



I-MEASURED

Investigating MEAsures of SURvival and REsidence among persons with Dementia

Josiah Drakes
SUMR & GEAR-UP Scholar
Dr. Catherine Auriemma, MD, MSHP



Josiah Drakes

- Psychology Pre-medical @ Xavier University of Louisiana
- SUMR & GEAR-UP Scholar
- Conducting research in the PAIR & BETTER Center



Background



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graph TD; A[Background] --> B[Aims]; B --> C[My roles]; C --> D[Preliminary Findings]; D --> E[Takeaways]
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Aims

My roles

Preliminary Findings

Takeaways

PAIR CENTER



Director: Dr. Scott Halpern MD, PhD

Mission:

We generate high-quality evidence to advance healthcare policies and practices with the goals of improving the lives of all people affected by serious illness and removing the barriers to health equity that seriously ill patients commonly face.

BACKGROUND



In 2020, Alzheimer's Disease and Related Dementias (AD/ADRD) were affecting 5.8 million Americans



It was believed that hospital-free days (HFDs) was seen as a “Good day”



Current HFD assessment methods treat all hospital days as uniformly negative and all home days as uniformly positive.



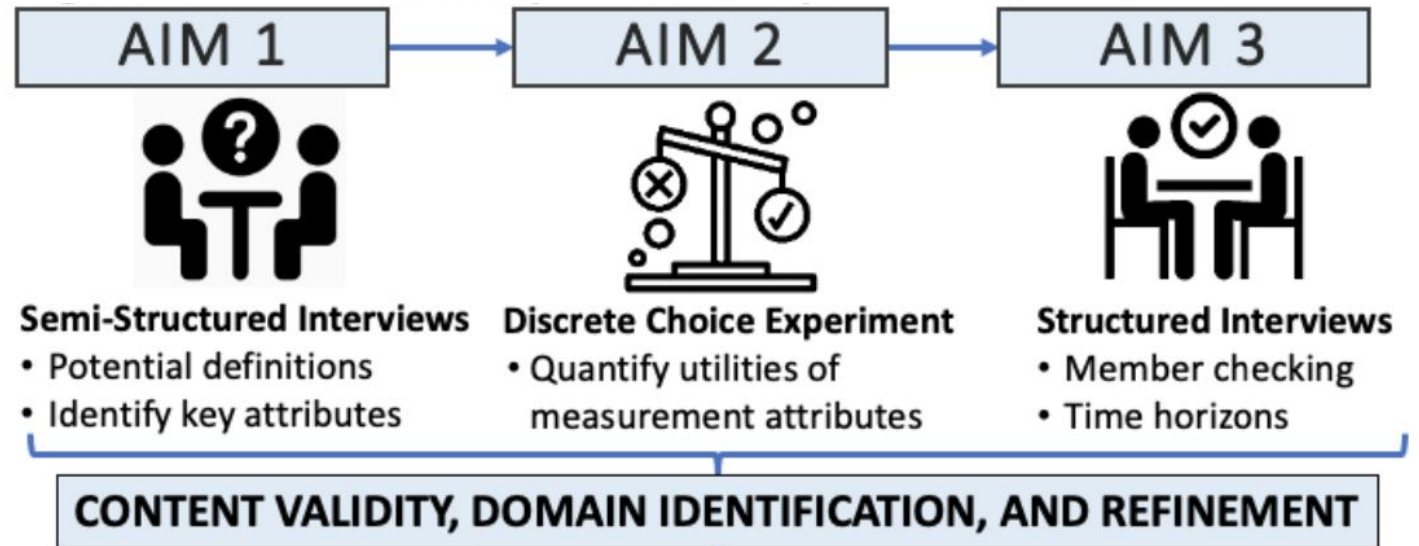
Ensures continued design and utilization of measures aligned with patient and family needs



I-MEASURED STUDY

- Interview Persons living with Dementia (PWD) and their family Caregivers to understand how Aging in Place (AIP) aligns with values and decision making
- "Aging in place" refers to the concept of PWD living in a residence as they age, rather than other care facilities.
- Main focus is to to highlight family & PWD's voices as it relates to patient outcomes

