An e-coaching intervention to maximize benefit of respite among caregivers

ARCH Webinar - May 2025

Research Team

Rebecca Utz
Dale Lund
Alexandra Terrill
Bob Wong
Catharine Sparks

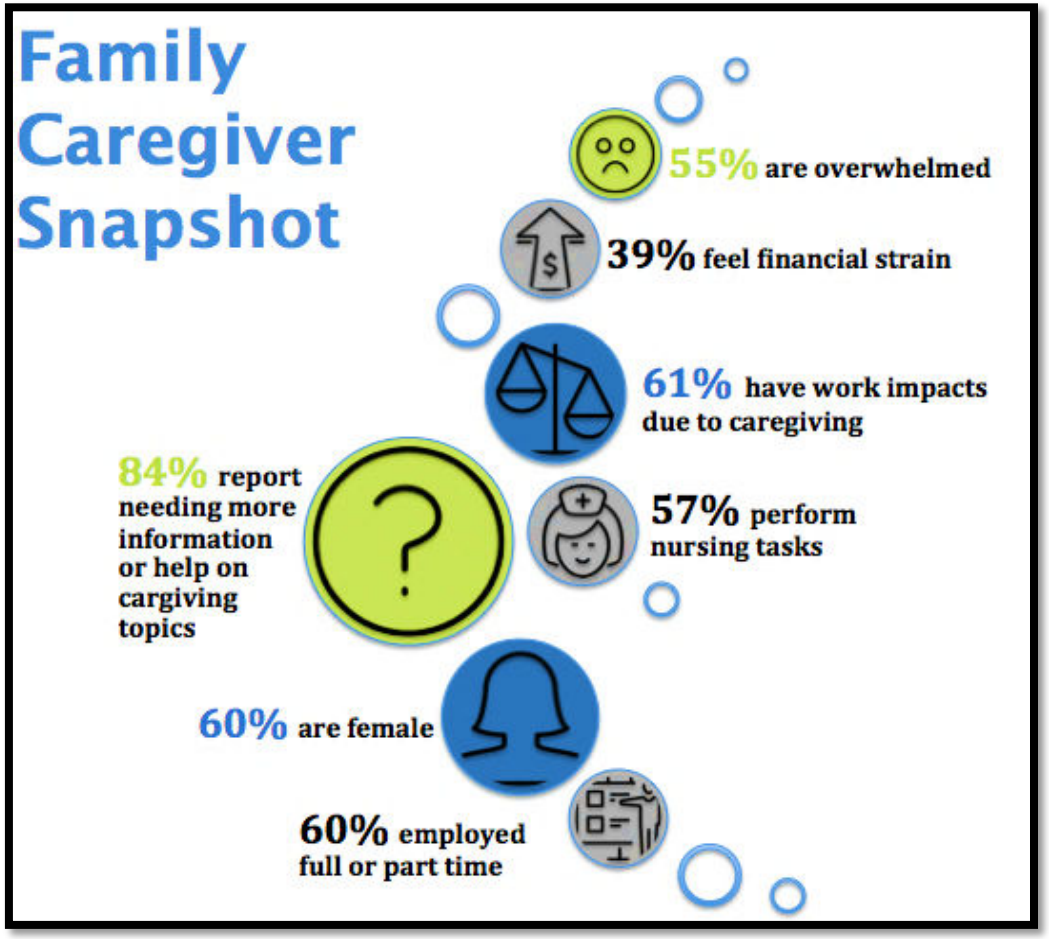
Mike Caserta
Louisa Stark
Eli Iacob
Amber Thompson

[1] Department of Sociology, College of Social & Behavioral Science, [2] Consortium for Families & Health Research (C-FAHR), [3] College of Nursing, [4] Gerontology Interdisciplinary Program, [5] Occupational & Recreational Therapies, College of Health, [6] Department of Human Genetics, School of Medicine, [7] Genetics Science Learning Center, [8] Center for Clinical and Translational Science, [9] Center on Aging. University of Utah & Cal State San Bernardino

Funded by National Institute on Aging

R01-AG061946 2019-2024

https://reporter.nih.gov/search/opvvUDsibUG58jl-uuyMow/project-details/9983551



In the U.S., family caregivers provide an estimated **36 billion hours of care** – worth *nearly $600 billion* – to their parents, spouses, partners, and friends.

The total **economic value of family caregiving**

- is more than all out-of-pocket spending on U.S. health care, and
- roughly three times the amount Medicaid spent on long-term services and supports

Source: AARP Public Policy Institute

What do caregivers most need or want?

Respite

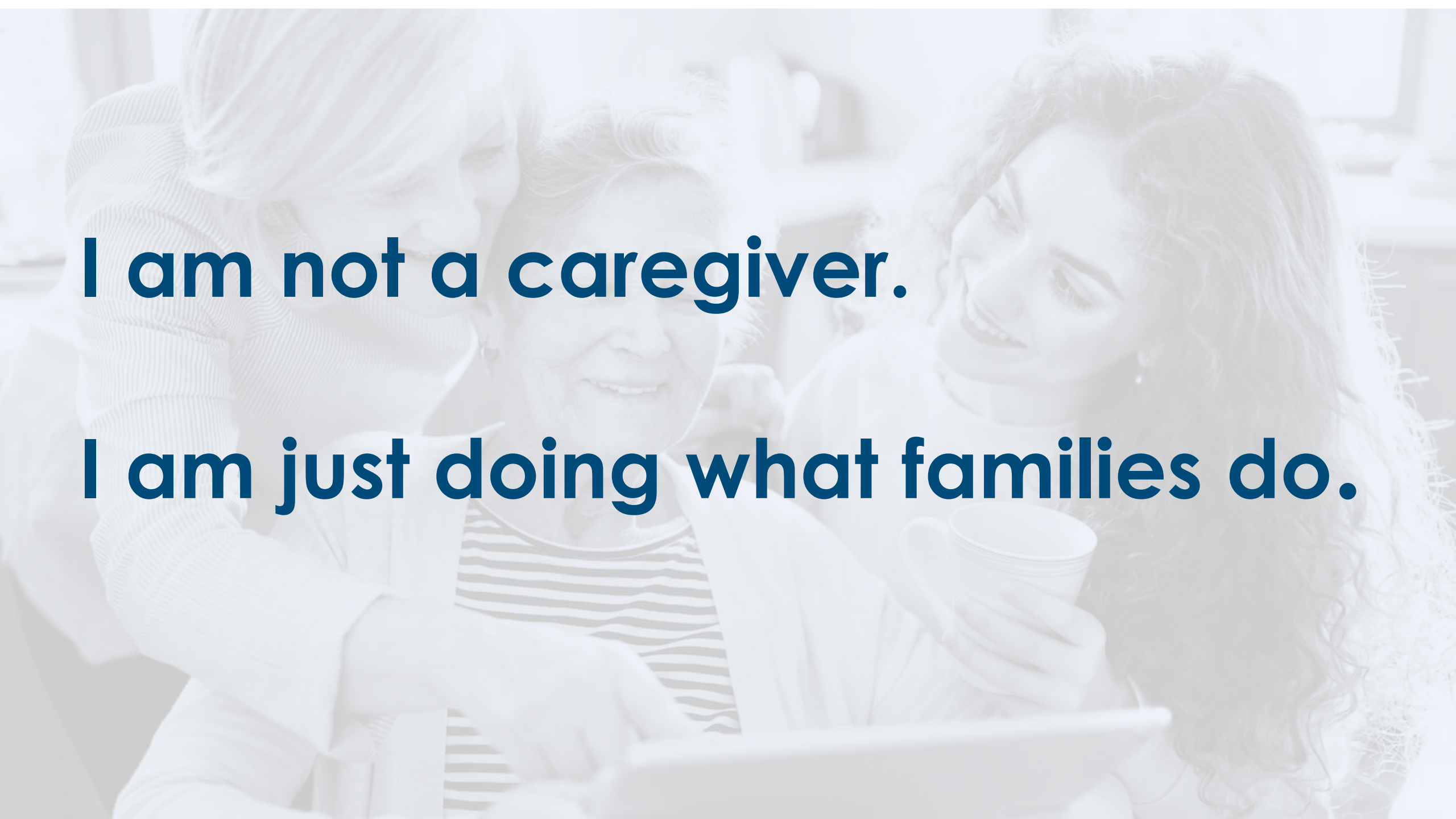
Respite. (noun). Planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult

In-home **Day Centers** **Residential/Overnight**

About half of caregivers reported being **"not satisfied"** with their respite time

Lund, D. A., Utz, R., Caserta, M. S., & Wright, S. D. (2009). Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology*, *28*(1), 109-131.

