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### ONLINE ACT FOR CAREGIVERS: A LONGITUDINAL MIXED METHODS STUDY

by

Jacob D. Gossner

A dissertation submitted in partial fulfillment of the requirements for the degree

of

### DOCTOR OF PHILOSOPHY

in

Human Development and Family Studies

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2024

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#### ABSTRACT

#### Online ACT for Caregivers: A Longitudinal Mixed Methods Study

by

Jacob D. Gossner, Doctor of Philosophy

Utah State University, 2024

Major Professor: Dr. Elizabeth B. Fauth Department: Human Development and Family Studies

Family caregivers for people with dementia experience high levels of stress and are at risk of negative outcomes, including care-related burden, depressive symptoms, anxiety symptoms, suicidal ideation, and lower levels of positive aspects of caregiving and quality of life. Multiple interventions for family caregivers have demonstrated effectiveness in improving outcomes, but significant time and location constraints make them difficult to access for many caregivers. Online, self-guided interventions are one approach to making interventions more accessible for family caregivers. The purpose of this dissertation is to evaluate the impact of ACT for Caregivers, a six session online, self-guided program for caregivers for people with dementia based on Acceptance and Commitment Therapy. The study used longitudinal mixed methods in a convergent parallel design to analyze quantitative caregiver outcomes (n = 113) at three time points (pre-test, 30 day post-test, and 6 week follow-up) and to analyze semi-structured interviews (n = 28) at two time points (30) day post-test and 6 week follow-up). Participants had an average age of 61.93 (SD = 13.69), average caregiving duration of 4.69 years (SD = 4.74), and were primarily female (84.1%) and White (87.7%). Fifty-four percent were spousal caregivers and fifty three percent lived in the Mountain time zone. Quantitative analyses using multi-level models demonstrated

significant improvement during the intervention for all care-related outcomes (caregiver's stress reactions to symptoms of dementia, burden, positive aspects of caregiving, quality of life, depressive symptoms, and sleep quality), with standardized mean differences as effect sizes ranging from .19 (positive aspects of caregiving) to .60 (depressive symptoms). Psychological flexibility and subscales of behavioral awareness, openness to experience, and valued action also improved during the intervention, with standardized mean differences ranging from .20 (valued action) to .70 (openness to experience for those who completed the program). All effects were maintained or increased at follow-up. Qualitative results using deductive qualitative analysis corroborate patterns of change and provide additional context about common areas of change reported by participants. Attention is given to negative case participants and suggestions for future research are offered.

(194 pages)

#### PUBLIC ABSTRACT

#### Online ACT for Caregivers: A Longitudinal Mixed Methods Study

Jacob D. Gossner

Family caregivers for people with dementia are a resilient population operating under stressful circumstances that can put them at risk of multiple negative outcomes. Existing interventions may be difficult for family caregivers to access due to time and transportation constraints; an alternative is online, self-guided interventions that caregivers can access from their own homes. The purpose of this dissertation is to evaluate the impact of ACT for Caregivers, a six session online, self-guided program based on the principles of Acceptance and Commitment Therapy. Participants had an average age of 61.93 (SD = 13.69), had been caregiving for an average of 4.69 years (SD = 4.74), and were primarily female (84.1%) and White (87.7%). Fifty-four percent were spousal caregivers and fifty three percent lived in the Mountain time zone. Both statistical data at three time points (n = 113 family caregivers) and semi-structured interviews at two time points (n = 28 family caregivers) were used to examine the impact of the program on multiple outcomes, including stress reaction to symptoms of dementia, burdensomeness of caregiving, positive aspects of caregiving, quality of life, depressive symptoms, sleep quality, and psychological flexibility. Quantitative results demonstrated improvement in all outcomes during the intervention that was maintained or increased at follow-up. Qualitative results converged with the quantitative results and highlighted common aspects of change across outcomes. Results suggest that the program is a promising avenue for intervention with family caregivers.

## DEDICATION

To past, current, and future family caregivers for persons with dementia—may the way forward be a little brighter.

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Jacob Darius Gossner

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#### CHAPTER I INTRODUCTION

In the United States, there are an estimated 11 million family caregivers for people with dementia, providing an annual value of care that exceeds \$340 billion dollars (Alzheimer's Association, 2023). Alzheimer's disease and related dementias (ADRD) are a cluster of major degenerative neurocognitive diseases that have slightly different symptom profiles and different etiologies, but ultimately necessitate caregiving as the person with ADRD gradually loses cognitive and physical function. An estimated 83% of persons with ADRD are cared for by family caregivers (Alzheimer's Association, 2023). As the population continues to age, there are increasing numbers of family caregivers: in 2015, only 16% of family caregivers in the United States between the ages of 18 and 50 were providing care for someone with dementia; by 2023, this had increased to 23% (Alzheimer's Association, 2023).

The most common form of dementia is Alzheimer's disease, diagnosed in an estimated 6.7 million Americans (Soria Lopez et al., 2019). Estimates suggest that Alzheimer's disease accounts for between 60% to 80% of all dementia cases, yet autopsies reveal that brain changes typical of other forms of dementia often co-occur with Alzheimer's disease (Alzheimer's Association, 2023). Each year, there are an estimated 910,000 new cases of Alzheimer's disease in the United States (Alzheimer's Association, 2023).

The prognosis of Alzheimer's disease follows a well-established spectrum, moving from the preclinical phase, where there is evidence of brain changes but no observable symptoms, to mild cognitive impairment, where there are occasional lapses in memory encoding and retrieval, to mild, moderate, or severe dementia due to Alzheimer's disease based on the extent to which the disease interferes with an individual's ability to function. As dementia progresses, the amount and type of caregiving that is required increases significantly (Zarit & Whitlach, 2023).

While early-stage family caregiving focuses primarily on management and engagement, caregiving gradually transitions to providing assistance with instrumental activities of daily living, such as managing finances and maintaining doctor appointments, and eventually supporting physical activities of daily living, such as showering, toileting, and feeding. Caregiving can be considered a progressive form of ambiguous loss as the care receiver maintains being physically present but their decreasing cognitive and physical functioning result in caregivers feeling their absence even while they are alive (Boss, 2000). The higher the level of care, the more stressful caregiving can be (Kishita et al., 2020b; van den Kieboom et al., 2020).

#### **Demographics of Caregivers**

Roughly two thirds of family caregiving for persons with ADRD is done by women, and women are more likely to provide higher amounts of care and to assist with more challenging aspects of care (e.g., toileting; Alzheimer's Association, 2023; Cohen et al., 2019). Women are also more than two times as likely to co-reside with the person with ADRD. In part due to this higher level of care, female caregivers also report higher stress and depressive symptoms relative to male caregivers (Alzheimer's Association, 2023).

Approximately half of family caregivers for persons with ADRD are adult children or adult children-in-law, and, of these, half are concurrently raising a minor child. These socalled "sandwich generation" caregivers are at elevated risk for stress due to the need to balance competing demands of caregiving while adequately rearing their child(ren) (Pashazade et al., 2023). A substantial portion of caregivers are spouses, and 10% of all spousal caregivers in the United States are caregiving for a spouse with ADRD (Alzheimer's Association, 2023).

As far as age is concerned, nearly a third of family caregivers for people with dementia are over the age of 60 themselves. Age and the stress of caregiving puts them at increased risk for chronic health conditions, which is part of why many caregivers have a chronic health condition themselves (Alzheimer's Association, 2023).

In terms of ethnicity, two-thirds of caregivers are White, roughly 10% are Black, 8% are Hispanic, and 5% are Asian American. Until recently, only limited information was available about non-White family caregivers. Recent evidence suggests that, compared with White family caregivers, Black family caregivers are more likely to provide more than 40 hours of caregiving and are significantly less likely to access respite services (Alzheimer's Association, 2023). Due to systemic racism and financial instability, Black male caregivers report significantly more financial burden from caregiving than other family caregivers report significantly more financial burden from caregiving than other family caregivers report slightly higher overall wellbeing than White family caregivers, in addition to endorsing more positive aspects of caregiving (Alzheimer's Association, 2023).

#### **Caregiver's Objective Stress**

Due to the chronic, degenerative nature of ADRD, nearly 90% of caregivers have been providing care for at least a year, and close to 60% of caregivers have been providing care for four or more years (Alzheimer's Association, 2023). Caregiving intensity increases drastically towards end of life, but caregivers for persons with ADRD are still more involved throughout the process than caregivers for other conditions (Reckrey et al., 2021).

In addition, over 40% of caregivers are the only ones involved in caring for their

loved ones (Alzheimer's Association, 2023). This lack of respite care and social support can lead to feelings of isolation, loneliness, burden, and depressive symptoms (del-Pino-Casado et al., 2018; Gutiérrez-Sánchez et al., 2023).

As dementia progresses, many persons with dementia begin to exhibit behavioral and psychological symptoms of dementia (BPSD), also referred to as neuropsychiatric symptoms (Radue et al., 2019). Common BPSD include apathy, depressive symptoms, difficulty sleeping, anxiety, irregular motion patterns, delusions, and hallucinations (Radue et al., 2019). Managing these BPSD can be very challenging for family caregivers; evidence suggests that the frequency and intensity of BPSD is one of the most impactful care receiver characteristics on caregiver burden (Chiao et al., 2015; Contreras et al., 2021). While all BPSD can be stressful, evidence suggests that caregivers may report increased stress from disruptive behaviors and agitation and less stress from more common BPSD such as depressive symptoms and apathy (Fauth & Gibbons, 2014).

#### **Caregiver Subjective Stress and Related Outcomes**

Meta-analyses demonstrate that the stresses and strains of caregiving for someone with ADRD can lead to negative outcomes for family caregivers, including high levels of burden, depressive symptoms, anxiety symptoms, and suicidal ideation, and lower levels of positive aspects of caregiving and quality of life (Collins & Kishita, 2020; Contreras et al., 2021a; del-Pino-Casado et al., 2019; Quinn & Tomms, 2019).

Compared with caregivers for other chronic conditions or non-caregivers in the community, dementia caregivers report higher levels of stress, burden, depressive symptoms, anxiety, and suicidal ideation (Alzheimer's Association, 2023). Similarly, compared with caregivers for other chronic conditions or non-caregivers in the community, family caregivers

for persons with ADRD are at an increased risk for developing chronic conditions themselves, including hypertension, diabetes, heart disease, stroke, and cancer.

#### Interventions

As a result of the rapid increase in the number of family caregivers for persons with ADRD and the documented risk of negative outcomes for these caregivers, multiple interventions have been developed and tested to assist this population. In general, meta-analytic evidence suggests that these programs are beneficial for family caregivers for persons with ADRD (Cheng & Zhang, 2020; Walter & Pinquart, 2020). Due to the large number of interventions and conflicting inclusion criteria, the exact proportion of interventions that are psychoeducational versus those that are psychotherapeutic is unclear, as is the proportion of interventions that are delivered exclusively face to face versus those that include an online component. As one indicator, in their meta-review, Cheng and Zhang included 60 systematic analyses or meta-analyses that together included the results of over 500 intervention studies, including 14 reviews for psychoeducation and 10 reviews for psychotherapeutic intervention. However, despite a large number of interventions, fewer than 40% of Area Agencies on Aging offer evidence-based programs for family caregivers, and this is especially true for rural counties (Alzheimer's Association, 2023).

One of the primary obstacles to offering these programs is staffing difficulties, since intensive training and high turnover rates impede intervention delivery. Additionally, these interventions require family caregivers for persons with ADRD to leave the care receiver and to engage with the intervention at a designated location at a pre-specified time. These requirements may make these interventions inaccessible for some caregivers, particularly those who are most in need of services (Bayly et al., 2020; Ng, 2009).

5

#### **Study Purpose**

The purpose of this dissertation is to describe an online, self-guided intervention, ACT for Caregivers, and to examine preliminary longitudinal convergent parallel evidence (Creswell & Plano Clark, 2018) for the effectiveness of this program in improving BPSD stress reaction, positive aspects of caregiving, burden, quality of life, depressive symptoms, sleep quality, and psychological flexibility. The quantitative (QUANT) strand uses multilevel models (Hox et al., 2017) to examine relevant outcomes using three time points nested within individuals: pre-test, 30-day post-test, and six-week follow-up. The qualitative (QUAL) strand uses deductive qualitative analysis (DQA; Gilgun, 2014) to examine the impact of the intervention within the framework of Pearlin et al.'s (1990) stress process model of caregiving, informed by psychological flexibility, the guiding mechanism for change at the core of Acceptance and Commitment Therapy (ACT; Hayes et al., 2013). Guided by Schumacher et al.'s (2021) explication of longitudinal mixed methods research, the QUANT and QUAL strands are integrated to allow for a holistic description of the impact of the intervention on relevant caregiver outcomes.

#### CHAPTER II LITERATURE REVIEW

In the United States, there are an estimated 11 million family caregivers for people with Alzheimer's disease and related dementias (ADRD; Alzheimer's Association, 2023). Alzheimer's disease and related dementias are a grouping of major neurocognitive diseases that have a variety of symptom profiles depending on the condition. Types of dementia include Alzheimer's disease, vascular dementia, Lewy body dementia, Parkinson's dementia, and frontotemporal degeneration. Alzheimer's disease is the most common form of dementia and is likely the underlying pathology in 60-80% of dementia cases; however, brain autopsies reveal that a significant portion of persons with dementia experience brain changes that suggest more than one type of dementia (Alzheimer's Association, 2023). Estimates suggest that there are approximately 6 million persons with Alzheimer's disease in the United States, with another 1 to 2 million individuals with another type of dementia (Alzheimer's disease each year (Alzheimer's Association, 2023). There are over 910,000 new cases of Alzheimer's disease each year (Alzheimer's Association, 2023).

The majority of care for persons with ADRD is provided by informal, unpaid family caregivers (Alzheimer's Association, 2023; Kasper et al., 2015). It is not until the end of life that many persons with ADRD receive formal, paid caregiving through hospice, skilled nursing facilities, or home nurses (Zarit & Whitlach, 2023). Representative research suggests that the intensity of caregiving for a person with ADRD is significantly greater than the intensity of caregiving for a person without dementia (Kasper et al., 2015; Reckrey et al., 2020). One potential contributor to this increased stress is that dementia constitutes a form of ambiguous loss, where the care receiver is physically present but increasingly psychologically absent (Boss, 2000). Ambiguous losses may be more difficult to grieve due

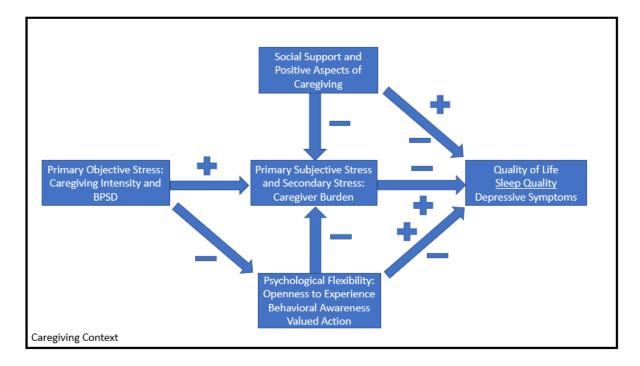
to their complexity and lack of culturally sanctioned coping rituals.

Family caregivers for persons with ADRD exhibit a number of strengths as they navigate the difficulties of caregiving, and many caregivers report that there are positive aspects of caregiving (Yu et al., 2018). Nevertheless, the chronic, progressive nature of the condition collides with other stressors to contribute to poor caregiver outcomes, including increased burden, depressive symptoms, and anxiety, and poorer physical health and quality of life (Collins & Kishita, 2020; Contreras et al., 2021; Kasper et al., 2015; Kishita et al., 2023; van den Kieboom et al., 2020).

#### **Conceptual Framework**

Pearlin et al.'s (1981; 1990) stress process model of caregiving offers a useful conceptual framework for understanding how caregiving for a person with ADRD can lead to negative outcomes for family caregivers. We adapt salient elements of this model to the current study in Figure 1. The stress process model is perhaps the best known and most frequently referenced model for understanding caregiver outcomes (Zarit & Whitlatch, 2023). Although now well accepted, it is worth noting that Pearlin et al.'s (1981) framework was innovative in conceptualizing caregiver stress as a process, rather than a series of disconnected events, and in proposing mechanisms by which disparate constructs were related.

#### Figure 1



Conceptual Framework for the Current Study, Informed by Pearlin et al. (1990)

*Note.* Positive and negative signs suggest the direction of anticipated associations.

In conceptualizing the stress process for caregivers, Pearlin et al. (1990) propose that primary objective stressors, such as the amount of time caregiving, lead to primary subjective stressors, such as burden, and secondary stressors, such as role conflict and intrapersonal conflict. Taken together, these stressors then lead to caregiver outcomes, such as depressive symptoms. They considered that social support and coping, particularly personal mastery, may mediate or moderate the stress process, and that the entire process is influenced by contextual factors such as kinship status and previous relationship quality with the person with dementia (Aneshensel et al., 1995; see also Fauth et al., 2012).

In 1995, Aneshensel et al. wrote a book that expanded the stress process model in a number of important ways. One of the most significant expansions was describing caregiving

as a career that can be divided into three stages: role acquisition, focusing on the different pathways to caregiving; role enactment, focused on continued adjustments as the disease progresses; and role disengagement, focused on grieving the loss of the person with ADRD and re-engaging with other areas of life. Aneshensel et al. (1995) proposed that the stress that caregivers experience is influenced by the stage of the caregiving career that they are currently in and by how they have navigated previous stages, captured in the caregiving history.

This understanding aligns well with Baltes' lifespan development theory (Baltes et al., 2006), a macro-level theory that provides a developmental lens for exploring caregiving and its impact. Within this theory, the historical and social context of caregiving is paramount, along with an understanding of the multidimensional way in which caregivers' physical, emotional, and psychosocial dimensions interact with their experiences with caregiving. Particularly relevant to caregiving is Baltes' assertion that all development involves both gains and losses, such as gaining the experience of caregiving even as the caregiver loses the care receiver. This theoretical orientation also supports the emphasis on both demands of caregiving and positive aspects of caregiving in order to understand the full impact of caregiving on caregivers.

#### **Primary Objective Stressors**

Primary objective stressors refer to stressors that are germane to caregiving itself, including the cognitive and functional impairment of the person with ADRD, behavioral and psychological symptoms of dementia, amount of time caregiving, and relative intensity of caregiving actions.

Cognitive and Physical Capacity of Person with ADRD. Within Perlin et al.'s

(1990) stress process model, the cognitive functioning of the person with ADRD is a significant source of primary stress. Due to its nature as a degenerative condition, the cognitive and physical capacity of persons with ADRD decreases over time, and this significantly increases caregiver stress and burden (Contreras et al., 2021a; Zarit & Whitlatch, 2023). Systematic reviews suggest that the cognitive functioning of the person with ADRD consistently predicts caregiver outcomes (van den Kieboom et al., 2020).

**Behavioral and Psychological Symptoms of Dementia.** Related to but distinct from the cognitive functioning of the person with ADRD is behavioral and psychological symptoms of dementia (BPSD; also referred to as neuropsychiatric symptoms, Radue et al., 2019). Common BPSD include apathy, depressive symptoms, difficulty sleeping, anxiety, irregular motion patterns, delusions, and hallucinations (Radue et al., 2019). BPSD constitute a source of significant stress for caregivers due to their intensity, unpredictability, and progressive nature. Both a systematic review (Chiao et al., 2015) and a meta-analysis (Contreras et al., 2021a) suggest that BPSD is the most significant care receiver characteristic on caregiver burden. BPSD often reach their peak level of intensity during the middle stages of ADRD (Radue et al., 2019), which may be why caregiver stress is often at its highest during this stage (Zarit & Whitlach, 2023). While all BPSD can be stressful, evidence suggests that caregivers may experience relatively greater stress from disruptive behaviors and agitation and relatively less stress from more common BPSD such as depressive symptoms and apathy (Fauth & Gibbons, 2014).

**Daily Caregiving Hours.** Hours of caregiving per day is consistently associated with caregiver outcomes such as burden, anxiety, and depressive symptoms (Kishita et al., 2020b; Park et al., 2015). Thus, hours of caregiving per day is a common metric of caregiving

intensity. However, accurately assessing the hours of caregiving can be difficult, since caregivers' definitions of what constitutes caregiving may differ. Compared with family caregivers for people without dementia, family caregivers for people with ADRD report consistently higher amounts of weekly caregiving for all but the last year of life (Reckrey et al., 2020). Higher amounts of caregiving are consistently associated with increased risk for poor outcomes (van den Kieboom et al., 2020).

#### **Primary Subjective Stressors and Secondary Stressors**

Primary objective stressors lead to and exacerbate primary subjective stressors and secondary stressors in the form of perceived burdensomeness of caregiving in two domains: role conflict and intrapersonal strains. Secondary stressors are temporally secondary, but not secondary in terms of influence on caregiver outcomes; once established, secondary strains can be as harmful as primary stressors (Pearlin et al., 1990).

Role conflict refers to the extent to which a caregiver perceives that caregiving leads to conflict in other domains, such as with other family members or with work (Pearlin et al., 1990). Intrapersonal strains refer to a caregivers' diminished self-concept, sense of self, or sense of mastery. Role conflict and intrapersonal strains constitute the two factors of the most common measure of burden, the Zarit Burden Interview (Bédard et al., 2001). Based on meta-analytic results, family caregivers report a high prevalence of burden, with roughly 49% of caregivers considering caregiving to be burdensome (Collins & Kishita, 2020). Coresiding with the person with dementia often increases perceived burden and is therefore frequently included in models as a control variable (Viñas-Diez et al., 2017).

Conceptually and empirically, burden operates as an intermediate care-specific outcome between primary stressors and outcomes such as depressive symptoms and quality

of life; for this reason, meta-analyses suggest that burden is associated with higher depressive symptoms (del-Pino-Casado et al., 2019) and poorer quality of life (Contreras et al., 2021a). del-Pino-Casado et al.'s (2019) finding that higher levels of burden predicted higher levels of depressive symptoms was strengthened by their inclusion of longitudinal studies in their meta-analysis, allowing them to demonstrate that earlier reports of burden predicted later depressive symptoms. This supports Pearlin et al.'s (1990) conceptualization of burden as an intermediary outcome between primary stressors and caregiver outcomes.

#### **Outcomes**

According to Pearlin et al.'s (1990) model, primary and secondary stressors lead to caregiver outcomes in the form of increased anxiety and depressive symptoms, reduced physical health, and, if not ameliorated, eventual yielding of the caregiver role. Pearlin et al. (1990) proposed that, while each of these outcomes can occur in isolation, there may be a developmental cascade such that increased depressive symptoms leads to and exacerbates reduced physical health, which increases the likelihood of yielding the caregiver role in the form of transferring responsibilities to another family member or placing the person with ADRD into a skilled nursing facility.

**Depressive Symptoms.** One of the most salient outcomes of caregiving for family caregivers is increased depressive symptoms (Alzheimer's Association, 2023; del-Pino-Casado et al., 2019; Pearlin et al., 1990). In their meta-analysis of caregiver outcomes, Collins and Kishita (2020) found that roughly 31% of family caregivers meet the cutoff criteria for depressive symptoms. This prevalence is higher than among family caregivers for persons with other conditions and among non-caregiver older adults. Odds ratios from this meta-analysis suggested that female caregivers are 1.45 times more likely to meet cutoff

criteria for depressive symptoms than male caregivers. Interestingly, their meta-analysis found no consistent association for depressive symptoms and kinship status. Importantly, family caregiver depressive symptoms is a risk factor for increased suicidal ideation, and is therefore an essential target for intervention (O'Dwyer et al., 2016).

**Quality of Life.** A related outcome for family caregivers is quality of life. Although quality of life is a somewhat ambiguous concept, the World Health Organization defines it as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 2023). At its core, quality of life is about the subjective experience of a life well-lived. Evidence suggests that family caregivers for people with dementia are at risk for diminished quality of life (Alzheimer's Association, 2023; Contreras et al., 2021a).

Contreras et al. (2021a) conducted a meta-analysis examining factors associated with family caregiver quality of life across multiple countries. They found using pooled correlations that there was a significant large (-0.58) effect for depressive symptoms, a significant moderate (-0.47) effect for caregiver burden, and a significant small effect for the care receiver's BPSD (-0.24). This same study found that these effects did not vary between countries with different development statuses. This supports Pearlin et al.'s (1990) model by demonstrating that primary objective stressors (BPSD), subjective stressors (burden), and outcomes (depressive symptoms and quality of life) are associated in the expected directions.