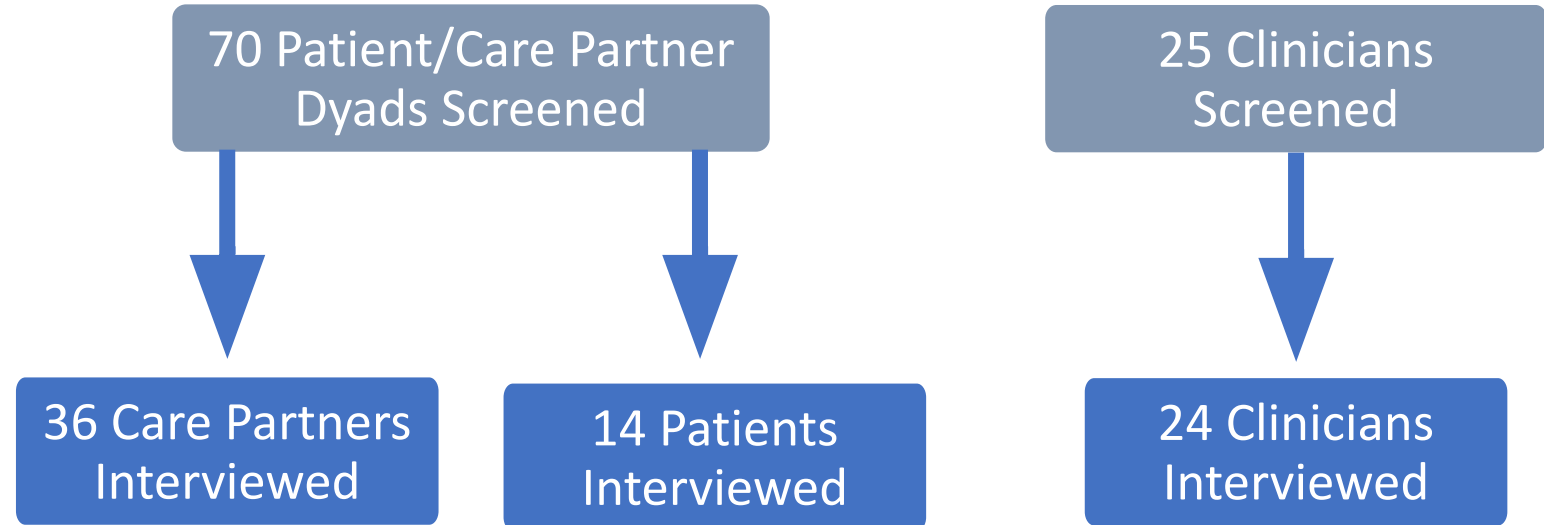
Aims



Aim 1 - Explore stakeholders' priorities for living with dementia and factors influencing decisions around care setting



- Semi-structured interviews:
 - Patients
 - Care Partners
 - Clinicians



Analytic Methods:

- Qualitative content analysis and constant comparison techniques
- Emergence of themes and codebook development
- Identification of attributes for DCE

