Illuminating Theology With Psychological Science

Interventions and Expressive Writing

Expressive Writing:
In Research & Practice

Dr. Angie LeRoy

Cross-training Workshop 2024

What’s my “why”?

To understand?

To help?

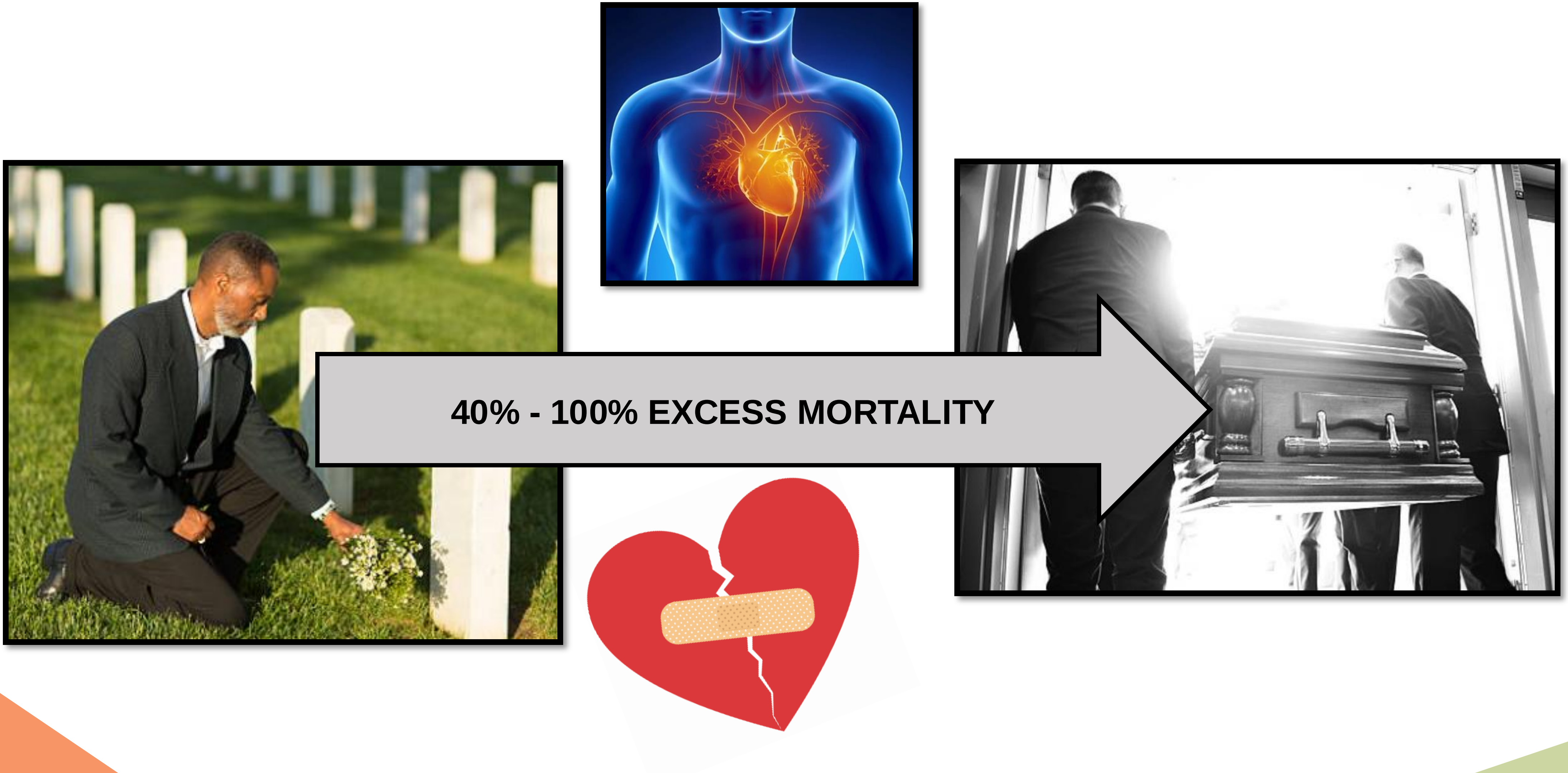
To describe?

Who am I
(as a researcher)?

I am a “health psychologist” & “interventionist”

Health psychology is a branch of psychology that studies how **mind and behavior** affect health and illness

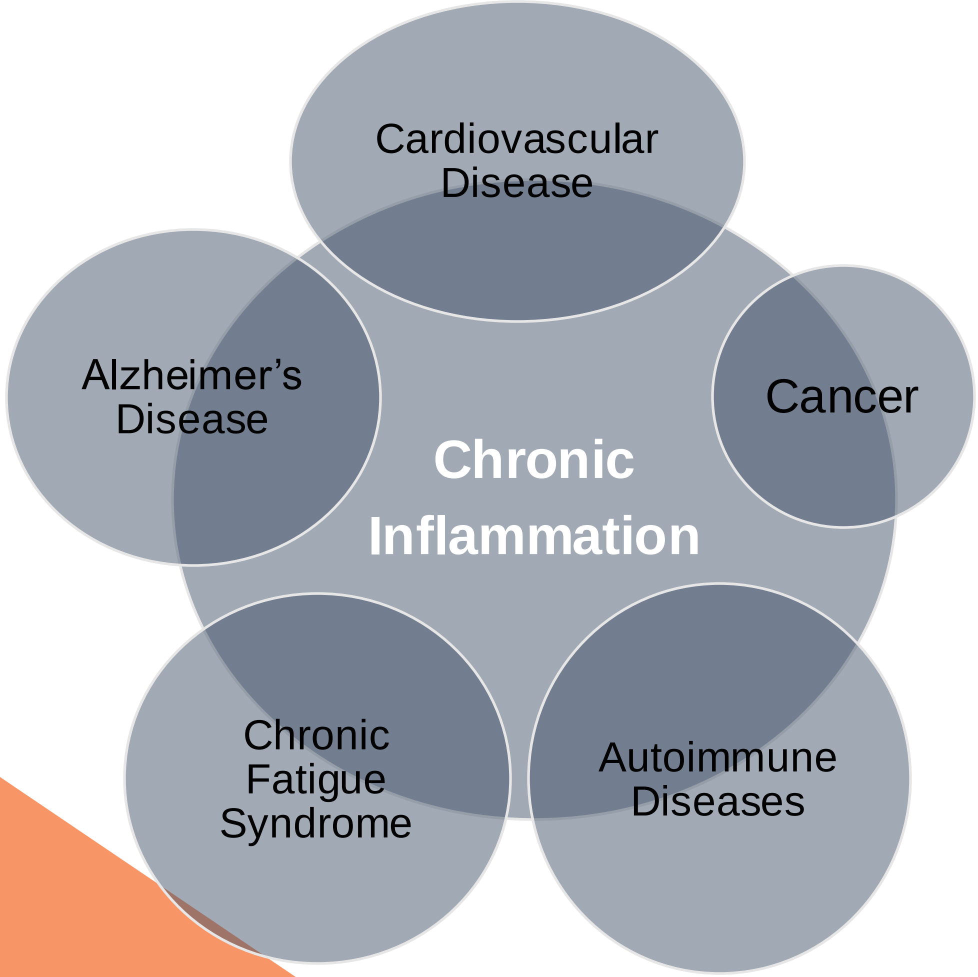
Develop, tailor, and implement novel interventions to improve health and well-being



40% - 100% EXCESS MORTALITY

Gullotta & Bloom, 2003; Manor & Eisenbach, 2003; Martikainen & Valkonen 1996; Schaefer, Quesenberry, & Wi, 1995; Stroebe, Schut, & Stroebe, 2007; Shear & Mulhare, 2008

Caregiving for a partner with Alzheimer’s or a Related Dementia (ADRD) as a model of loss