Research Questions



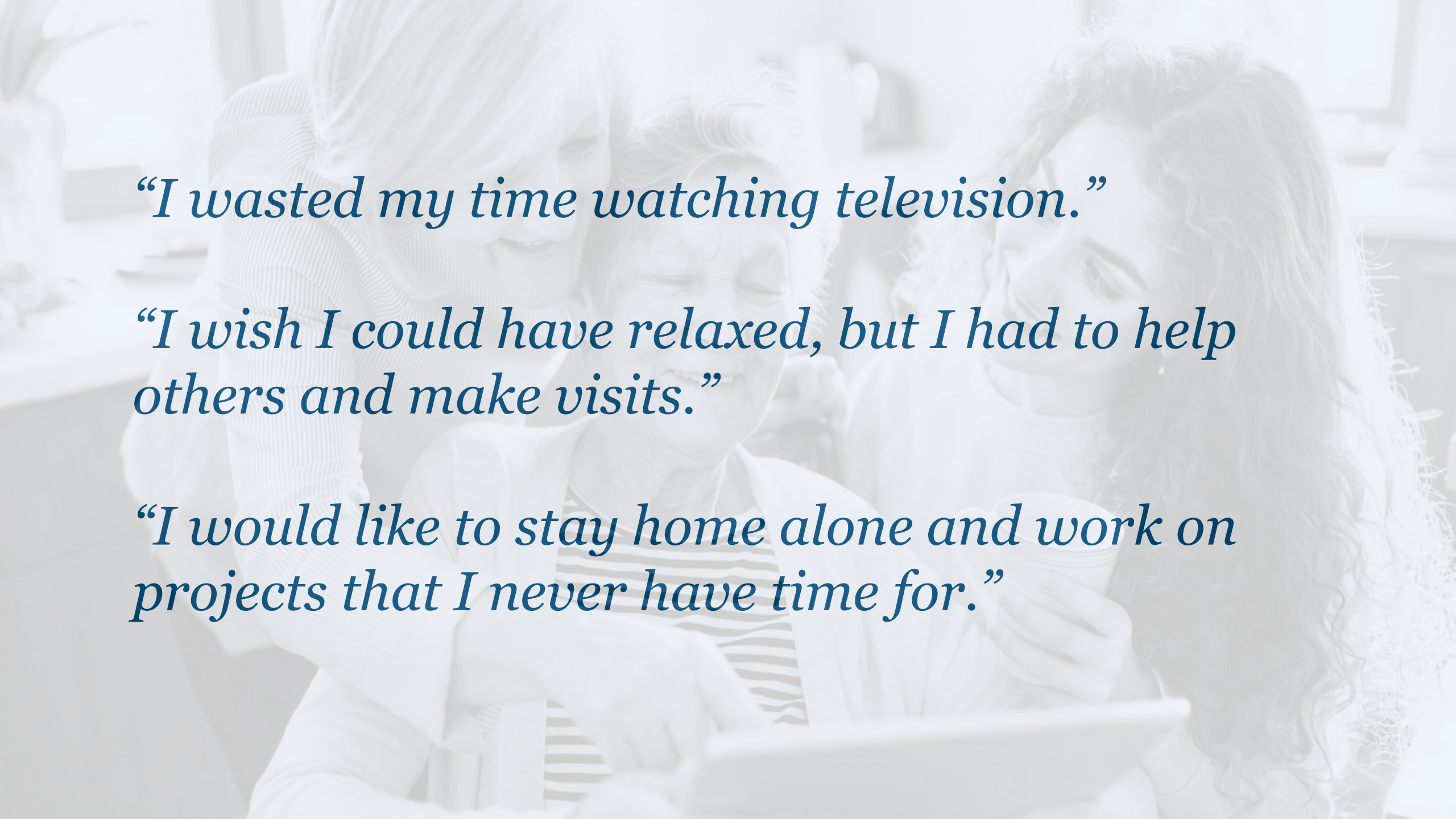
I am not a caregiver.

I am just doing what families do.

> The house is a wreck. I haven't had time to clean. I don't want anyone coming over until I clean.

Why do I get a break, when she has to stay home? She will be mad at me for leaving her at home.

I am embarrassed that he won't treat the staff very well. He can be pretty mean.



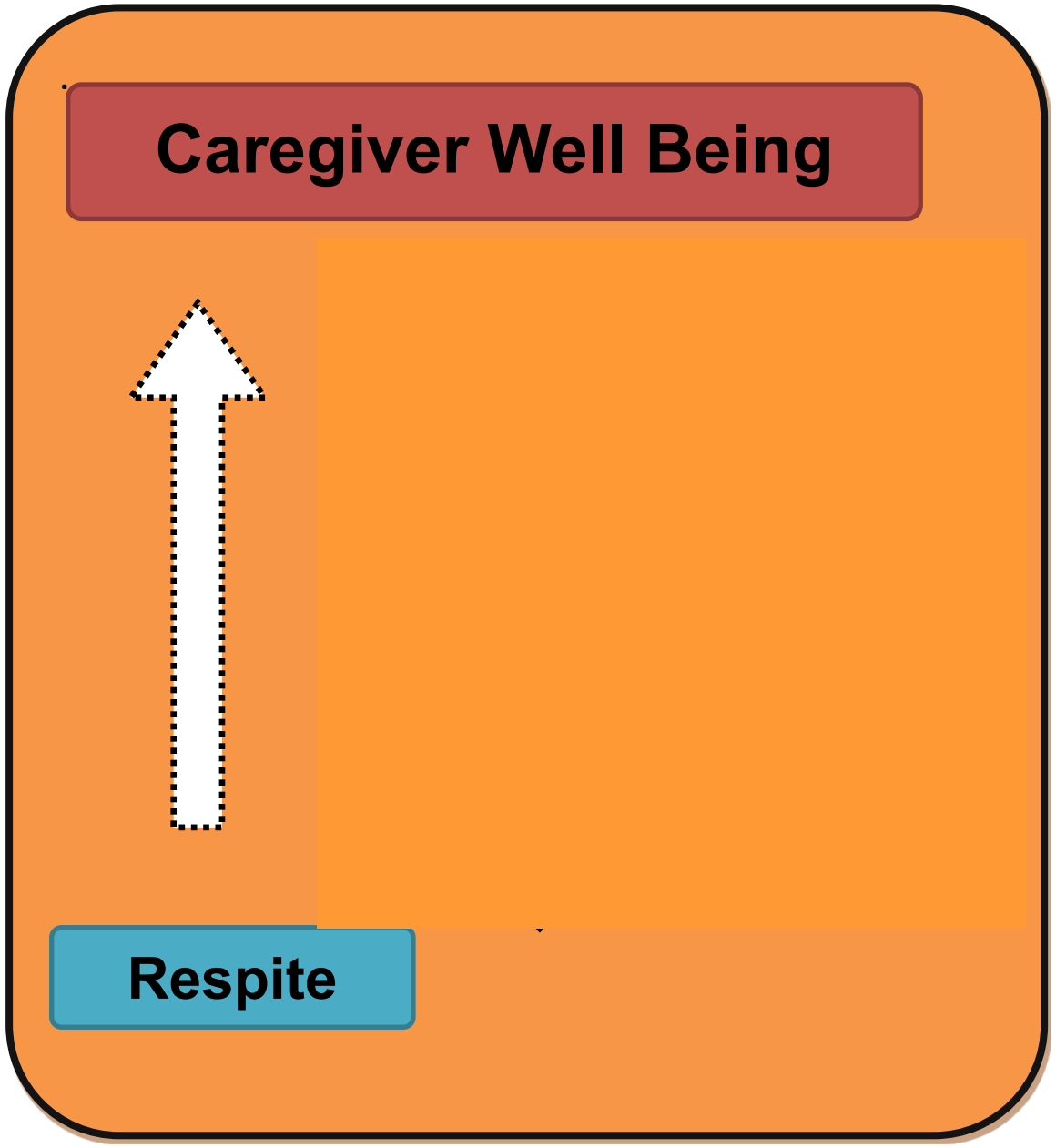
“I wasted my time watching television.”

“I wish I could have relaxed, but I had to help others and make visits.”

“I would like to stay home alone and work on projects that I never have time for.”