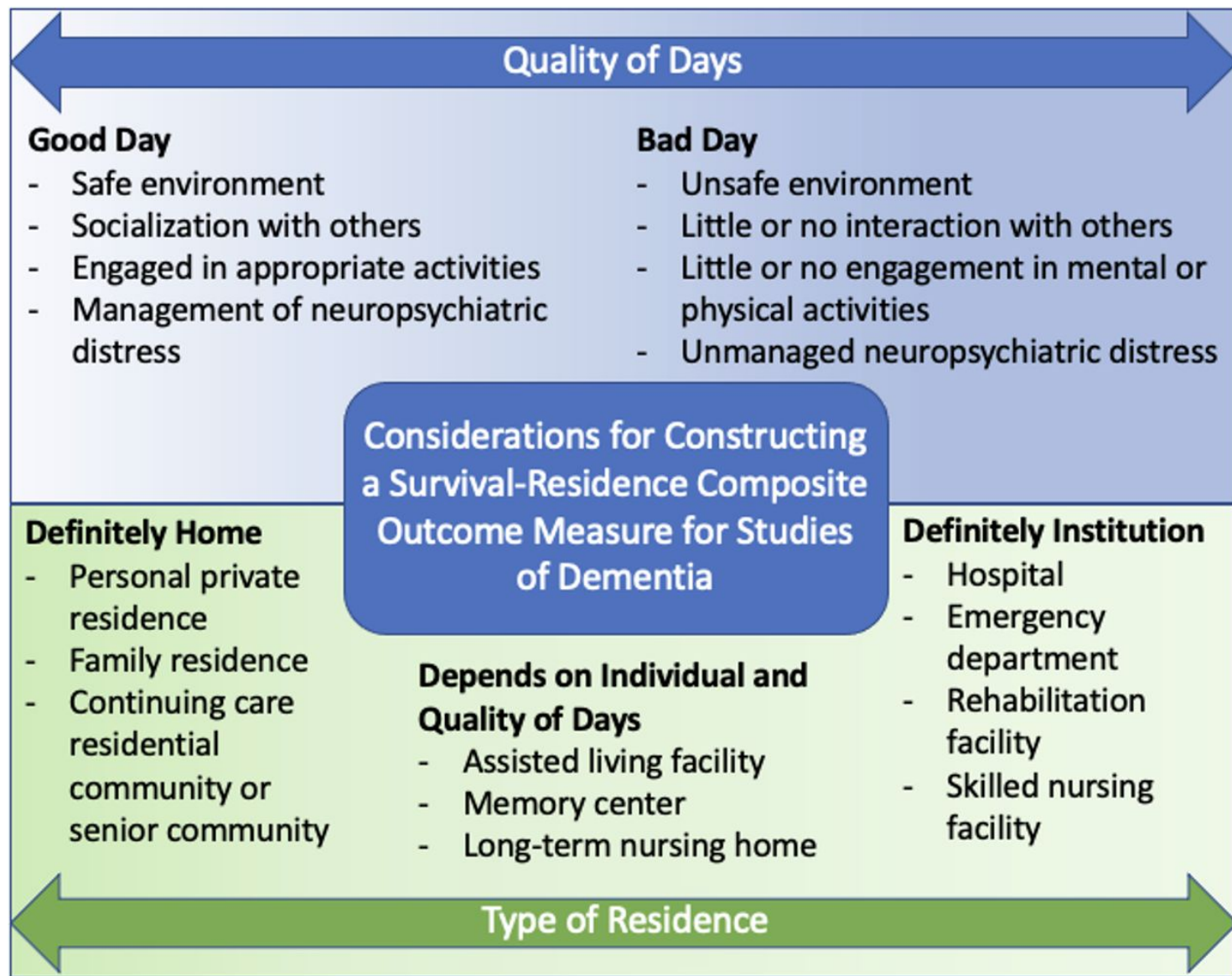
Tradeoff between Caregiver Burden and Guilt

- **I feel so badly** for her, like this is just terrible and **I wish I could bring her home, I wish she could live with me, but that's really not realistic.** And, you know, it just a never-ending cycle.

- *Caregiver of patient with moderate dementia*

- **Not being a burden...** I don't require a lot of attention during the day, and **as long as it remains non-burdensome, that's great.**

- *Patient with mild dementia*



Looking Ahead... Aim 2 – Quantify stakeholders’ utilities for attributes of a survival-residence composite outcome measure



- Discrete Choice Experiment:
 - Patients
 - Care Partners

1. Quantify utilities for attributes from Aim 1

Figure 4. Sample discrete choice experiment task













Which of the two days described below would you prefer?

	Day 1	Day 2
Care setting	Home	Long-term Nursing Facility
Physical function	Slight problems with physical activities	Slight problems with physical activities
Cognitive function	Moderate memory impairment	Severe memory impairment
Symptom Control (pain, shortness of breath)	Some uncontrolled symptoms	No uncontrolled symptoms
Care Support	Informal (family) caregivers	Professional caregivers

Please select one:

	Day 1	Day 2
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DCE Table

		With Treatment A	With Treatment B
Brain function: Measured by your score on a test	 Memory & Thinking  Language	Your loved one's test scores get worse more slowly .	There's no change in how fast your loved one's test scores get worse.
Distressing symptoms like:	 Agitation  Combativeness	Your loved one has less days with agitation and combativeness.	There's no change in the number of days your loved one has agitation and combativeness.
Physical Function: Your ability to do daily tasks	 Getting Dressed  Taking a Bath	Your loved one can do daily tasks by themselves for longer .	There's no change in how long your loved one can do daily tasks by themselves.
Home Time: Days spent outside a care facility	 	Your loved one can live at home longer .	There's no change in how long your loved one can live at home.
Family Caregiver Stress: Impact on family due to the act or cost of caregiving	 Physical & Emotional Stress  Financial Stress	Your family feels less caregiving stress.	There's no change in the caregiving stress your family feels.
Socialization & Engagement: Time spent with others or involved in activities	 Games with Others  Physical Activity	Your loved one can spend more time socializing with others and doing activities.	There's no change in how much time your loved one spends socializing with others and doing activities.

Summary of Results

Factors influencing choice
and ability to “age in place”

Attributes for quality of
days

Numerous factors influence
the AIP

Limitations

- Maintaining patient-centered, accessible language for participants with a range of cognitive impairments
- Achieving economic and education level diversity within our study sample





Future Goals

- Finish completing DCE tables
- DCE piloting with patients and care partners
- Structured interviews in AIM 3
- Create change in current & future policy

My Role

- Calculate cognitive function scores in excel
- Working through DCE: AIMS 2(piloting)
- Redcap

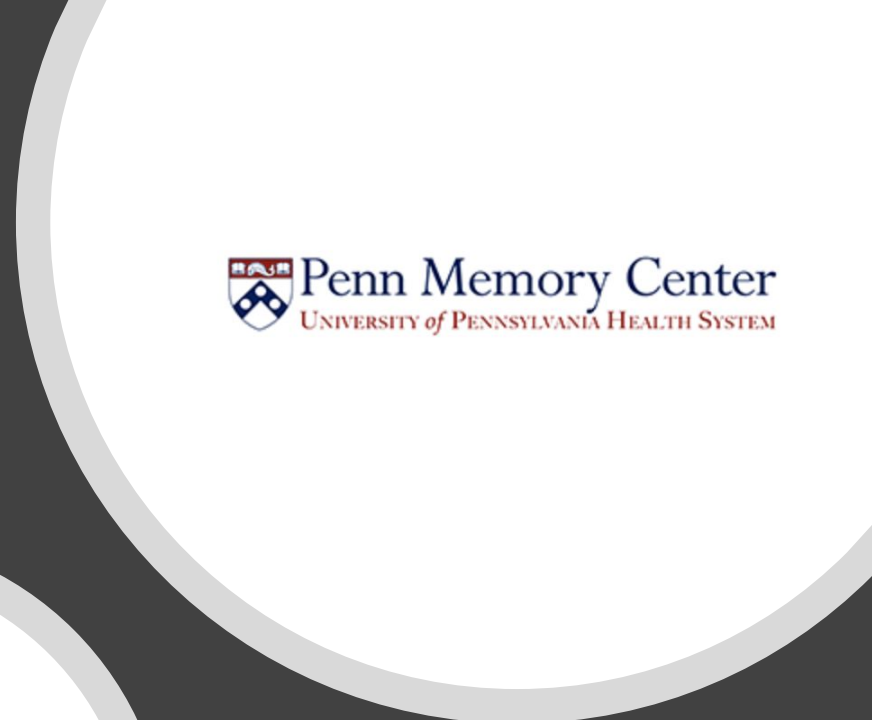


Lessons Learned

- Dry lab
- The ebbs and flows of research
- Research/medicine
- Excel, Recap & Word proficiency
- Qualitative methods
- Shadowing
- Networking

Acknowledgments

- Dr. Catherine Auriemma
- Maayra Butt
- Jasmine Silvestri
- Tamar Klaiman
- Erich Dress
- Dr. Scott Halpern
- Dr. Gary Weissman
- Joanne Levy
- Chinwe Nwadiogbu
- SUMR/GEAR-UP 2023 Cohort



Dr. Catherine Auriemma

- Intersection of Medicine & Research
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ANY QUESTIONS

Josiah Drakes

Jdrakes@xula.edu

Josiah.drakes@pennmedicine.upenn.edu

PAIR Center

[215-898-0861](tel:215-898-0861)

pair@pennmedicine.upenn.edu

300 Blockley Hall

423 Guardian Drive

Philadelphia, PA 19104-6021