Cardiovascular Disease

Alzheimer’s Disease

Cancer

Chronic Inflammation

Chronic Fatigue Syndrome

Autoimmune Diseases

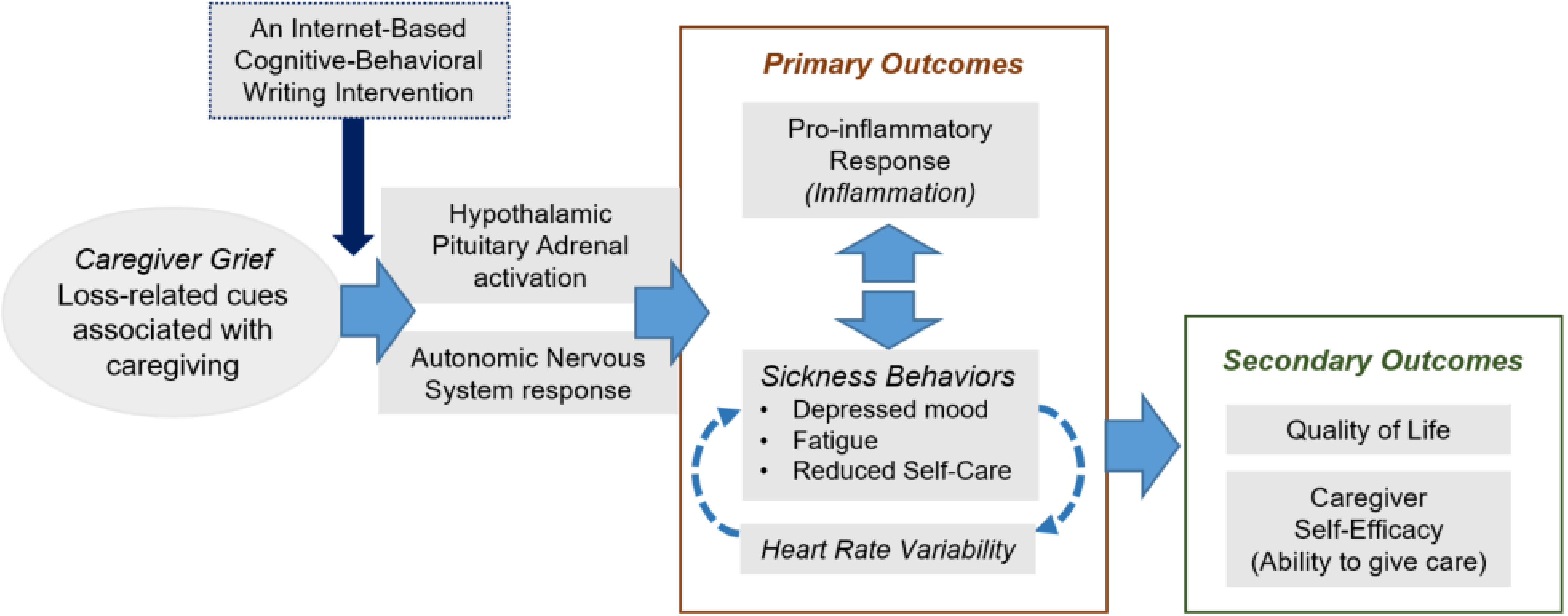
- Caregivers show marked declines in immune responses leading up to the death of a partner with ADRD

- Caregivers are themselves at a higher risk for dementia themselves

- Those with better stress outlets recovered better after the physical loss
  - *How can we provide a stress outlet?*

Wilson et al., 2020; Wu-Chung et al., 2022

Can a writing intervention mitigate these effects?



An Internet-Based Cognitive-Behavioral Writing Intervention

Caregiver Grief
Loss-related cues associated with caregiving

Hypothalamic Pituitary Adrenal activation

Autonomic Nervous System response

Primary Outcomes

Pro-inflammatory Response
(Inflammation)

Sickness Behaviors
- Depressed mood
- Fatigue
- Reduced Self-Care

Heart Rate Variability

Secondary Outcomes

Quality of Life

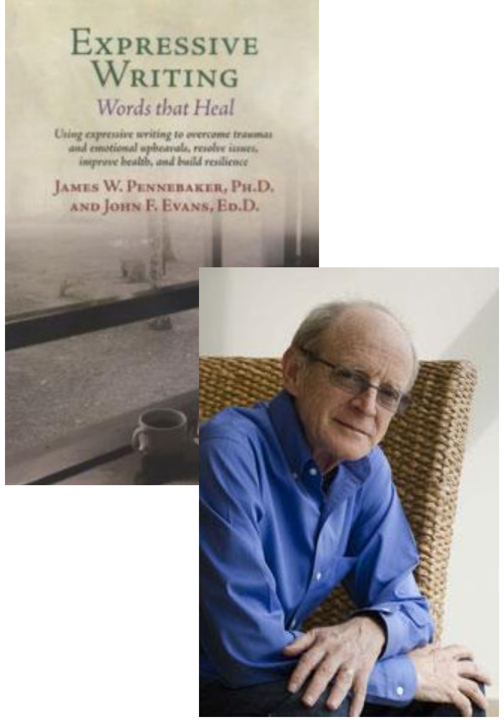
Caregiver Self-Efficacy (Ability to give care)

Writing & Health

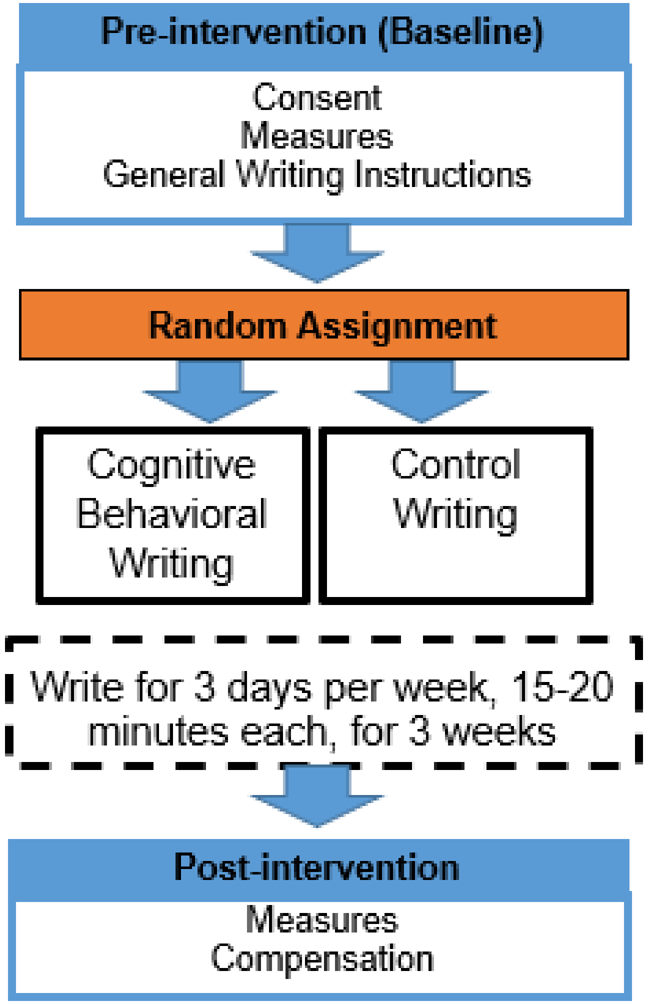
- Expressive writing (EW) can improve *self-regulation of physiological responses, emotional experiences, and behaviors*, which thereby lead to better **physical and mental health** outcomes (Lepore, 2022), particularly among people who have experienced stressful life events.

- Older adults who wrote about upsetting life events demonstrated improved **wound healing** compared to those who wrote about every-day control group topics (Koschwanez et al., 2013).

- Writing *objectively* may be enough to improve health; In a writing study among family caregivers of physically frail and cognitively impaired older adults, those who wrote objectively about how they spent their time experienced more **mental and physical health** improvements than comparison groups (Mackenzie et al., 2007)



Expressive Writing
Words that Heal
Using expressive writing to overcome traumas and emotional upheavals, resolve issues, improve health, and build resilience
James W. Pennebaker, Ph.D. and John F. Evans, Ed.D.



Pre-intervention (Baseline)
Consent
Measures
General Writing Instructions

Random Assignment

Cognitive Behavioral Writing

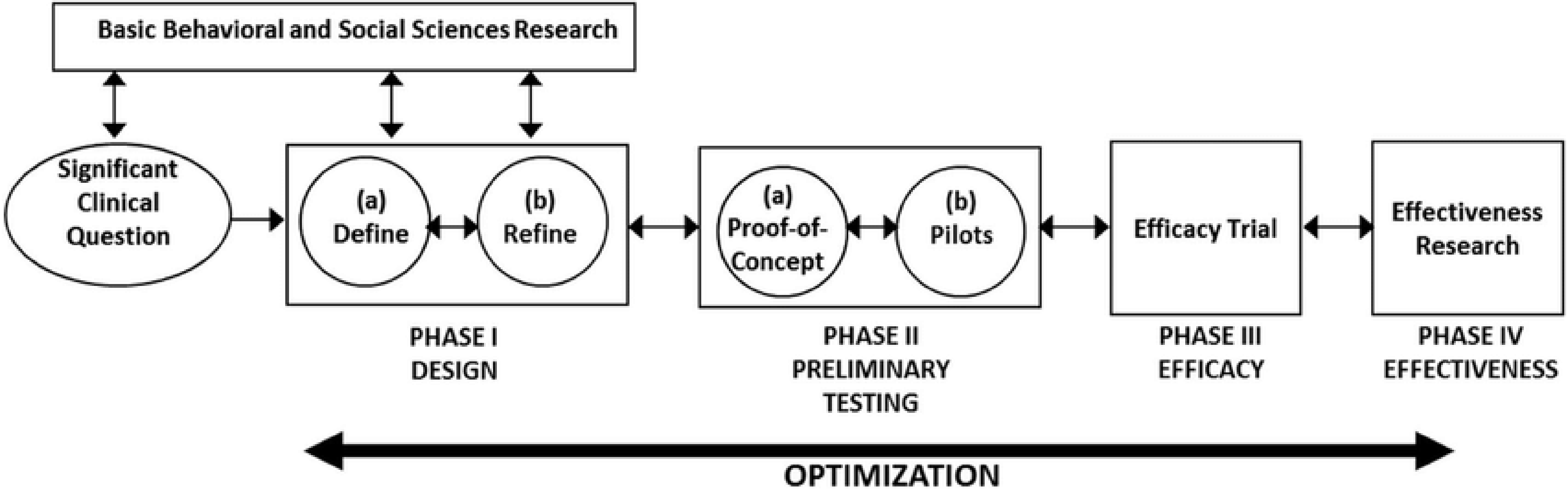
Control Writing

Write for 3 days per week, 15-20 minutes each, for 3 weeks

Post-intervention
Measures
Compensation

How can we tailor an expressive writing intervention for the stressful contexts of caregiving, using a grief-informed approach?

