

Background

- 5.7 million persons in the U.S. with **Alzheimer's Disease & Related Dementias** (ADRD). AD tends to develop slowly and worsens gradually over several years, with patients requiring significant care for many years.
- **Informal family caregivers** are providing an estimated 18.4 billion hours of unpaid care to persons with ADRD, with an annual economic value of \$232 billion. Family caregivers are often unprepared to be caregivers and are susceptible to adverse caregiving-related physical and mental health outcomes, given the prolonged and challenging care they provide. Caregivers have been called "hidden patients" since their health and well-being is often not the focus.
- **Respite** is the most often requested service by family caregivers. It is defined as "time away from caregiving" and may be provided formally by home health agencies or adult day centers or informally by family members or friends provide the primary caregiver with an opportunity for scheduled time away.
- Findings on the effectiveness of respite are mixed. Our previous work shows that a majority of caregivers are **not satisfied with their respite time-use**, and felt they wasted their time and did not get the benefit of their time away.

Intervention Description

Time for Living & Caring (TLC) is an online, self-administered behavioral intervention, with goal of providing family caregivers with resources and support to maximize the benefit of their respite time-use.

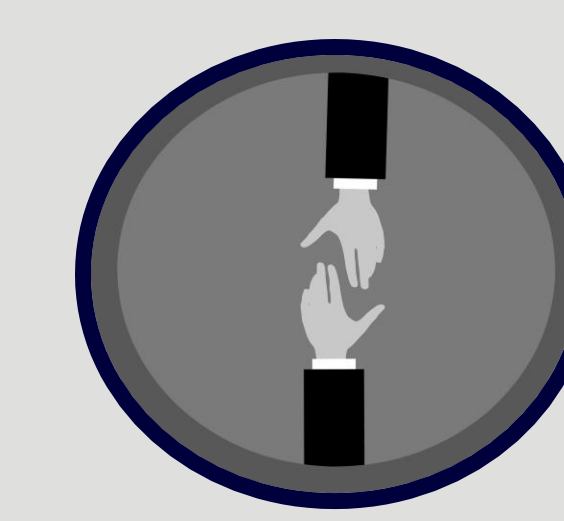
The primary feature is a **virtual coach** (a series of automated prompts, reminders, and suggestions delivered electronically through an interactive calendar) that guides caregivers through **assessment, goal setting, and goal review** for each planned respite period. Other modules are more static and provide information and resources. Participants are prompted by the virtual coach at least once a week for a minimum of 8-weeks.



Virtual Coach
How do I use respite?



Information & Education
What is Respite?



Resources & Referral
How do I get more respite?

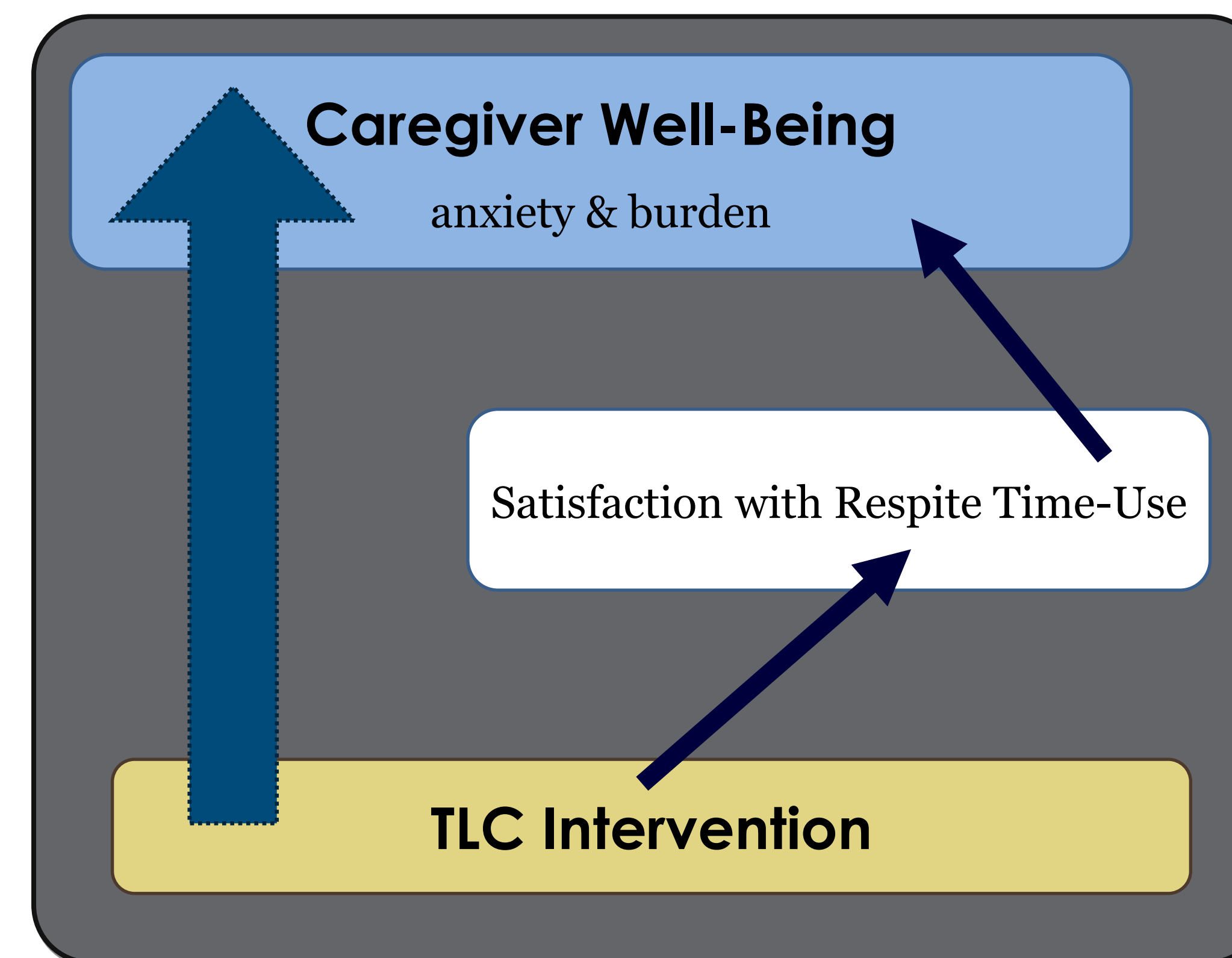


Figure. Conceptual Model Linking Respite With Caregiver Well-Being. TLC, as a general form of caregiver support, is hypothesized to directly improve caregiver well-being over time (large blue arrow). Represented by the thin black arrows, time-use satisfaction is hypothesized to be the pathway or **mechanism** through which the TLC intervention achieves its effect.

Pilot Study

Randomized waitlist control design with full-powered pilot sample (n=150). Intervention exposure for 8 weeks, with follow-up data collection including these measures:

- Primary outcomes to establish initial efficacy (anxiety, caregiver burden), assessed by survey pre-intervention and then every 4 weeks;
- Mechanisms (respite time-use, time-use satisfaction) assessed using ecological momentary data collected via text messaging over 20-week time period;
- Feasibility, usability, and acceptability of TLC intervention assessed using fixed-choice and open-ended responses collected post-intervention.

Community engaged research practices are used in all phases of intervention development and pilot study to ensure maximum scalability of the TLC intervention.