Respite Activities	Desired Time-Use (in hours) Mean	Desired Time-Use (in hours) Std Dev	Actual Time-Use (in hours) Mean	Actual Time-Use (in hours) Std Dev
1. Time with family	3.0	(5.8)	3.1	(6.2)
2. Housework	2.4	(4.0)	3.3	(3.6)
3. Rest and relaxation	2.0	(4.8)	1.3	(3.2)
4. Read or write	1.8	(2.5)	2.1	(4.4)
5. Help others	1.7	(3.3)	1.7	(3.5)
6. Watch TV	1.6	(3.5)	1.8	(4.0)
7. Sleep or nap	1.5	(6.2)	0.7	(1.6)
8. Cook	1.5	(2.2)	1.8	(2.2)
9. Eat	1.4	(1.9)	1.8	(1.8)
10. Shop	1.4	(2.2)	1.6	(1.8)
11. Time with friends	1.2	(1.9)	0.7	(1.3)
12. Hobby	0.9	(2.4)	0.5	(1.5)
13. Exercise	0.8	(2.0)	0.8	(2.0)
14. Personal or medical care	0.7	(1.3)	1.0	(1.6)
15. Listen to radio	0.6	(1.3)	0.6	(1.0)
16. Religious activity	0.5	(1.3)	0.4	(1.1)
17. Travel	0.5	(1.1)	0.6	(1.2)
18. Recreation	0.4	(1.1)	0.3	(1.0)
19. Attend support group	0.2	(0.7)	0.1	(0.4)

Respite Time-Use


Caregiver Well Being
Respite

Intervention

Goal: to help caregivers maximize the benefit of respite by focusing on their time-use

TIME FOR LIVING & CARING

- *"I made a greater effort to find fun things to do and ACTUALLY got around to doing them…lead to other fun things which I did and will do in the future."*
- *"It invigorated me. I am alive and [illegible] when I achieved my goals."*
- *"I never h[illegible] obligated - like a promise I [illegible]*
- *"I was unconsciously sliding into a resigned death of my own until I started this study. This program really woke me up to the fact that I needn't give up – rather, that by setting goals, I can move forward and feel success even though my circumstances have not changed. I feel like a new, happier person!"*

Not Possible

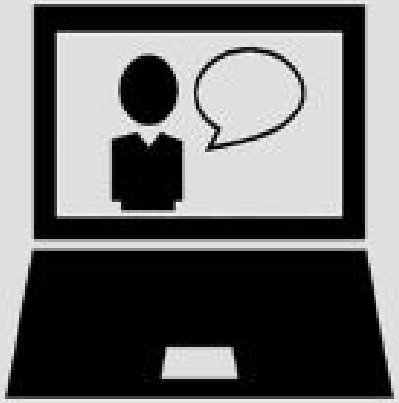
A self-administered, technology-delivered intervention to maximize benefit of respite

Funded by National Institute on Aging

1.

Information & Education

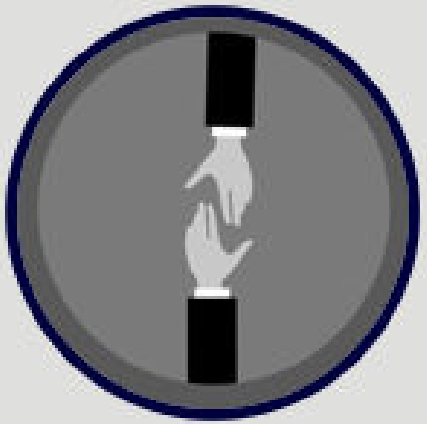
What is Respite?



2.

Virtual Coaching

How do I use respite?



3.

Resources & Referral

How do I get more respite?

Goal Setting, Goal Review
Calendar

Research Objective:

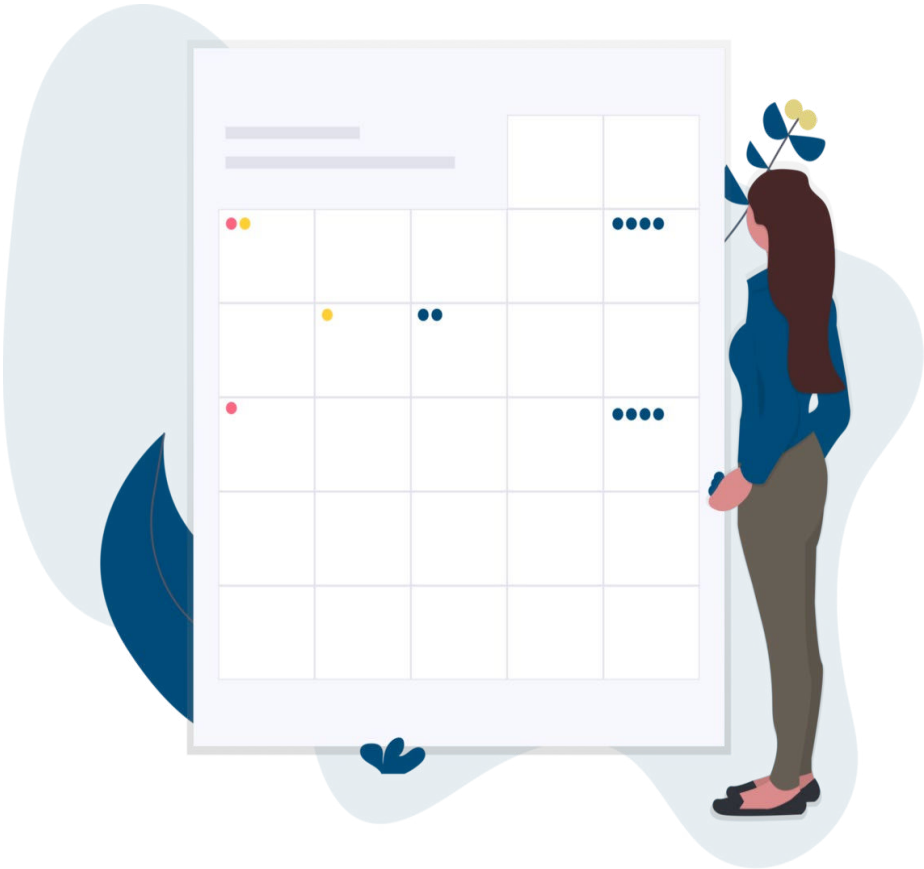
To assess the feasibility and usability of a self-administered, technology-delivered intervention to improve caregiver's use of respite, and to improve their overall well-being and ability to be a caregiver

TLC

TIME FOR LIVING & CARING

Evaluating the TLC App

- Randomized control trial (waitlist control)
- Sample of dementia caregivers (n=166)



For more information about recruitment:
Sparks, C., Hsu, A., Neller, S.A., Eaton, J., Thompson, A., Wong, B., Iacob, E., Terrill, A.L., Caserta, M., Stark, L. and Utz, R.L., 2024. Comparison of recruitment methodologies for clinical trials: Results from the time for living and caring (TLC) intervention study. *Contemporary Clinical Trials*, *140*, p.107518.

For more information about TLC study protocol:
Utz, R.L., Caserta, M., Iacob, E., Sparks, C., Stark, L., Terrill, A., Thompson, A. and Wong, B., 2023. Maximizing the benefit of respite for dementia caregivers: A study protocol describing the development & evaluation of the time for living & caring (TLC) intervention. *OBM integrative and complimentary medicine*, *8*(4).


TLC

Research Design & Results

TLC
TIME FOR LIVING & CARING

Method of TLC Study

- Randomized control trial (waitlist control)
- Sample of dementia caregivers (n=166)
    - Used TLC app for 16 weeks
    - Completed monthly surveys
      (upon enrollment, and then @ 4, 8, 16, 20 weeks)
    - Received cash compensation
    - Provided with technology and wifi, if needed

For more information about recruitment:
Sparks, C., Hsu, A., Neller, S.A., Eaton, J., Thompson, A., Wong, B., Iacob, E., Terrill, A.L., Caserta, M., Stark, L. and Utz, R.L., 2024. Comparison of recruitment methodologies for clinical trials: Results from the time for living and caring (TLC) intervention study. *Contemporary Clinical Trials*, *140*, p.107518.

For more information about TLC study protocol:
Utz, R.L., Caserta, M., Iacob, E., Sparks, C., Stark, L., Terrill, A., Thompson, A. and Wong, B., 2023. Maximizing the benefit of respite for dementia caregivers: A study protocol describing the development & evaluation of the time for living & caring (TLC) intervention. *OBM integrative and complimentary medicine*, *8*(4).