National Institute on Aging
K01 AG 073824
PI: Angie LeRoy



Basic Behavioral and Social Sciences Research

Significant Clinical Question

(a) Define

(b) Refine

PHASE I
DESIGN

(a) Proof-of-Concept

(b) Pilots

PHASE II
PRELIMINARY
TESTING

Efficacy Trial

PHASE III
EFFICACY

Effectiveness Research

PHASE IV
EFFECTIVENESS

OPTIMIZATION

Czajkowski et al., 2015

Qualitative Approach

ALZHEIMERS & DEMENTIA CAREGIVERS

FOCUS GROUPS

We want to hear from you!

This study aims to understand how taking care of a spouse with dementia affects the mental and physical health of caregivers. Our goal is to help researchers develop a writing intervention for stress and grief that is unique to the experience of caring for a spouse with dementia.

If you agree to take part in this study, you will be invited to participate in up two 90-minute focus groups moderated by Dr. LeRoy and a research assistant. Participants will be compensated $30 for each focus group they participate in.

ELIGIBILITY

- Self-identify as the primary caregiver to your spouse (with a diagnosis of ADRD)
- Devote at least 4 hours of daily caring of your spouse for at least the last 3 months
- Must be married or self-defined as a long-term committed partner to your spouse with ADRD for at least 3 years
- 60 years or older.

INTERESTED?

CONTACT US AT:
HEALingresearch@baylor.edu
(254) 710-1550

Wave 1 | N=20 caregivers

- Feasibility
- Acceptability

Wave 2 | n=10 returning caregivers
n=10 new caregivers

- Iteratively generating the intervention product based on stakeholder feedback

Wave 1 Qualitative Results
Using Framework Analysis

e.g., Goldsmith, 2021

1st Impressions of Writing
- Time
- Emotional Capacity
- Openness to writing
- Apprehensions about writing

Timing of Writing Sessions
- Spouse occupied, during respite
- Energy
- Stress

Modality
- Privacy + Security
- Speed
- Accessibility

Motivations for Writing
- Release
- Form of Support
- Reference Point
- Desire for Positivity
- Helps Communicate with Others

Goal: Design an intervention “product” that meets these caregivers’ needs

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Tuesday, April 2nd

Good morning, Allison

Your first writing prompt is ready

Writing 1 of 9

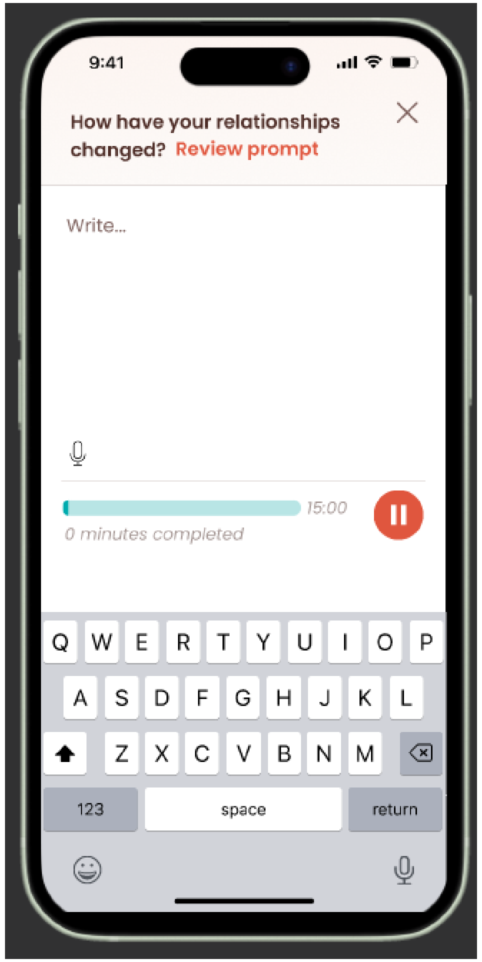
Relationships with others

Many caregivers report feeling disconnected with friends and loved ones they spent time with before their spouse was diagnosed with Alzheimer’s or a related dementia...

How have your relationships changed?

Many caregivers report feeling disconnected with friends and loved ones they spent time with before their spouse was diagnosed with Alzheimer’s or a related dementia.

For the next 15 minutes, write about how your relationships with others have changed, or how they might change in the future. You might write about your relationships with family members, friends, co-workers, medical providers, pets, or others who are important to you.

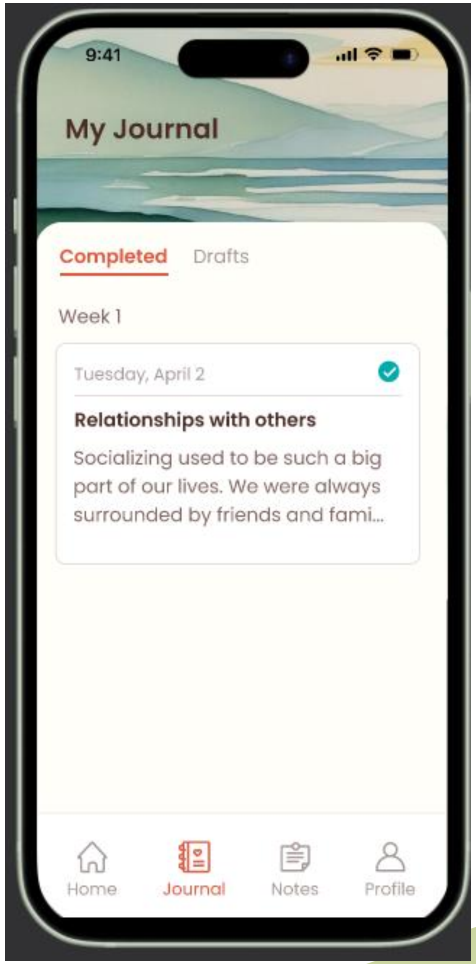


How have your relationships changed? Review prompt

Write...