**Person-Centered Care.** A relevant outcome for family caregivers for people with ADRD is providing person-centered care for the person with ADRD. Person-centered care is a concept that comes out of the skilled nursing field and refers to treating the person with

ADRD as an individual, with values and preferences that need to be acknowledged and compassionately met, insofar this is possible (Lee et al., 2020). Pearlin et al. (1990) did not directly discuss providing person-centered care in their stress process model of caregiving. However, they conceptualized yielding of the caregiver role, either partially or totally, as an outcome of the caregiver stress process. We conceptualize providing person-centered care as the opposite of yielding of the caregiving role because it signifies increased emotional engagement and responsiveness to needs (Galovan & Schramm, 2019). It signifies that the caregiver is managing the stress process in such a way that they are able to maintain their focus on the personhood of the person with ADRD.

While person-centered care is a well-established hallmark of competent medical care, it has only been applied to people with ADRD in relatively limited ways. Some scholarship has emphasized the importance of medical professionals providing person-centered care for family caregivers (Parmar, 2021a; Parmar et al., 2021b), but has not directly examined family caregivers' provision of person-centered care for people with ADRD. Limited evidence suggests that person-centered care benefits both the caregiver and the care receiver. Although focused on paid caregivers rather than family caregivers, meta-analytic results suggest that for persons with ADRD in residential care, person-centered care is associated with improved quality of life (Kim & Park, 2017) and reduced incidence of BPSD (Lee et al., 2020). The extent to which these findings hold for family caregivers is a topic for further study.

#### **Mediators and Moderators**

Pearlin et al. (1981; 1990) proposed that the entire caregiver stress process could potentially be buffered (moderation) or even pass through (mediation) caregivers' coping strategies, positive aspects of caregiving, and social support. **Caregiver Coping.** Pearlin et al.'s (1990) stress process model focused on three forms of coping behaviors: managing the stressor itself; managing the meaning of the stressor such that stress is reduced; and managing the stress symptoms (see also Pearlin et al., 1981). Broadly, these map on to Lazarus' and Folkman's (1984) problem-focused coping and emotion-focused coping. Interestingly, in Aneshensel et al.'s (1995) expansion of Pearlin et al.'s (1990) model, they focused only on caregivers' sense of mastery as the primary form of coping.

Perhaps because many aspects of caregiving are beyond the control of the caregiver, evidence examining caregivers' use of problem-focused coping is mixed. In a systematic review examining the association between different coping strategies and caregiver burden, del-Pino-Casado et al. (2011) found heterogenous effects for problem-focused coping. In their systematic review and meta-analysis, Li et al. (2014) found that problem-focused coping (which they referred to as solution-focused coping) did not significantly correlate with caregiver depressive symptoms or anxiety. Nevertheless, individual studies suggest that problem-focused coping can help caregivers (Caga et al., 2021; Wong et al., 2014).

More recently, coping has been conceptualized in terms of avoidance-oriented coping or acceptance-based coping (del-Pino-Casado et al., 2011). This is a distinct understanding of coping that differs significantly from the way Pearlin et al. (1990) originally conceptualized coping. There is strong evidence that avoidance-oriented coping is associated with negative outcomes for caregivers. Avoidance-oriented coping and psychological inflexibility are associated with increased anxiety and depressive symptoms (Kishita et al., 2020b; Kishita et al., 2023; Lappalainen et al., 2021a; Li et al., 2014), higher caregiver distress (Spira et al., 2007), higher levels of burden (del-Pino-Casado et al., 2011), reduced perception of rewards from caregiving (Henriksson et al., 2015), and poorer quality of life (Contreras et al., 2021b).

In contrast to avoidance-oriented coping, emotionally supportive and acceptancebased coping is associated with reduced anxiety (Li et al., 2014), reduced burden, and reduced depressive symptoms (Gilhooly et al., 2016; Li et al., 2014; Luiu et al., 2020). This form of coping also includes behaviors; appropriate self-care is associated with lower burden (Coen et al., 2002) and commitment to personal values is associated with lower depressive symptoms and higher emotional acceptance (Romero-Moreno et al., 2016).

While there is significant evidence for the direct effect of different coping strategies on family caregiver outcomes, there is less conclusive evidence that coping strategies play a mediating or moderating role in the stress process. In support of the role of coping in moderating the stress process, Barrera-Caballero et al. (2022) found that cognitive fusion, defined as believing thoughts are true and acting on them as if they are reality, moderates the effectiveness of interventions for family caregivers on depressive symptoms. Similarly, Van Hout et al. (2023) found that experiential avoidance, trying to negate or avoid private experiences, strengthened the association between subjective burden and caregiver anxiety. In support of mediation, Romero-Moreno et al. (2016) found that ruminating and avoidanceoriented coping mediated the association between BPSD and caregiver anxiety. Though not specific to family caregivers, a systematic review suggests that both acceptance-based coping and cognitive fusion can mediate the process of change (Stockton et al., 2019).

**Caregiving Uplifts.** While Pearlin et al.'s (1990) stress process model of caregiving focused on negative influences on caregiver outcomes, they also gave attention to two uplifts of caregiving that can potentially reduce (moderate) the influence of primary and secondary stressors on caregiver outcomes: competence and gains. The specific location of these uplifts

in the caregiver stress process model has shifted over the years; in Pearlin et al. (1990), they were located in the intrapsychic strains as potential counteracting influences; in Anashensel et al.'s (1995) description, they were embedded into the section on mediators and moderators of the stress process.

Competence has often been operationalized as self-efficacy and refers to caregivers' perception that they are capable of providing adequate care to the person with ADRD while caring for themselves at the same time (Khan et al., 2021). Self-efficacy has been shown to both moderate and partially mediate the impact of some primary stressors—BPSD—on secondary strains (Cheng et al., 2019; Zhang et al., 2014).

What Pearlin et al. (1990) referred to as gains from caregiving has come to be called positive aspects of caregiving (Carbonneau et al., 2010). Flowing out of positive psychology, the recent focus on positive aspects of caregiving is in part an effort to balance descriptions of caregiving by focusing on both the positives and the strains of caregiving (Yu et al., 2018). However, there is little consensus about what elements of caregiving can be considered positive, and a variety of measures have been used. Yu et al. (2018) conducted a systematic review of 41 articles on positive aspects of caregiving and found that positive aspects of caregiving can be divided into four distinct domains: a sense of personal accomplishment and fulfilment, feelings of mutuality in the relationship, increased family functioning or cohesion, and a sense of personal growth and purpose in life.

Building on Yu et al.'s (2018) work, Quinn and Toms (2019) conducted a systematic review of the impact of positive aspects of caregiving on caregiver outcomes. They found that positive aspects of caregiving were associated with reduced depressive symptoms and burden, and with increased quality of life, self-efficacy, and satisfaction with the caregiver role. Their results suggest that positive aspects of caregiving may serve as a protective factor that buffers against some of the stressors of caregiving and are therefore highly relevant in understanding caregiver outcomes (see also Yang et al., 2018).

**Social Support.** Pearlin et al. (1990) conceptualized social support as a salient potential mediator or moderator on caregiver outcomes. Over 40% of family caregivers for people with ADRD are the only ones providing care (Alzheimer's Association, 2023). Navigating the challenges of caregiving without the support of other family members or formal caregivers can exacerbate stress. However, in their sample of family caregivers for people with ADRD, Aneshensel et al. (1995) found that social support in the form of emotional support or instrumental support—direct assistance with the person with ADRD had a significant direct effect on primary stressors, secondary stressors, and outcomes, but did not meet the conditions for mediation or moderation. This is consistent with other literature on family caregivers in general. Specifically, two meta-analyses on family caregivers found that perceived social support is moderately associated with reduced burden (del-Pino-Casado et al., 2018) and with reduced depressive symptoms (Gutiérrez-Sánchez et al., 2023). Importantly, both meta-analyses also found that perceived social support had a larger effect size than actual received social support.

#### Context

Pearlin et al.'s (1990) model and Baltes et al.'s (2006) theory give significant weight to the context in which caregiving occurs. In particular, they emphasize that sociodemographic variables, kinship status, caregiving history, previous relationship with the person with ADRD, family and support network composition, and availability of quality medical care are salient aspects of context that can influence the extent to which caregivers

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report stress from the caregiving career.

Supporting Pearlin et al.'s (1990) assertion that caregiver characteristics and contextual factors must be taken into consideration, a number of studies have explored the influence of demographic variables, contextual variables, and caregiver outcomes. Supporting the overall structure of the stress process model, most studies have found that while sociodemographic and contextual factors are relevant, they are not as large of predictors of caregiver outcomes as primary stressors, secondary stressors, and coping (Park et al., 2015; Viñas-Diez et al., 2017).

**Kinship Status.** Kinship status refers to the relationship type between the family caregiver and the person with ADRD, and is often divided into spousal caregivers and adult child caregivers. Qualitative and theoretical work suggest that the experience of caregiving for a spouse may be different in key ways from caregiving for a parent (Tatangelo et al., 2018a; Tatangelo et al., 2018b; Viñas-Diez et al., 2017). Whereas spouses may anticipate, at least to some extent, the need to care for each other as they age, the demands of caregiving may be unanticipated by adult child caregivers. In addition, roughly half of adult child caregivers are concurrently providing care to a minor child still living at home (Alzheimer's Association, 2023). These "sandwich generation" caregivers experience stress pileup as they attempt to balance the needs of their offspring and their parent(s); this puts them at elevated risk for negative outcomes (Pashazade et al., 2023).

Several individual studies have found that either spousal (Park et al., 2015) or adult child caregivers (Viñas-Diez et al., 2017) are at increased risk for poor outcomes. Even metaanalytic results are unclear. In their meta-analysis, Pinquart and Sorenson (2011) found that, compared to adult child caregivers, spousal caregivers reported higher levels of burden, worse physical health, and higher levels of depressive symptoms. However, Collins' and Kishita's (2020) meta-analysis did not find a significant difference in risk of depressive symptoms between spousal and adult child caregivers, in part because there were individual studies that found that either spousal or adult child caregivers had worse depressive symptoms.

**Caregiver Gender.** Caregiver gender has consistently been highlighted as being meaningfully associated with caregiver stress and other outcomes (Cohen et al., 2019; Collins & Kishita, 2020; Park et al., 2015; Viñas-Diez et al., 2017). On average, female caregivers provide more hours of care per week than male caregivers and are 2.5 times more likely to coreside with the person with ADRD than males (Alzheimer's Association, 2023). Daughters and daughters-in-law are more likely to act as caregivers than sons or sons-in-law (Alzheimer's Association, 2023). Many women provide care out of a desire to give back to the person with ADRD; others report feeling pressured by family members to take up the caregiving role primarily due to their gender (Tatangelo et al., 2018b). In part due to their higher amount of care, female caregivers report higher levels of burden than male caregivers (Park et al., 2015) and are at significantly increased risk for depressive symptoms (Collins & Kishita, 2020).

**Previous Relationship Quality.** Previous relationship quality with the care receiver is associated with caregiver outcomes, but the direction of this relationship is mixed depending on the outcome. Using longitudinal linear mixed effects modeling of 234 caregiver-care receiver dyads, Fauth et al. (2012) found that higher relationship closeness at the onset of care predicted less depressive symptoms and better overall mental health. However, they also found that those who had closer relationships with the care receiver reported steeper decreases in affect and overall mental health over time.

**Duration of Caregiving.** Compared with caregivers for persons with other conditions, family caregivers for people with ADRD are caregivers for significantly more time (Reckrey et al., 2021). Over 90% of caregivers have been caregiving continuously for at least 1 year, and close to 60% of caregivers have been caregiving continuously for four or more years (Alzheimer's Association, 2023). Aneshensel et al.'s (1995) emphasis on family caregiving for persons with ADRD as a career highlights that the demands of caregiving shift over time, and these periods of transition are likely to be particularly challenging to navigate. Perhaps because of the constantly changing nature of caregiving, the number of years as a caregiver is not consistently associated with caregiver outcomes (Park et al., 2015).

**Caregiver and Care Recipient Age.** Age of the caregiver and care receiver may or may not influence caregiver outcomes (Conde-Sala et al., 2010). On the one hand, older family caregivers are at greater risk of personal health challenges, which can reduce resources and thus exacerbate caregiver stress (Park et al., 2015; Tsai et al., 2021). In addition, the oldest old are likely to have multiple other chronic health challenges, which may complicate care (Tsai et al., 2021). At the same time, not all older family caregivers experience disease-related secondary aging while caregiving. Caregivers for the oldest old are more likely to be adult children than spouses, and report high levels of role strain and perceived burden of caregiving (Win et al., 2017).

#### **Interventions with Family Caregivers**

Due to the high risk of negative outcomes for dementia family caregivers, many interventions have been developed and implemented. Multiple systematic reviews and metaanalyses have been conducted in an attempt to synthesize the disparate outcomes from these interventions. In their comprehensive meta-review of systematic reviews and meta-analyses, Cheng and Zhang (2020) reported that interventions effectively led to reductions in caregiver depressive symptoms, improved quality of life, and improved sense of mastery, whereas the effectiveness of interventions on anxiety, burden, and social support was inconclusive. In their meta-analysis, Walter and Pinquart (2020) found that interventions have significant small (<0.4) effect sizes on burden, depressive symptoms, quality of life, and care receiver symptoms. Supporting Walter's and Pinquart's (2020) findings, Williams et al.'s (2019) metaanalysis of RCTs found a significant small decrease in burden following intervention.

Since the body of family caregiver interventions has demonstrated effectiveness, increasing scholarly attention has focused on the content of effective interventions. Cheng and Zhang (2020) reviewed 60 systematic reviews and meta-analyses and concluded that both psychoeducational and psychotherapeutic interventions have been shown to be effective, although they may target different outcomes. They also concluded that support groups and respite care were not significantly predictive of caregiver outcomes, although some studies have found that respite (Vandepitte et al., 2016) and support groups (McLoughlin, 2022) are effective for certain caregiver outcomes.

Similar to Cheng and Zhang (2020), Kishita et al.'s (2018) meta-analysis, which included only RCTs, found that psychoeducational interventions were slightly more effective than psychotherapeutic interventions in reducing caregiver burden, but that psychotherapeutic interventions were more effective at reducing depressive symptoms and anxious symptoms.

### Acceptance and Commitment Therapy

In the past, most psychotherapeutic interventions with family caregivers for people

with ADRD were based in cognitive behavioral therapy (CBT). However, over the last decade, an increasing number of psychotherapeutic interventions have been developed based on Acceptance and Commitment Therapy (ACT; Han et al., 2020; Han et al., 2021a).

ACT is a third-wave behavioral therapy that focuses on increasing individuals' psychological flexibility, defined as individuals' "ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" (Hayes et al., 2006, pg. 8). In layman's terms, psychological flexibility is the ability to be aware of the here and now, stay open to one's own experience, and to engage in doing what matters (Francis et al., 2016). Within ACT, psychological flexibility is the primary mechanism and target of change. As individuals develop greater psychological flexibility, they are better able to navigate the challenges of their specific context.

Psychological flexibility consists of six interrelated within-person processes: acceptance, cognitive defusion, being present, self as context, values, and committed action (Hayes et al., 2006; Hayes et al., 2013). These six processes are often grouped into three pillars of psychological flexibility: being open (acceptance and defusion); being aware (present moment awareness and self-as-context); and being engaged (values and committed action) (Hayes et al., 2011). Each of these processes is jointly a skill and a marker of psychological flexibility. Briefly defined, acceptance refers to the ability to be willing to have some difficult internal experiences in service to pursuing a valued life (Hayes et al., 2006). Cognitive defusion refers to the ability to recognize thoughts as cognitions rather than reflections of reality and the related ability to choose how much weight to give a particular thought depending on whether it is helpful. Present moment awareness and self-as-context are interrelated and refer to an individual's ability to be present with their current experience without getting caught up in trying to control it or responding automatically. Clarifying values and committed action refer to an individual's ability to recognize what matters to them personally and to pursue these values intentionally and flexibly. Though conceptually distinct, these processes are interrelated and together form the foundation for psychological flexibility, a measurable mechanism of change.

In light of the similarities between CBT and ACT, it is relevant to highlight salient differences, particularly in mechanisms of change. The mechanism of change in CBT is correcting cognitive distortions such that faulty cognitions are no longer believed and acted on. In contrast, the mechanism of change in ACT is psychological flexibility, changing one's relation to thoughts and feelings such that they no longer dictate behavior, and instead aligning behavior with personally chosen values. Both CBT and ACT have demonstrated effectiveness with family caregivers for people with dementia (Han et al., 2021a; Hopkinson et al., 2019; Losada et al., 2015). However, ACT may be particularly suited to this population due to the emphasis on acceptance and committed action. There are many aspects of caregiving that are beyond the control of the caregiver, such as disease progression, BPSD, and the caregiver's own experience of grief. ACT emphasizes accepting these experiences, while at the same time taking committed action to act in alignment with what matters. The coupling together of both elements presents a conceptually sound avenue for intervention. In addition, ACT is a transdiagnostic approach, allowing for a highly contextualized, nonsymptom specific intervention that can help caregivers whether they are experiencing mild, moderate, or severe distress (Bannon et al., 2022; Faustino et al., 2021).

ACT with a therapist is highly effective in helping family caregivers of persons with dementia to reduce depressive symptoms, anxiety, and experiential avoidance (Coon et al.,

2003; Han et al., 2021a; Losada et al., 2011; Losada et al., 2015). More broadly, a systematic review of meta-analyses concluded that ACT has demonstrated effectiveness with a variety of populations in reducing depressive symptoms and anxiety (Gloster et al., 2020). Interestingly, this review also found that ACT was superior to most other active interventions, excluding CBT.

Psychological flexibility and its components can be considered broadly applicable coping skills that can serve to moderate or mediate Pearlin et al.'s (1990) caregiver stress process. They are mechanisms of change that provide caregivers with the resources to alter their behavior and their experience. There is a developmental component to psychological flexibility in that the focus is on living towards psychological flexibility, rather than arriving at a point where one is psychologically flexible. Evidence suggests that acceptance, defusion, and values might be particularly important potential mediators or moderators between caregiver stress and outcomes (Rahal & Gon, 2020; Stockton et al., 2019). Interestingly, one meta-analysis suggests that ACT-based interventions may improve psychological flexibility in general rather than a specific component (Han et al., 2020).

Evidence for the effectiveness of ACT-based interventions with family caregivers for people with ADRD is encouraging. In their meta-analysis, Han et al. (2021a) found that ACT had a significant moderate effect on depressive symptoms and quality of life, a significant small to moderate effect on stress, and a significant small effect on anxiety. In a broader meta-analysis of mindfulness and acceptance-based interventions with family caregivers for people with ADRD, Collins and Kishita (2019) found a significant large effect on depressive symptoms and a significant moderate effect on burden, both of which were largely maintained at follow-up. These meta-analyses support the use of ACT-based interventions with family caregivers for people with ADRD and the importance of psychological flexibility as a mechanism of change.

### Intervention Delivery

Despite the wealth of evidence supporting various interventions for family caregivers with people with ADRD, accessing these existing interventions is often difficult. In particular, caregivers' limited time, transportation constraints, and unpredictable schedules constitute significant barriers in utilizing existing services (Bayly et al., 2020; Ng, 2009). Additionally, only 40% of Area Agencies on Aging, the county-based dispensaries of services for older adults, offer evidence-based interventions for family caregivers, and few rural counties offer these services (Alzheimer's Association, 2023).

Due to the limitations of traditional, face-to-face interventions, multiple technologybased interventions have recently been developed for use with family caregivers for people with dementia (Cheng et al., 2019). Godwin et al. (2013) provided the first published systematic review of technology-based interventions with family caregivers for people with dementia. They found that at the time, there was insufficient evidence to either support or refute the use of technology-based interventions with family caregivers. Using a slightly different sample, Boots et al. (2014) found that technology-based interventions for family caregivers can be beneficial, although they are most effective when they involve some level of individualization. Writing five years later, Cheng et al. (2019) conducted a focused review and found that technology-based interventions can be effective in reducing caregiver burden and depressive symptoms and improving confidence.

There is a spectrum of technology-based interventions ranging from completely selfguided, with no interaction during the intervention, to various degrees of being guided or coached during the intervention. Self-guided interventions have the benefit of greater scalability and reduced cost, whereas guided interventions have the benefit of personal interaction, real-time support, and personalization. Boots et al. (2014) concluded that, at the time, guided technology-based interventions demonstrated slightly better outcomes than online, self-guided interventions, although none of the studies were RCTs.

**Technology-assisted ACT-based Interventions.** Several technology-assisted ACTbased interventions with family caregivers have recently been developed. All of these interventions are currently in the early phase of testing, so none can be considered evidencebased at present. However, the preliminary results are promising. While not specific to caregivers, a systematic review and meta-analysis found that online ACT was effective in treating depressive symptoms, but that there was insufficient evidence to conclude about the effectiveness for well-being or anxiety (Brown et al., 2016).

For guided technology-based interventions, Fowler et al. (2021) demonstrated that ACT concepts could be effectively deployed with family caregivers for persons with ADRD via telephone calls. Their program, called Telephone Acceptance and Commitment Therapy Intervention for Caregivers (TACTICS) consisted of six 1-hour phone calls that combined metaphors and experiential exercises. To promote scalability, the intervention was delivered by a bachelor's-level non-clinician. Despite small sample size, the intervention demonstrated a significant large effect for reduced anxiety and a significant moderate effect for reduced caregiver burden.

Han et al. (2021b) delivered ten hour-long sessions of guided online ACT to seven family caregivers for persons with ADRD via live, structured teletherapy. Prior to the first session, participants received psychoeducational materials about dementia and caregiving. The program integrated metaphors, activities, and behavioral activation techniques to allow participants to personally craft their engagement with the program based on their needs. The intervention was delivered by a licensed professional counselor. Due to their small sample size, Han et al. (2021b) used Wilcoxon signed rank tests, a non-parametric test, to measure mean differences from pre-test to post-test and demonstrated moderate (e.g., 0.54-0.63) effect sizes in reducing depressive symptoms, anxious symptoms, stress, and burden, and small (e.g., 0.36-0.45) effect sizes in reducing cognitive fusion and experiential avoidance.

Participants also completed semi-structured interviews which were analyzed using interpretive phenomenological analysis (Han et al., 2021b). Based on their analysis, they categorized the impact of the intervention into two broad themes: renewed strength, with subthemes of new techniques to manage stress, improved self-care, and increased patience with the care receiver; and a journey towards acceptance and values based living, with subthemes of accepting thoughts and feelings, gaining power over thoughts, and living a values-based life.

Lappalainen et al. (2021b) conducted an evaluation of an online ACT-based program for family caregivers for people with ADRD called CareACT. This 12-week intervention involved caregivers working through six online modules, roughly one every two weeks. In addition to the modules, participants had access to a web journal to record what they were learning, were able to select favorite exercises for ease of access, and participated in an online supportive discussion board. To promote engagement, at the conclusion of every module, participants received a supportive phone call from an undergraduate student 'coach' to discuss the intervention, participants' self-selected homework, and to resolve any technical difficulties. These student coaches also conducted one 1.5-2 hour semi-structured interview with each participant.

To evaluate the effectiveness of CareACT, Lappalainen et al. (2021b) conducted a three-branch quasi-experimental study where participants were either recruited to participate in CareACT, rehabilitation care, or caregiver association activities (e.g., peer support groups and guidance on family care issues). No information was available for average length of time participants engaged with the intervention. Compared to participants who received rehabilitation care or who participated in caregiver association activities, participants assigned to CareACT reported significantly less depressive symptoms at four months and significantly less thought suppression at 10 months. However, at 10 months, the mean level of depressive symptoms was not significantly different for those in the CareACT condition compared with participants who received rehabilitation care or participants who received rehabilitation care or participants.

Kishita et al. (2022) developed an online, guided program using ACT called iACT4Carers. This eight-session program was intended to integrate certain aspects of support groups (e.g., provision of support, normalization, and suggesting new strategies for care situations) with ACT skills and involved asynchronous feedback from a therapist after participants completed each session. Additionally, participants had the option of participating in three support group meetings over the course of the intervention. No information is available about the average time required to complete the program, although 70% of participants who began the intervention completed at least seven sessions. In a qualitative evaluation of the program, Contreras et al. (2022) found that caregivers found the program useful and accepted the online delivery. They also reported that the program helped them to be more aware of their own needs and to take values-based action. Fauth et al. (2021) developed an online, self-guided program called ACT for Caregivers. In contrast to other web-based programs, this program did not involve any builtin interaction with research staff after participants began the intervention. Participants completed 10 sessions, each of which integrated several ACT processes. Sessions were accessed at home, at times convenient for participants, and were anticipated to take between 20-30 minutes each. Using repeated measures ANOVA, without a control group, Fauth et al. (2021) demonstrated statistically significant improvement across depressive symptoms, burden, stress, positive aspects of caregiving, quality of life, and ACT-specific skills. All effects were sustained at 4-week follow up.