Innovation in Aging, 2024, **8**, igae043
https://doi.org/10.1093/geroni/igae043
Advance access publication 26 April 2024
Original Research Article

GSA GERONTOLOGICAL SOCIETY OF AMERICA® OXFORD

Evaluating the Efficacy of Time for Living and Caring: An Online Intervention to Support Dementia Caregivers' Use of Respite

Eli Iacob, PhD,[1] Michael Caserta, PhD,[1] Gary Donaldson, PhD,[1] Catharine Sparks, MS,[2] Alexandra Terrill, PhD,[2] Amber Thompson, MS,[3] Bob Wong, PhD,[1] and Rebecca L. Utz, PhD[3,*]

[1]College of Nursing, University of Utah, Salt Lake City, Utah, USA.
[2]College of Health, University of Utah, Salt Lake City, Utah, USA.
[3]College of Social and Behavioral Sciences, University of Utah, Salt Lake City, Utah, USA.
*Address correspondence to: Rebecca L. Utz, PhD. E-mail: rebecca.utz@utah.edu

Decision Editor: Amanda N. Leggett, PhD, FGSA

Abstract

Background and Objectives: Respite, defined as time away from caregiving, is the most requested type of caregiver support. Time for Living and Caring (TLC) is a virtual coaching "app" that helps caregivers schedule and plan their respite time-use. The objectives of this analysis are: (1) to assess the efficacy of the TLC intervention on respite time-use and on caregiver well-being and (2) to identify the key features of the intervention that serve as the likely mechanism of action.

Research Design and Methods: A sample of dementia caregivers ($n = 163$, 79% female, 84% White, 6% Hispanic, average age 62) were randomized into one of two intervention delivery methods. Intervention efficacy was evaluated using pre/post-comparisons of respite time-use in an additive "dosing" model that estimated unique parameters associated with the exposure to each specific intervention component.

Results: Both immediate and delayed-attention groups reported increased respite time. They also improved in their ability to plan and benefit from their respite time-use over the 16-week intervention period. At 8 weeks, the immediate group did not change in anxiety, but the delayed group worsened ($p < .001$). At 16 weeks, the groups were similar in their anxiety levels. By the 20-week follow-up, neither group had access to TLC, both experienced an increase in anxiety.

Original Research Article

Using Digital Inequality Framework to Evaluate a Technology-Delivered Intervention for Caregivers: Age, Education, and Computer Proficiency

Amber D. Thompson, MA[1], Catharine Sparks, MSc[1], Bob Wong, PhD[2], Eli Iacob, PhD[2], Alexandra L. Terrill, PhD[3], Michael Caserta, PhD[4], and Rebecca L. Utz, PhD[1]

Journal of Aging and Health
2024, Vol. 0(0) 1–11

DOI: 10.1177/08982643241232173
journals.sagepub.com/home/jah
Sage

Abstract

Objectives: Using "digital inequality" as a conceptual framework, this study evaluates the feasibility and usability of a technology-delivered intervention (an "app") for Alzheimer's and related dementia family caregivers. Time for Living and Caring (TLC) is an on-line intervention that provides virtual coaching and self-administered education and resources. **Methods:** A sample of family caregivers ($n = 163$) used the tool for 16 weeks, which included completing the Computer Proficiency Questionnaire (CPQ-12) at baseline. Analyses investigate the relationship between age, CPQ scores, intervention use, appraisal, and caregiver outcomes. **Results:** Age was inversely associated with CPQ; however, CPQ scores did not have a significant relationship with participant's self-perceived benefits or intervention appraisal. Computer Proficiency Questionnaire scores provided insight regarding research feasibility, with lower scores associated with greater odds of discontinuing engagement. **Discussion:** CPQ-12 scores can be used as a screening tool to identify those who may need additional support to engage with and benefit from technology-delivered interventions.

Innovation in Aging, 2024, **8**, igae043
https://doi.org/10.1093/geroni/igae043
Advance access publication 26 April 2024
Original Research Article

Evaluating the Efficacy of Time for Living and Caring: An Online Intervention to Support Dementia Caregivers' Use of Respite

Eli Iacob, PhD,[1] Michael Caserta, PhD,[1] Gary Donaldson, PhD,[1] Catharine Sparks, MS,[2] Alexandra Terrill, PhD,[2] Amber Thompson, MS,[3] Bob Wong, PhD,[1] and Rebecca L. Utz, PhD[3,*]

[1]College of Nursing, University of Utah, Salt Lake City, Utah, USA.
[2]College of Health, University of Utah, Salt Lake City, Utah, USA.
[3]College of Social and Behavioral Sciences, University of Utah, Salt Lake City, Utah, USA.