15:00

0 minutes completed



My Journal

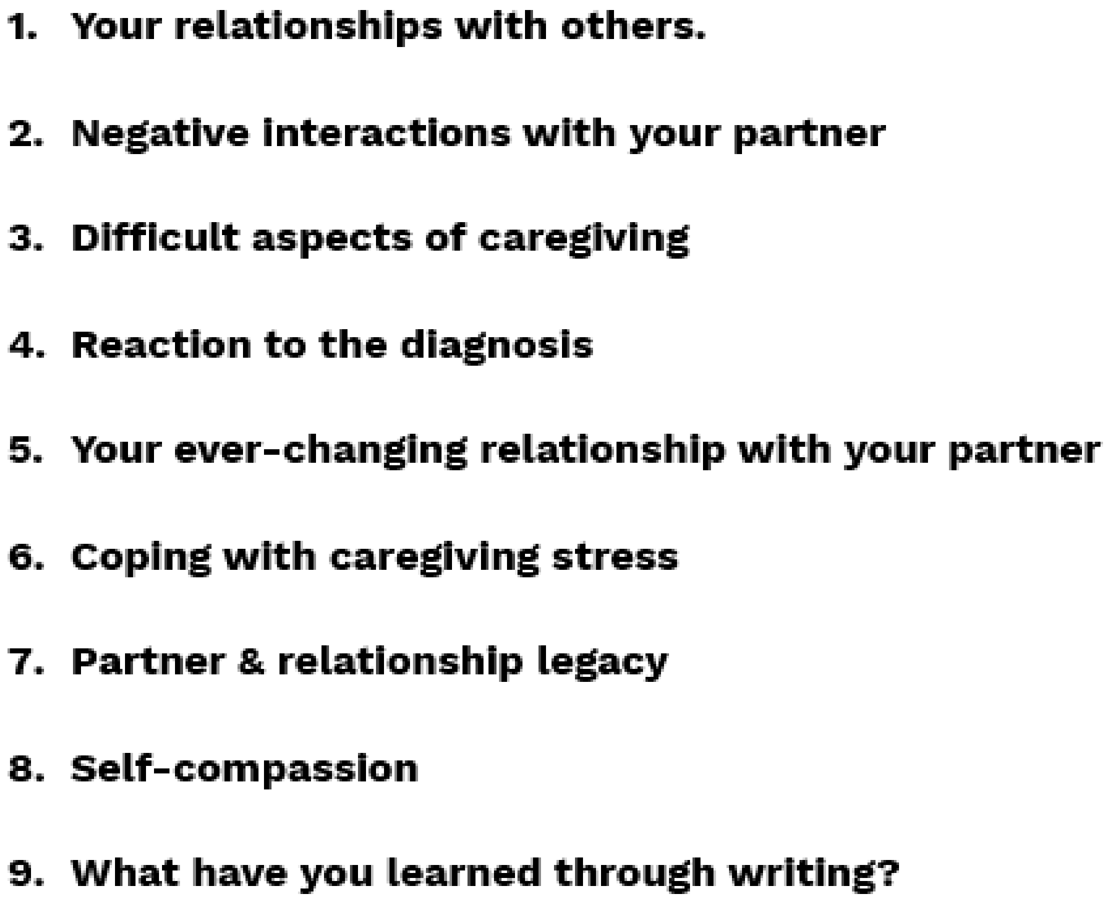
Week 1

Tuesday, April 2 ✓

Relationships with others

Socializing used to be such a big part of our lives. We were always surrounded by friends and fami...

How can we tailor an expressive writing intervention for the stressful contexts of caregiving, using a grief-informed approach?



1. **Your relationships with others.**
2. **Negative interactions with your partner**
3. **Difficult aspects of caregiving**
4. **Reaction to the diagnosis**
5. **Your ever-changing relationship with your partner**
6. **Coping with caregiving stress**
7. **Partner & relationship legacy**
8. **Self-compassion**
9. **What have you learned through writing?**

HEAL LAB

Partner & relationship legacy prompt

Many caregivers report concern about maintaining their partner's dignity and/or legacy. In addition, many people want to hold on to the good memories they had with their partner before they were living with Alzheimer's or a related dementia. What would the perfect legacy look like for you and your partner? For the next 15 minutes, write about how you want to remember your partner, and how you want your partner to be remembered by others. What do you hope others will remember about the two of you as a couple—for example, perhaps things you enjoyed doing, or things you accomplished together.

“Rules” of expressive writing

- **Write for at least 15 minutes**
- **Don’t worry about spelling, punctuation, grammar, sentence structure, just keep writing!**
- ***“leav[ing] all your thoughts and feelings on the page”***
- **The “flip out” rule – if you find that writing about something is too much at the moment, write about something else instead**

Now your turn!

Take a moment to reflect back on your journey in this cross-training program over the past year. ***What are some areas of personal and/or professional growth you've experienced during this time?*** For example, you might reflect on any personal qualities or skills that you've developed.

Can you identify a time when overcame a significant challenge? Or, perhaps you still find yourself faced with a particular challenge. ***How has this experience shaped your confidence?***

How has the process of learning to conduct research changed your ***perspective of psychology***? How have these training experiences changed your ***perspective of your own field*** and the problems you are trying to solve, within it?

Analyzing Expressive Writing-related Data

What’s my “why”?

To understand?

To help?

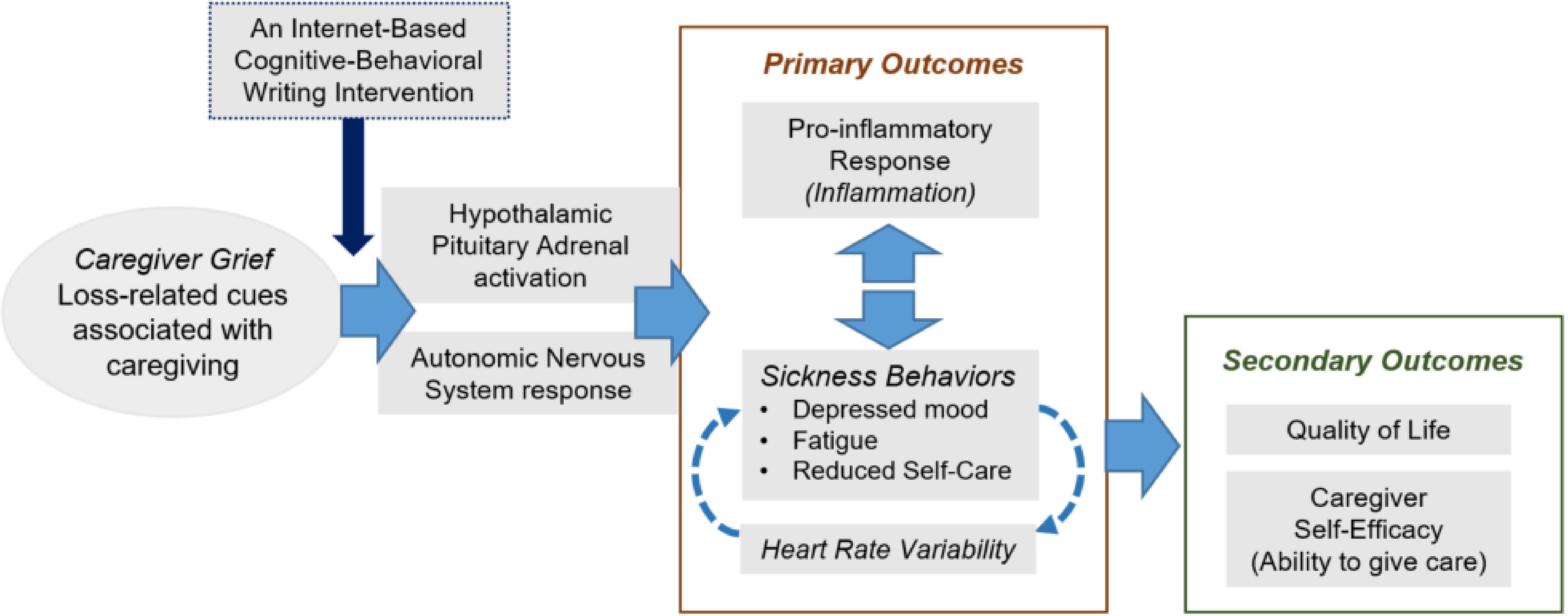
To describe?

Analyzing Expressive Writing-related Data

Does the act of writing improve people's ______?

Scores on the Beck
Depression Inventory
(a self-report measure)

Can a writing intervention mitigate these effects?



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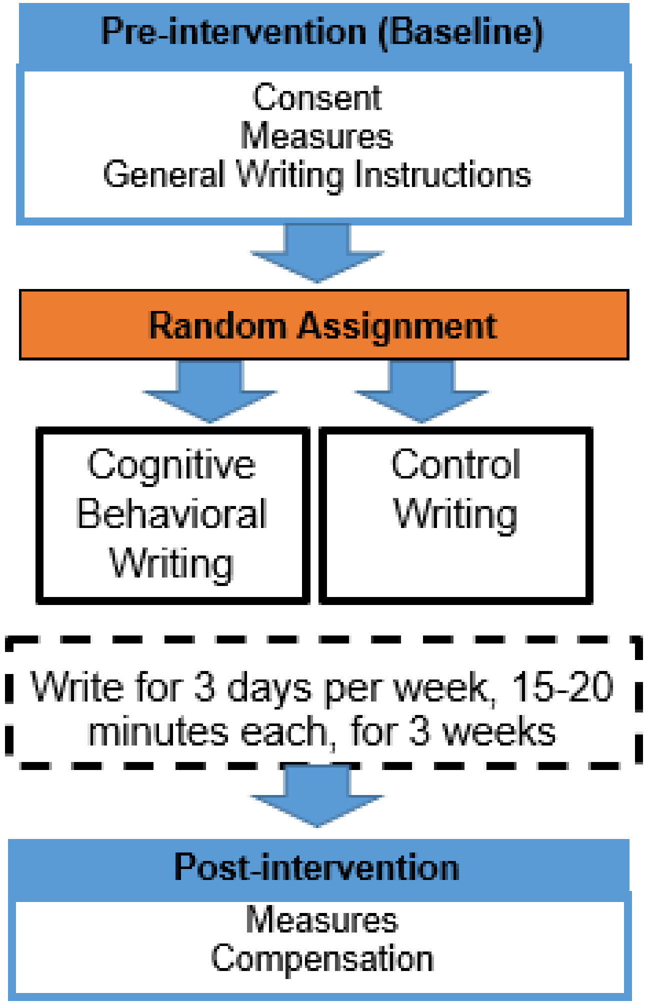
Analyzing Expressive Writing-related Data