Qualitative evaluation of the impact of ACT for Caregivers suggests that participants learned multiple skills from the program that helped them to manage the stressors of caregiving (Gossner et al., in preparation). Participants reported clarifying their values and acting on their values to do more of what matters to them, as well as accepting the painful realities of dementia caregiving rather than avoiding their feelings.

### The Current Study

The current study is a longitudinal mixed methods (Schumacher et al., 2021) evaluation of a revised ACT for Caregivers program, building on the version evaluated in Fauth et al. (2021) and Gossner et al. (in preparation). The study uses convergent parallel mixed methods (Creswell & Plano Clark, 2018) and a within-person design to examine the effectiveness of the program in impacting key caregiver outcomes. This study is guided by the following research aims:

Aim 1 QUANT: to empirically evaluate ACT for Caregivers with a larger sample (n = 113) using multi-level models (Hox et al., 2017) to analyze data at pre-test, 30-day post-test,

and 6-weeks follow-up to examine (a) care-related outcomes (stress reaction to BPSD, burden, positive aspects of caregiving, quality of life, depressive symptoms, and sleep quality), and (b) ACT-related outcomes of psychological flexibility (comprising openness to experience, behavioral awareness, and values-based living).

Hypothesis 1: There will be significant reductions in behavioral and psychological symptoms of dementia, burden, depressive symptoms, and significant increases in positive aspects of caregiving, quality of life, and overall psychological flexibility and each of its subscales over time.

Hypothesis 2: There will be a significant main effect for dosage (number of ACT for Caregivers sessions completed within 30 days) and a significant interaction between time and dosage, with those who have completed more sessions reporting more change over time.

Hypothesis 3: Kinship status will significantly predict caregiver outcomes over time (non-directional)

Aim 2 QUAL: to qualitatively explore the experiences of caregiving and change over time using deductive qualitative analysis (DQA; Gilgun, 2014; Fife & Gossner, 2024) to analyze semi-structured qualitative interviews with a subsample of family caregivers (n = 28at each time point, 56 interviews total) who completed the program within 30 days and who completed both interviews. This is necessary in order to understand unanticipated impacts of the program and to provide participants with the opportunity to elaborate on quantitative results.

Aim 3 MIXED: to integrate quantitative and qualitative findings and examine convergence and divergence across findings over time in order to present a holistic

evaluation of the extent to which change occurred and patterns of change (Schumacher et al., 2021). Additionally, to examine negative cases, defined as participants who reported no improvement from the program qualitatively or worsening quantitatively.

This study fills an important gap in the literature in a number of ways. First, this study builds on promising results from the pilot evaluation of ACT for Caregivers (Fauth et al., 2021; Gossner et al., in preparation) to further refine the ACT for Caregivers intervention, in preparation for developing an improved program for use by family caregivers for people with dementia among the public.

The second contribution of the present study is the use of mixed methods to provide a holistic evaluation of the impact of ACT for Caregivers. ACT as an intervention is typically evaluated quantitatively, and while this is important, it leaves several process questions unaddressed and potentially limits the understanding of the holistic impact of ACT-based interventions. While Han et al. (2021b) included both quantitative and qualitative evaluation of their online, guided ACT-based intervention, our study differs from theirs in a number of ways. First, their sample was seven family caregivers for people with ADRD, which necessitated the use of non-parametric tests and limited the generalizability of their study. Second, they did not directly integrate or mix the results of the qualitative evaluation with the quantitative evaluation. Our study design allows us to quantitatively examine the extent to which change occurred using advanced statistical methods (multi-level models; Hox et al., 2017) and to qualitatively examine the experience of change using a larger sample and two time points.

### CHAPTER III METHODS

### Design

The current study is a longitudinal convergent parallel mixed methods evaluation (Creswell & Plano Clark, 2018) of a revised online, self-guided ACT for Caregivers program, building on the version evaluated in Fauth et al. (2021) and Gossner et al. (in preparation). Data for this study come from an already collected sample, although the full sample has not been previously analyzed. The comparison between participants assigned to the waitlist and treatment from pre-test to post-test has been analyzed separately. In addition, moderation analyses with psychological flexibility and its subscales as moderators are planned, but will not be conducted as part of this dissertation. Sleep quality, although assessed in the study, will not be examined in this dissertation.

The current study integrates multi-level models (Hox et al., 2017) of quantitative data at three time points (pre-intervention, post-intervention, and 6-weeks follow-up) with deductive qualitative analysis (DQA; Gilgun, 2014) of semi-structured interviews collected at two time points (post-intervention and 6-weeks follow-up) to address the grand tour MIXED research question, "What is the impact of ACT for Caregivers?" The primary QUANT research question is, "What is the influence of the intervention on care-specific outcomes (stress reaction to BPSD, positive aspects of caregiving, burden, depressive symptoms, quality of life) and psychological flexibility?" The primary QUAL research question is, "What changes do caregivers report as a result of ACT for Caregivers, and to what extent do these changes persist over time?"

### **Program Modifications**

The ACT for Caregivers program is based on an online, self-guided program developed for college students that has demonstrated effectiveness for depressive symptoms (Levin et al., 2014). The pilot version of ACT for Caregivers consisted of 10 sessions and was evaluated in Fauth et al. (2021) and Gossner et al. (in preparation). The program is housed on Qualtrics.com, which allows participants to interact with the program using a variety of activities, including selecting options from drop-down lists, selecting which of several vignettes to explore further, and dragging and sorting different options (see Figure 2 for an example activity). I collaborated with a skilled ACT therapist and two of the developers of the first ACT for Caregivers program to maintain fidelity to key components of the original intervention while condensing content from 10 to 6 sessions to make it more manageable for participants.

## Figure 2

## Example Activity from Session 1 of ACT for Caregivers Program

	Letting Be	Away Move
Asking for help with providing care even though you're worried about "burdening" others	0	0
Getting out of bed and greeting the person you care for even though you feel depressed and want to avoid them	0	0
Giving up on trying to get time to yourself because finding someone to stay with your loved one is too hard	0	0
Eating too many unhealthy food to try to "de- stress"	0	0
Acknowledging that you feel lonely and rejected, without trying to reassure yourself or deny how you feel	0	0
Telling yourself that you shouldn't feel ashamed of your loved one's outbursts and that you need to let it go	0	0

Each session is anticipated to take participants approximately 30 minutes to complete (for a breakdown of session content, see Table 1; for a visual of the six sessions, see Figure 3). Additionally, this version of the program uses the choice point (Harris, 2019) as a visual metaphor to tie together the concepts from the different sessions (see Figure 4). The choice point simplifies the presentation of ACT concepts by organizing the present moment into situations, thoughts, and feelings; responses that move the participants away from who they

want to be (called "away moves"); and responses that move the participants towards who they want to be (called "towards moves"). To illustrate course concepts, we added a vignette to each session based on clinical experience and aggregated stories from caregivers who completed the pilot ACT for Caregivers program.

# Table 1

Session	ACT Principles
Session 1: Your Choice Point	Acceptance; Values; Committed Action;
	Present Moment Awareness
Session 2: Moving Towards What Matters	Values; Committed Action
Session 3: What Gets in the Way?	Defusion; Acceptance; Present Moment
	Awareness
Session 4: Getting Unhooked	Defusion; Present Moment Awareness
Session 5: Opening Up	Acceptance; Present Moment Awareness
Session 6: Moving Forwards	Values; Committed Action

ACT Principles from ACT for Caregivers Program

# Figure 3

# Visual of ACT for Caregivers Sessions

**Program Sessions** 



Session 1: Your Choice Point



Session 4: Getting Unhooked



Session 2: Moving Towards What Matters



Session 5: Opening Up



The Way?



Session 6: Moving Forwards Access information about Alzheimer's disease, dementia, caregiving, and aging here:

#### Education Library

Access mindfulness recordings you can use in your everyday life here:

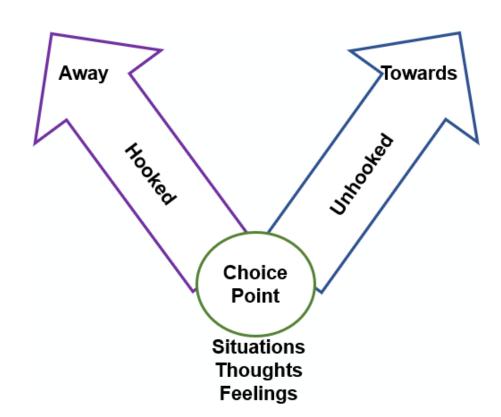
Mindfulness Activities

If you have any questions about how to complete ACT for Caregivers, or run in to technical difficulties, click on the "Troubleshooting" button below. You do not need your Study ID.

Troubleshooting

## Figure 4

Choice Point Diagram



# **Your Choice Point**

## Participants

Participants in this study are family caregivers for persons with ADRD or significant memory loss. To be eligible for the present study, caregivers needed to meet the following screening criteria: be over the age of 18, be a family caregiver for a person with dementia or significant memory loss, be moderately stressed by the role (as evidenced by a score of 4 or greater on a single item, "how stressed are you by caregiving?"), have access to a computer, tablet, or smart phone with the internet, be in the United States, and read English. Participants were not limited based on diagnosis of the person with ADRD.

One hundred thirty-three participants were screened for participation, 113 participants completed the pre-test (assessment 2 for those in the waitlist), 84 participants completed the post-test, and 80 participants completed the follow-up (70.7% of those who completed the pre-test). Rather than a traditional intent-to-treat approach, participants were only eligible to complete the post-test if they completed at least one session of ACT for Caregivers. Participants had a mean age of 61.93 (SD = 13.69) and had been caregiving for an average of 4.69 years (SD = 4.74; see Table 2). The sample was roughly balanced between spousal and adult child caregivers (54.0% spousal caregivers) and was disproportionately female (84.1%) and White (87.7%). Nearly two-thirds (65.4%) of the sample was co-residing with the person with ADRD. The majority (52.2%) of participants were not employed other than caregiving. In terms of geographic region based on time zone, 53.1% of participants were Mountain time, 24.8% were Eastern time, 10.6% were Central time, 9.7% were Pacific time, and 0.9% were missing.

# Table 2

Full Sample Demographics and Pre-test Assessment
--

Attribute ( $n = 113$ )	Count/Mean (%/SD)	Range
Age (Years)	61.93 (13.69)	28-88
Duration of Caregiving (Years)	4.69 (4.74)	0.08-40.83
Gender		
Female	95 (84.1%)	
Male	18 (15.9%)	
Kinship Status		
Spousal Caregiver	61 (54.0%)	
Adult Child Caregiver	49 (43.4%)	
Other	3 (2.7%)	
Race		
White	100 (87.7%)	
Hispanic	6 (5.3%)	
Black	5 (5.3%)	
Asian	4 (3.5%)	
Pacific Islander	1 (0.9%)	
Middle Eastern	1 (0.9%)	
Employment Status		
Employed full-time	34 (30.1%)	
Employed part-time	13 (11.5%)	
Not employed	59 (52.2%)	
Coresiding with Care Receiver		
Coresiding	74 (65.4%)	
Not coresiding	39 (34.5%)	
Geographic Region		
Mountain	60 (53.1%)	
Eastern	28 (24.8%)	
Central	12 (10.6%)	
Pacific	11 (9.7%)	
Missing	1 (0.9%)	
Mean BPSD Frequency	1.56 (0.59)	0-4
Mean BPSD Stress Reaction	1.61 (0.84)	0-4
Burden	23.03 (9.67)	5-45
Positive Aspects of Caregiving	26.79 (9.23)	9-45
Psychological Flexibility	82.80 (20.90)	35-129
Quality of Life	63.56 (21.47)	16-100
Depressive Symptoms	12.34 (5.91)	0-27
Sleep Quality	5.11 (2.59)	0-10

The qualitative subsample (n = 28) had similar demographics to the full sample, with a few distinctions (see Table 3 for qualitative subsample demographics). Participants who completed the qualitative portion of the project had a mean age of 64.21 (SD = 13.25) and had been caregiving for an average of 4.02 years (SD = 3.28). Most interview participants were spousal caregivers (71.4%), female (82.1%), White (89.2%), co-residing with the person with ADRD (82.1%), and not employed other than caregiving (60.7%).

### Table 3

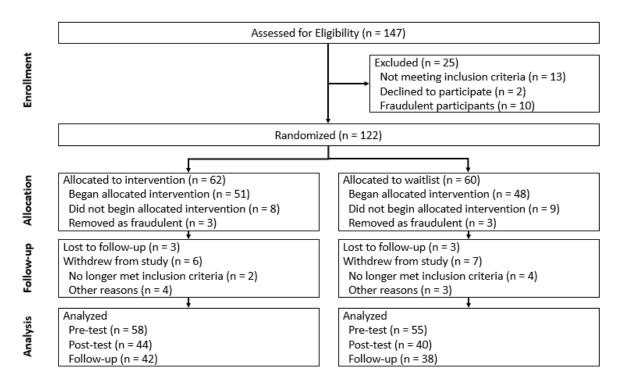
Attribute $(n = 28)$	Count/Mean (%/SD)
Age (Years)	64.21 (13.25)
Duration of Caregiving (Years)	4.02 (3.28)
Gender	
Female	23 (82.1%)
Male	5 (17.9%)
Kinship Status	
Spousal Caregiver	20 (71.4%)
Adult Child Caregiver	8 (28.6%)
Race	
White	25 (89.2%
Black	1 (3.6%)
Hispanic	1 (3.6%)
Asian	1 (3.6%)
Employment Status	
Employed full-time	8 (28.6%)
Employed part-time	2 (7.2%)
Not employed	17 (60.7%)
Coresiding with Person with ADRD	
Coresiding	23 (82.1%)
Not coresiding	5 (17.9%)

Demographics for Qualitative Subsample

### Procedures

Prior to beginning the study, all procedures were approved by the Institutional Review Board at Utah State University (USU IRB #13040). Partway through the study, all procedures were also approved by the Utah Department of Health and Human Services IRB (DHHS IRB #1014), allowing for recruiting through Area Agencies on Aging. The study procedures were pre-registered on Clinicaltrials.gov in accordance with an open science paradigm. Recruitment materials were distributed through existing listservs, caregiver associations (e.g., The Association for Fronto-Temporal Degeneration, the Alzheimer's Association's TrialMatch), a radio broadcast in northern Utah, and community events. Participant recruitment and follow-up occurred from January 2023 to February 2024 (see Figure 5 for flowchart of study progression based on CONSORT guidelines).

## Figure 5



CONSORT Flowchart

Interested caregivers contacted the research team using the contact information provided on IRB-approved recruitment materials. Participants were managed using REDCap,

a secure service which housed all participant information and linked all assessments together. Upon establishing contact, each participant was verbally asked the eligibility questions listed above. Due to technical difficulties, some participants completed this information electronically and emailed their responses back to the research team.

Participants who met eligibility requirements received additional information about the study and received an electronic copy of the informed consent (see Table 4 for study timeline). They then scheduled a time for a follow-up phone call with the research team to give them ample time to review the informed consent. After participants completed the informed consent, they went on to complete the first survey, which included sociodemographic questions, all quantitative assessments, and four short response questions about their experiences with caregiving. At the conclusion of the pre-test, participants created a six-character unique study ID made up of the first three letters of the month they were born, the first letter of the city where they currently live, the first initial of the first name of the care receiver, and the first initial of their own middle name.

### Table 4

Week	0	4	8	10	12
Treatment	Gain access	Anticipated		Receive	
group (TG)	to ACT for	completion		compensation	
	Caregivers	of ACT for			
		Caregivers			
Waitlist		Gain access	Anticipated		Receive
group (WG)		to ACT for	completion		compensation
		Caregivers	of ACT for		
			Caregivers		
Quantitative	Pre-test	Post-test	Post-test	Follow-up	Follow-up
data	assessment	assessment	assessment	assessment	assessment
collection	(TG/WG)	(TG)	(WG)	(TG)	(WG)
		Waitlist			
		baseline			
		(WG)			
Qualitative		Semi-	Semi-	Semi-	Semi-
data		structured	structured	structured	structured
collection		post-test	post-test	follow-up	follow-up
		interview	interview	interview	interview
		(TG)	(WG)	(TG)	(WG)

Timeline of Data Collection and Intervention Engagement

After participants completed the pre-test, participants were randomized to either the waitlist or treatment condition based on a previously created random number generator. Block randomization was used to generate the random number sequence, with block size of 6 and list length of 140. A member of the research teach who was not involved in enrolling or assigning participants generated the random allocation sequence. In the case of multiple participants being randomized in one day, participants were randomly assigned in order based on the time they completed the informed consent and pre-test. Participants in the treatment condition were added to the list of users in Qualtrics.com that allowed them to use their unique study ID to log in to the program and received an auto-generated email informing them that they could begin accessing the program immediately. Participants in the

waitlist condition received an auto-generated email informing them that they were being asked to wait 30 days prior to beginning the program, and that in 30 days they would receive a second survey that was identical to the first, following which they would receive program access.

During the scheduled phone call after completing the informed consent and pre-test, a member of the research team welcomed participants to the study, informed them of their assignment to the waitlist or treatment condition, and answered any questions they had. Those in the treatment condition received brief instruction in how to navigate the program, including bookmarking the page where the program was located, logging in using the unique study ID, and keeping track of which sessions had been completed. Participants in the waitlist condition received instruction about the purpose of the waitlist and were encouraged to complete a second survey in 30 days. The research team scheduled a follow-up call for shortly after the waitlist participant received their second survey to orient them to the program. During this orientation, they received the same instructions as those in the treatment condition.

Participants completed the ACT for Caregivers program at their own pace, but were encouraged to engage with two sessions each week with time between each session. In order to receive the post-test survey, participants were required to complete the first session. This was treated as their course access date, and all subsequent assessments were based on this date. Participants who did not complete at least the first session did not receive additional surveys. To facilitate participant engagement in the course, for four weeks after participants first accessed the program, they received a weekly reminder email to prompt them to engage in the course. The email also included an option to request assistance from the research team. The research team monitored participant engagement electronically weekly and recorded the dates of each session completed, including the number of sessions completed within 30 days of first accessing the program.

Thirty days after participants first accessed the program, they received a 30-day posttest survey via email, regardless of how far they progressed in the course, provided they completed the first session. This survey included all the quantitative measures assessed earlier. Six weeks after participants first received the post-test survey, they received a followup survey via email. Participants received up to five auto-generated email reminders to complete each survey.

### Lapsed Participation

Participants who had received a survey invitation but had not completed it for 5 or more days, or participants who had not completed a session within 10 days, were contacted by a member of the research teams to resolve any technical difficulties or other barriers to program engagement. Attempts to contact participants were limited to two attempts per issue, and only once if contact was successfully established. For the purposes of monitoring, participants who had not submitted a session were considered to have completed the session if they had completed at least 60% of the content.

### Semi-Structured Interviews

As part of the informed consent, participants checked whether they were interested in being interviewed about their experiences as a caregiver as part of the study. Contrary to expectations, all participants consented to semi-structured interviews. At the beginning of the research project, all participants who consented to participate in semi-structured interviews were invited to complete an interview. As the study progressed, we limited our invitations to participate in semi-structured interviews to those who had completed at least four sessions. Towards the conclusion of the study, we further limited our invitations to participate in semistructured interviews to only adult child caregivers or male caregivers in order to ensure we had a wide variety of caregiving experience.

Participants who consented to semi-structured interviews were invited by telephone call or email to schedule an interview within two weeks of completing the post-test survey. At the start of each interview, the interviewer ensured that the participant was in a private place, reminded them that their participation was voluntary, and read the following statement verbatim: "Utah law mandates any person who has reason to believe that a vulnerable adult is being abused, neglected, or exploited must immediately notify Adult Protective Services or the nearest law enforcement office. The information you may share in this interview is not exempt from this mandate."

After receiving consent to record the interview, the interviewer conducted the semistructured interview based on an interview guide, with additional probes as needed to promote elaboration and aid in ongoing analysis. Example interview questions are, "How has your experience of caregiving changed over time?" and "What are the most helpful things you learned from ACT for Caregivers?" (see Appendix B for the full interview guide).

Following the principle of constant comparison (Charmaz, 2014), the interview guide was adapted over the course of data collection to ensure that the data could address emergent questions that arose during the analysis. For example, the original interview guide asked participants "How has what you learned from ACT for Caregivers influenced your caregiving?" and "How has what you learned from ACT for Caregivers influences other areas of your life?" To help us better understand the impact of the program on caregivers' relationship with care receivers, we later inserted the question, "How has what you learned from ACT for Caregivers influenced your relationship with the person with dementia?"

At the conclusion of the post-test interview, participants who had completed all six sessions within thirty days were invited to schedule a follow-up interview. The same procedures were followed at the follow-up interview, with a slightly different interview guide (see Appendix B for the follow-up interview guide). For a variety of reasons, 5 individuals who completed post-test interviews and were eligible to schedule a follow-up interview were not able to be interviewed. Their qualitative data is not used in this dissertation.

### **Compensation**

In the informed consent, participants were notified that they would be compensated for the surveys and interviews they completed, rather than the number of sessions they had finished. After participants completed the 6-week follow-up survey, or 28 days after they first received a link to complete the 6-week follow-up survey, participants received compensation in the form of Amazon.com electronic gift cards according to the number of surveys and semi-structured interviews completed. Participants received \$25 for completing two surveys, an additional \$25 for completing three or four surveys, and an additional \$25 for each semistructured interview, for a total possible compensation of \$100.

### Fraudulent Participants

In the process of recruiting participants for the study, some study recruitment materials were posted to social media. This led to an uptick of requests to participate in the study, many of which were identified as fraudulent or potentially fraudulent based on their pattern of engagement. They would not turn their camera on during interviews, gave vague answers non-specific to dementia care, and had mismatching email addresses. Some of these individuals had seen the study advertised on the What's App platform, which was not a platform we had advertised on. They also provided phone numbers based on internet-based carriers. To help in accurately identifying potentially fraudulent participants, participants who used a phone number that was not linked to a cellular carrier or land line were required to submit a traceable phone number in order to continue with the study. Participants who did not do so within two weeks were deactivated. To limit the likelihood of admitting future fraudulent participants, the research team only screened potential participants as eligible if they could verify that they had learned about the study from a valid source. In all, 16 potential participants were identified as fraudulent or potentially fraudulent and deactivated; only 6 of them had completed the informed consent and pre-test. All of their data was excluded from analyses.

### **Quantitative Strand**

#### Measures

The following sociodemographic and program engagement variables were assessed: caregiver age (years), caregiver gender, kinship status (spousal, adult child, or other), race, employment status, duration of caregiving (years and months), coresidency with person with ADRD (dichotomous yes/no variable), and dosage of ACT for Caregivers (number of sessions completed within 30 days ranging from 0 to 6). We attempted to collect data on length of time participants spent on each session, but this data was distorted by participants lingering on webpages without engaging with the program and was therefore dropped from analyses. Program acceptability was assessed using eight items adapted from the Systems Useability Scale (Brooke, 1996), with responses ranging from 1 (strongly disagree) to 5 (strongly agree). An additional five items about program content and visual appeal were also asked, with responses ranging from 1 (strongly disagree) to 5 (strongly agree).

The following quantitative measures were included in the survey at each time point.

**Behavioral and Psychological Symptoms of Dementia (BPSD).** Behavioral and psychological symptoms of dementia (BPSD) were assessed using the 24-item Revised Memory and Behavior Problem Checklist (Teri et al., 1992). This measure assesses both frequency of BPSD and stress reactivity via linked items. An example item is "Asking the same question over and over again," with responses ranging from 0 *never occurred* to 4 *occurred daily or more often.* Responses are averaged to calculate the relative frequency of all BPSD symptoms. If participants answer anything but 0 for frequency, they are asked, "How much did the behavior bother you?" Reactivity responses range from 0 *not at all* to 4 *extremely*, and scores are averaged to calculate relative stress reaction. Due to the nature of the scale capturing disparate BPSD (the presence of one symptom is not expected to be correlated to the presence of another symptom), Cronbach's alpha is not calculated.

**Burden.** Burden was assessed using the 12-item [short] Zarit Caregiver Burden Interview (Bédard et al., 2001). Participants rate the impact of caregiving on physical, emotional, and social health. Each item has the stem, "How often do you feel..." with an example item of "That because of the time you spend with your relative that you don't have enough time for yourself?" Responses range from 0 *never* to 4 *nearly always*. A total possible summed score is 48. Higher scores indicate higher burden (time 1  $\alpha$  = .91, time 2  $\alpha$  = .82, time 3  $\alpha$  = .85).

**Positive Aspects of Caregiving.** Positive aspects of caregiving were assessed using the 9-item Positive Aspects of Caregiving measure (Tarlow et al., 2004). Items use the following stem "Providing help/care to or ensuring provision of care to the person with

dementia has...", with example items such as "made me feel useful" and "enabled me to appreciate life more." Responses range from 1 *disagree a lot* to 5 *agree a lot*, and items are summed with a possible score of 45. Higher scores indicate more positive aspects of caregiving (time 1  $\alpha$  = .92, time 2  $\alpha$  = .88, time 3  $\alpha$  = .90).