*Address correspondence to: Rebecca L. Utz, PhD. E-mail: rebecca.utz@utah.edu

Decision Editor: Amanda N. Leggett, PhD, FGSA

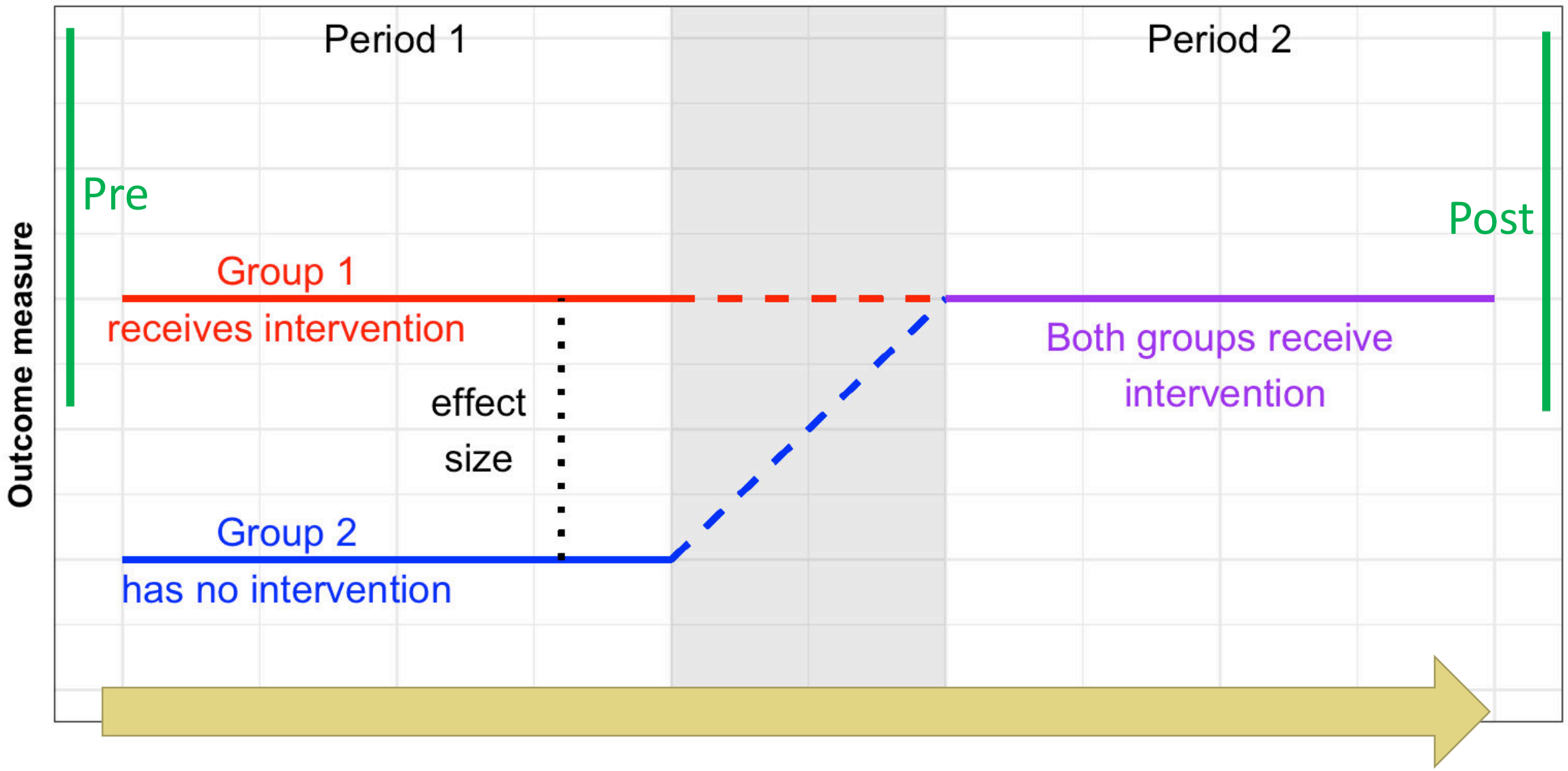
Abstract

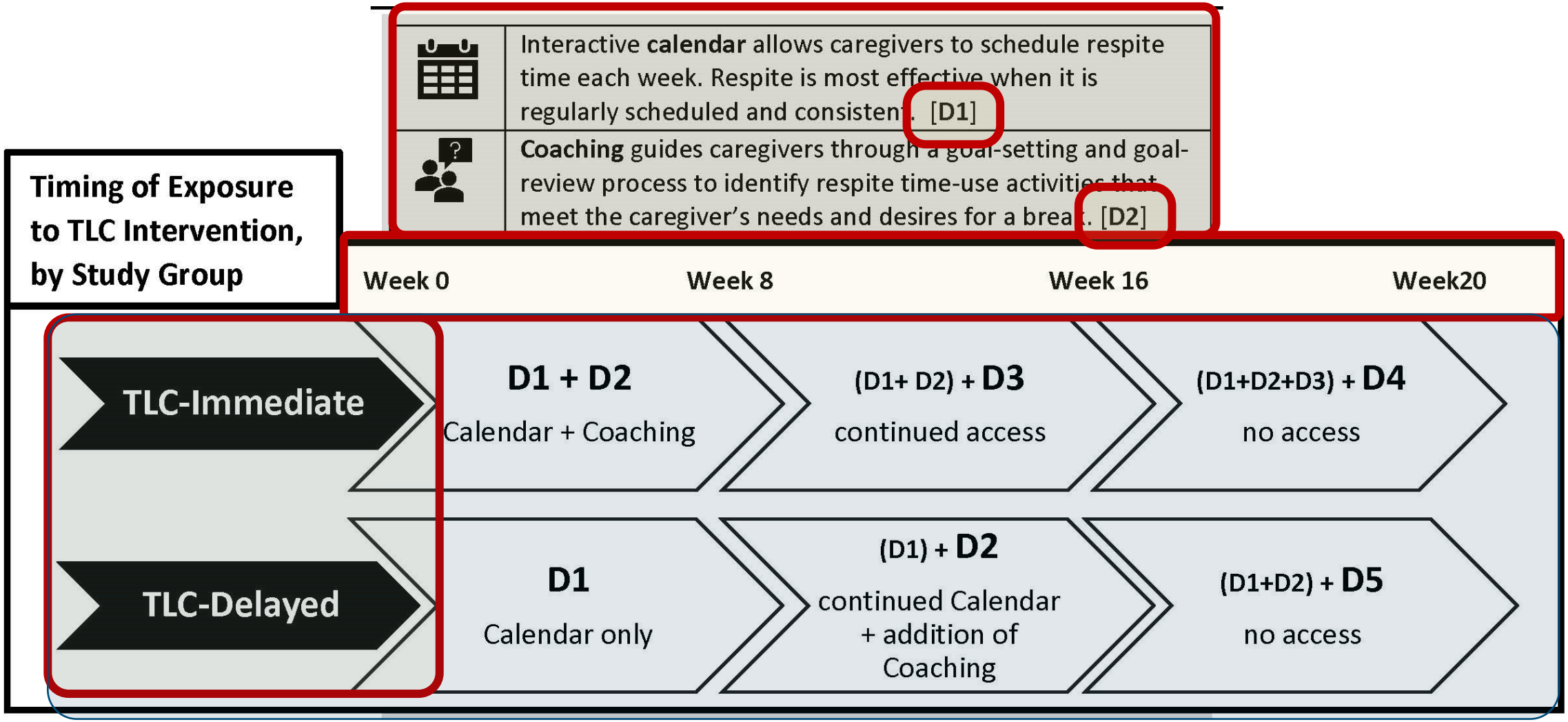
Background and Objectives: Respite, defined as time away from caregiving, is the most requested type of caregiver support. Time for Living and Caring (TLC) is a virtual coaching "app" that helps caregivers schedule and plan their respite time-use. The objectives of this analysis are: (1) to assess the efficacy of the TLC intervention on respite time-use and on caregiver well-being and (2) to identify the key features of the intervention that serve as the likely mechanism of action.

Research Design and Methods: A sample of dementia caregivers (n = 163, 79% female, 84% White, 6% Hispanic, average age 62) were randomized into one of two intervention delivery methods. Intervention efficacy was evaluated using pre/post-comparisons of respite time-use and an additive "dosing" model that estimated unique parameters associated with the exposure to each specific intervention component.

Results: Both immediate and delayed-attention groups reported increased respite time. They also improved in their ability to plan and perceive benefit from their respite time-use over the 16-week intervention period. At 8 weeks, the immediate group did not change in anxiety, whereas the delayed group worsened ($p < .001$). At 16 weeks, the groups were similar in their anxiety levels. By the 20-week follow-up period, when neither group had access to TLC, both experienced an increase in anxiety.

Outcome:
Caregiver Anxiety


Period 1
Period 2
Pre
Post
Outcome measure
Group 1
receives intervention
effect
size
Group 2
has no intervention
Both groups receive
intervention



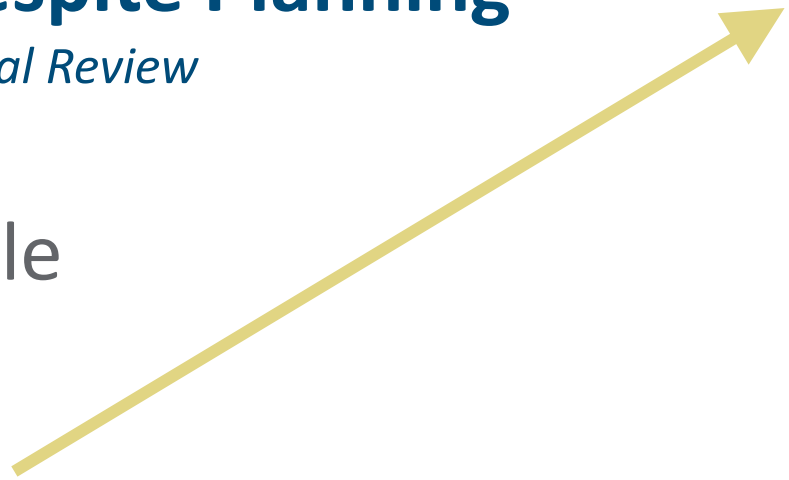
Iacob, … Utz. (2024).Time for Living and Caring: An Online Intervention for Dementia Caregivers' Use of Respite. *Innovations in Aging.* Forthcoming.

Virtual Coaching

Weekly Respite Planning

Goal Setting- Goal Review

1. Schedule
2. Plan
3. Review



Experienced Time-Use

- Did you have respite this week?
- Did you do the activities you had scheduled?

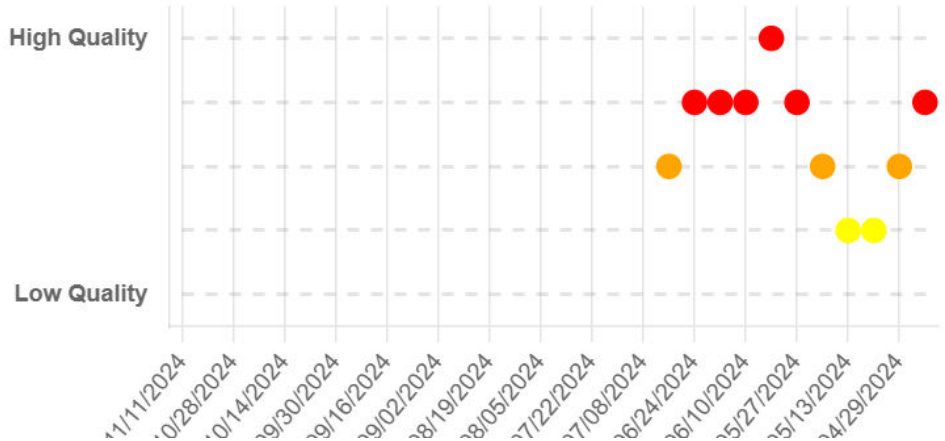
Evaluative Time-Use

- I had enough respite this week
- I am happy with how I spent my respite time this week
- I am a better caregiver because of the respite I had this week

Average Respite Quality by Week

This score is calculated based on how you responded to your Weekly Respite Review. The goal is to see an increase over time.

Complete Surveys



Hours of Respite Per Week

This graph shows the number of hours of respite you received each week. The goal is to achieve consistent respite each week, increase the amount of respite over time, and/or meet your respite goal (yellow line).