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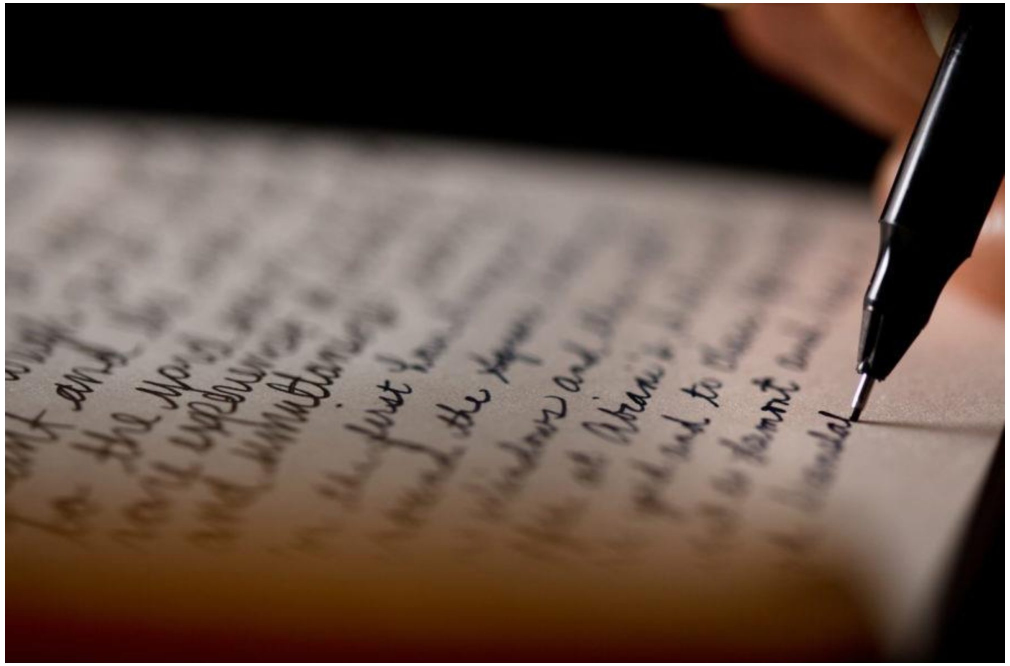
Compensation

Analyzing Expressive Writing-related Data

What can we learn from people’s writing about _____?

Analyzing Expressive Writing-related Data

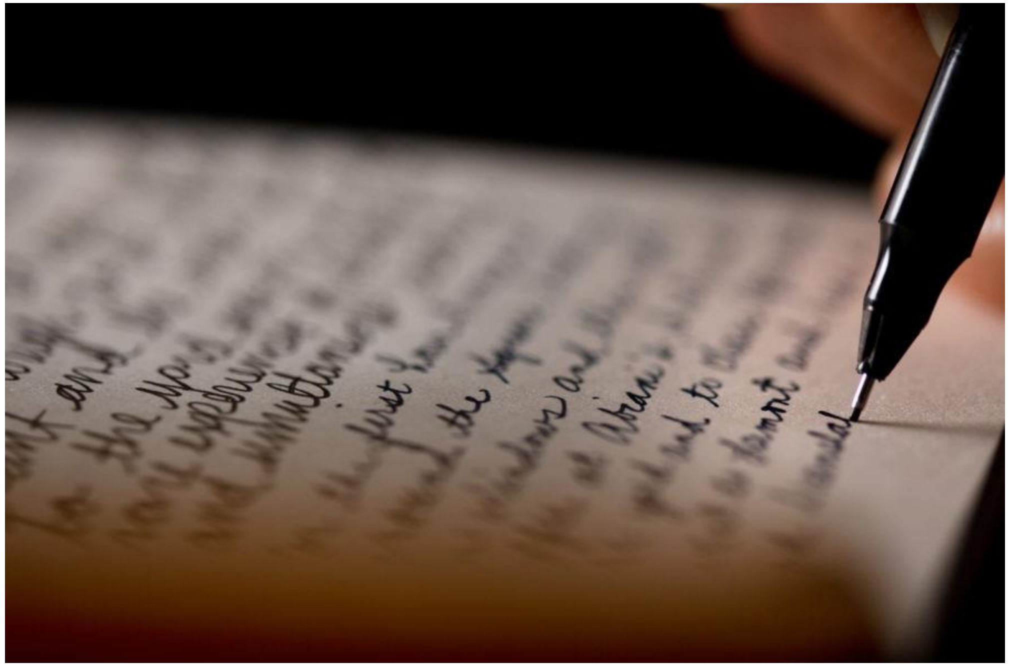
Our data =
what they
actually wrote

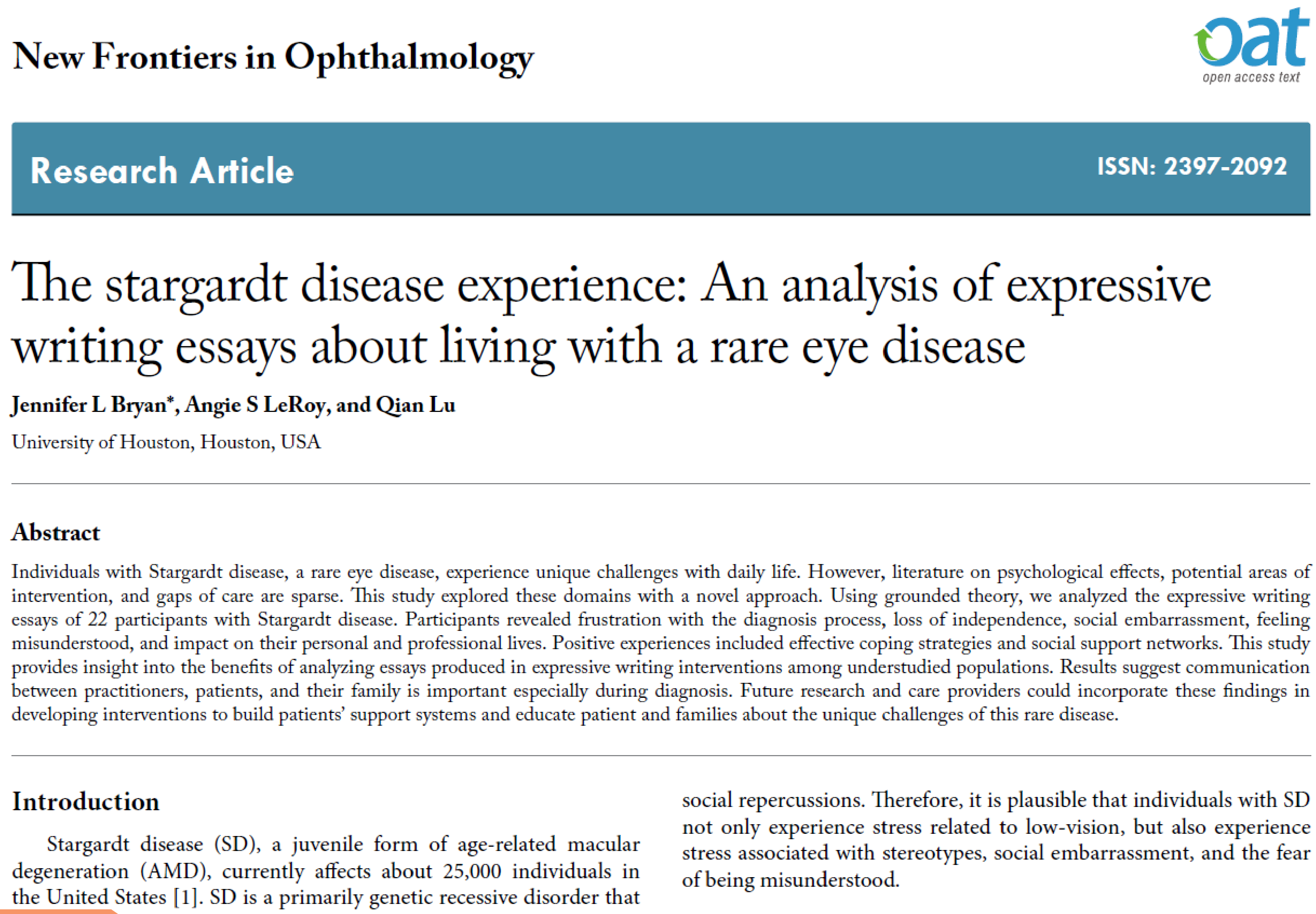


Analyzing Expressive Writing-related Data

Our data =
what they actually wrote

- Qualitatively
- Quantitatively





New Frontiers in Ophthalmology

Research Article ISSN: 2397-2092

The stargardt disease experience: An analysis of expressive writing essays about living with a rare eye disease