**Quality of Life.** Quality of life was assessed using a 1-item visual analogue scale (de Boer et al., 2004) ranging from 0 to 100, with higher scores indicating higher quality of life. de Boer et al. (2004) found that the approach has high repeated measures reliability (intraclass correlation coefficient (ICC) = .87) and anchor-based responsiveness compared to multi-item questionnaires.

**Depressive Symptoms.** Depressive symptoms were assessed using the 10-item [short] Center for Epidemiological Studies Depressive symptoms Scale (CES-D; Andresen et al., 1994). Participants rate the frequency of depressive symptoms during the past week. An example item is "I was bothered by things that usually don't bother me." Responses range from 0 *rarely or none of the time* to 3 *all of the time*, with a possible summed score of 30. Higher scores indicate more depressive symptoms (time 1  $\alpha$  = .85, time 2  $\alpha$  = .83, time 3  $\alpha$  = .78).

Sleep Quality. Sleep quality was assessed using a 1-item Sleep Quality Scale (Snyder et al., 2018). Respondents are asked to consider the overall quality of sleep on most nights over the last seven days only. Responses range from 0 *terrible* to 10 *excellent*, with higher scores indicating higher sleep quality. Snyder et al. (2018) report that the scale has good validity and acceptable test-retest reliability ( $\alpha = .74$ )

**Psychological Flexibility.** Psychological flexibility was assessed using the 23-item CompACT (Francis et al., 2016). The CompACT can be used as a sum score indicator of psychological flexibility or divided into three subscales: behavioral awareness (5 items), openness to experience (10 items), and valued actions (8 items). An example item for the behavioral awareness subscale is, "Even when doing the things that matter to me, I find myself doing them without paying attention" (reverse scored). An example item for the openness to experience subscale is, "I am willing to fully experience whatever thoughts, feelings and sensations come up for me, without trying to change or defend against them." An example item for the valued actions subscale is, "I make choices based on what is important to me, even if it is stressful." Responses range from 0 *strongly disagree* to 6 *strongly agree*, and items are summed with a possible total score of 138. Some items are reverse scored. Higher scores indicate more psychological flexibility (overall  $\alpha$ : time 1 = .90, time 2 = .91, time 3 = .92; openness to experience  $\alpha$ : time 1 = .80, time 2 = .86, time 3 = .85; behavioral awareness  $\alpha$ : time 1 = .86, time 2 = .89, time 3 = .86; valued action  $\alpha$ : time 1 = .85, time 2 = .85, time 3 = .87).

### Data Analysis for the Current Study

The focus of this study is a within-person design for all participants, pooling those in the waitlist and treatment condition who completed at least the pre-test; those who completed at least one session were eligible to complete post-test and follow-up assessments. The waitlist-treatment group comparison is not the focus of this dissertation. The data for this study are nested into two levels, repeated observations within individuals. The repeated observations lead to non-independent data, suggesting the need for multilevel models (MLM; Hox et al., 2017). Additionally, substantial portions of the sample who were missing one or more observations made repeated measures analysis of variance (ANOVA) undesirable due to requiring list-wise deletion and subsequently limiting power and resulting in biased estimates. MLM uses observation-specific deletion, such that participants who were missing post-test or follow-up observations were still included in the model for the intercept (pre-test only) or the intercept and slope (pre-test and post-test data). MLM allows researchers to model fixed effects, random effects (random intercepts or random slopes, determined by a grouping variable such as "participant id") and unexplained error. This allows researchers to determine how much of the change in outcomes is determined by person-to-person differences versus how much is explained by the fixed effects, and is important in intervention research so that the impact of the intervention is accurately assessed at a withinperson level.

Models for each outcome variable (BPSD stress reaction, burden, positive aspects of caregiving, quality of life, depressive symptoms, and psychological flexibility) were built using the six-step bottom-up approach recommended by Hox et al. (2017). A model for BPSD frequency was also fit to explore a potential confounding factor. Insignificant variables were dropped from future models. Time was treated as a categorical variable, with pre-test functioning as the reference category. This allows for modeling of non-linearity in the trajectory of each dependent variable across time.

All models followed the same procedure. First, a null model with no predictors and only random intercepts by participant ID was fit using restricted maximum likelihood (REML); the intraclass coefficient (ICC), interpreted as the amount of variance in the outcome attributable to person-to-person differences, was extracted from this model. Second, each null model was refit using full-information maximum likelihood (ML) to allow for comparing of nested models; then, time was added as a level 1 predictor. Third, dosage and kinship status were added as level 2 predictors; if either of these was not significant, the model was refit without them. Fourth, for models where time and dosage were both significant, a cross-level interaction between time and dosage was fit. The best fitting model from the preceding steps was refit using REML and pseudo-R<sup>2</sup> was calculated and main effects and significant interactions were interpreted. Due to a small sample size, high heterogeneity between participants, and only three time points, random slopes were not added for any models.

Models were compared using the Chi-squared likelihood ratio test, which has degrees of freedom equal to the difference in number of parameters between the nested models. A significant difference between the models was interpreted as the more complex model fitting the data better, whereas a non-significant difference between the models was interpreted as the more parsimonious model fitting the data better. The best fitting model proceeded to the next step of analysis. Residual diagnostics assessed the assumptions of normally and homoscedastic of the conditional distribution of the dependent variable (standardized residuals), as well as the normality of the random effects. Any relevant violations will be discussed in the results.

The significance of main effects was calculated using Wald t-tests with Satterthwaite degrees of freedom. Significant interactions were probed using simple slopes and estimated marginal means (Lenth, 2022; Fox, 2019). Pairwise effect sizes standardized the mean differences (SMD) by dividing the difference in means by the pooled standard deviation and comparing these using Kenward-Rogers degrees of freedom without adjusting for multiple comparisons (Luke, 2017). Although their formula differs from Cohen's *D*, standardized mean differences are similar in interpretation, with small (<.5), moderate (.5-.79) and large (>0.8) effect sizes (Westfall et al., 2014). Although  $R^2$  cannot be calculated for MLM in the

same way as linear regression, several pseudo- $R^2$  values can be calculated for MLM. The most common of these, Nakagawa et al.'s (2017) pseudo  $R^2$ , partitions variance explained into conditional  $R^2$ , the portion of variance explained by all random and fixed effects, and marginal  $R^2$ , the portion of variance explained only by fixed effects. Both conditional and marginal  $R^2$  are reported.

All analyses were conducted in R 4.3.1 (R Core Team, 2023) and utilized the following packages: *lme4* (Bates et al., 2015), *lmerTest* (Kuznetsova et al., 2017), *performance* (Lüdecke et al., 2021), *emmeans* (Lenth, 2022), and *effects* (Fox, 2019). All syntax, output, and additional tables and figures are included as supplemental materials.

### **Qualitative Strand**

### Methodology

Longitudinal qualitative research allows researchers to analyze patterns of change over time, including positive change, negative change, and no change (Saldaña, 2003). It is typical with longitudinal qualitative research to first divide data into different pools based on time point, and then to compare what is similar and different between the times points. Following these conventions, we sorted data into two pools, linked by participant number: post-test interviews and follow-up interviews. After coding each time point, we then reviewed coded excerpts at both time points to better understand the common elements of change. Of note, we did not employ recoding of data based on within-person change over time across qualitative interviews. That will be completed in a separate analysis outside of the scope of this dissertation.

To analyze the data, we used deductive qualitative analysis (DQA), a qualitative methodology suited to examining and refining theory (Gilgun, 2014). DQA shares historical

roots with grounded theory in the Chicago School, but differs in that while grounded theory is used to generate theory, DQA allows researchers to use an existing theory to aid in understanding a particular phenomena. DQA was an ideal methodology for the present study because it allowed us to directly examine inductively-derived changes within key components of Pearlin et al.'s (1990) stress process model. Research using DQA follows five iterative steps: selecting a guiding theory and research question, collecting a purposive sample, generating sensitizing constructs, coding and analyzing data, and theorizing (Fife & Gossner, 2024).

Selecting Guiding Theory and Research Question. Pearlin et al.'s (1990) stress process model served as a conceptual framework to guide the analysis. This theory informed both the quantitative measures selected and, to a lesser extent, the qualitative questions asked during the semi-structured interview. The research question was, "What are the changes caregivers report from participating in ACT for Caregivers, and to what extent do these changes persist over time?"

**Collecting Purposive Sample.** As with most qualitative researchers, researchers using DQA collect a purposive sample that is capable of addressing the primary research question. As part of the larger study, over 70 interviews were conducted. Through consultation as a research team, we determined that those participants who completed the ACT for Caregivers program in 30 days and who completed both interviews were best situated to answer our primary research question. We therefore limited our sample to participants who met those criteria. This led to a sample of 28 participants and 56 interviews (see Table 3 for qualitative subsample demographics).

Generating Sensitizing Constructs. In DQA, researchers operationalize the guiding

theory using sensitizing constructs, key components of the theory that would be salient if the guiding theory was supported (Gilgun, 2014). Sensitizing constructs offer an initial, deductive lens through which to analyze the data. As in grounded theory (Charmaz, 2014), they must earn their place in the analysis by being supported by the data. Prior to being used in a study, researchers operationalize the sensitizing constructs.

Operationalizing sensitizing constructs requires a thorough, in-depth understanding of the guiding theory (Fife & Gossner, 2024) and is aided by a conceptual framework. We created preliminary sensitizing constructs based on Pearlin et al.'s (1981; 1990) stress process model and the three pillars of ACT (Francis et al., 2016; Hayes et al., 2011). We initially identified eight sensitizing constructs: caregiver context, caregiving intensity, caregiver burden, positive aspects of caregiving, change in behavioral awareness, change in openness to experience, change in valued action, and change in quality of life. These sensitizing constructs map onto context and primary stressors (caregiver context and caregiving intensity), secondary stressors (caregiver burden and positive aspects of caregiving), coping skills (change in behavioral awareness, change in openness to experience, change in valued action), and outcomes (change in quality of life). We anticipated that coping skills (psychological flexibility) and outcomes (quality of life) would improve at post-test, whereas we anticipated improvement in secondary stressors, coping skills, and outcomes at follow-up.

Our focus on quality of life in the qualitative arm of the study bears some elaboration. Pearlin et al.'s (1990) model included three related primary outcomes: caregiver mental health, specifically depressive symptoms; caregiver physical health; and yielding of the caregiver role. They proposed that if the stress process continued unabated, caregiver depressive symptoms led to or exacerbated physical health problems, which ultimately led to yielding of the caregiver role. The primary reason we selected quality of life as the main qualitative outcome of interest was rooted in our assumption, based on the pilot data (Fauth et al., 2021), that *participants would report enhanced quality of life, rather than merely reduced depressive symptoms*. The second, more pragmatic reason was that if we had used reduced depressive symptoms as our primary qualitative outcome of interest, we would in essence be looking for the absence of something, whereas focusing on enhanced quality of life allowed us to look for the presence of something. Importantly, we did not define quality of life for participants, but following qualitative traditions we allowed them to interpret quality of life as they desired.

After identifying these sensitizing constructs, we tentatively defined them using definitions sourced from Pearlin et al. (1990), Francis et al. (2016), and Yu et al. (2018). We then categorized data from two post-test interviews to determine how effectively our sensitizing constructs were capturing the impact of ACT for Caregivers. Based on team discussion and individual theorizing, we determined that the preliminary sensitizing constructs needed to be expanded in order to adequately categorize the impact of ACT for Caregivers.

We therefore added two sensitizing constructs: social support (or the lack thereof) and person-centered care. Although not initially included as sensitizing constructs, both of these constructs are well-supported by the literature and consistent with the conceptualized framework. Pearlin et al. (1990) considered social support to be one of the most significant influences on the stress process. We initially did not include it as a sensitizing construct due to limited quantitative data on social support within the present study and a resultant lack of ability to mix our findings. However, through discussion, we determined that since the qualitative data did allow participants to speak to the presence or lack of social support, it warranted inclusion as a sensitizing construct.

We included person-centered care as a sensitizing construct to capture participants' descriptions of changes in their relationship with the caregiver that could be connected with their engagement in ACT for Caregivers. Within Pearlin et al. (1990) conceptual model, they included yielding of the caregiver role as the final outcome of the caregiver stress process because it effectively ends the caregiving career. They characterized yielding of the caregiver role as gradual or abrupt disengagement with caregiving, exemplified by transferring caregiving responsibilities or placing the person with ADRD into a care facility. On the opposite end of the spectrum of caregiver engagement is providing person-centered care. Person-centered care is described as treating the care receiver as an individual, with values and preferences that need to be compassionately considered (Lee et al., 2020). Providing person-centered care constitutes an engagement and investment in the caregiving role that is anchored in the well-being of the caregiver. We therefore selected it as a sensitizing construct and conceptualized it as a secondary outcome variable related to yet distinct from changes in quality of life.

#### **Data Preparation**

Prior to coding the data, the audio files were transcribed using Podflow, an IRBapproved AI-based software that ensures confidential transcription. The transcripts were then checked by a member of the research team and any inaccuracies were corrected; identifying information was also removed at this time. Any questions about difficult to understand audio excerpts of interviews were resolved by the interviewer. Interviews were organized by

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headings in Microsoft Word to facilitate identification of which portion of the interview an excerpt came from.

The cleaned interview files were then uploaded to NVIVO 14, a qualitative data analysis software (QSR International, 2023). We created a codebook based on the sensitizing constructs to track the process of our analysis. The interviewer categorized post-test data into the sensitizing constructs, with assistance from a trained research assistant, and categorized follow-up data into the same sensitizing constructs using the process developed for the posttest data.

#### Coding and Analyzing Data

Coding and analysis followed similar procedures for post-test and follow-up interviews. The sensitizing constructs derived from our conceptual framework provided an initial, deductive focus as we categorized data according to which sensitizing construct(s) it aligned with. To encourage an inductive, rigorous analysis, each team member individually read the data that had been sorted into each sensitizing construct and created a list of 5-10 codes that seemed to adequately describe participants' experience of that sensitizing construct. Each team member presented their list of codes in team meetings and these codes were discussed until a preliminary list of 5-7 inductively derived codes was selected through consensus. Tentative definitions of each code were added to the codebook to promote consistency in application. To help ensure that relevant data was not missed, we also included an uncategorized code for each sensitizing construct that was used for instances that seemed important but did not fit into an existing code.

At least two team members coded each data excerpt using the inductively derived codes, paying particular attention to exemplary quotes for each sensitizing construct, data

that did not fit within the existing coding scheme, and, for the outcome variables, participants' descriptions of no change occurring. At subsequent team meetings, we discussed the utility of the coding scheme and made any needed changes to code names, definitions, or organization. In some instances, this resulted in only minor changes (for example, slight changes in the definition for some of the quality of life codes); for other sensitizing constructs, this resulted in substantial changes (for example, with burden).

The analytic process for burden illustrates the strength of this iterative approach. After following this pattern to generate initial codes and analyze burden, we determined via team meetings that the initial codes did not adequately capture the data. We discussed alternate codes and created new labels and definitions in the codebook, and recoded the data for burden. This second pass led to significantly improved coding and greater agreement across coders on the salient elements of burden represented in our dataset.

After coding the data, we then compiled exemplary quotes for each theme and analyzed negative cases, instances in the data where participants reported no change or had responses that were dissimilar from other coded excerpts. We continued to code until each sensitizing construct had multiple well developed facets, illustrated by exemplary quotes. We then engaged in thorough team analysis of what conclusions were warranted about participants' experiences and patterns of change in the sensitizing constructs at post-test and follow-up. We recorded these patterns and updated the codebook to reflect the conclusions of our analysis.

After thoroughly coding the data at each time point, we compiled the results for each sensitizing construct at post-test and follow-up to allow us to describe different ways participants described the impact of the program at each time point. Each team member

reviewed the full draft of the results and added any information deemed necessary to ensure that our report adequately captured the full range of participants' reports. To ensure full utilization of participants' responses, there are 100 quotes from participants in the results section and all participants are quoted at least once, for an average of 3.57 quotes per participant.

We analyzed participants who were identified as potential negative cases based on their reporting of no impact of the program on at least one of the four categories where program impact was assessed at both time points (change in behavioral awareness, openness to experience, valued action, or quality of life). As part of this, we considered patterns of these responses and analyzed participants' own explanations for no change as well as their attributes, contextual factors, and quantitative results.

## Trustworthiness and Reflexivity

Two hallmarks of rigorous qualitative research are trustworthiness and reflexivity. In qualitative research, trustworthiness refers to the extent to which the conclusions of the study can be depended on based on the quality of analysis and adherence to established standards in study conceptualization, data collection, and analysis (Connelly, 2016). In the present study, we used a number of strategies to promote trustworthiness of analysis, including using a research team, ensuring that at least two persons coded each data segment, and regular memoing, a process of keeping a written log of the ongoing analysis (Saldaña, 2016). Our use of a research team was particularly important in establishing trustworthiness, as it ensured that a variety of perspectives were brought to bear on the data and allowed us to challenge each other's conclusions throughout the study process. Because we met regularly as a research teach throughout the analysis, each analytical decision integrated feedback and

perspectives of team members with different experience levels with qualitative research, gerontology, and ACT.

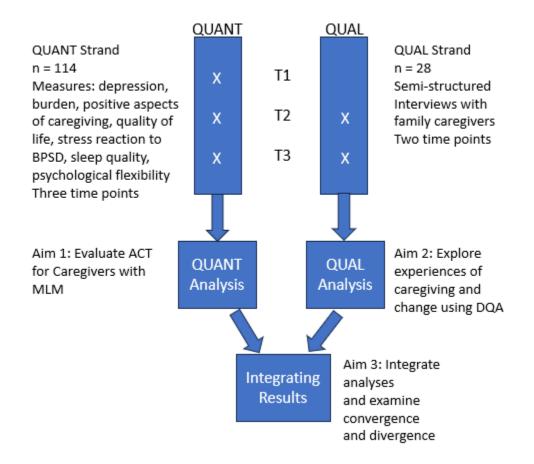
Reflexivity refers to the process of being conscious of how the researchers are influencing every step of the study (Braun & Clarke, 2021). To promote reflexivity, we engaged in regular structured and unstructured memoing about analytic decisions, positionality related to the project, and personal reactions to the data. This helped to ensure that we were conscious of and intentional about our influence on the analytic process. The data was coded by three individuals: a male PhD student with experience in qualitative research and gerontology who is trained in ACT as an associate marriage and family therapist and who conducted all interviews; a female PhD student with experience in qualitative research and gerontology and cursory training in ACT; and a female undergraduate student who received training in both qualitative research and ACT.

#### **Mixing and Integrating Analyses**

The heart of a mixed methods study is integration between methods, defined as "the creation of purposeful interdependence between methods" (Bazeley, 2018, pg. 16). In longitudinal mixed methods, mixing and integration occur at each time point and overall, once each strand is fully analyzed (Schumacher et al., 2021). Thus, mixing and integrating results is the final stage of analysis (see Table 1A in Appendix A for mapping of quantitative measures and qualitative questions onto mixed constructs).

After completing the QUANT and QUAL analyses, we integrated the findings for each sensitizing construct (see Figure 6). In integrating results, we focus on areas of convergence (e.g., agreement in results across methods) and divergence (e.g., disagreement in results across methods). Integrated findings are presented through joint displays (Bazeley, 2018). Convergent findings are useful because they increase confidence in the conclusions that are drawn from the analysis; divergent findings are useful because they help to uncover contextual factors that influence results, perhaps suggesting the need for improvements in quantitative or qualitative data collection (Bazeley, 2018). For divergent findings, neither strand will be viewed as the primary source of truth. Instead, we will allow both strands to contribute to a holistic understanding of the impact (or non-impact) of ACT for Caregivers.

#### Figure 6



Integration of QUANT and QUAL Strands

*Note*. Figure based on Schumacher et al. (2021)

#### CHAPTER IV RESULTS

#### **Quantitative Data Preparation**

Data were checked for accuracy and completeness and values that should have been NA were added. Kinship status was dichotomously coded as "spousal" and "other." Mean and standard deviation were calculated for each variable at each time point and outliers were calculated based on a Z-score greater than or less than 3. Using this criteria, seven participants were identified as potential outliers, with two of them for two outcomes. Outliers were kept in the present analyses since no participant was an outlier on all outcomes and extreme z-score values were deemed probable based on high (though non-extreme) z-scores on other related measures.

In the process of data familiarization, correlations between variables at each time point were calculated and visualized, as well as correlations within each variable over time. Of necessity, these comparisons used pairwise complete observations.

## Missing Data

MLM allows for use of participants who are missing one or more observation via time-point specific list-wise deletion. This maximizes power and promotes accuracy of results. For the whole sample, 113 participants completed the pretest, 84 completed the post-test, and 80 completed the follow-up survey. This constitutes a 71% retention rate, which is acceptable for the time frame of the study. Of the 33 participants who did not complete the study, 12 contacted the study team and requested to be withdrawn from the study and 21 were lost to follow-up.

In addition to participants missing an observation, a small percentage of participants had missing data for individual items on the measures (see Table X2 for a summary of missing data). To allow for accurate calculation of sum scores for the measures, participants who had at least 80% of items on a given measure had their mean value imputed for missing variables. This allowed for the imputing of all item-based missing data. Several participants did not complete the quality of life measure at one or more time points; because this was a single item measure, they were marked as NA and no imputation was conducted. Multiple participants were missing data for the frequency of experiencing BPSD. As a research team, we concluded that participants skipped responding to BPSD that they had not experienced and thus coded these missing responses as 0 to allow for an accurate sum of the frequency of BPSD.

#### **Pooling Sample**

The original study design was a parallel randomized controlled trial that used block randomization to assign participants to the treatment or waitlist condition. Because the present study uses a within-person analysis of participants completing the intervention in both groups, we pooled data from participants in both conditions. We removed the first baseline for waitlist so that all participants in the pooled data had their baseline and followup data points aligned. Prior to conducting the main analyses, however, pre-test data for both groups was compared using t-tests (see Table 5). Participants in the waitlist vs. immediate treatment group did not differ on gender (p = .52), kinship status (p = .76), dosage (p = .75), depressive symptoms (p = .40), quality of life (p = .32), burden (p = .71), frequency of BPSD (p = .92), stress reactions to BPSD (p = .81), or psychological flexibility (p = .47). Participants did differ in age (p = .03), with those in the waitlist being significantly younger, but since age was not included in any analyses the sample was pooled for all analyses.

Attribute	Waitlist $(n = 55)$	Treatment $(n = 58)$	P-Value
	Count/Mean (%/SD)	Count/Mean (%/SD)	1
Age	64.76 (12.89)	59.19 (13.99)	.031*
Caregiver Gender			.517
Female	48 (87.3%)	47 (81%)	
Male	7 (12.7%)	11 (19%)	
Kinship Status			.760
Other	24 (43.6%)	28 (48.3%)	
Spousal	31 (56.4%)	30 (51.7%)	
Dosage of ACT for			
Caregivers	3.62 (2.77)	3.78 (2.55)	.753
BPSD Frequency	1.55 (0.63)	1.56 (0.54)	.916
<b>BPSD</b> Stress Reaction	1.62 (0.91)	1.60 (0.77)	.895
Burden	22.68 (10.62)	23.37 (8.76)	.705
Positive Aspects of			
Caregiving	27.00 (8.79)	26.59 (9.70)	.817
Quality of Life	65.78 (22.57)	61.64 (20.47)	.320
Depressive Symptoms	11.85 (6.02)	12.80 (5.81)	.399
Sleep Quality	5.36 (2.60)	4.86 (2.57)	.305
Psychological Flexibility	84.27 (21.62)	81.40 (20.29)	.467
* <i>p</i> < .050.			

Comparison between Treatment and Waitlist at Pre-test

To control for a potential impact of engaging in an interview focused on ACT concepts, which could constitute an additional dosage of intervention, we used independent samples t-tests to compare change scores from pre-test to post-test and from pre-test to follow-up for all outcomes for participants who did both qualitative interviews with participants who did no interviews. Aside from number of ACT sessions completed, which was anticipated to be different due to completing all six sessions being the inclusion criteria for a follow-up interview, the only significant difference was that participants who did qualitative interviews reported slightly greater decrease in BPSD frequency from pre-test to post-test, t(95) = 2.36, p = .02. As the post-test assessment during which this change was located occurred prior to any qualitative interviews, we did not detect a significant confounding effect of the qualitative interviews.