Change Goal

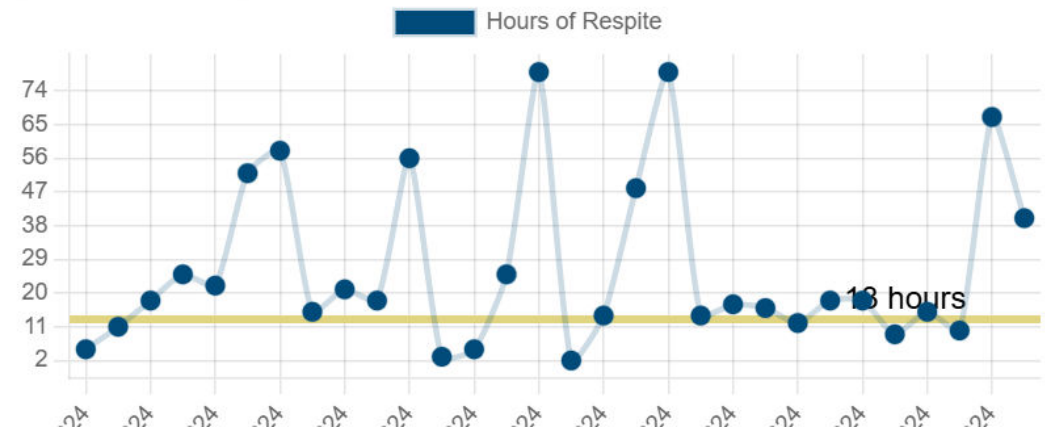
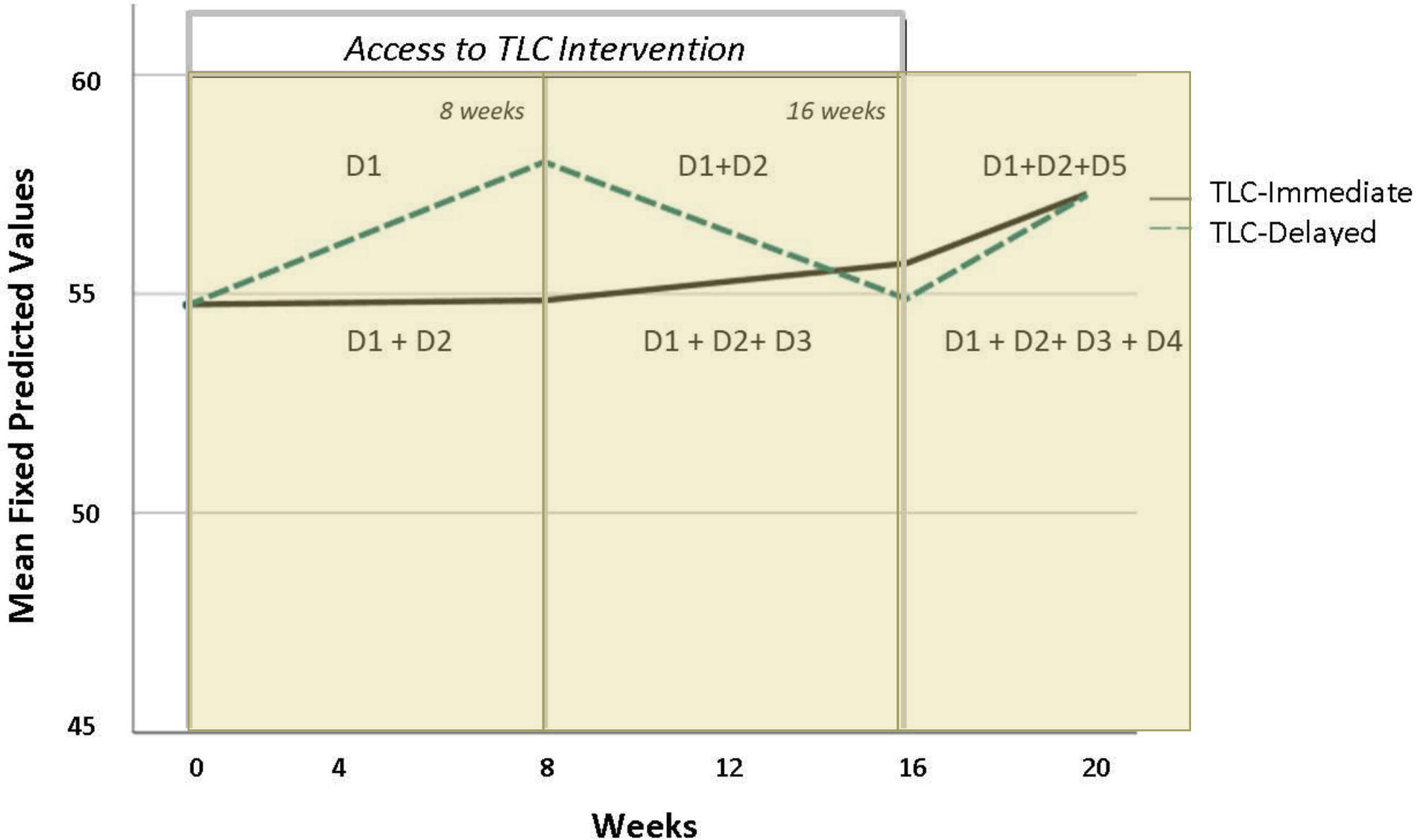
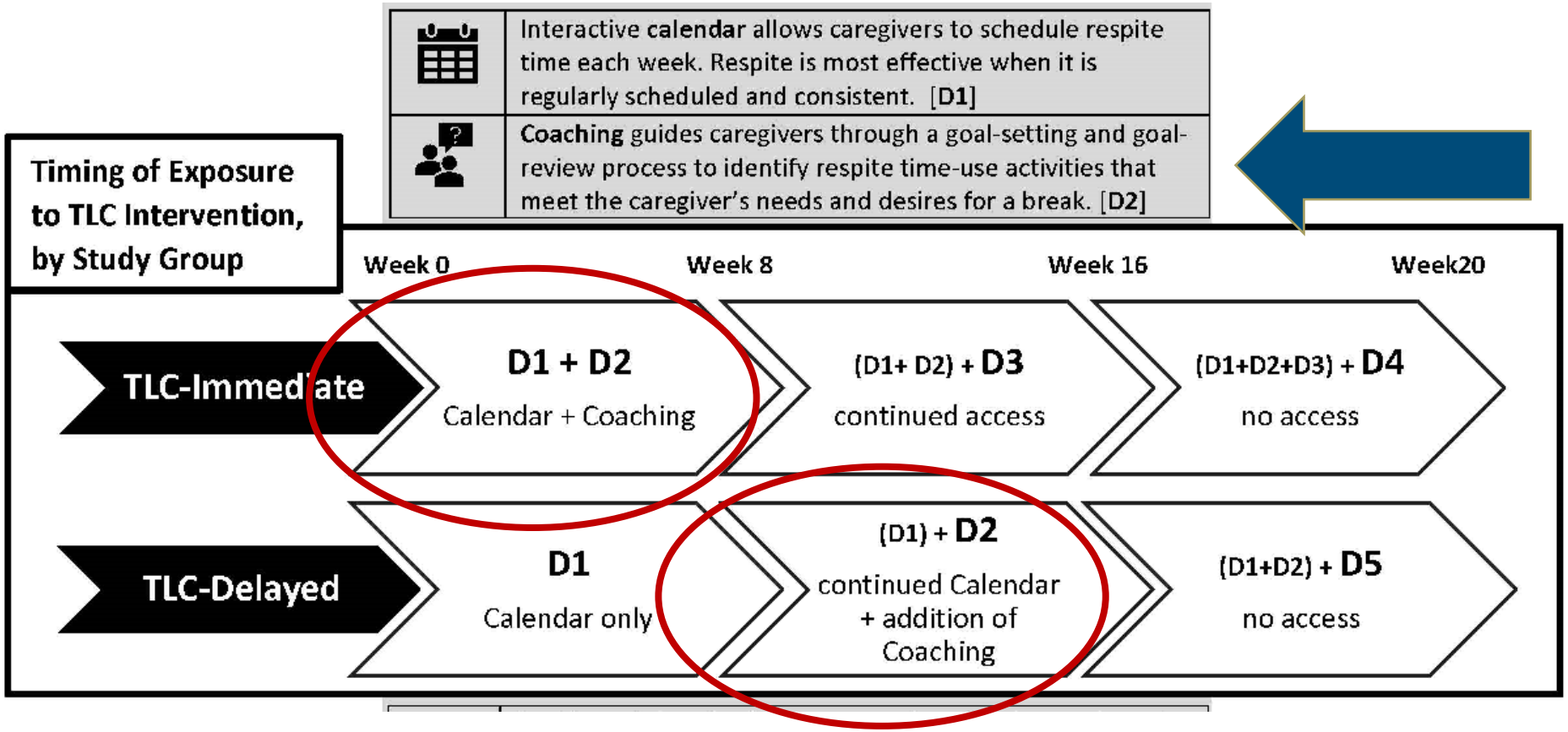


Figure. Mean Predicted Anxiety Scores, plotted by time (in weeks). Each time point represents exposure to different components (D=doses) of the TLC intervention



Iacob, … Utz. (2024).Time for Living and Caring: An Online Intervention for Dementia Caregivers' Use of Respite. *Innovations in Aging.* Forthcoming.



Virtual Coaching

Iacob, … Utz. (2024).Time for Living and Caring: An Online Intervention for Dementia Caregivers' Use of Respite. *Innovations in Aging.* Forthcoming.