Jennifer L Bryan*, Angie S LeRoy, and Qian Lu

University of Houston, Houston, USA

Abstract

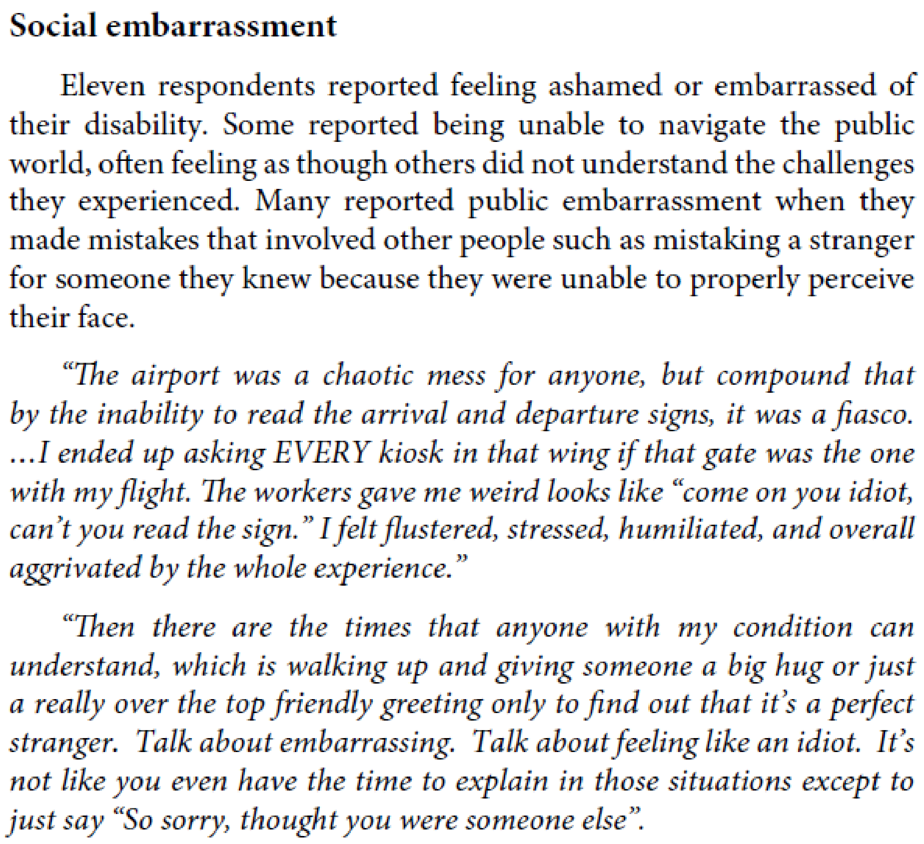
Individuals with Stargardt disease, a rare eye disease, experience unique challenges with daily life. However, literature on psychological effects, potential areas of intervention, and gaps of care are sparse. This study explored these domains with a novel approach. Using grounded theory, we analyzed the expressive writing essays of 22 participants with Stargardt disease. Participants revealed frustration with the diagnosis process, loss of independence, social embarrassment, feeling misunderstood, and impact on their personal and professional lives. Positive experiences included effective coping strategies and social support networks. This study provides insight into the benefits of analyzing essays produced in expressive writing interventions among understudied populations. Results suggest communication between practitioners, patients, and their family is important especially during diagnosis. Future research and care providers could incorporate these findings in developing interventions to build patients' support systems and educate patient and families about the unique challenges of this rare disease.

Introduction

Stargardt disease (SD), a juvenile form of age-related macular degeneration (AMD), currently affects about 25,000 individuals in the United States [1]. SD is a primarily genetic recessive disorder that

social repercussions. Therefore, it is plausible that individuals with SD not only experience stress related to low-vision, but also experience stress associated with stereotypes, social embarrassment, and the fear of being misunderstood.

Qualitative Analysis: Derived Themes



Social embarrassment

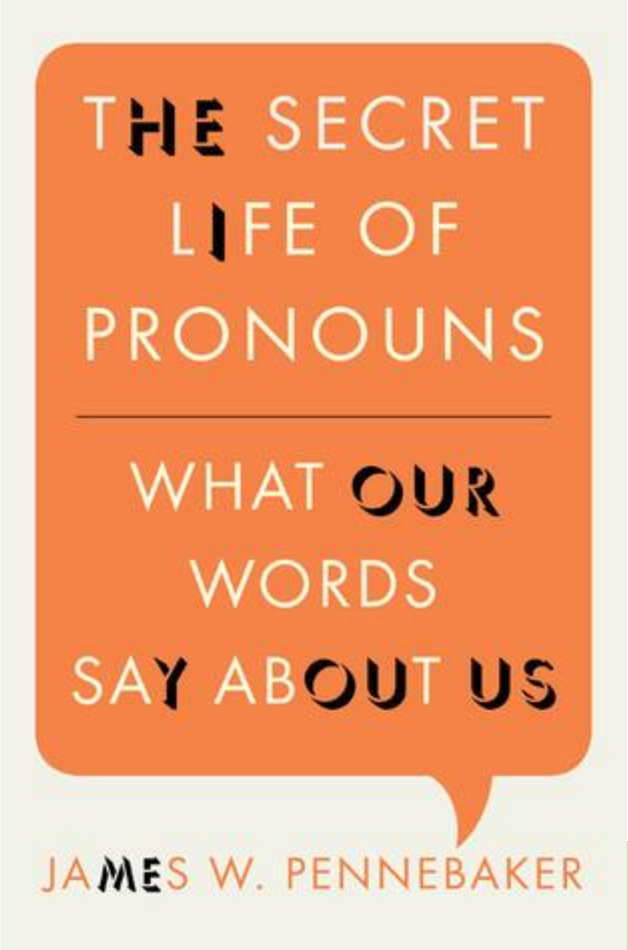
Eleven respondents reported feeling ashamed or embarrassed of their disability. Some reported being unable to navigate the public world, often feeling as though others did not understand the challenges they experienced. Many reported public embarrassment when they made mistakes that involved other people such as mistaking a stranger for someone they knew because they were unable to properly perceive their face.

"The airport was a chaotic mess for anyone, but compound that by the inability to read the arrival and departure signs, it was a fiasco. …I ended up asking EVERY kiosk in that wing if that gate was the one with my flight. The workers gave me weird looks like "come on you idiot, can't you read the sign." I felt flustered, stressed, humiliated, and overall aggrivated by the whole experience."

"Then there are the times that anyone with my condition can understand, which is walking up and giving someone a big hug or just a really over the top friendly greeting only to find out that it's a perfect stranger. Talk about embarrassing. Talk about feeling like an idiot. It's not like you even have the time to explain in those situations except to just say "So sorry, thought you were someone else".

Quantitative Analysis: LIWC
“Linguistic Inquiry & Word Count”

e.g., use of “I…”


THE SECRET LIFE OF PRONOUNS

WHAT OUR WORDS SAY ABOUT US

JAMES W. PENNEBAKER

Other uses of writing methods in research: Inducing mood states or “re-living” paradigms

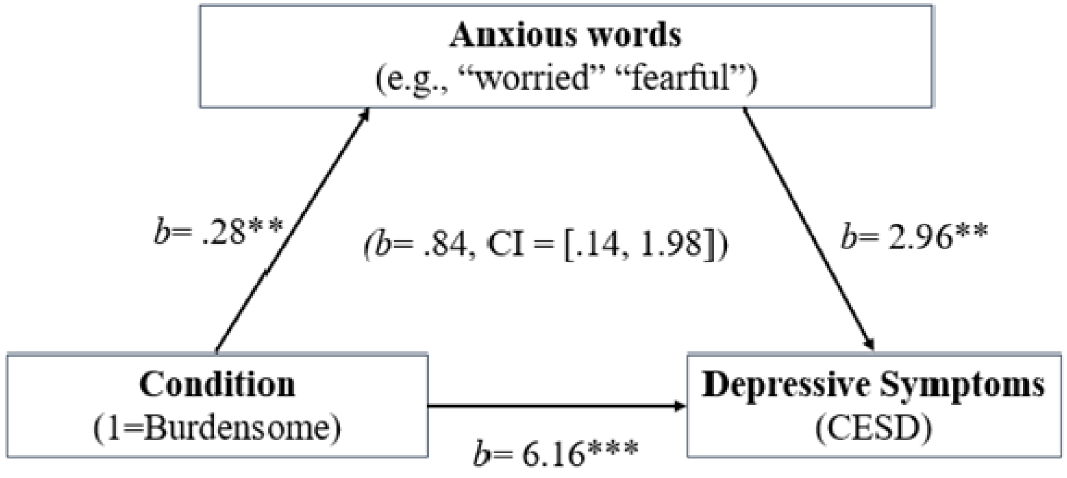


Figure 1. Anxious words mediate the relationship between condition and depressive symptoms (Study 1).

HEAL
LAB

If a researcher were to reflect on your writing, what conclusions might they draw?

Can you name some take-away “themes” or pull some stand-out words from your writing?

