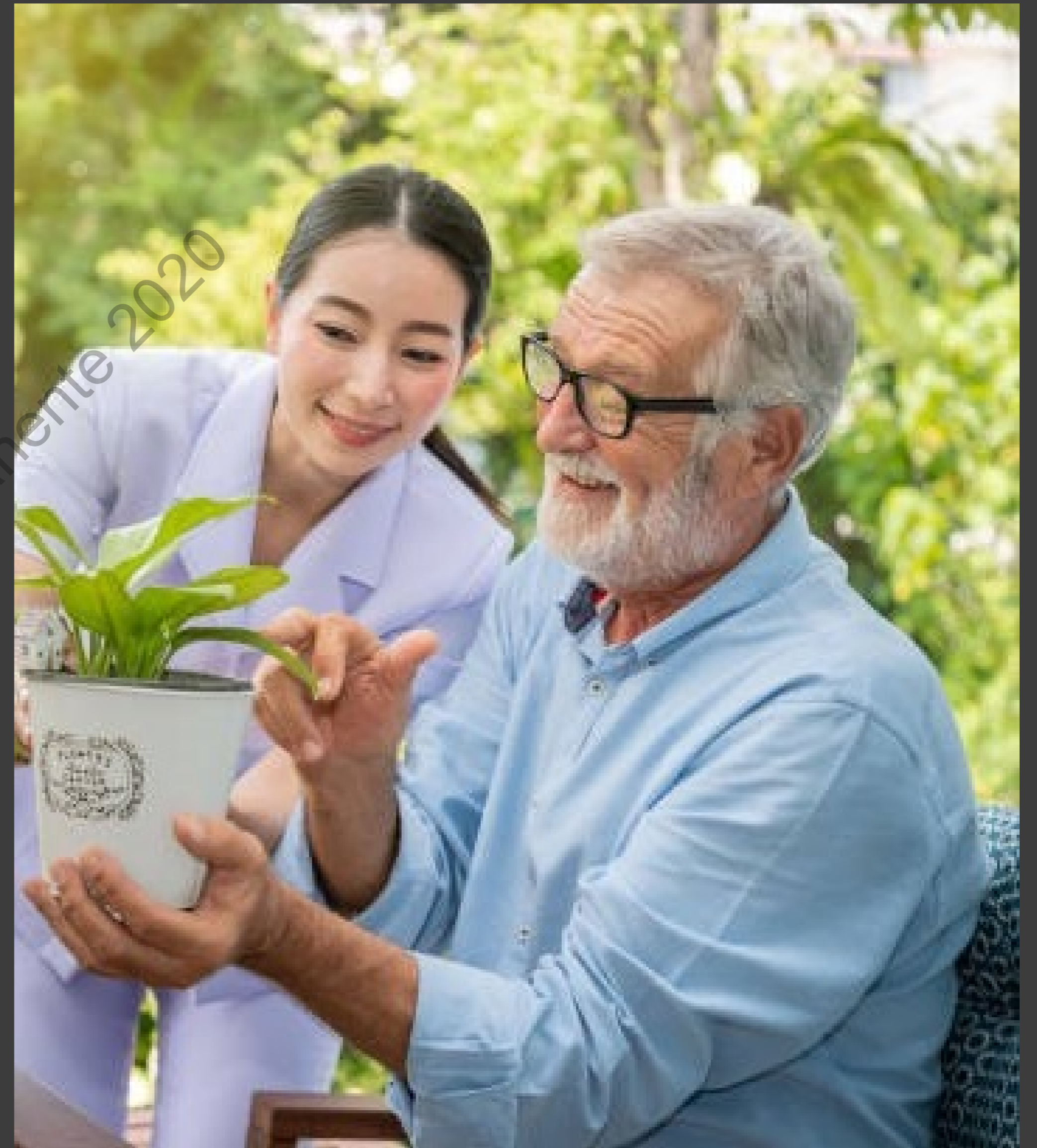
- Screening questions
  - Are you the right caregiver?
  - Do you live with PWD? Within 8 miles? At least 8 hours of care?
  - Are you the DPOA?
  - Dementia screen