Of the 113 participants who completed the pre-test, 29 participants did not complete the post-test; 21 of these participants did not complete any sessions of ACT for Caregivers. Independent samples t-tests showed that these participants had baseline data that was significantly worse than participants who did complete the post-test, including higher depressive symptoms (p = .002), lower quality of life (p = .009), higher BPSD stress reaction (p = .013), and lower overall psychological flexibility (p = .021).

## **Descriptive Information**

Sample demographics and pre-test values are shown in Table 2. 113 participants completed the pre-test, with 84 completing the post-test and 80 completing the follow-up survey. For program dosage (number of sessions completed within 30 days), 53 participants completed all 6 sessions, 10 completed 5 sessions, 9 completed 4 sessions, 6 completed 3 sessions, 8 completed 2 sessions, 6 completed 1 session, and 21 did not complete any sessions.

Despite efforts to track how long participants engaged with each session within the program, quantitative data on length of time for session engagement was distorted due to participants leaving the program open for prolonged periods of time without completing the session (as an illustration, the average length of time participants had session 1 open on their computer was 35.1 hours). Qualitative participants were asked about their estimated time of engagement for each session at post-test. These results need to be interpreted with caution, but the modal response was 30 minutes per session, followed by 30-45 minutes and then 60

minutes. Only two qualitative participants reported spending less than 30 minutes per session.

# **Program Acceptability**

In assessing the acceptability of the program, we used 8 items adapted from the Systems Useability Scale (Brooke, 1996; see Table 7). Participants reported somewhat agreeing with statements about using the skills from the program frequently, that the program was easy to use, that the various concepts were well integrated, and that other caregivers would benefit from the program. Participants reported somewhat disagreeing with the program being too complicated, needing more computer support to use the program, there being too much inconsistency in the program, and the program being cumbersome to use.

Table	7
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Variable ( $n = 84$ )	Mean (SD)	Range			
Dosage of ACT for Caregivers	3.93 (2.41)	0-6			
Number of sessions completed in 30 days		0-6			
0 (none)	21				
1	6				
2	8				
3	6				
4	9				
5	10				
6 (all)	53				
Average Time to Complete Program (days)	23.83 (11.61)	1-70			
Systems Useability Scale					
Average for Positively Valanced Items	3.22 (0.82)	0.25-4			
Average for Negatively Valanced Items	0.61 (0.73)	0-3			
<i>Note.</i> Dosage of ACT for Caregivers includes only the number of sessions completed within					

30 days. For participants that completed 1+ session, mean number of sessions completed within 30 days = 4.83 (SD = 1.66). Average time to complete program is calculated using all 63 participants who completed the program.

Five additional questions were also used to assess participants' satisfaction with the program. Participants somewhat agreed that they felt very confident using the program (M = 3.23, SD = 0.99), that they liked the graphics and layout (M = 3.05, SD = 1.01), that they felt the program was made for someone like them (M = 3.01, SD = 1.24), that they would like to use the sessions again (M = 3.17, SD = 1.11), that they would recommend the program to other caregivers (M = 3.44, SD = 0.97), and that the education information provided in the program was helpful (M = 3.42, SD = 0.94).

#### **Orientation to Results**

To take advantage of the convergent parallel mixed methods nature of this study, we organize our results into six sections based on the conceptual framework. For constructs with both quantitative and qualitative results, we first present the quantitative results, and then elaborate on them with the qualitative results (see Tables 6 and 7 for care-related outcomes; see Tables 8 and 9 for psychological flexibility; see Table 10 for joint display integrating findings). The first section is primary stressors, including the intensity of caregiving (QUAL), BPSD frequency (QUANT), and BPSD stress reaction (QUANT). The second section is secondary stressors, including burden (MIXED) and positive aspects of caregiving (MIXED). The third section is the impact of the program on participants' quality of life (MIXED), self-compassion (QUAL), depressive symptoms (QUANT), and providing personcentered care (QUAL). The fourth section is the impact of the program on participants' overall psychological flexibility (QUANT) and each of its subscales (MIXED). The fifth section is participants' descriptions of contextual factors, including social support, that influenced their experience of caregiving (QUAL). The sixth section is negative cases, participants who reported little or no impact from the program (MIXED).

	Mean BPSD Frequency	Mean BPSD Stress Reaction	Burden	Positive Aspects of	Quality of Life	Depressive Symptoms	Sleep Quality
	b (SE)	b (SE)	b (SE)	Caregiving <i>b (SE)</i>	b (SE)	b (SE)	b (SE)
FIXED EFFECTS	p-value	p-value	p-value	p-value	p-value	p-value)	p-value
Intercept	1.56 (0.06) <.001***	1.21 (0.19) <.001***	23.03 (0.80) <.001***	28.90 (1.09) <.001***	59.84 (3.70) <.001***	14.43 (0.93) <.001***	5.11 (0.23) <.001***
Time (ref = pre- test)							
Post-test	-0.11 (0.04) .005**	-0.18 (0.07) .006**	-3.78 (0.71) <.001***	1.61 (0.75) .034*	8.10 (1.77) <.001***	-3.16 (0.46) <.001***	0.53 (0.23) .024*
Follow-up	-0.16 (0.04) <.001***	-0.24 (0.07) <.001***	-5.76 (0.72) <.001***	2.93 (0.76) <.001***	12.10 (1.79) <.001***	-3.8 (0.47) <.001***	0.91 (0.24) <.001***
Dosage		-0.09 (0.03) .003**			1.96 (0.72) .007**	-0.53 (0.20) .009*	
Kinship Status				-3.90 (1.41)	-7.71 (3.18)		
(ref = other)				.007**	.017*		
BPSD Frequency		0.47 (0.09) <.001***					
RANDOM							
EFFECTS	Var	Var	Var	Var	Var	Var	Var
Between-Person (Intercepts)	0.28	0.34	50.94	43.82	208.23	18.87	3.82
Within-Person (Residual)	0.07	0.19	21.76	24.77	130.43	9.04	2.35
$R^2$ Marginal	.01	.20	.08	.07	.16	.16	.02
(Conditional)	(.80)	(.72)	(.73)	(.66)	(.68)	(.73)	(.63)

Parameter Estimates from Two-level MLMs for Care-Related Quantitative Outcomes Over Time

Note. BPSD frequency, burden, positive aspects of caregiving, and depressive symptoms models fitted on 277 observations of 113

individuals. Sleep quality model fitted on 276 observations of 113 individuals. BPSD stress reaction model fitted on 275 observations of 113 individuals. Quality of life model fitted on 268 observations of 109 individuals.

\*p < .050. \*\*p < .010. \*\*\*p < .001.

# Table 7

	Pre-test to	Post-test	Post-test to	Follow-up	Pre-test to ]	Follow-up
Variable	SMD	p-value	SMD	p-value	SMD	p-value
	0.19	.005**	0.08	.279	0.27	<
Mean BPSD Frequency						.001***
Mean BPSD Stress	0.25	.008**	0.08	.374	0.34	<
Reaction						.001***
	0.44	<	0.23	.008**	0.68	<
Burden		.001***				.001***
Positive Aspects of	0.19	.034*	0.16	.091	0.35	<
Caregiving						.001***
	0.44	<	0.22	.030*	0.66	<
Quality of Life		.001***				.001***
	0.60	<	0.14	.127	0.74	<
Depressive Symptoms		.001***				.001***
	0.21	.024*	0.15	.114	0.37	<
Sleep Quality						.001***

Follow-up Pairwise T-Tests Comparing Estimated Marginal Means Across Time for Care-Related Quantitative Outcomes

*Note*. SMD = Standardized Mean Difference

\**p* < .050. \*\**p* < .010. \*\*\**p* < .001.

	Overall Psychological	Behavioral Awareness	Openness to Experience	Valued Action
	Flexibility Final Model	Final Model	Final Model	Final Model
	b (SE)	b (SE)	b (SE)	b (SE)
FIXED EFFECTS	p-value	p-value	p-value	p-value
Intercept	76.11 (3.47)	15.51 (0.82)	30.08 (1.74)	29.88 (1.30)
	<.001***	<.001***	<.001***	<.001***
Time (ref = pre-test)				
Post-test	-5.31 (5.20)	1.70 (0.62)	-2.96 (2.65)	1.45 (0.63)
	.309	.006**	.267	.023*
Follow-up	-1.17 (5.52)	2.19 (0.63)	-0.56 (2.82)	3.06 (0.64)
_	.832	<.001***	.844	<.001***
Dosage	1.70 (0.75)		0.84 (0.38)	0.69 (0.28)
	.025*		.028*	.015*
Kinship Status		2.46 (1.04)		
(ref = other)		.020*		
Time x Dosage				
Post-test	2.71 (1.00)		1.62 (0.51)	
	.007**		.002**	
Follow-up	2.57 (1.05)		1.42 (0.54)	
	.016*		.009**	
RANDOM EFFECTS	Var	Var	Var	Var
ID (Intercepts)	248.76	22.46	61.16	37.68
Residual	120.41	16.92	31.59	17.13
R <sup>2</sup> Marginal	0.16	0.06	0.19	0.07
(Conditional)	(0.73)	(0.60)	(0.72)	(0.71)

Parameter Estimates from Two-level MLMs for Psychological Flexibility Over Time

Note. All models fitted on 277 observations on 113 individuals.

† 
$$p < .100. * p < .050. * * p < .010. * * p < .001.$$

Follow-up Pairwise T-Tests Comparing Estimated Marginal Means Across Time for Psychological Flexibility and Subscales

	Pre-test	to Post-test	Post-test te	o Follow-up	Pre-test te	o Follow-up
Variable	SMD	p-value	SMD	p-value	SMD	p-value
Overall Psychological						
Flexibility	-0.28	.310	0.22	.481	-0.06	.832
0 Sessions	0.28	.007**	0.19	.090†	0.46	<.001***
3.93 sessions	0.57	<.001***	0.17	.104	0.74	<.001***
6 Sessions						
Behavioral Awareness	0.27	.006**	0.08	.454	0.35	<.001***
Openness to Experience						
0 Sessions	-0.31	.268	0.25	.424	-0.06	.844
3.93 sessions	0.35	<.001***	0.17	.135	0.52	<.001***
6 Sessions	0.70	<.001***	0.13	.244	0.83	<.001***
Valued Action	0.20	.023*	0.22	.014*	0.42	<.001***

*Note*. SMD = Standardized Mean Difference. Signs of standardized mean differences have been reversed such that a negative is

interpreted as a decrease in the relevant construct.

 $\dagger p < .100. * p < .050. * * p < .010. * * * p < .001.$ 

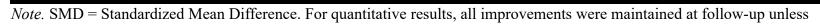
**Quantitative Findings Qualitative Findings** Construct (N = 113)(N = 28)Post-test Follow-up Exemplary Quote Intensity of "It's become much more • Increasing intensity of • Most participants reported Caregiving intense. It's become caregiving stability in their level of • Physical tasks much more full time. I involvement didn't expect it to be as • Some reported more • Medical tasks full time as it is now." • Physical and emotional involvement and some reported less (Participant 20 post-test) presence Mean BPSD • Significant small decrease Frequency during the intervention (SMD = 0.19, p = .005).Mean BPSD • Significant small decrease Stress during the intervention Reaction (SMD = 0.25, p = .008).Burden Most challenging aspects: Since beginning the "[I'm] not being so • Significant small decrease reactive, taking during the intervention • Feeling bound by the program: concrete, clear focus on (SMD = 0.44, p < .001)caregiving role • Better able to navigate the what the problem at that further decreased • Dealing with emotions challenges of caregiving hand is, and trying to get between post-test and (loss and worry) • Increased ability to be a resolution without follow-up (SMD = 0.23, p • Providing unwanted care, emotionally flexible. getting emotionally =.008). • Bridging with medical strung out about it." providers and family (Participant 49 followmembers up)

Joint Display of Integrated Findings for All Outcomes: Small effects (<.5), moderate effects (.5-.79), large effects (>.8)

Positive Aspects of Caregiving	• Significant small increase during the intervention ( <i>SMD</i> = 0.19, <i>p</i> = .034).	<ul> <li>Most meaningful aspects:</li> <li>Showing love for the care receiver</li> <li>Cherishing small moments of connection and lucidity</li> <li>Experiencing personal growth.</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Increased ability to focus on the meaningful aspects of caregiving</li> <li>Renewed focus on values</li> </ul>	"I'm not as resentful as I was [before ACT for Caregivers] A couple of months ago, nothing that I would do for his care was meaningful. And that's sad to say, but, you know, it wasn't." (Participant 18 follow- up)
Quality of Life	• Significant small increase during the intervention ( <i>SMD</i> = 0.44, <i>p</i> < .001) that further increased between post-test and follow-up ( <i>SMD</i> = 0.22, <i>p</i> = .030).	<ul> <li>Since beginning the program:</li> <li>Reduced stress and increased calm</li> <li>Feeling more balanced in carrying out their caregiving responsibilities.</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Continued reduced stress and increased calm</li> <li>Increased sense of mastery leading to less anxiety.</li> </ul>	"I think I'm calmer. I think that I enjoy more. My pace is still pretty much busy, but it doesn't feel as uncomfortable, and that's a big thing." (Participant 9 follow-up)
Self- Compassion Depressive Symptoms	<ul> <li>Significant moderate decrease during the</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Better at acknowledging and meeting own needs</li> <li>More forgiving of personal mistakes and limitations</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Continued increased ability to acknowledge and meet own needs</li> <li>Giving self more grace with mistakes</li> </ul>	"[The program has] made me realize that I have to take some time for myself you have to step aside from the horribleness of it so that you can regroup and start all over again." (Participant 84 follow- up)

Person- Centered Care	intervention ( <i>SMD</i> = 0.60, <i>p</i> < .001).	<ul> <li>Since beginning the program:</li> <li>Kinder and more compassionate with care receiver</li> <li>Valuing the care receiver's personhood</li> <li>Remembering the purpose of caregiving.</li> </ul>	<ul> <li>Since beginning the program:</li> <li>More patient with the care receiver</li> <li>Intentionally providing care receiver with simple ways to choose and have responsibilities</li> <li>Reconnected with their feelings of the care</li> </ul>	"When I do feel like I'm getting short with [the care receiver,] I recognize that I need to, like, wait a minute, that's not right stop and think about my thoughts and feelings and instead of just reacting."
Sloop Quality			receiver's worth and value as a human being.	(Participant 134 post- test)
Sleep Quality	• Significant small increase during the intervention ( <i>SMD</i> = 0.21, <i>p</i> = .024).			
Overall Psychological Flexibility	<ul> <li>3.93 sessions: Significant small increase (<i>SMD</i> = 0.28, p = .007)</li> <li>6 sessions: Significant moderate increase (<i>SMD</i> = 0.57, p &lt; .001).</li> </ul>			
Behavioral Awareness	• Significant small increase during the intervention ( <i>SMD</i> = 0.27, <i>p</i> = .017).	<ul><li>Since beginning the program:</li><li>Increased awareness of away moves</li><li>Increased ability to</li></ul>	<ul> <li>Since beginning the program:</li> <li>Continued increased awareness of away moves</li> <li>Increased ability to make</li> </ul>	"[I'm] aware of what's going on versus being a victim to it It's just slowed me down and I feel like I'm not having,
		interrupt these actions, especially reactivity.	difference choices,	it's not reacting, but having a direction versus just thoughtlessly

			especially in stressful situations	reacting to situations that are difficult." (Participant 25 post-test)
Openness to Experience	<ul> <li>3.93 sessions: Significant small increase (<i>SMD</i> = 0.35, <i>p</i> &lt; .001).</li> <li>6 sessions: Significant moderate increase (<i>SMD</i> = 0.70, <i>p</i> &lt; .001).</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Acknowledging feelings rather than avoiding them</li> <li>Stepping back from thoughts</li> <li>Using the strategies taught in the program to manage thoughts and feelings more effectively.</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Continued increased ability to acknowledge feelings and move on</li> <li>Continued ability to step back from thoughts and pause in stressful situations.</li> <li>Less reactive</li> </ul>	"[Acknowledging my emotions] helps prevent me from becoming that volcano, where I can just be like, 'okay, I felt upset, hurt, frustrated, angry when this happened. I lived it. I'm dealing with it."" (Participant 100 post- test)
Valued Action	• Significant small increase during the intervention ( <i>SMD</i> = 0.20, <i>p</i> = .023) that further increased from post-test to follow- up ( <i>SMD</i> = 0.22, <i>p</i> = .014).	<ul> <li>Since beginning the program:</li> <li>Clarified what was important to them</li> <li>Aligned their choices with their core values</li> <li>Been more flexible and intentional in the context of the constraints of caregiving.</li> </ul>	<ul> <li>Since beginning the program:</li> <li>Continued increased clarity about what matters to them</li> <li>Increased consistency in aligning choices with core values</li> <li>Continued increased flexibility and intentionality in living</li> </ul>	"It's opened my eyes to what's important to me and what matters to me . It makes me happy to be able to do the things that I love to do, even though I'm doing them on my own. And it seems to have a well- rounded feeling about my life." (Participant 104 follow- up)



otherwise specified. For qualitative results, stems at beginning of cells reflect the focus of interview questions at each time point.

#### **Section 1: Primary Objective Stressors**

In this section, we discuss participants' descriptions of the intensity of caregiving (QUAL), BPSD frequency (QUANT), and BPSD stress reaction (QUANT).

# Intensity of Caregiving (QUAL)

**Qualitative Analysis.** At post-test, nearly all participants reported that caregiving had increased in intensity over time. Participant 20 (male spousal caregiver for 2.1 years) explained, "It's become much more intense. It's become much more full time. I didn't expect it to be as full time as it is now." Additionally, participants' responses revealed an ambiguity around what activities constituted caregiving and an uncertainty about how many hours of caregiving they engaged in weekly.

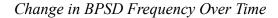
Participants highlighted that the aspects of caregiving that took the most time were presence and management of the care receiver, the physical tasks of caregiving, and the medical tasks of caregiving. Revealing the general ambiguity of whether or not monitoring constituted caregiving, Participant 11 (female spousal caregiver for 4.5 years) reported, "It depends on what you define as caregiving. I would say most of the time I am with him, I am concerned or watching or helping . . . all day, every day." Participant 84 (male spousal caregiver for 8.2 years) illustrated many of the physical tasks of caregiving when he explained that he helped the care receiver with, "Everything. Bathroom, dressing, bathing, eating, fixing meals, complete care basically. . . . It's just basically taking care of a two-year-old who gets worse, not better." Participant 104 (female spousal caregiving involved, "Making doctors' appointments, ran out medication, reading up on medication, finding out what the side effects are . . . [and] being an advocate."

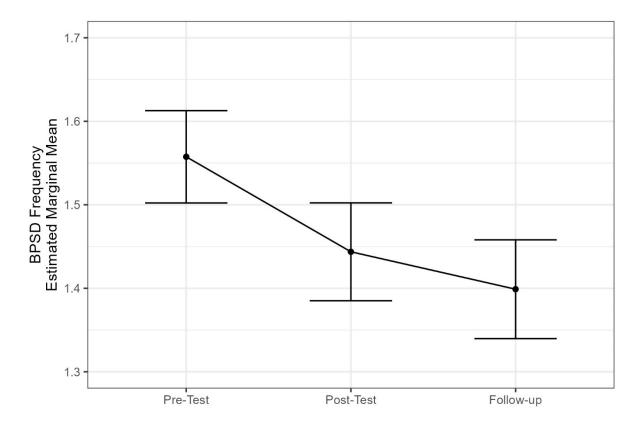
At follow-up, participants were asked whether their involvement in care or the intensity of caregiving had changed between post-test and follow-up. Their responses suggest a high level of variability in involvement, with 8 participants reporting increased involvement or time, 14 participants reporting no change, and 6 participants reporting less involvement. Those who reported increased involvement of care emphasized the care receiver's diminishing physical and cognitive capacity, like Participant 53 (female spousal caregiver for 2.2 years) who explained that in the time between interviews, "My husband's physical mobility has decreased fairly significantly, which has been challenging."

#### **BPSD** Frequency (QUANT)

Person-to-person differences account for 79% of the variance in BPSD frequency, ICC = .79. The best fitting model included time, not dosage or kinship status,  $\chi^2$  (2) = 0.84, p= .656. Time explained 1% of the variance in BPSD frequency, marginal  $R^2$  = .01. Time and random intercepts explained 80% of variance, conditional  $R^2$  = .80. There was a small decrease in BPSD frequency during the intervention (SMD = 0.19, p = .005) that was maintained at follow-up (SMD = 0.08, p = .279; see Figure 7). The non-stability in BPSD frequency over time was unanticipated.

## Figure 7





Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

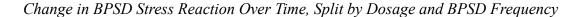
#### **BPSD** Stress Reaction (QUANT)

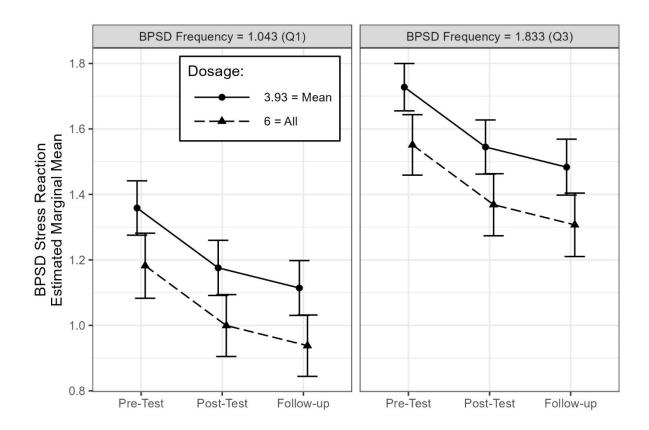
To adjust for the finding that there was a significant decrease in BPSD frequency over time, the mean stress reaction for BPSD was used rather than the sum BPSD stress reaction. Person-to-person differences account for 64% of the variance in BPSD stress reaction, *ICC* = .64. Adding BPSD frequency as an additional level 1 predictor significantly improved model fit when compared to the model that included time and dosage,  $\chi^2(1) = 27.91$ , p < .001.

Time, dosage, and BPSD frequency explained 21% of the variance in BPSD stress reaction over time, marginal  $R^2 = .21$ ; Time, dosage, BPSD frequency, and random intercepts

explained 72% of the variance in BPSD stress reaction over time, conditional  $R^2 = .72$ . There was a significant decrease in BPSD stress reaction during the intervention (*SMD* = 0.25, *p* = .008), that was maintained at follow-up (*SMD* = 0.08, *p* = .374; see Figure 8). Dosage of ACT for Caregivers was negatively associated with BPSD stress reaction, *b* = - 0.09, *SE* = 0.03, *p* = .003. Experiencing higher mean frequency of BPSD was positively associated with BPSD stress reaction, *b* = 0.47, *SE* = 0.09, *p* < .001.

## Figure 8





Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

#### Section 2: Primary Subjective Stressors, Secondary Stressors, and Uplifts

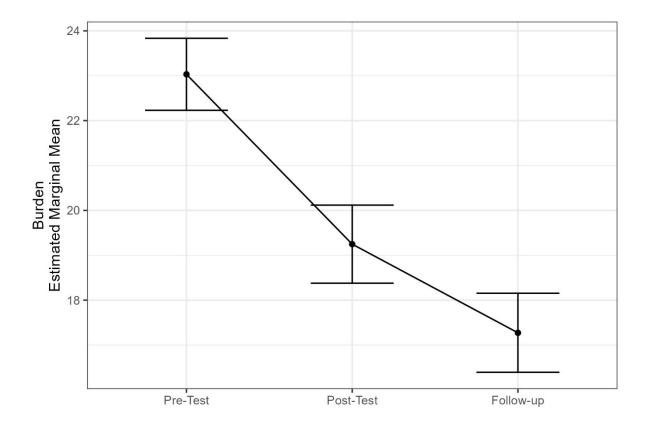
In this section, we present participants' results for burden (MIXED) and positive aspects of caregiving (MIXED). We note that interview questions at post-test focused on the experience of burden and positive aspects of caregiving, whereas the follow-up interview focused on changes in burden and positive aspects of caregiving since beginning the program; our qualitative results therefore focus on common elements of experience at posttest and changes at follow-up.

#### Burden (MIXED)

**Quantitative Analysis.** Person-to-person differences accounted for 62% of the variance in burden, ICC = .62. The best fitting model included only time as a predictor and not dosage or kinship status,  $\chi^2 (2) = 2.38$ , p = .30. Time explained 8% of variance, marginal  $R^2 = .08$ . Time and random intercepts explained 72% of variance, conditional  $R^2 = .72$ . There was a significant small decrease in burden during the intervention (SMD = 0.44, p < .001), and burden further decreased between post-test and follow-up (SMD = 0.23, p = .008), for a moderate decrease in burden overall (SMD = 0.68, p < .001; see Figure 9).