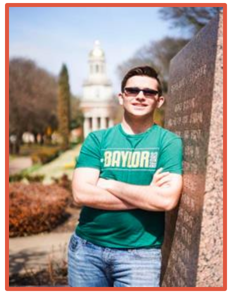

Valentina
Maza


Samantha
Weiss


Allie Henderson


Kate Harris


Olivia Carney


Ashton Richards


Shreyas
Srinivasan


Sierra
Wickline

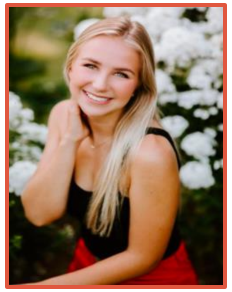

Katherine
Beach


Sofia Villarreal-
Ibarra


Dylan Puepke


Carlos
Carbajal


Brighton Garrett


Maddie
Edlund

HEAL
LAB


Grant Shrable


Victoria Norton


Emily Kolb


Leona
Liskovec


Christopher
Fagundes

Thank you!

Angie_LeRoy@baylor.edu

Baylor HEAL LAB

Studying Health Across the Lifespan

Writing to Heal: A Cognitive-based Writing Intervention for ADRD caregivers

National Institute on Aging

K01 AG 073824
PI: Angie LeRoy

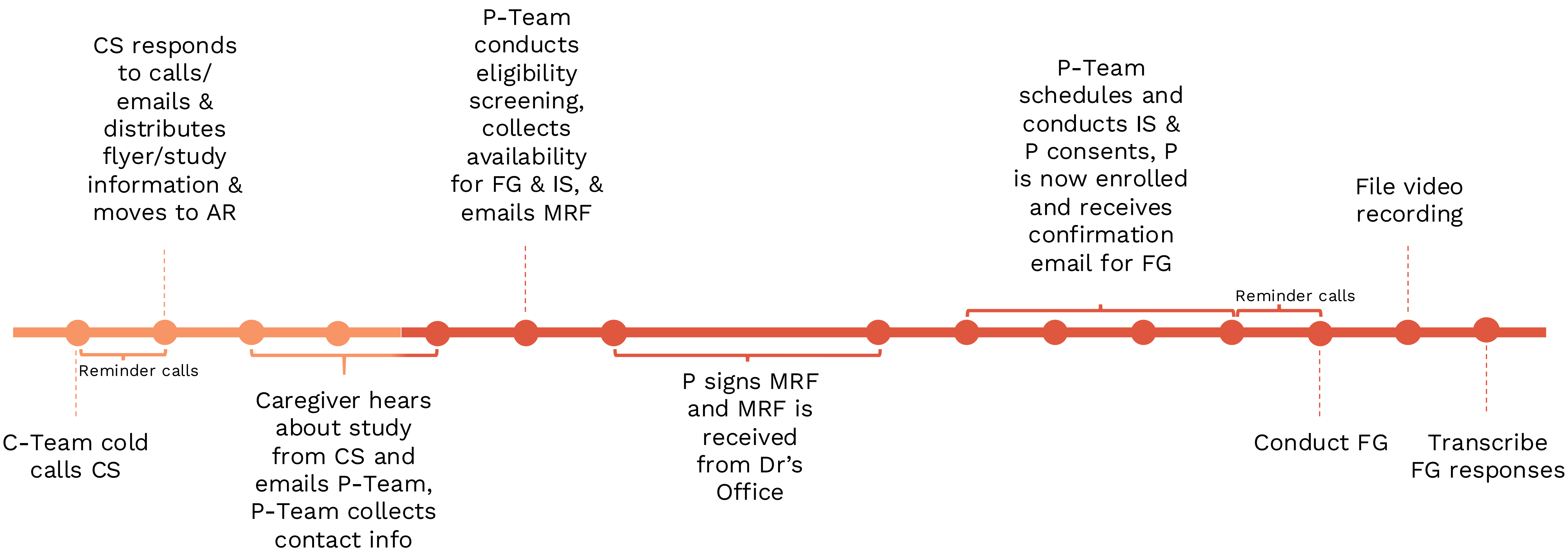
(Aim 1) Identify opportunities for targeted treatment and potential barriers to the intervention.

(Aim 2) Adapt and optimize a Cognitive-based writing intervention for stress and grief during ADRD spousal caregiving

(Aim 3) To test the intervention for acceptability, feasibility, and preliminary effects

Community Outreach Team

Participant Outreach Team



C-Team cold calls CS

Reminder calls

CS responds to calls/ emails & distributes flyer/study information & moves to AR

Caregiver hears about study from CS and emails P-Team, P-Team collects contact info

P-Team conducts eligibility screening, collects availability for FG & IS, & emails MRF

P signs MRF and MRF is received from Dr's Office

P-Team schedules and conducts IS & P consents, P is now enrolled and receives confirmation email for FG

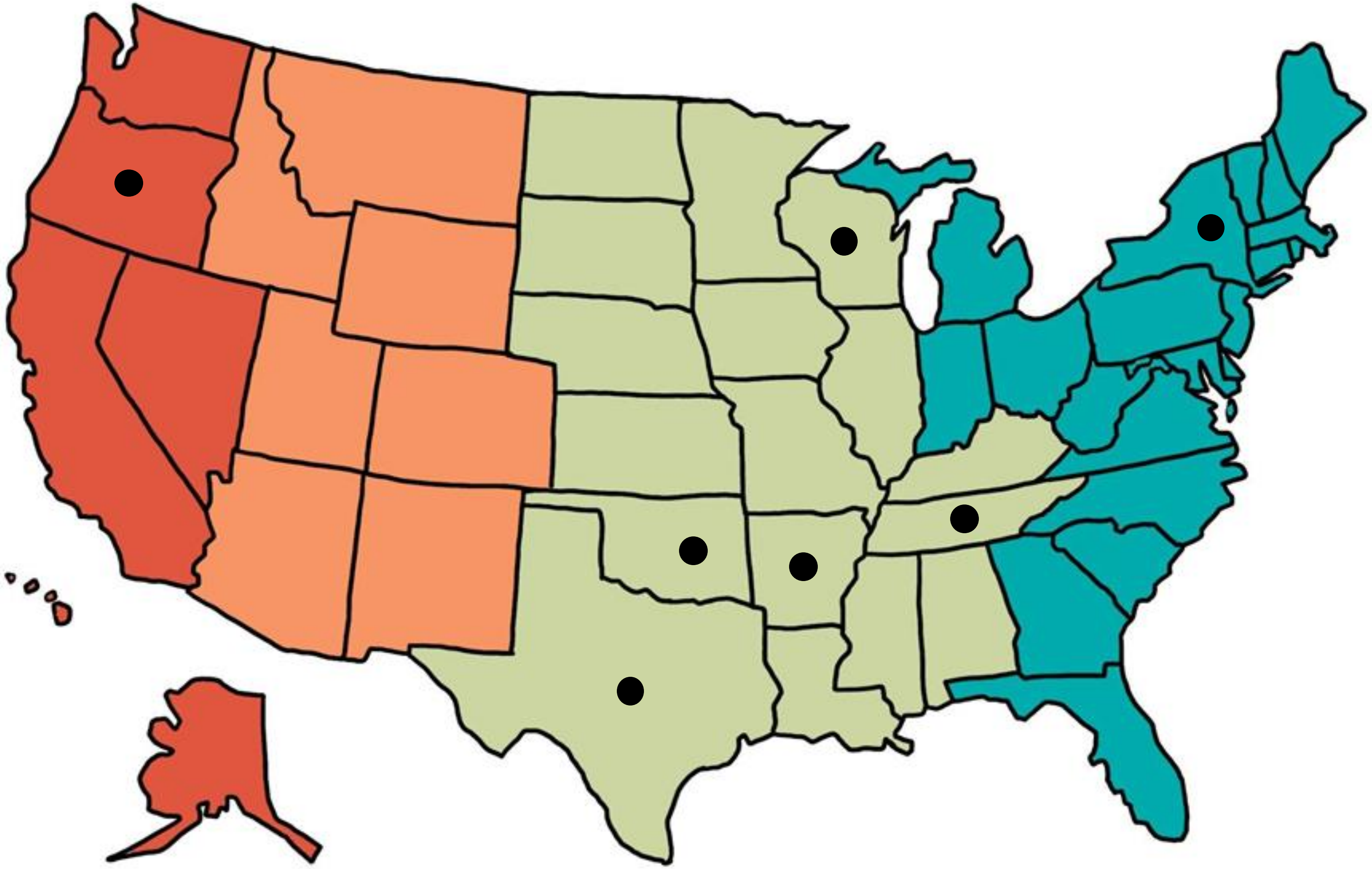
Reminder calls

Conduct FG

File video recording

Transcribe FG responses

Key:
AR = Active Recruitment
FG = Focus Group
IS = Information Session
PP = Prospective Participant
MRF = Medical Release Form
P = Participant
CS = Community Sites



How can we tailor an expressive writing intervention for the stressful contexts of caregiving, using a grief-informed approach?