Original Research Article

Using Digital Inequality Framework to Evaluate a Technology-Delivered Intervention for Caregivers: Age, Education, and Computer Proficiency

Journal of Aging and Health
2024, Vol. 0(0) 1–11

DOI: 10.1177/08982643241232173
journals.sagepub.com/home/jah
Sage

Amber D. Thompson, MA[1], Catharine Sparks, MSc[1], Bob Wong, PhD[2], Eli Iacob, PhD[2], Alexandra L. Terrill, PhD[3], Michael Caserta, PhD[4], and Rebecca L. Utz, PhD[1]

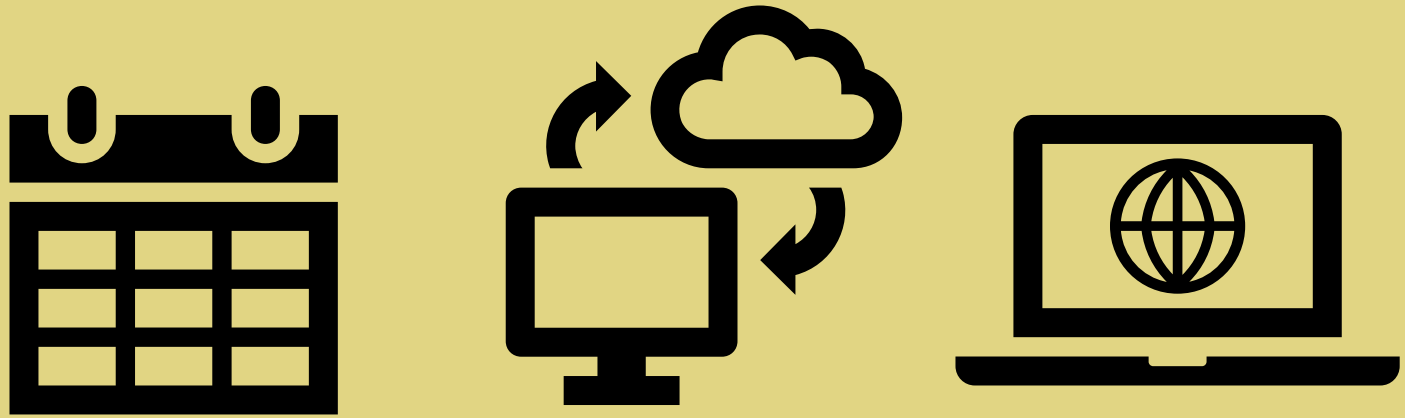
Abstract

Objectives: Using "digital inequality" as a conceptual framework, this study evaluates the feasibility and usability of a technology-delivered intervention (an "app") for Alzheimer's and related dementia family caregivers. Time for Living and Caring (TLC) is an on-line intervention that provides virtual coaching and self-administered education and resources. **Methods:** A sample of family caregivers (n = 163) used the tool for 16 weeks, which included completing the Computer Proficiency Questionnaire (CPQ-12) at baseline. Analyses investigate the relationship between age, CPQ scores, intervention use, appraisal, and caregiver outcomes. **Results:** Age was inversely associated with CPQ; however, CPQ scores did not have a significant relationship with participant's self-perceived benefits or intervention appraisal. Computer Proficiency Questionnaire scores provided insight regarding research feasibility, with lower scores associated with greater odds of discontinuing engagement. **Discussion:** CPQ-12 scores can be used as a screening tool to identify those who may need additional support to engage with and benefit from technology-delivered interventions.

Computer Proficiency Questionnaire

or CPQ

standardized assessment tool (12 items), measuring proficiency with computers, printing, communication, internet, calendaring software, and multimedia.



Never Tried (1)
Not at all (2)
Not very easily (3)
Somewhat easily (4)
Very Easily (5)

It has been used to help identify subgroups and areas to focus technology-related training and support (Boot et al., 2015). Age is among the strongest predictors of CPQ scores (Boot, et al., 2015), with older adult typically scoring significantly lower on CPQ than younger persons.

Yes, age is associated with CPQ.

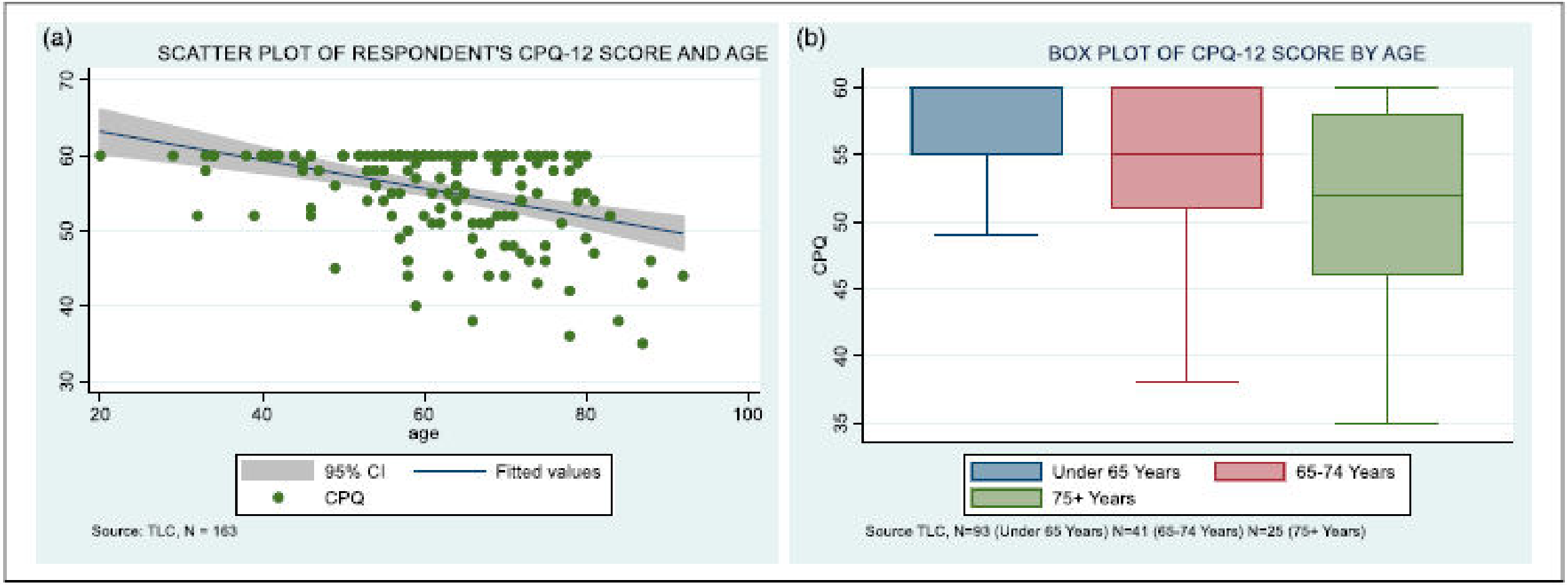


Figure 1. Computer proficiency by age: Scatter (a) and box (b) plots.

Neither *Age* nor *Computer Proficiency* was associated with:

- **Number of log-ins**
- **Time spent on app**
- **Overall assessment of intervention benefit**

*Very low Computer Proficiency was associated with attrition (rare in this sample), and possible greater request for hands-on personal assistance/orientation.

If you need help with this website or want to talk to someone about your respite needs, contact us. One of our coaches will get back to you within 48 hours - by phone, email, or text (whichever you prefer).

Full Name:

Full Name...

Preferred Comunication:

Phone

Phone or email to contact

contact...

What would you like to talk about?

Comments...