## Figure 9

Change in Burden Over Time



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

**Qualitative Analysis: Burden.** At post-test and follow-up, participants were asked about the most challenging parts of caregiving; at follow-up, participants were also asked whether the way they navigated those challenges had changed since beginning ACT for Caregivers.

*Post-test Analysis.* At post-test, participants reported multiple aspects of caregiving as being the most challenging, including feeling bound by the caregiving role, dealing with emotions, providing unwanted care, and bridging with medical providers and family members. Participant 32 (female spousal caregiver for 2 years) gave voice to the ways she

felt constrained by her role when she expressed, "I do find it limiting. . . I never know when I'm going to be interrupted. Can't make a phone call to a friend. Can't make a business phone call . . . my outside attachments are limited." Similarly, Participant 100 (female adult child caregiver for 2.8 years) reported struggling with feeling that, "I have to be the strong person because my dad is collapsing, my grandparents are collapsing, and I'm just here in the middle . . . [but] I have my own life too."

Many participants reported that the most challenging part of caregiving was managing their own emotions, particularly grief and loss; some participants also reported struggling to manage anxiety for the future. Participant 5 (female spousal caregiver for 4.5 years) explained, "The biggest challenge is to realize this isn't the person you knew anymore and to stop trying to relate to them the same way that you used to." She continued, "I know that on the intellectual level, but can you do that on the emotional level? It's harder."

Some caregivers also expressed that what made caregiving hard was providing unwanted care, either in the sense of care that the care receiver did not desire to receive or care that the caregiver did not feel comfortable giving (nearly always related to incontinence). Participant 40 (female adult child caregiver for 1.2 years) explained, "It is difficult to care for someone who doesn't think they need care. . . it's really difficult to care for someone in those aspects where they're like, 'no, I can do that.""

Some caregivers also reported that scheduling and attending medical visits was challenging, and some reported feeling criticized by family members who were less involved in caregiving. Highlighting the challenges of extensive medical care, Participant 104 (female spousal caregiver for 6.5 years) explained, "The doctors' appointments are getting longer and harder to get to. . . right now, that is probably the biggest challenge." In discussing the difficulty of navigating family relationships, Participant 41 (male adult child caregiver for 1.2 years) reported that the fact that relationships had been distant prior to caregiving made things even harder. He explained, "Getting pulled back into the family, where I haven't really been part of that family for so long, it's been very challenging."

*Follow-up Analysis.* At follow-up, many participants reported that the same aspects of caregiving that they had reported at post-test were still the most challenging. Of these, the most common were feeling bound to the caregiver role, dealing with loss, and managing the constant demands of caregiving. Participant 27 (female spousal caregiver for 3.3 years) highlighted all three aspects, explaining,

"I'm exhausted. Just there's always so much to do, so much to be done. And believe it or not, it's exhausting to be cheerful all the time. So those things are the most difficult for me. And to see him the way [he is now,] this is what Alzheimer's disease has done to him, and you're remembering who he used to be."

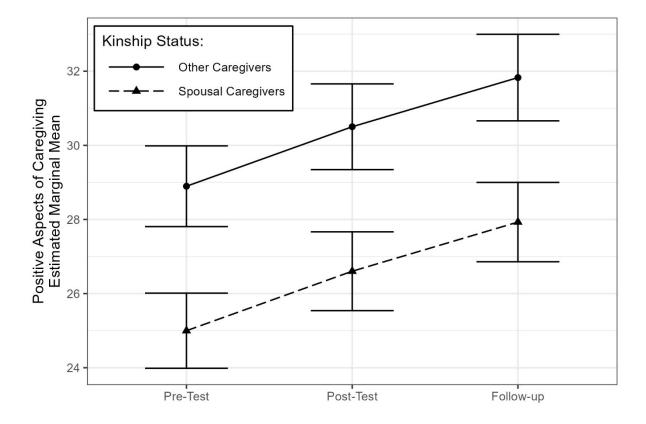
Nearly all participants reported that the things they learned from the program were helping them to navigate the challenges of caregiving more effectively and to be more emotionally flexible. Participant 18 (female spousal caregiver for 15.5 years) explained, "I don't get as frustrated as I used to. . . I've calmed down a lot and I allow myself to . . . express my frustration to myself, and then I'm able to just let it go." Similarly, Participant 20 (male spousal caregiver for 2.1 years) reported, "I'm able to switch gears and not let it bother me as much as it did before. . . It's my ability to let my emotions come and go, basically. . . just let it be."

Multiple participants reported that they were trying new strategies with the care receiver since beginning ACT for Caregivers and that this had made their challenges more manageable. Participant 49 (female spousal caregiver for 8 years) explained that because of the program she was, "Not being so reactive, taking concrete, clear focus on what the problem at hand is, and trying to get a resolution without getting emotionally strung out about it." She reported that this had significantly improved her experience of caregiving.

#### Positive Aspects of Caregiving (MIXED)

**Quantitative Analysis.** Person-to-person differences accounted for 64% of the variance in positive aspects of caregiving, ICC = .64. Dosage was non-significant, but adding kinship status to the model with only time significantly improved model fit,  $\chi^2$  (1) = 7.54, p = .006. Time and kinship status together explained 7% of variance in positive aspects of caregiving, marginal  $R^2 = .07$ . Time, kinship status, and random intercepts explained 66% of variance, conditional  $R^2 = .66$ . There was a significant small increase in positive aspects of caregiving during the intervention (SMD = 0.19, p = .034) that was maintained at follow-up (SMD = 0.16, p = .091; see Figure 10). Spousal caregivers reported significantly lower positive aspects of caregiving than other caregivers, b = -3.90, SE = 1.41, p = .007.

## Figure 10



Change in Positive Aspects of Caregiving, Split by Kinship Status

Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

**Qualitative Analysis.** At post-test and follow-up, participants were asked about the parts of caregiving they found most meaningful; at follow-up, participants were also asked whether their ability to focus on those aspects had improved since beginning ACT for Caregivers.

*Post-test Analysis.* Participants emphasized that what they found meaningful about caregiving was showing love for the care receiver, cherishing small moments of connection and lucidity, and experiencing personal growth. Participant 8 (male spousal caregiver for 7.92 years) explained, "In a very real way, [caregiving is] the way that I can—although it's

not necessarily reciprocated or even understood—it's the way that I can express my love." Expressing the depth of her emotion, Participant 27 (female spousal caregiver for 3.3 years) reported, "I love him very much. It goes beyond Hallmark cards. It's very deep, clear into my soul. So all of it is meaningful."

Participants reported that they found small moments of lucidity and interaction with the care receiver meaningful. Participant 14 (female spousal caregiver for 2.2 years) reported that she found it meaningful, "Just enjoying his company. . . I love watching his observations of like, 'oh, did you see that?'" She explained that focusing on the small, sweet moments helped her to navigate the challenges of caregiving, reporting, "Then when you get to the frustrating parts, if you can appreciate the positives, it kind of balances a little bit some of the frustrations or the sadness."

Some participants emphasized feeling like they were experiencing personal growth as a caregiver, such as becoming more "patient" or "kinder." Participant 80 (female adult child caregiver for 5 years) explained, "my relationship with [the care receiver] has grown deeper just because I'm caring for him and just because he's happy to rely on me, and I realize I'm a kinder person." Participant 11 (female spousal caregiver for 4.5 years), who reported not finding much meaning in caregiving, reported, "I guess I'm learning patience, so that's good."

While most participants endorsed that there were parts of caregiving that were meaningful, they also nuanced their responses with acknowledgement of the difficulty of caregiving. Participant 56 (female spousal caregiver for 5 years) reported that in her experience, "the meaningful might be 20% [of the time] and the difficult is 80%." She then contrasted caregiving for someone with dementia with other forms of caregiving, explaining, "When you're really caregiving to a person who's receiving, that's a different kind of reward; this is not that kind of situation, they're not receiving. You're just managing difficult moments the whole time."

Seven participants reported that caregiving was not meaningful for them and that they did not see positives to it. Participant 5 (female spousal caregiver for 4.5 years) reported that she sometimes felt a sense of guilt when asked about what she found meaningful about caregiving, because, "Most of the time, [caregiving] gives me a sense of frustration. So if there's supposed to be something wonderful about it, I haven't yet found that."

*Follow-up Analysis.* At follow-up, participants continued to emphasize that the parts of caregiving they found meaningful were finding purpose in caregiving in a loving way and savoring small moments with the care receiver. Participant 27 (female spousal caregiver for 3.3 years) reported, "For the first 42 years of our relationship, he took care of me . . . so now I'm giving back. I'm returning what he's given me. . . I feel honored." For some participants, knowledge of the impending end of caregiving helped them to focus on the meaningful parts of caregiving. Participant 49 (female spousal caregiver for 8 years), who had reported that there were no meaningful parts of caregiving at post-test, reported at follow-up that, "[Caregiving] is more meaningful than it had been, seeing the end is coming closer."

Many participants reported that what they found meaningful about caregiving was the small moments of interaction they were able to have with the care receiver. Participant 14 (female spousal caregiver for 2.2 years) described taking a flight with the care receiver and being "next to each other and just holding hands through the whole flight." She continued, "It was just like a tender moment of this is who he is, [he's] still who he is. He's not like he was, but he's still who he is."

Many participants reported that their ability to focus on the meaningful aspects of caregiving had increased in part due to what they learned in ACT for Caregivers, particularly their values. Participant 32 (female spousal caregiver for 2 years) reported, "[ACT for Caregivers] helps the thinking of, 'okay, like, this is tough. I'm not going to pretend it isn't tough, it's tough. Acknowledge it, sit with it, this is what you value.""

For some participants, applying what they had learned in the program led them to be less stressed, which gave them more time and energy for the portions of caregiving they found meaningful. Participant 18 (female spousal caregiver for 15.5 years) reported, "I'm not as resentful as I was [before ACT for Caregivers]. . . A couple of months ago, nothing that I would do for his care was meaningful. And that's sad to say, but, you know, it wasn't."

Four participants continued to report that they did not currently find any part of caregiving meaningful or worthwhile. Participant 41 (male adult child caregiver for 1.2 years) explained, "[Caregiving] needs to be done. But I don't know that I necessarily find it meaningful. If I am getting the satisfaction, I think I'm not recognizing that."

#### Section 3: Quality of Life, Depressive symptoms, and Person-Centered Care

In this section, we describe participants' responses about the impact of the program on their quality of life (MIXED), depressive symptoms (QUANT), and on their relationship with the care receiver (QUAL).

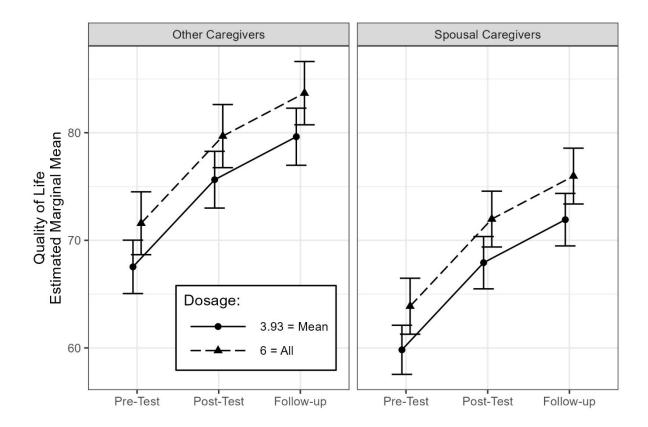
#### Quality of Life (MIXED)

Quantitative Analysis. Person-to-person differences accounted for 59% of the variance in quality of life, ICC = .59. The best fitting model included time, dosage, and kinship status, but no interaction between time and dosage,  $\chi^2(2) = 1.97$ , p = .37. Time, dosage, and kinship status together accounted for 16% of the variance in quality of life,

marginal  $R^2 = .15$ . Time, dosage, kinship status, and random intercepts accounted for 68% of the variance, conditional  $R^2 = .68$ . There was a significant small increase in quality of life during the intervention (*SMD* = 0.44, *p* < .001), that further increased between post-test and follow-up (*SMD* = 0.22, *p* = .030), for a moderate increase in quality of life overall (*SMD* = 0.66, *p* < .001; see Figure 11). Completing more sessions was associated with higher quality of life, *b* = 1.96, *SE* = 0.72, *p* = .007. Being a spousal caregiver was associated with significantly lower quality of life, *b* = - 7.71, *SE* = 3.18, *p* = .017.

## Figure 11

Change in Quality of Life Over Time, Split by Dosage and Kinship Status



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

Qualitative Analysis. At post-test and follow-up, participants were asked about the

impact of the program on their quality of life overall and the extent to which they felt the program had met their needs as caregivers.

*Post-test Analysis.* At post-test, participants reported that engaging in the program had led them to experience reduced stress and increased calm and to feel more balanced in carrying out their caregiving responsibilities. The most common benefit participants reported from the program was feeling less stressed about caregiving and instead feeling a sense of calm. Participant 8 (male spousal caregiver for 7.92 years) explained, "the biggest effect is making me more calm and peaceful and at peace with where I'm at and what I'm doing." Most participants who reported this benefit attributed it to renewed perspective and to getting better at managing their thoughts and feelings. Participant 49 (female spousal caregiver for 8 years) explained that she was "trying to keep thing more in perspective" and that as a result "I'm not getting escalated and sort of wound up in some thoughts."

Multiple participants reported that since beginning the program, they were managing the responsibilities of caregiving better, such that they felt less overwhelmed by the many things they needed to do. Participant 41 (male adult child caregiver for 1.2 years) reported that prior to beginning the program, "Everything was consumed [by caregiving]. And so [the program has] allowed me to kind of push back on that. . . I'm making healthier food choices. I'm exercising. I'm able to get some work done."

*Follow-up Analysis.* At follow-up, participants continued to report improvements in their quality of life in the form of reduced stress and increased calm and greater self-compassion; they also reported an increased sense of mastery leading to less anxiety. Similar to the post-test results, many participants reported that the primary improvement in their quality of life came from feeling less stressed and more calm, even peaceful. Participant 9

(female spousal caregiver for 1.5 years) explained, "I think I'm calmer. I think that I enjoy more. My pace is still pretty much busy, but it doesn't feel as uncomfortable, and that's a big thing for me." Similarly, Participant 27 (female spousal caregiver for 3.3 years) reported, "[ACT for Caregivers has] made me calmer, it's given me a lot of insight into what's going on and what my responses are actually being, how I'm able to respond to situations as they get worse."

Multiple participants reported feeling more positive about the future and like they could move forward more effectively because of what they learned from the program. Participant 41 (male adult child caregiver for 1.2 years) explained, "I've been working on diet and exercise. I've lost, like, 50 pounds. I'm running a half marathon here shortly. I'm feeling good about myself. I'm feeling positive about the future. And overall, I think just more put together."

Similarly, Participant 67 (female spousal caregiver for 1.5 years) explained,

"[ACT for Caregivers] gave me an insight into what I can do with my husband and what I can do for me. Like I said before, I have to take care of myself so I can take care of him. It has taught me that I can do both, where I thought, 'no, there's no hope.' But now, yeah, there is hope. I can do both of them, and I have."

## Self-Compassion (QUAL)

At post-test and follow-up, participants were asked whether the way they treated themselves had changed since beginning ACT for Caregivers. Although originally grouped under quality of life, we separated this theme due to participants' repeated referencing of meeting their own needs and giving themselves more grace as important impacts of the program.

Post-test Analysis. Multiple participants emphasized that since beginning the

program they were acknowledging their own needs more and actively working to meet those

needs. Participant 104 (female spousal caregiver for 6.5 years) explained, "As a caregiver you often forget about what is important to you, and I think since being in this program, I've come to terms with the fact that I need to take better care of me." Multiple participants reported that the program gave them "permission" or "allowed" them to have needs, without feeling weak or selfish for needing to take care of themselves.

Participants also reported that they were being more accepting of personal limitations and mistakes since beginning the program. Participant 27 (female spousal caregiver for 3.3 years) reported realizing, "I don't have to feel guilty because of these mistakes I've made. I can just think about them and try and figure out how I can do it better and bring some peace to my own mind."

**Follow-up Analysis.** Similar to the post-test results, many participants continued to emphasize increased awareness of their needs and spending time to meet them and giving themselves grace as caregivers. Several participants reported newly realizing that they had needs, like Participant 18 (female spousal caregiver for 15.5 years) expressed, "I was not aware I had any needs. I thought I was just perfect, everything was him. . . [now I see] it's okay for me to have [needs.]" The result of working to meet their needs was an increased ability to engage in caregiving effectively. Participant 84 (male spousal caregiver for 8.2 years) explained,

"[The program has] made me realize that I have to take some time for myself, that I have to realize that if I am completely tied up and everything is weighing me down, I'm not going to be able to take care of my loved one. You have to take time for self, and you have to have some ability to get away and step aside for a period of time. Maybe not a long period of time, but you have to step aside from the horribleness of it so that you can regroup and start all over again."

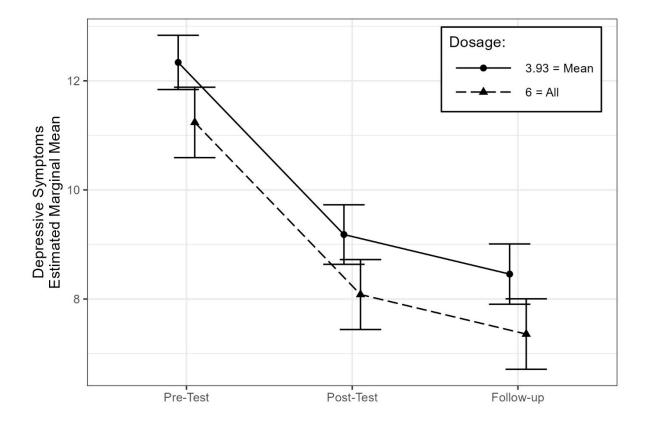
Participants also reported that they were giving themselves grace about personal limitations or mistakes. Participant 26 (female adult child caregiver for 5 years) explained,

"[The program gave me] more permission, maybe less needing to be the best at something or to do something perfectly based on an idea of what perfect is." Similarly, Participant 104 (female spousal caregiver for 6.5 years) reported that acting on the things she learned in the program, "I definitely treat myself better . . . it's brought me inner peace, a better understanding of the person that I am and what I do and what I go through. And I'm not so hard on myself as I used to be."

#### **Depressive Symptoms (QUANT)**

Person-to-person differences accounted for 62% of the variance in depressive symptoms, ICC = .62. The best fitting model included time and dosage, but not an interaction between time and dosage,  $\chi^2(2) = 2.37$ , p = .30. Time and dosage together accounted for 16% of the variance in depressive symptoms, marginal  $R^2 = .16$ . Time, dosage, and random intercepts accounted for 73% of variance, conditional  $R^2 = .73$ . There was a significant moderate decrease in depressive symptoms during the intervention (SMD = 0.60, p < .001) that was maintained at follow-up (SMD = 0.14, p = .127; see Figure 12). Completing more sessions of ACT for Caregivers was associated with lower depressive symptoms, b = -0.53, SE = 0.20, p = .009.

## Figure 12



## Change in Depressive Symptoms Over Time, Split by Dosage

Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

#### Person-Centered Care (QUAL)

**Post-test Analysis.** At post-test, participants reported that the things they learned from the program had influenced their relationship with the care receiver by helping them to be kinder and more compassionate, value the care receiver's personhood, and remember the purpose of caregiving. In general, participants reported that they had been engaging in these behaviors to some extent prior to the program, but that the program had helped them to be more intentional and aware of what they were doing. For example, Participant 8 (male spousal caregiver for 7.92 years) explained that the program had helped him to tune in to

what matters to him when confronted with the difficulties of caregiving, explaining, "I just try to center myself and think about why I'm doing what I'm doing, and it helps to calm the emotions. We've been married for 49 years. There's a reason why I'm here: because I love that woman."

Many participants reported that since beginning the program they were being more kind, patient, and compassionate with the care receiver. Participant 134 (female adult child caregiver for 4 years) reported that the program had heightened her awareness of times when she was not treating the care receiver the way she wanted, commenting, "When I do feel like I'm getting short with [the care receiver,] I recognize that I need to, like, wait a minute, that's not right. . . stop and think about my thoughts and feelings and instead of just reacting." Multiple participants reported that separating the care receiver from the dementia helped them to treat them with more compassion, like Participant 104 (female spousal caregiver for 6.5 years) who reported, "There was nothing that [the care receiver] did to make himself sick. It's just the way things are. And I've learned to show more compassion."

Many participants reported renewing their efforts to focus on the worth of the care receiver, including communicating this to the care receiver insomuch as this was possible. Participant 46 (spousal caregiver for 2.7 years) reported that since beginning the program, "I'm learning to validate his feelings" and "trying to walk him through this and let him know that when he truly says something, that I'm really listening and trying to tend to his needs and in a respectful way." As part of this effort, participants reporting trying to find ways to allow for choice and appropriate responsibility for the care receiver. Participant 14 (female spousal caregiver for 2.2 years) reported that she was finding "things that he can still do and point out those things that he does well. . . things that I can find for him to do that still gives him some

sense of value and worth."

In part due to changing how they interacted with the care receiver, multiple participants reported that their relationship with the care receiver had improved since beginning the program. Participant 60 (female spousal caregiver for 7.3 years) explained, "I felt like [our relationship] was going completely backwards or going away, where now I feel like we're working towards a better relationship because I'm able to talk to him better." Several participants reported that changing how they interacted with the care receiver seemed to lead to less stress, anxiety, and acting up from the care receiver. Participant 9 (female spousal caregiver for 1.5 years) explained, "If we can just kind of reduce worry, frustration, anxiety for him, it also ripples down into not as much forgetting, not as much anxiousness, not as much fear in his world, and it just creates more of a balance."

*Follow-up Analysis.* At follow-up, participants emphasized that the program had helped them to be more patient with the care receiver, to intentionally provide them with simple ways to choose and have responsibilities, and to reconnect with their feelings of the care receiver's worth and value as a human being. Multiple participants reported that since beginning the program, they were being more patient with the care receiver. Participant 11 (female spousal caregiver for 4.5 years) explained, "I started using the word 'patient' as a verb. I am patient in my way and not reacting from it." She reported reminding herself, "[Feelings] can be there if they need to be there but I'm just going to be myself and take care of this in a way that I would like to take care of it." Participants continued to emphasize that separating the care receiver from the dementia was helpful in being patient, like Participant 22 (female adult child caregiver for 0.5 years) who emphasized, "[The program] allowed me to recognize that these changes are going to happen, and it's not his fault. He can't control it any more than I can. So, it helps me to try and keep things on an even keel."

Several participants reported that since beginning the program they had been even more intentional in providing the care receiver with the opportunity to make choices or to fulfill realistic responsibilities. Participant 14 (female spousal caregiver for 2.2 years) explained, "I've learned to kind of have a game of finding and praising him, like, and letting him be in charge of certain things. . . I want him to still know he has strengths and contributes."

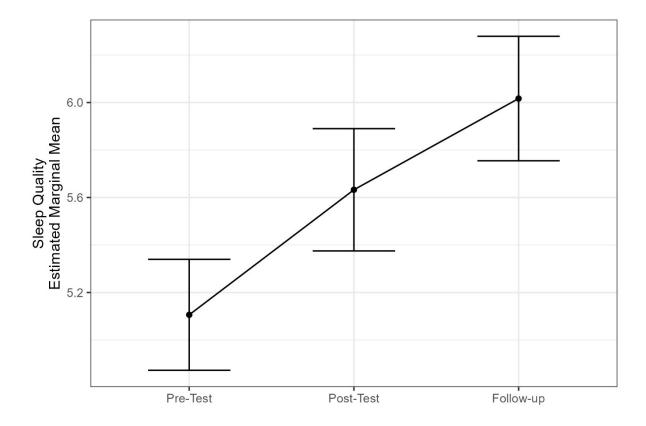
Several participants emphasized that since beginning the program, they had a renewed focus on the importance and worth of the care receiver as a human. As a result, they were able to re-engage with caregiving in a kinder, more loving way. Participant 26 (female adult child caregiver for 5 years) reported, "I would just say my hands aren't as tightly gripped. . . I have more room to get to know him. And get to hear him, and get to stay steady with also what's important to him." Several participants referenced their values in describing their caregiving, like Participant 80 (female adult child caregiver for 5 years) who reported, "What matters to me is to be patient, to be loving, to be kind, and just to take care of my dad. . . [so] instead of just going out and doing what needs to be done, I'll bring my dad out with me."

#### Sleep Quality (QUANT)

Person-to-person differences accounted for 60% of variance in sleep quality, ICC =.60. The best fitting model included only time as a predictor, not dosage or kinship status,  $\chi^2$ (2) = 1.09, p = .58. Time explained 2% of the variance in sleep quality, marginal  $R^2 = .02$ . Time and random intercepts explained 63% of variance, conditional  $R^2 = .63$ . There was a significant small increase in sleep quality during the intervention (SMD = 0.21, p = .024) that was maintained at follow-up (SMD = 0.15, p = .113; see Figure 13).