Self-compassion prompt

In the busyness of caregiving, it is easy to forget to be kind to yourself. Oftentimes the way we would speak to a friend in our situation is much kinder than how we tend to speak to ourselves. For the next 15 minutes, pretend to write a letter to a friend who also is caregiving for a spouse living with ADRD. How could you validate this friend’s feelings and be understanding about what they are going through? How might you comfort this friend? What advice might you give them? How might you instill hope for the future? Now, re-read your letter as if you are speaking to yourself.

How can we tailor an expressive writing intervention for the stressful contexts of caregiving, using a grief-informed approach?

- Dosing of the intervention for effectiveness, but also feasibility
  - Duration of writing sessions
  - Frequency of writing sessions
  - Overall program timeline (3 weeks vs 4-5 weeks)
  - Emotional energy required for each prompt

“What would you hope that writing might improve about your experience with caregiving?”

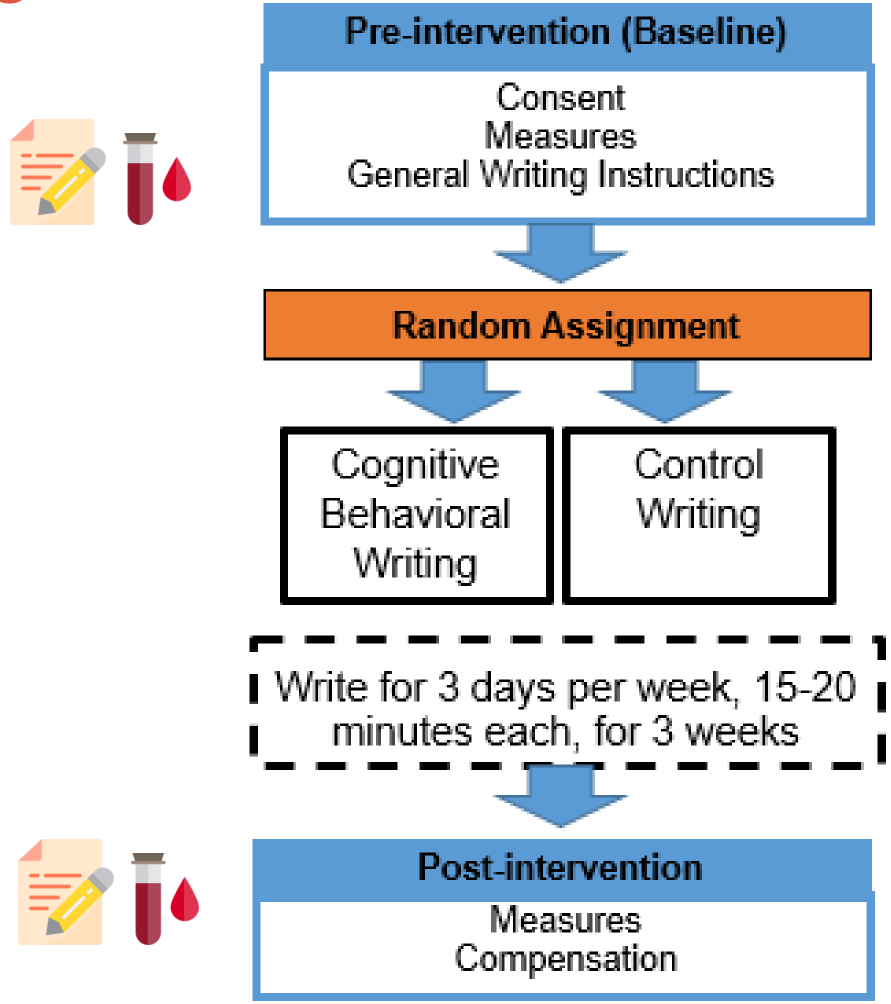
Primary outcomes

- Caregiver grief
- HRV
- Inflammation and sickness behaviors (depressed mood, fatigue, self-care)

Secondary outcomes

- Quality of life
- Caregiving self-efficacy
- (i.e., perceived ability to give care).

“What would you hope that writing might improve about your experience with caregiving?”



Pre-intervention (Baseline)

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Cognitive Behavioral Writing	Control Writing

Write for 3 days per week, 15-20 minutes each, for 3 weeks

Post-intervention

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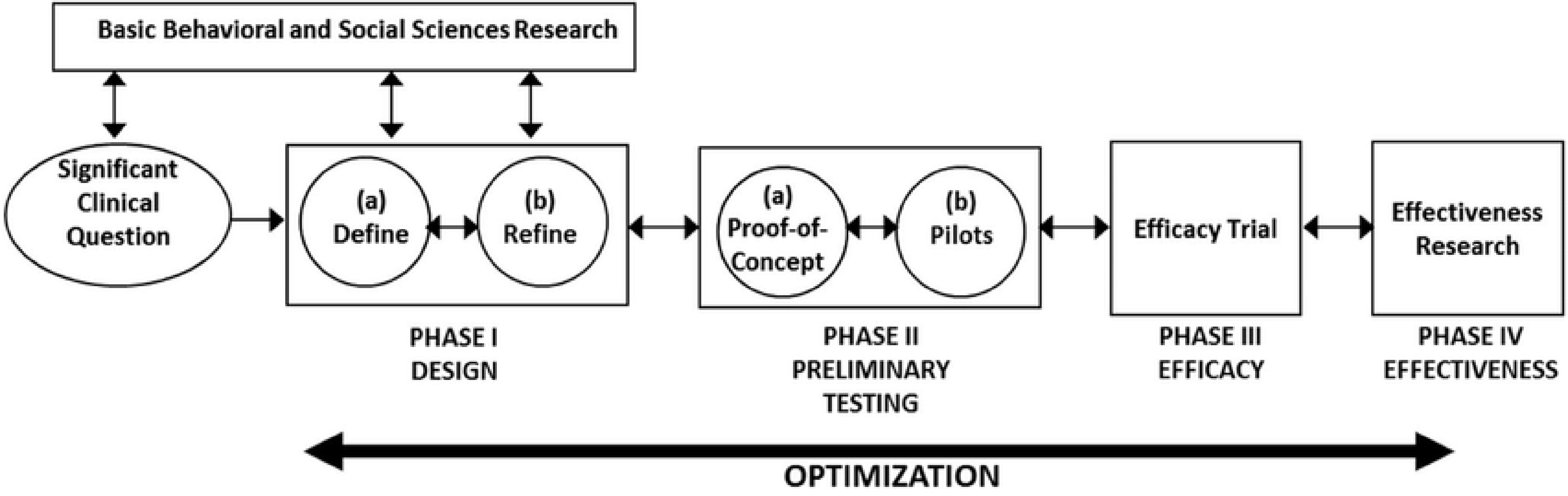
Compensation

Future Directions at UNF



Basic Behavioral and Social Sciences Research

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(b) Refine

(a) Proof-of-Concept

(b) Pilots

Efficacy Trial

Effectiveness Research

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OPTIMIZATION

Czajkowski et al., 2015

Updated Prototype in real time

https://www.figma.com/proto/PpxUNHJKmlztSZRWln5o1Y/W2H?page-id=176%3A1090&type=design&node-id=224-7050&viewport=1436%2C30%2C0.5&t=hY45R5v2s7Fw0xD6-1&scaling=scale-down&starting-point-node-id=224%3A7050&mode=design

W2H Recruitment Abstract

Title: Recruiting Caregivers of Spouse's with Alzheimer's or a Related Dementia for online focus groups: Lessons learned from a feasibility study

Authors: Sierra Wickline, Trudy Widjaja, Tori Norton, Ashton Richards, Samantha Weiss & Angie LeRoy

Abstract *(must be 250 words, or less)*:

Caring for a spouse with Alzheimer's Disease or a Related Dementia (ADRD) is incredibly stressful; improving caregivers' quality of life begins with conducting research that aims to understand caregiver's needs. According to past research, ADRD spousal caregivers are more reluctant to participate in research studies compared to other familial caregivers, adding to the importance of developing, tracking, & evaluating recruitment strategies. Through nationwide community outreach, beginning with "cold calls" to organizations that may have access to caregivers, we recruited 14 ADRD spousal caregivers for focus groups that assessed the feasibility & acceptability of a writing intervention. In total, we made 529 attempts (i.e., calls, voicemails, & emails) across 228 sites all over the U.S.; 71 sites (31%) agreed to distribute study information to their stakeholders via listservs, word-of-mouth, or posting online. This yielded 40 interested caregivers, who contacted the lab (by phone or e-mail) and completed an eligibility screening. We confirmed ADRD diagnosis upon receipt of the spouse's medical records, obtained after appropriate communication between the participant, research team, & the spouse's medical office, & documentation of a signed medical release form(s)—35% of eligible caregivers were retained through the end of this process. A modified version of this recruitment method will be used in an upcoming pilot RCT, where we will target community sites that may yield a higher number of minority caregivers. Overall, we recommend that researchers persist in their community outreach efforts (every 37 contact attempts yielded 1 enrolled caregiver) & maintain relationships with supportive community partners.