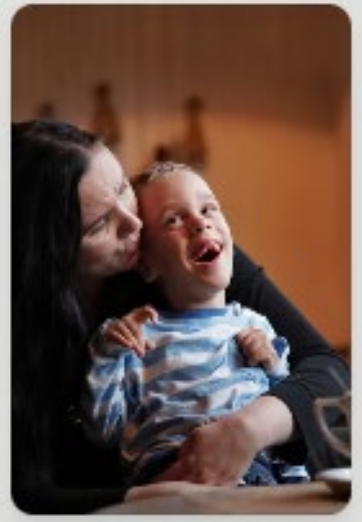
Submit

An e-coaching intervention to maximize benefit of respite among caregivers

Caregivers may need an orientation as they initiate respite

1. Caregivers need and deserve a break

2. Respite planning helps caregivers maximize the of respite time

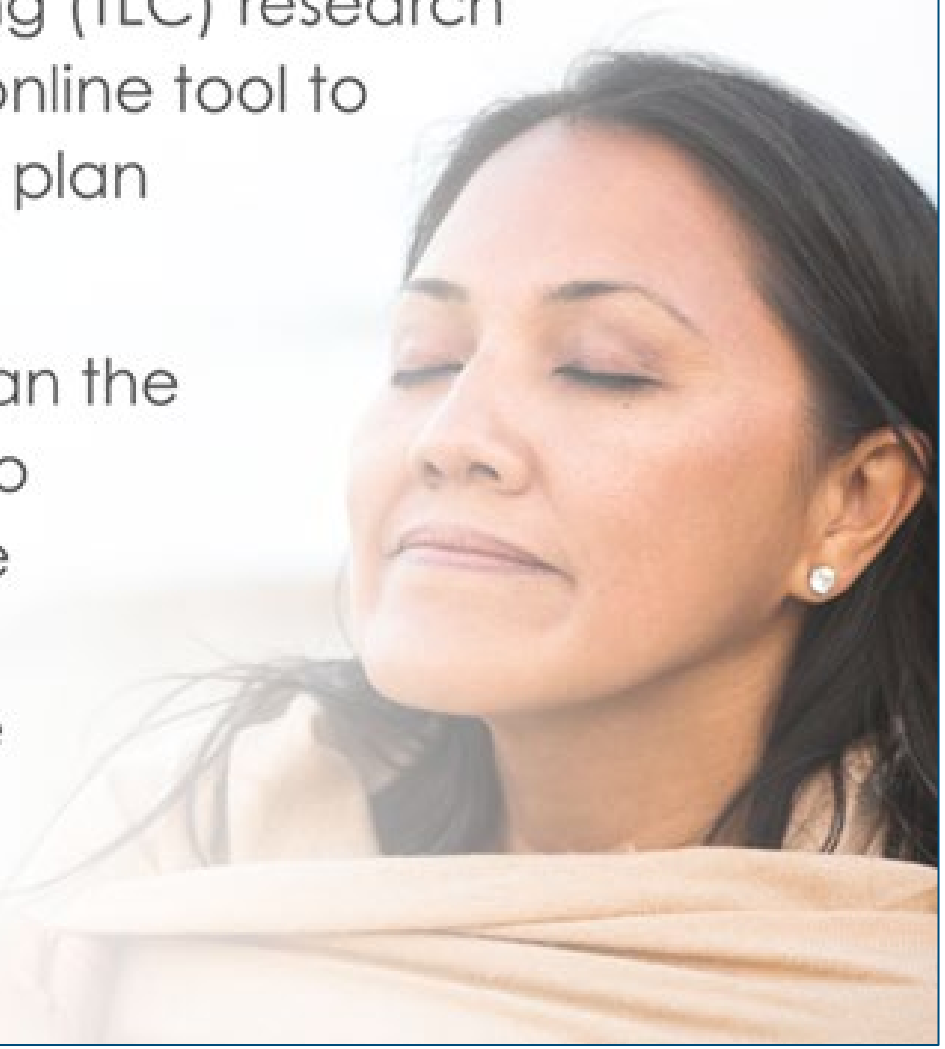


Are you a family caregiver?

The Time for Living a Caring (TLC) research team has developed an online tool to help caregivers track and plan their respite.

Visit the TLC website or scan the QR code to learn more and to access the free tool.

www.tlc-respite.com



Home Resources Research Login/Sign up

TLC

TIME FOR LIVING & CARING

Resources

testimonials

Here are three resources that may help you take a break:

1

Create a detailed information sheet to leave with your respite provider. This may help you build trust and faith that the respite provider knows how to take care of your loved-one while you are away.

Download Sample Info Sheet for Respite Provider

2

Caregivers often feel like they don't have time to take a break. They may feel like they are too busy. They may feel like they can't afford to take a break. Try this short guided meditation to help reset and overcome these types of feelings.

0:00 / 7:58

3

Note to Self. Journaling can benefit you in many ways. Some of these include organizing your thoughts, setting and achieving goals, and relieving stress. Plus, it is free, fast and portable.

Here are some prompts to get you started on your own journaling journey:

- ✓ Celebrate your wins! What wins did you experience this week?
- ✓ What kind of day are you having, and why?
- ✓ Break up your goals into to-do lists.
- ✓ Dear past/future me...
- ✓ Let it go! What are you holding on to that is causing you stress?
- ✓ People I have helped or who have helped me.

apps & web resources

Where can I find respite care services?

Family Care Navigator from Family Caregiver Alliance

Learn more →

ARCH National Respite Network – Respite Locator

Learn more →

State Respite Coalition & Lifespan Respite Grantee Contacts

Learn more →

How do I increase opportunities for informal respite care?

ATLAS OF CARE

Draw a Care Map to see who in your family or friend network might be able to help you.

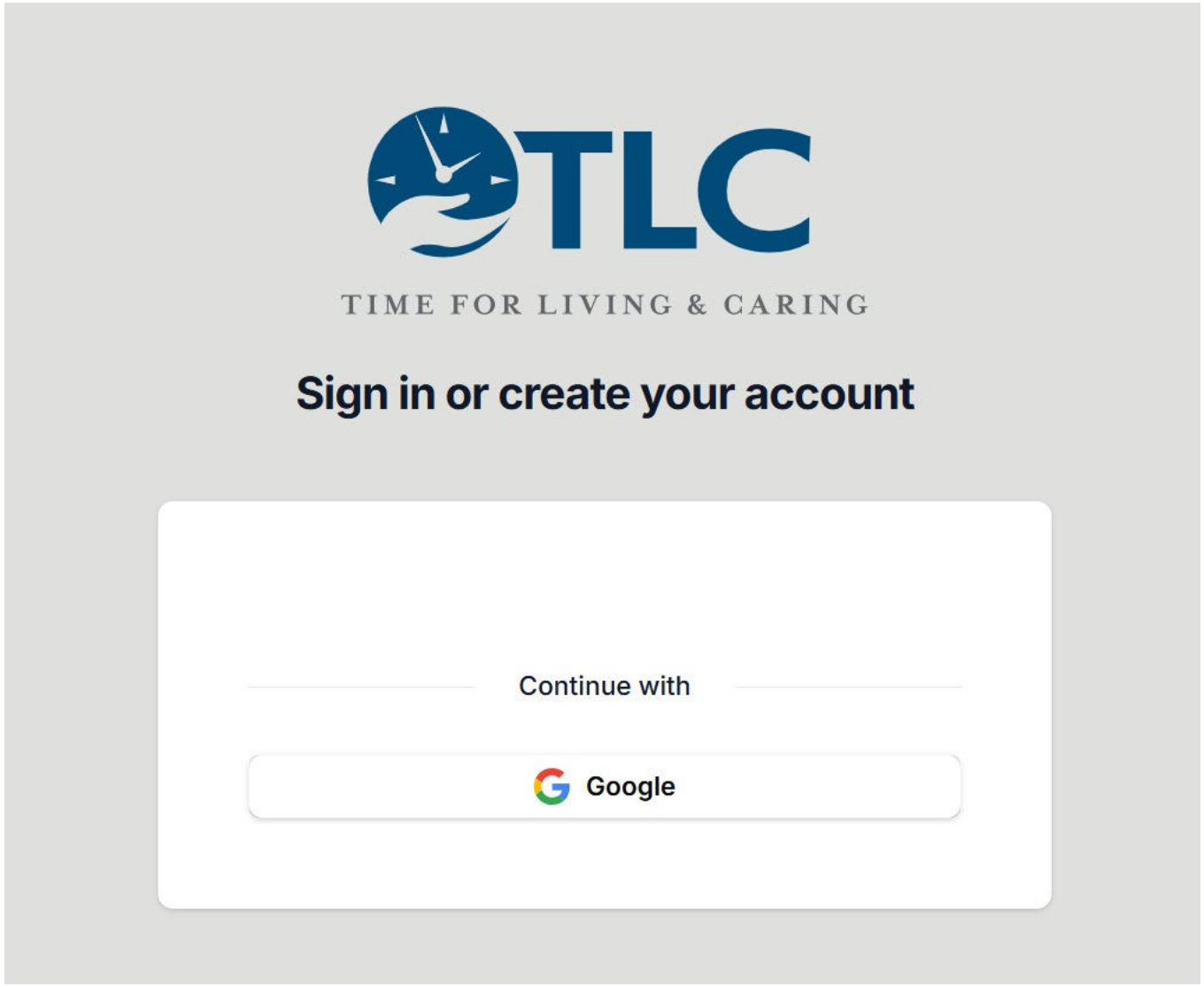
Learn more →

AARP

Call a Family Meeting to discuss how others may help you provide care and take a break.

Learn more →

Calendar – Virtual Coaching



TIME FOR LIVING & CARING