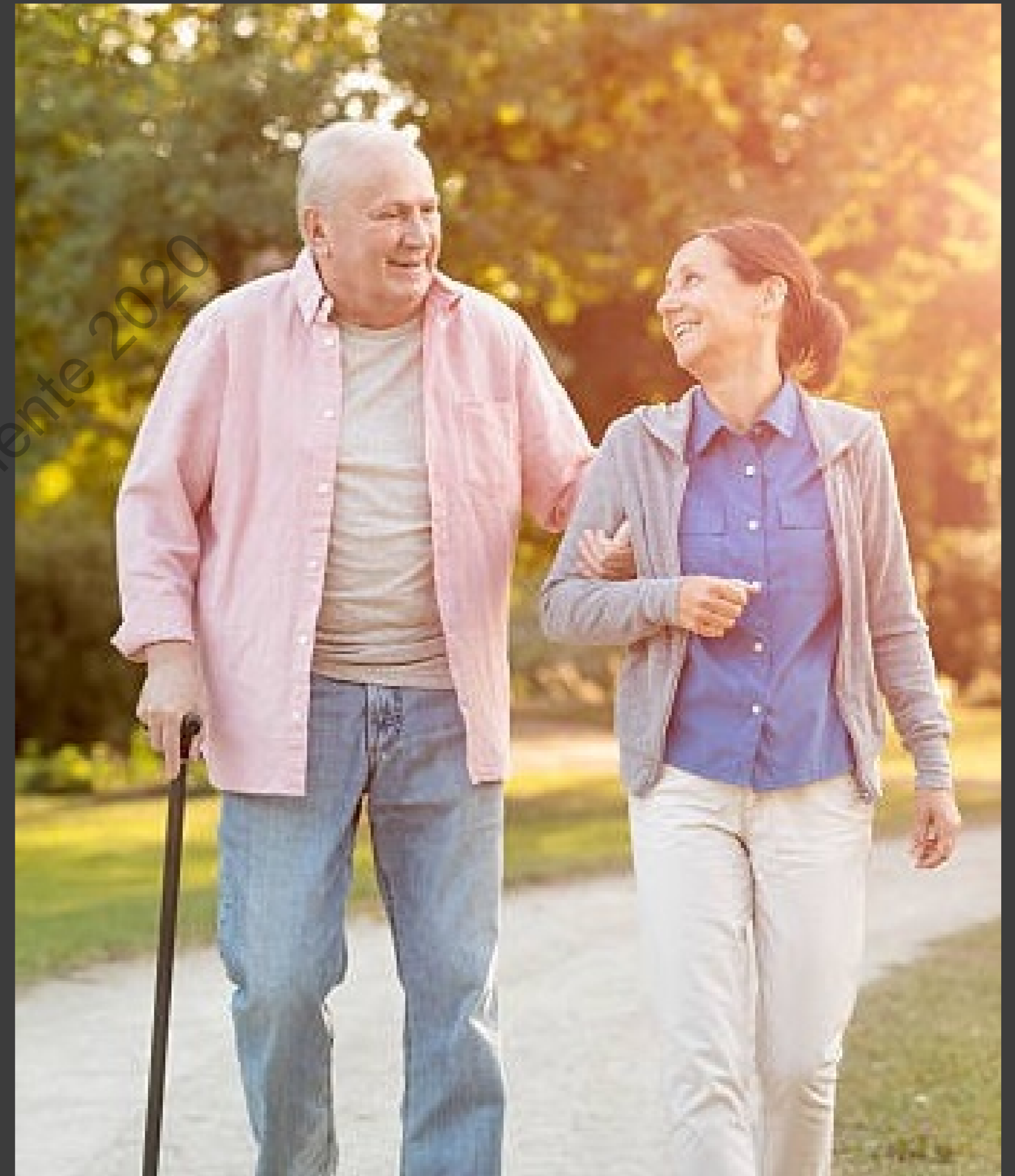
# Pragmatic Trial Issues: Consent

- Need consent from the PWD because using medical records downstream
- Can the PWD consent on “good days”?
- What if caregiver is not the DPOA?
  - First consent the DPOA on behalf of the PWD



# Pragmatic Trial Issues: Measures

- Ideally collected in Epic EHR
  - Spent months trying to implement
- “Standard of care” is to note caregiver issues in the PWD chart.
  - Can’t do this in research
  - Privacy
  - Legal disputes (e.g., adult children)
  - Treatment confusion  
PWD vs CG PHQ-9



# Pragmatic Trial Issues: EHR Governance

- What about a caregiver Epic profile?
  - About 50% of caregivers are not KPWA members
- Need to develop a solution for documenting caregiver issues
  - Making all the decisions for PWD
  - Caregiver functioning directly impacts PWD medically, QOL
  - Caregiver module?



## Conclusion – Lessons Learned on STAR-VTF So Far

### Need to Act

The prevalence of ADRD is increasing and scalable, family-centered programs like STAR-C (STAR-VTF) need implementation

### Antipsychotics Still Common

Despite the Choosing Wisely Guidelines, prescribing of antipsychotics is surprisingly common (7-10 new starts per week at KPWA)

### Elders are Going Virtual

Caregivers are increasingly using patient portals and becoming facile in internet-based learning and digital communication with clinicians.

### Pragmatic Recruitment

Difficult to identify caregivers with existing automated data.

### “Pragmatic” Consent

Diminished capacity and divided responsibility make consent difficult from a pragmatic point of view.

### Pragmatic Measurement

Until governance issues are resolved, pragmatic outcomes collection is not possible.

[More presentation tips](#)

UW

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**THANK YOU!!**