# Figure 13

## Change in Sleep Quality Over Time



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

## Section 4: Coping and Psychological Flexibility

In this section, we discuss changes participants reported experiencing in psychological flexibility overall (QUANT) and in the three aspects of psychological flexibility: behavioral awareness, openness to experience, and valued action (MIXED). Interview questions at both post-test and follow-up focused on changes experienced in these areas since beginning the program.

### Psychological Flexibility (QUANT)

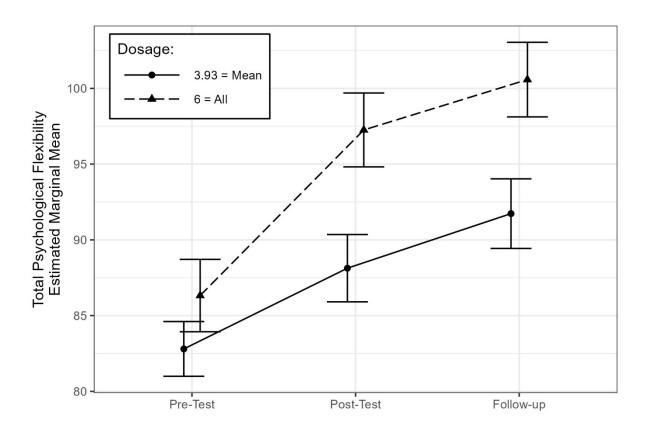
Quantitative Analysis: Overall Psychological Flexibility. Person-to-person differences accounted for 65% of the variance in overall psychological flexibility, *ICC* = .65. Parameter estimates are provided in Table 8 for the MLM supporting moderation of trajectory by dosage,  $\chi^2$  (2) = 9.44, *p* = .009. Time, dosage, and the interaction between them explained 16% of the variance in psychological flexibility, marginal  $R^2$  = .16. Time, dosage, their interaction, and random intercepts explained 73% of the variance, conditional  $R^2$  = .73. After modeling the interaction, the main effect of time was not significant (pre-post, *p* = .310; pre-follow-up, *p* = .83), but completing more sessions of ACT for Caregivers was associated with higher psychological flexibility, *b* = 1.70, *SE* = 0.75, *p* = .025.

While dose did not differentiate levels at pre-test, higher dose was associated with greater improvement over time (see Figure 14). Participants who completed 3.93 sessions of ACT for Caregivers (the mean value for the full sample) reported a significant small increase in psychological flexibility during the intervention (SMD = 0.28, p = .007) and an increase in psychological flexibility from post-test to follow-up that was approaching significance (SMD = 0.19, p = .090). Participants who completed all 6 sessions of ACT for Caregivers reported a significant moderate increase in psychological flexibility during the operation of the session of ACT for Caregivers reported a significant moderate increase in psychological flexibility during the intervention (SMD = 0.19, p = .090). Participants who completed all 6 sessions of ACT for Caregivers reported a significant moderate increase in psychological flexibility during the intervention (SMD = 0.57, p < .001) that was maintained from post-test to follow-up (SMD = 0.17, p = .104).

## Figure 14

Change in Overall Psychological Flexibility Over Time, Split by Dosage with Time x Dosage

## Interaction



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

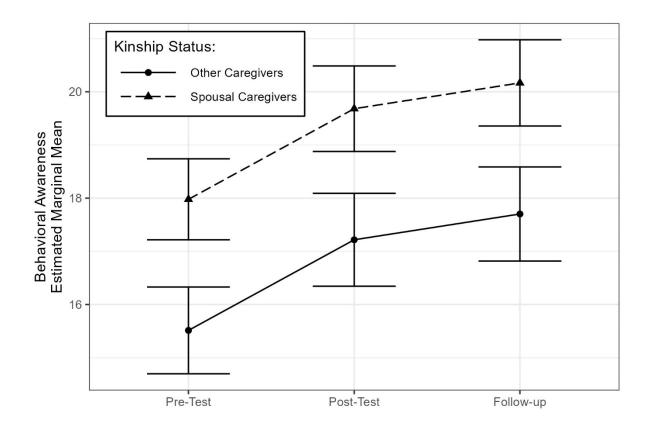
#### **Behavioral Awareness (MIXED)**

Quantitative Analysis: Behavioral Awareness Subscale of CompACT. For the behavioral awareness component of psychological flexibility, person-to-person differences accounted for 58% of the variance, ICC = .58. The best fitting model included time and kinship status,  $\chi^2$  (2) = 5.55, p = .018. Time and kinship status together explained 6% of the variance in behavioral awareness, marginal  $R^2 = .06$ . Time, kinship status, and random intercepts explained 60% of variance, conditional  $R^2 = .60$ . There was a significant small

increase in behavioral awareness during the intervention (SMD = 0.27, p = .006) that was maintained from post-test to follow-up (SMD = 0.08, p = .454; see Figure 15). Being a spousal caregiver was associated with significantly higher behavioral awareness, b = 2.46, SE = 1.04, p = .020.

# Figure 15

Change in Behavioral Awareness Over Time, Split by Kinship Status



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

#### Qualitative Analysis: Behavioral Awareness. At post-test and follow-up,

participants were asked about the impact of the program on recognizing times when they were making 'away moves' and at interrupting these away moves rather than doing things automatically. Away moves were one element of the choice point used throughout the program and were described in the interview as "times when you are doing things that move you away from the person you want to be and the things that matter to you."

*Post-test Analysis.* All but four participants reported that they were more aware of their away moves since beginning the program. Several participants reported that this awareness was new for them, like Participant 60 (female spousal caregiver for 7.3 years), who explained, "I think I was moving away a lot and not knowing it, just like avoiding things."

In addition to increased awareness of their away moves, many participants shared instances when they had recognized they were moving away from who they wanted to be and had redirected their behavior, particularly around being less reactive with the care receiver. Participant 20 (male spousal caregiver for 2.1 years) explained, "Today, instead of responding, I just didn't say anything. . . that's a very new awareness that I have right now is that I don't have to be responding right away." Participant 9 (female spousal caregiver for 1.5 years) described the "spiral" she used to get pulled into of being stuck in her thoughts and frustrated about caregiving but reported that now, "It's like, do you want to do dishes angry for 30 minutes, or do you want to just do dishes and listen to music or listen to your kids? . . . It just pulls you back to the present."

Multiple participants reported that since beginning the program they were more present and focused on what they were doing in the moment. Participant 25 (female adult child caregiver for 0.5 years) explained she was learning to be "aware of what's going on versus being a victim to it. . . now, I slow down and take a minute and think about it and try to observe what's going on." She reported that as a result, "It's just slowed me down and I feel like I'm not having, it's not reacting, but having a direction versus just thoughtlessly reacting to situations that are difficult."

*Follow-up Analysis.* At follow-up, all but two participants reported that they were better able to recognize away moves since beginning the program. Participant 40 (female adult child caregiver for 1.2 years) reported she was getting better at recognizing, "'Hey, this is not who I want to be. This is not the person I am.'" Participant 18 (female spousal caregiver for 15.5 years) explained, "I wasn't aware that I would sit and just play games on the iPad for hours because I didn't want to face anything else because I can't fix it." She continued, "I've just become aware of that. And to just stop myself and take a deep breath or turn around and walk away."

As Participant 18 makes clear, multiple participants reported that their increased awareness of their away moves was helping them to choose differently. Participant 8 (male spousal caregiver for 7.92 years) explained, "It's just a matter of redirection. If you're aware of doing something that's taking you off the path you want to be on, then obviously it's much easier to get back to where you belong." Participants emphasized learning how to pause in stressful situations and to focus on who whey wanted to be rather than motivating themselves with "should" statements like they had done in the past. Participant 25 (female adult child caregiver for 0.5 years) explained that she was working to stop her away moves "because it's the right thing to do to get closer to who I want to be versus stopping it because I should."

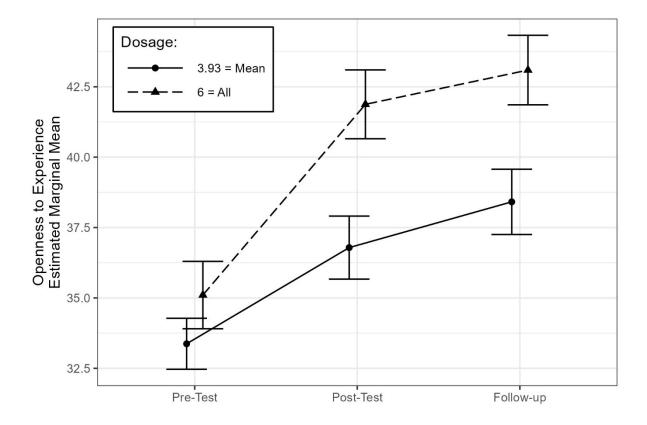
Some participants reported that acting on what they learned in the program was helping them to be more present in general, not just in stressful situations. Participant 9 (female spousal caregiver for 1.5 years) reported, "I think that [the program's] given me permission to kind of work through those range of human emotions, and I think I am a more present caregiver, I think more in the moment." As a result of living more in the moment, participants reported an increased ability to respond effectively to situations as they arose. Participant 104 (female spousal caregiver for 6.5 years) explained, "It's more peaceful, it's more centered in reality by being able to understand what's going on at that particular point in time and what I need to do to help myself as well as my loved ones."

#### **Openness to Experience (MIXED)**

Quantitative Analysis: Openness to Experience Subscale of CompACT. For the openness to experience component of psychological flexibility, person-to-person differences explained 63% of variance, ICC = .63. Parameter estimates are provided in Table 8 for the MLM supporting moderation of trajectory by dosage,  $\chi^2$  (1) = 12.22, p = .002. Time, dosage, and their interaction explained 19% of variance in openness to experience, marginal  $R^2 = .19$ . Time, dosage, their interaction, and random intercepts explained 72% of variance, conditional  $R^2 = .72$ . After modeling the interaction, the main effect of time was not significant (pre-post, p = .267; pre-follow-up, p = .844), but completing more sessions of ACT for Caregivers was associated with higher openness to experience, b = 0.84, SE = 0.38, p = .028.

While dose did not differentiate levels at pre-test, higher dose was associated with greater improvement over time (see Figure 16). Participants who completed 3.93 sessions of ACT for Caregivers (the mean value for the full sample) reported a significant small increase in openness to experience during the intervention (SMD = 0.35, p < .001) that was maintained from post-test to follow-up (SMD = 0.17, p = .135). Participants who completed all 6 sessions of ACT for Caregivers reported a significant moderate increase in openness to experience during the intervention (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.70, p < 0.001) that was maintained from post-test to follow-up (SMD = 0.13, p = .244).

## Figure 16



Change in Openness to Experience, Split by Dosage with Time x Dosage Interaction

Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

#### Qualitative Analysis: Openness to Experience. At post-test and follow-up,

participants were asked about the way they navigate challenging emotions and thoughts, and whether this had changed since beginning the program.

*Post-test Analysis.* At post-test, many participants reported that they were better able to acknowledge their feelings rather than avoiding them and to step back from their thoughts. Illustrating the change she was experiencing, Participant 80 (female adult child caregiver for 5 years) explained, "Now it's more acknowledging those feelings, where before it was just like, oh, well, just bottling them up inside and you just do what you have to do." Similarly,

Participant 11 (female spousal caregiver for 4.5 years) referenced the metaphor from the program of thoughts and feelings being like a beachball and explained, "that's what this program has been good at, is letting me put those emotions there and the guilt is there and grief there, and it can all just come along for the ride."

As a result of acknowledging their emotions, participants reported that they were less reactive. Participant 100 (female adult child caregiver for 2.8 years) compared avoiding her feelings to being like "a volcano" and reported, "[Acknowledging my emotions] helps prevent me from becoming that volcano, where I can just be like, 'okay, I felt upset, hurt, frustrated, angry when this happened. I lived it. I'm dealing with it."

Some participants reported that taking the time to acknowledge their emotions was helping them to understand and appreciate their emotions more. Participant 20 (male spousal caregiver for 2.1 years) explained,

"[I] let the wave sort of wash over me in terms of feeling the real emotion come out and then I feel a lot more calm and, I guess it's a healing process. It's helped me to deal with [it], by letting emotions come out. At first I was afraid that emotions were bad, but I can see that that's part of, a very important part of the way I handle difficult situations."

Participants reported that since beginning the program they were better able to step back from their thoughts and see them as separate from themselves or reality. Participant 104 (female spousal caregiver for 6.5 years) explained, "We all have thoughts that beat us up, but it's only thoughts and you have to learn to separate thoughts from reality. And I think that's helped me as far as not being as anxious as I once was."

In describing their growing ability to step back from thoughts, participants often referenced specific strategies taught in the program, including the guided meditation "leaves on a stream," the metaphors of seeing thoughts and feelings as being like passengers on a bus or like a beachball floating next to them, and picturing thoughts as words on paper or being said in different voices. Participant 26 (female adult child caregiver for 5 years) referenced the leaves on a stream guided meditation and reported that when her concerns became too much in the "forefront" she would practice "acknowledging that that's there and making space for that and then placing some of it on leaves so that I could reorient to what's the most important thing right now."

Participant 56 (female spousal caregiver for 5 years) recounted her experience with writing her most troubling thought in a textbox and then practicing various defusion exercises, reporting,

"I chose [to see my thought in] little letters. I thought, oh, my God, this is so funny, it's so tiny. My biggest existential fear is right there in these tiny letters. And then it said, sing it. And I thought, 'you have got to be kidding me,' I laughed so hard, and what popped into my mind as a tune was 'The Battle Hymn of the Republic' . . . it just put it in perspective."

*Follow-up Analysis.* At follow-up, participants continued to emphasize their increased ability to acknowledge feelings and move on and to step back from thoughts. Multiple participants reported that through the program they were better able to acknowledge their feelings and to not get bogged down in them. Several participants specifically highlighted how they had transitioned from fighting against their emotions to simply allowing them to be there. Participant 18 (female spousal caregiver for 15.5 years) reported, "I allow myself to have them [emotions] rather than fighting them. And if I just let myself feel those emotions rather than trying to push them back, it's easier. I get over it quicker."

Several participants reported going beyond acknowledging their feelings to actively "befriending" them and seeing that they serve a purpose. Participant 32 (female spousal caregiver for 2 years) reported that she was learning to "be the friend to those hard things." As a result, she was able to work through her disappointment at asking family for help with caregiving and being turned town, rather than "kind of scold myself or say I shouldn't feel this way." Participant 14 (female spousal caregiver for 2.2 years) explained, "You just have to acknowledge the sadness and the grief and say it serves a purpose," then elaborated that her feelings of grief were a sign of the love she felt for her husband.

Multiple participants reported that since beginning the program they had been better able to step back from their thoughts and to see them as thoughts, and that this had freed up their time and energy to focus on what they cared about. Participant 53 (female spousal caregiver for 2.2 years) reported that she was, "acknowledging that they're just thoughts, they're not necessarily reality. They're temporary." As a result, she said, "I'm able to stay calmer most of the time." Similarly, Participant 104 (female spousal caregiver for 6.5 years) reported learning, "Thoughts are just thoughts. They don't make or break a person, but you have to learn to put them in a category or put them on a shelf and let them just be that, just a thought." This helped her to "put things in perspective" rather than feeling like she was "running around in circles and just not understanding what was happening."

As a result of their efforts to acknowledge feelings and step back from thoughts, many participants reported that they were less reactive and better able to address underlying issues in a healthy way. Participant 25 (female adult child caregiver for 0.5 years) explained she was "able to deal with them [my thoughts and anxiety and worry] in a healthy way instead of being dominated by them. I kind of am just right next to them and being okay with it." Similarly, Participant 9 (female spousal caregiver for 1.5 years) explained, "It's freeing in a way. It doesn't take away the experience, it doesn't take away the frustration, but it just acknowledges it and moves on."

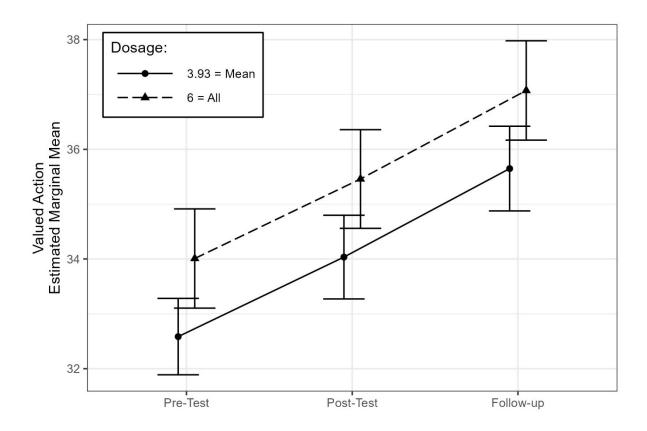
## Valued Action (MIXED)

Quantitative Analysis: Valued Action Subscale of CompACT. For the valued

action component of psychological flexibility, person-to-person differences accounted for 68% of the variance, ICC = .68. The best fitting model included time and dosage but not an interaction between time and dosage,  $\chi^2 (2) = 5.84$ , p = .054. Time and dosage together accounted for 7% of the variance in valued action, marginal  $R^2 = .7$ . Time, dosage, and random intercepts accounted for 71% of the variance, conditional  $R^2 = .71$ . There was a significant increase in valued action during the intervention (SMD = .20, p = .023) that further increased following the intervention (SMD = .22, p = .014; see Figure 17). Completing more sessions of ACT for Caregivers was associated with higher valued action, b = 0.69, SE = 0.28, p = .015.

## Figure 17

Change in Valued Action Over Time, Split by Dosage



Note. Error bars represent plus-or-minus one standard error for the mean (SEM).

**Qualitative Analysis: Valued Action.** At post-test and follow-up, participants were asked about the extent to which they felt they were able to move towards what mattered to them, and whether this had changed since beginning ACT for Caregivers.

*Post-test Analysis.* At post-test, participants reported that since beginning the program, they had clarified what was important to them, aligned their choices with their core values, and been more flexible and intentional in the context of the constraints of caregiving. Many participants reported that the program had helped them to clarify what was important to them, whether this was a specific value or a general sense of what they cared about. Participant 26 (female adult child caregiver for 5 years) reported connecting with her value of being "adventurous" and said that it "feels like it got renewed through having sat and gone through the lessons from ACT. . . it's brought me out of a percentage of being task-oriented into being life-based."

Multiple participants reported that since participating in the program they had an increased awareness of their choices and felt increased freedom to become who they wanted to be. Participant 11 (female spousal caregiver for 4.5 years) explained she used to struggle with thinking, "I am now tied down and I have to do this," but that "the idea that it's okay to move towards what matters to me was really helpful to change that way of thinking." In the process of aligning their choices with their core values, participants reported recognizing that various actions were not in line with who they wanted to be and that they were actively working to change these behaviors. Participant 22 (female adult child caregiver for 0.5 years) provides one illustrative example, explaining,

"I took some games off [my phone] because I realized, number one, I think

they actually were not helping me, [they] were interrupting my sleep at night. And then I thought, 'is this who I want to be, a video phone game person?' And I thought, 'I actually don't.' So I ended up deleting those."

Multiple participants reported that they had become more flexible and expansive in what living their values could look like within their current context since beginning the program. Participants reported re-engaging with socializing, cooking, and other hobbies and professional endeavors. Participant 67 (female spousal caregiver for 1.5 years) explained, "For a while, I was not doing my cross stitch because I felt it took up too much time away from him. . . I have taken back what I like to do, what I feel is important to me." She described the result as, "Absolutely wonderful. . . Oh, it was just liberating, shall I say? It's something that I can't hardly explain. But it is so freeing."

*Follow-up Analysis.* At follow-up, participants continued to emphasize that since beginning the program, they had clarified what matters to them, been more consistent in aligning their choices with their core values, and been more flexible and intentional in their choices. Multiple participants reported that they continued to think about their values even after the program ended. Participant 25 (female adult child caregiver for 0.5 years) explained that "The value clarification is awesome, and it kind of set the groundwork." Now she reported that she was living, "very intentionally. . . being able to do what's right for me and what gives me meaning in my life." Similarly, Participant 104 (female spousal caregiver for 6.5 years) recounted, "It's opened my eyes to what's important to me and what matters to me and what makes me happy." The result of clarifying and acting on what matters to her was, "A clearer mind. It makes me happy to be able to do the things that I love to do, even though I'm doing them on my own. And it seems to have a well-rounded feeling about my life."

Participants reported that focusing on their values while making choices was helping them to be who they wanted to be more consistently. Participant 100 (female adult child caregiver for 2.8 years) explained, "I've became nicer. I think it's been useful in that alone. Just because it makes me a better wife, it makes me a better partner, makes me a better friend, it makes me more compassionate." Similarly, Participant 56 (female spousal caregiver for 5 years) reflected on the care receiver's experience and then reported, "I do these things because if I can be kind and good and patient and loving a little bit of time during the day, that goes a long way."

Multiple participants reported that they were able to live their values more flexibly and adjust to different situations while still aligning with what matters to them. Often, this required some ingenuity on the part of the caregiver. Participant 5 (female spousal caregiver for 4.5 years) acknowledged that many of the plans she had for retirement were not possible because of the care her husband required. However, she reported, "I just try to find other things to do when I can't do the things that I used to do. Like I took a collage class for caregivers, trying to find things I can do at home that are enjoyable."

In some cases, participants reported taking prolonged or extensive valued action. Participant 46 (spousal caregiver for 2.7 years), whose husband needed a wheelchair, reported that the program had helped her work up the motivation to convert a window into a doorway so that they, "Could spend some time outside [together]." She reported that this was important to her because, "He's always in his bedroom . . . That gives him freedom." Participant 8 (male spousal caregiver for 7.92 years) explained that because of the program he, "Rededicated myself to the goal of becoming more healthy." He reported that he had taken steps to accomplish this in the past but had not followed through; however, now he was doing so on "a more level and consistent basis." As a result, he reported, "It helps with my mental situation. It gives me a certain degree of peace."

#### Section 5: Context of Caregiving (QUAL)

In this section, we focus on participants' report of relevant aspects of their context that influenced their experience of caregiving. Participants' responses focused on three components: relationship history, transition to caregiving, and social support.

## **Relationship History**

Many participants highlighted that their experience of caregiving was influenced by their previous relationship with the care receiver. Participants' responses suggested that having a close relationship with the care receiver prior to caregiving increased feelings of connection and compassion, while also amplifying the grief caregivers experienced. Participant 60 (female spousal caregiver for 7.3 years) described her relationship with the care receiver prior to dementia as, "the best it had been our whole married life . . . I guess that was another frustration, that it's never going to be the way it was." Only a few participants reported a poor relationship with the care receiver prior to caregiving. Some of these caregivers reported that caregiving improved their relationship, like Participant 100 (female adult child caregiver for 2.8 years) who described her current relationship with the care receiver as, "a complete 180. . . the beauty in the disease is that we [have] become really close."

#### Transition to Caregiving

Most participants reported ambiguity around exactly when caregiving had begun, although some participants reported becoming caregivers due to a discrete event such as a hospitalization for the care receiver. Participant 9 (female spousal caregiver for 1.5 years) reported, "I've been providing care, technically almost a year since diagnosis. But obviously being in a marriage, you're caring for one another on and off." A few participants reported that prior experience with caregiving had helped them with the transition to caring for someone with dementia. Participant 61 (female spousal caregiver for 3.5 years) reported, "This isn't the first time I've done caregiving. I took care of my mother about 20 years ago with end stage cancer, so [I was] kind of aware of the expectations and what needs to get done." Although prior experience was helpful, these participants also emphasized that caregiving for someone with dementia was different than caregiving for someone with a different condition due to its progressive nature and loss of connection with the care receiver.

#### Social Support

At post-test participants described the involvement of others in caregiving and their relationships with others. Participants highlighted the importance of leaning into social support, building a caregiving network, and becoming willing to ask for help. Several participants reported that they were the only ones providing care for the care receiver.

While 20 participants reported that at least one other person was regularly involved in providing care, 8 participants reported that they were the only ones who regularly provided care. Most participants who were acting as sole caregivers or nearly so reported wishing that others would be more involved. Participant 53 (female spousal caregiver for 2.2 years) reported, "I've had some challenges getting his kids involved. . . sometimes I feel kind of alone with some of the decisions that have to be made."

Multiple participants emphasized the importance of family, friends, medical professionals, and faith as helpful resources to navigate the challenges of caregiving. Participant 134 (female adult child caregiver for 4 years) explained, "Mostly I just depend on my friends, like I say, that have gone through this. And my husband." Participant 84 (male spousal caregiver for 8.2 years) reported turning to God for support and praying, "God, give me the ability to cope with what's going on. You aren't going to make it better in this side of eternity, but I just hope I can cope and help her to get through the problem."

Many participants reported seeking interaction with other caregivers through support groups or social media to discuss challenges and seek and offer solutions. Participant 8 (male spousal caregiver for 7.92 years) explained that for him, the "exchange" of knowledge with "people that understood exactly what I was talking about" had been deeply helpful. Similarly, Participant 100 (female adult child caregiver for 2.8 years) reported that she would connect with other caregivers via social media and "try and take what's worked for others . . . and also share what I've learned."

At post-test, four participants (30, 32, 46, and 80) reported that the program had helped them to become more willing to ask for help and that this had improved their experience of caregiving. Participant 32 (female spousal caregiver for 2 years) explained, "We need the kids. Asking for help has been hard. I've had to learn, and the program has helped with that. I have to ask for help, and that's been big." At follow-up, these same four participants continued to emphasize that the program had helped them to become more willing to ask for help. Participant 80 (female adult child caregiver for 5 years) explained, "It's hard to ask for help because you think you need to take care of it . . . taking this class is like, you can ask for help and it will be okay."

#### Section 6: Negative Cases (MIXED)

We defined negative cases based on both qualitative and quantitative criteria. For the quantitative sample, we defined negative cases as participants who reported worsening in three or more quantitative outcomes over time.

## Identifying Negative Cases

**Qualitative Analysis.** For the qualitative subsample, we explored participants who reported little or no impact from the program in response to interview questions about change in quality of life, behavioral awareness, openness to experience, and valued action. Because all areas were assessed at both time points, this led to a range of zero to eight areas of little or no impact. We defined negative cases as participants who reported no impact from the program in at least two of the eight categories.

In their qualitative interviews, five participants reported only partial impact from openness to experience (either benefitting from stepping back from thoughts or from acknowledging feelings), two participants reported change in valued action but not because of the program, and four participants (Participants 30, 61, 84, and 112) reported no impact or little impact in five or more areas. These four participants were identified as self-reported negative cases.

**Quantitative Analysis.** To quantitatively identify negative cases, we explored raw change scores from time 1 to time 3 and flagged any participants who reported worsening in quantitative outcomes over time. Despite average improvement on all quantitative outcomes from pre-test to follow-up, fourteen participants reported some worsening in at least one area; only two participants (Participants 9 and 26) reported worsening on three or more outcomes. Participants 30 and 61 reported worsening in two areas. Although the small sample size of the negative cases prevents statistical comparisons, descriptive summaries are informative.

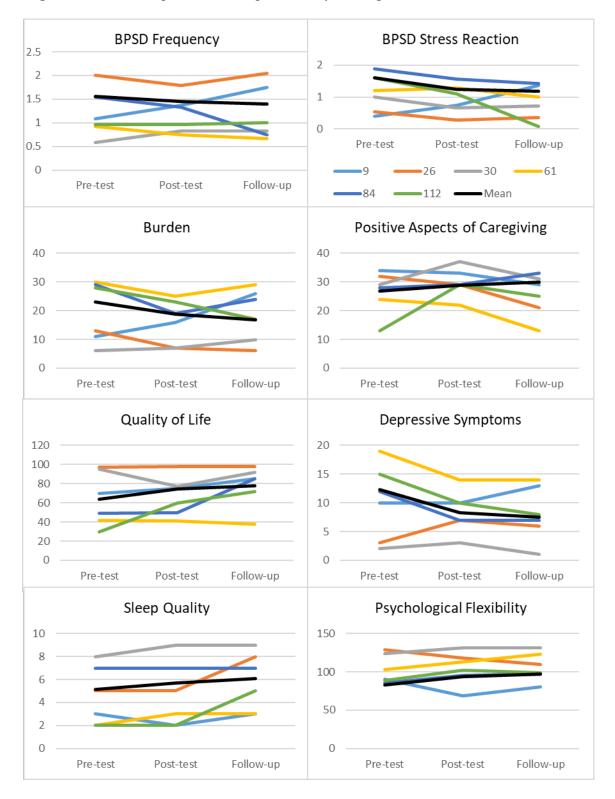
## **Exploring** Negative Cases

Six total participants were identified as negative cases: Participants 30, 61, 84, and 112 (QUAL), and Participants 9 and 26 (QUANT). In terms of demographics, five negative

case participants were spousal caregivers coresiding with the person with dementia and one participant (Participant 26) was an adult child who was not coresiding with the person with dementia. Four negative case participants were female and two were male, all were White, and all had been caregiving for at least two years. Two negative case participants had previous experience with caregiving; three were caregiving for someone with Alzheimer's disease and three were caregiving for someone with another diagnosed dementia.

**Quantitative Exploration.** Despite their qualitative report, Participants 84 and 112 reported improvement in all quantitative outcomes from pre-test to follow-up, with the exception of stable sleep quality for Participant 84 (see Figure 18 for raw scores and Figure 19 for change scores). While not examined statistically, it is interesting to note that they experienced more than double the improvement in quality of life compared with the full sample (84: change score = 36; 112: change score = 32; mean change score = 14.30). Interestingly, Participant 84 (male spousal caregiver for 8.2 years) reported a substantial reduction in BPSD frequency (change score = -19), whereas Participant 112 (male spousal caregiver for 2.1 years) reported a slight increase (change score = 1; mean change score = -3.73).

# Figure 18



# Negative Case Participants and Sample Means for All Quantitative Outcomes

*Note.* BP*SD* = Behavioral and Psychological Symptoms of Dementia. Legend provided in BPSD stress reaction chart matches all charts in the figure.

Participant 30 (female spousal caregiver for 2 years), who reported qualitatively that the program had not been much benefit to her due to her previous experience, had baseline ratings that may suggest a floor and ceiling effect. At baseline, she had very low depressive symptoms, very high quality of life, and high psychological flexibility. Thus, the slight worsening she reported in quality of life and burden may have been due to natural fluctuations. Despite her qualitative report, from pre-test to follow-up she did report slightly lower depressive symptoms (change score = -1; mean change score = -4.80), slightly higher positive aspects of caregiving (change score = 2; mean change score = 3.11), and slightly higher psychological flexibility (change score = 7; mean change score = 14.58), although the change seems less than the sample average.

# Figure 19



Comparing Change Scores for Negative Case Participants and Sample Average

*Note.* BPSD = Behavioral and Psychological Symptoms of Dementia. (-) = Negative scores are improvement. (+) = Positive scores are improvement. For sleep quality, some participants reported no change, so their columns are not shown on the graph.

Participant 9 and 26 both reported quantitative worsening in multiple outcomes. Participant 9 (female spousal caregiver for 1.5 years) reported worsening in burden and BPSD stress reaction from pre-test to follow-up. Interestingly, and supporting her assertion in the qualitative interview that the care receiver's dementia had progressed, she reported a large increase in BPSD frequency (change score = 16, mean change score = -3.73) from pretest to follow-up. She also reported slightly worse psychological flexibility (change score = -10, mean change score = 14.58) and depressive symptoms (change score = 3, mean change score = -4.80). Nevertheless, she reported an improvement in quality of life that was comparable to the full sample.

Participant 26 (female adult child caregiver for 5 years) started with very high quality of life and psychological flexibility and very low depressive symptoms, burden, and BPSD stress reaction; her positive aspects of caregiving was slightly higher than the mean (baseline = 32, mean for sample = 26.79). She reported worsening in positive aspects of caregiving and psychological flexibility from pre-test to follow-up. Although her worsening on psychological flexibility seems large (change score = -19, mean for sample = 14.95), she still scored 12.25 points higher than the mean value at follow-up. She reported a large worsening for positive aspects of caregiving (change score = -11, mean for sample = 3.3) that placed her well below the sample average (score = 21, mean for sample = 30.09). Despite this, she did report improvement in burden (change score = -7, mean change score = -6.16), quality of life (change score = 1, mean change score = 14.30), and BPSD stress reaction (change score = - 0.18, mean change score = -0.42). The slight worsening she reported for depressive symptoms (change score = 3, mean for sample = -4.80) may have been due to a floor effect and regression to the mean, as she still scored below the sample average.

At baseline, Participant 61 (female spousal caregiver for 3.5 years) had higher psychological flexibility (baseline = 103, mean for sample = 82.8) and lower BPSD stress (baseline = 1.20, mean for sample = 1.61) than the sample average. Her quality of life, depressive symptoms, and burden were all worse than the sample average at baseline. At time 3, she reported a very small improvement in burden (change score = -1, mean change score = -6.16), small improvement in BPSD stress reaction (change score = -0.20, mean change score = -0.42), improvement in depressive symptoms that was comparable to the full sample (change score = -5, mean change score = -4.80) and large improvement in psychological flexibility (change score = 20, mean change score = 14.58). She reported slight worsening in quality of life (change score = -4, mean change score = 14.30) and a large decrease in positive aspects of caregiving (change score = -11, mean change score = 3.11). She reported a relatively large reduction in BPSD frequency (change score = -6, mean change score = -3.73).

**Qualitative Exploration.** The four self-identified negative cases (30, 61, 84, and 112) reported that the primary reason they did not benefit from the program was because they already knew the skills the program was trying to teach them from previous caregiving experience, prolonged individual therapy, or other caregiving resources. At follow-up, Participant 30 (female spousal caregiver for 2 years) explained, "Because I've been through this for so many years, basically, the lessons that I read through are basically part of my scope anyway." All of the self-reported negative cases rated the program in some way—

giving it a "B" rather than an "A," "3" out of 5, or "5" out of 10. Their responses highlighted that they considered the program not altogether bad, just not useful for them personally. In light of this, three of them reported that ACT for Caregivers would have been helpful early on, like Participant 112 (male spousal caregiver for 2.1 years) who explained, "ACT for Caregivers might have been helpful at the start, but I had been through so much already."

In contrast to self-reported negative cases, Participants 9 and 26 were very positive about the impact of the program in their qualitative interviews. Participant 9 (female spousal caregiver for 1.5 years) reported feeling that her husband's dementia had significantly worsened over the time between assessments, explaining that caregiving had been more difficult "since starting the program to now because we've had a few weeks where we've seen a little bit more of the change." She reported being grateful for the timing of the program to help her navigate these changes. Participant 26 presents a more complicated case because there is little evidence in her qualitative interviews to explain worsening in quantitative outcomes. She reported that the program helped her to experience "renewal" and "to be able to breathe." She reported that prior to beginning the program, "I was starting to feel, like I said, depleted and stretched. And so the ACT [for Caregivers program] helped me remember and to kind of come back into the big tenets of who I am, what I live, what's important."

#### CHAPTER V DISCUSSION

The purpose of this study was to use longitudinal mixed methods in a convergent parallel design to examine the effectiveness of a shortened version of ACT for Caregivers (Creswell & Plano Clark, 2018; Schumacher et al., 2021). Quantitative evidence shows that after beginning ACT for Caregivers, participants on average experienced improvements in depressive symptoms, burden, positive aspects of caregiving, BPSD stress reaction, quality of life, and psychological flexibility, and that these improvements were either sustained or increased at follow-up. Qualitative evidence provides corroborating evidence for these improvements and offers insight into common aspects of change.

The present study constitutes a significant contribution to the work on online, selfguided interventions with family caregivers for people with dementia. Aligning with work by Lappalainen et al. (2021b) and Kishita et al. (2022) our results suggest that online interventions can be acceptable and helpful for family caregivers for people with dementia. Expanding beyond Lappalainen et al. (2021b) and Kishita et al. (2022), the ACT for Caregivers program was entirely online and self-guided, rather than including regular interaction with trained helpers or support groups. This is an important consideration in terms of scalability of the intervention, as no trained professionals are required to deploy the intervention once developed. This is particularly promising in light of the growing number of family caregivers and the lack of evidence-based resources at many Area Agencies on Aging (Alzheimer's Association, 2023).

The present study used Pearlin et al.'s (1990) stress process model as a conceptual framework to integrate the quantitative and qualitative arms of the study. In doing so, we mapped modern intervention strategies (ACT) onto a well-established model of caregiver

stress. This allowed us to be holistic in our examination of the impact of ACT for Caregivers on relevant outcomes for family caregivers. Results suggest that Pearlin et al.'s (1990) stress process model of caregiving captures many of the aspects of caregiving that are salient in understanding caregiver outcomes and that it can be well integrated with ACT.

The present study also makes a significant contribution in the realm of using mixed methods to evaluate ACT-based interventions. ACT evaluations are overwhelmingly quantitative, with a scant minority being qualitative; very few are mixed methods, and those that are typically rely on very small samples that limit the use of advanced statistical modeling techniques (e.g., Han et al., 2021b). In contrast, our study collected a sufficient sample size in both the quantitative and qualitative portions to allow for effective integration.

#### **Care-Specific Outcomes**

Based on Pearlin et al.'s stress process model of caregiving, several variables are identified as being specific to caregiving: BPSD stress reaction, burden, positive aspects of caregiving, quality of life, and depressive symptoms.

#### **Quantitative** Analyses

**Hypothesis 1.** Quantitative analyses support hypothesis 1, in that on average participants reported improvement in all care-related quantitative outcomes over time. All care-related quantitative outcomes assessed improved over time, primarily during the intervention. In addition, two quantitative outcomes (burden and quality of life) showed significant continued improvement between time 2 and time 3, suggesting the lasting impact of the program. Other quantitative outcomes (BPSD stress reaction, positive aspects of caregiving, and depressive symptoms) were trending towards continued improvement between time 2 and time 3, although this was not significant. The finding of stability in

improvements over time mirrors the results of the pilot study (Fauth et al., 2021), whereas the finding of continued improvement for quality of life and burden after the intervention suggests the lasting impact of the program.

Overall, quantitative findings suggest that the shorter version of ACT for Caregivers had similar or larger impact on caregiver outcomes as the longer version evaluated in the pilot study, based on statistical significance and effect sizes (Fauth et al., 2021). Standardized mean differences as effect sizes from pre-test to post-test ranged from a small improvement of 0.19 (positive aspects of caregiving) to a moderate improvement of 0.60 (depressive symptoms). Standardized mean differences from pre-test to follow-up ranged from a small improvement of .34 (mean BPSD stress reaction) to a moderate improvement of .74 (depressive symptoms).

Contrary to the pilot study results (Fauth et al., 2021), caregivers reported lower frequency of BPSD from pre-test to post-test, and dosage of ACT for Caregivers and kinship status were not significantly associated with this decrease. It is possible that caregivers were responding to the care receiver more appropriately, thus driving the decrease (see also Norton et al., 2009); it is also possible that other factors drove the change. Further research is necessary to determine whether this is replicable. This presents a potential confounding factor for results, as caregivers' outcomes may have improved at least in part due to experiencing fewer BPSD over time. This is particularly plausible for BPSD stress reaction and burden, since research suggests that BPSD frequency is the most significant care receiver characteristic on burden (Chiao et al., 2015; Contreras et al., 2021). However, the reduction in BPSD stress reaction over time remained significant even when BPSD frequency was included in the model. Further analyses are necessary to establish the robustness of the findings of significant moderate improvement in burden.

**Hypothesis 2.** In partial support of hypothesis 2, dosage of ACT for Caregivers was associated with higher quality of life and lower depressive symptoms and BPSD stress reaction. However, dosage was not significantly associated with burden or positive aspects of caregiving, and there were no significant interactions between dosage and time for any care-related outcomes. It may be that the current study was underpowered to detect a significant effect or interaction. Inclusion of dosage as a covariate is an important part of continued program development and constitutes a meaningful expansion of Fauth et al.'s (2021) pilot study, since their evaluation only included data from program completers. It is possible that participants who were less distressed at pre-test were better able to engage with the intervention. Further research is needed to explore this association.

**Hypothesis 3.** In partial support of hypothesis 3, kinship status was a significant predictor for positive aspects of caregiving and quality of life. For both outcomes, being a spousal caregiver was associated with poorer outcomes than other caregivers. Contrary to expectations, kinship status was not a significant predictor for BPSD stress reaction, burden, or depressive symptoms. It may be that the current study was underpowered to detect a significant effect. At the same time, previous research has found that kinship status is an inconsistent predictor for caregiver outcomes (Collins & Kishita, 2020). Our finding that spousal caregivers reported fewer positive aspects of caregiving may support earlier work that caregiving for a spouse is more anticipated, and therefore less likely to be interpreted as meaningful (Viñas-Diez et al., 2017).

## **Qualitative** Analyses

Qualitative results corroborate the general pattern of change observed in the full

sample, and provide additional information about areas of meaningful change. Although there were no direct comparisons for BPSD stress reaction or depressive symptoms, participants in the qualitative subsample self-reported experiencing meaningful improvement in the way they navigate the most challenging aspects of caregiving (burden) the extent to which they find caregiving meaningful (positive aspects of caregiving), and quality of life.

For burden, participants reported at follow-up that they were being less reactive to the challenges of caregiving and that they were better able to explore and implement alternative strategies for helping the care receiver. For positive aspects of caregiving, participants reported at follow-up that connecting with their values and applying the skills from the program to manage stress had both helped them to focus on the meaningful parts of caregiving. The qualitative subthemes for common elements of caregiving that participants highlighted as meaningful at post-test map on to the domains identified by Yu et al. (2018) in their meta-analysis. Participants responses included both descriptions of meaningful and challenging aspects of caregiving, supporting Baltes et al.'s (2006) emphasis on development involving both gains and losses. For quality of life, participants reported feeling less stressed and more calm, and that they had a general sense of increased capacity to manage the demands of caregiving.

Participants also reported that the program had helped them to take better care of themselves and to improve their relationship with the care receiver by helping them to be less reactive and to treat the care receiver with more kindness and compassion. Multiple participants referenced their values and reported that they were actively remembering and aligning their behavior with their values in the way they treated themselves and in their interactions with the care receiver. Many of participants' responses map onto the construct of person-centered care (Lee et al., 2020). Lending qualitative support to earlier quantitative work (Lee et al., 2020), some participants reported that changing the way they interacted with the care receiver led to less stress and reactivity from them, thus making caregiving itself slightly easier. This suggests that the program may have created interpersonal change, in addition to intrapersonal change. This finding merits further quantitative and qualitative exploration.

#### **Changes in Psychological Flexibility**

#### **Quantitative** Analyses

**Hypothesis 1.** Quantitative analyses for psychological flexibility support hypothesis 1, showing that there was significant improvement in mean psychological flexibility and each of its subscales—openness to experience, behavioral awareness, and valued action—over time. The main effect of time was significant in the models for behavioral awareness and valued action; in the models for overall psychological flexibility and openness to experience there was a significant interaction between time and dosage. Overall psychological flexibility, behavioral awareness, and openness to experience showed significant improvement during the intervention that was sustained from post-test to follow-up, whereas valued action showed significant improvement during the intervention changes in valued action takes time, since the pilot study similarly found that significant change in valued living (assessed using a different scale) did not occur until the follow-up assessment (Fauth et al., 2021).

Overall, quantitative analyses for psychological flexibility suggest that the program effectively improved psychological flexibility over time, but that the degree of change was influenced by the dosage of ACT for Caregivers. **Hypothesis 2.** Quantitative analyses for psychological flexibility lend partial support to hypothesis 2, showing that there was a significant interaction between time and dosage for overall psychological flexibility and openness to experience. Post-hoc comparisons using Kenward-Rogers degrees of freedom showed that participants who completed 3.93 sessions (the mean number of sessions completed in the program for the full sample) reported a significant small increase in overall psychological flexibility and openness to experience during the intervention and a significant moderate increase in overall psychological flexibility and openness to experience from pre-test to follow-up. The pattern of results for participants who completed all six sessions of ACT for Caregivers was similar for overall psychological flexibility and openness to experience, with larger standardized mean differences. These findings suggest that the impact of ACT for Caregivers is related to the dosage, further highlighting the need to include dosage in future studies.

In addition, as with the care-related outcomes, completing more sessions of ACT for Caregivers was associated with higher overall psychological flexibility, openness to experience, and valued action. Dosage was only marginally significant in the model for behavioral awareness, and so was dropped from the model. It is likely that our lack of finding a significant effect of dosage for behavioral awareness was due to being underpowered. This suggests that individuals who were already higher in psychological flexibility were more able to engage with the intervention. Further research is needed to explore what factors predict treatment adherence.

**Hypothesis 3.** In partial support of hypothesis 3, kinship status was significantly associated with behavioral awareness, with being a spousal caregiver associated with higher levels of behavioral awareness. Contrary to expectations, kinship status did not significantly

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predict overall psychological flexibility, openness to experience, or valued action. It may be that psychological flexibility is independent of kinship status, and that other contextual variables may be more salient (e.g., co-residing with the person with dementia, presence of additional health challenges).

## **Qualitative** Analyses

Qualitative results corroborate the general pattern of change observed in the full sample and suggest areas of meaningful change. It is important to note that due to our selection criteria for the qualitative subsample, all qualitative participants completed all six sessions of ACT for Caregivers, so, based on the quantitative results, they may have experienced more change in psychological flexibility than participants in the overall sample.

For behavioral awareness, openness to experience, and valued action, participants described meaningful changes at post-test and follow-up. Participants' responses suggested that the changes they had initiated at post-test were being maintained or added to. Within ACT, values is the element of psychological flexibility that is most closely connected with personal intrinsic motivation for change (Hayes, 2019). Consistent with this theoretical orientation, qualitative participants repeatedly emphasized clarifying their values and focusing on what matters as being key contributors to their change in other areas.

#### **Negative Case Analysis**

Six participants were identified as negative cases based on their qualitative report (four participants) or on their experiencing worsening in three or more quantitative outcomes (two participants). Quantitative and qualitative data largely converged for two negative case participants, Participants 30 and 61; they reported experiencing little improvement in their qualitative interviews, and their quantitative data corroborates that they experienced worsening on two outcomes each. However, quantitative and qualitative data diverged for Participants 84, 112, 9, and 26. Participants 84 and 112 reported experiencing little improvement in their qualitative interviews, but their quantitative data show that they experienced improvement at or above the mean change for nearly all outcomes. Participants 9 and 26 reported experiencing large improvement in their qualitative interviews, but their quantitative data show that they experienced little improvement and even worsening on multiple quantitative outcomes.

To some extent, Participant 9's qualitative report of the care receiver's worsened dementia converges with her quantitative report of higher BPSD frequency, BPSD stress reaction, and burden, particularly in light of research that strongly connects BPSD and burden (Chiao et al., 2015; Contreras et al., 2021).

However, the divergence for Participants 26, 84, and 112 is more difficult to reconcile. While response bias is a possible interpretation for Participant 26's divergent qualitative data, this seems unlikely considering the agreement between her two interviews. Rather than invalidating either quantitative or qualitative data, divergence of methods highlights the utility of mixed methods research in examining the holistic impact of interventions with family caregivers. Caregiving is complex and multifaceted, and it is possible that the qualitative questions highlighted different aspects of change than the quantitative questions, potentially allowing participants to have improved on the dimensions assessed qualitatively while worsening quantitatively, and vice versa. This seems particularly likely for Participants 84 and 112, since the qualitative questions assessed only some of the aspects of quality of life, behavioral awareness, openness to experience, and valued action. Future mixed methods evaluations should incorporate more aspects of each of these constructs within the qualitative interviews.

Self-identified negative cases reported that the reason for their perceived lack of improvement was that they had already learned much of the content from the program from other sources due to their extensive involvement with other caregiver resources. They also suggested that the program was most suited for caregivers who were early in the experience of caregiving, a sentiment that was echoed by several other qualitative participants who still reported benefitting from the program. Evidence suggests that the needs of caregivers change throughout the career of caregiving (Aneshensel et al., 1995; Zarit & Whitlach, 2023). Further research is needed to determine whether the effectiveness of the program is associated with duration of caregiving.

### **Clinical and Program Implications**

The high acceptability ratings for the revised version of ACT for Caregivers suggest that the program was acceptable and useful for participants and that the technology-based nature of the program was not a significant barrier. This is encouraging and supports continued efforts to improve and condense the program. The current study supports ACT as a transdiagnostic approach that can be usefully applied in a variety of contexts (Bannon et al., 2022).

The revised version of ACT for Caregivers built on the pilot version evaluated in Fauth et al. (2021) and made multiple modifications. In the process of condensing the sessions from 10 down to 6, the program used the visual metaphor of the choice point in each session to orient participants to the relevant content. Many qualitative participants referenced the idea of making choices and used language from the choice point (e.g., towards moves, away moves) and reported that this was helpful in their everyday lives. Results suggest that the choice point is a useful heuristic for understanding the various components of ACT, and should thus be included in future iterations of the program.

Several qualitative participants who were caregiving for someone with a form of dementia other than Alzheimer's disease opined that at times the examples from the program did not feel relevant to them (e.g., they were caregiving for someone with primary progressive aphasia and one of the examples included the care receiver asking the same question repeatedly). Future versions of the program should utilize participatory action research during program development to incorporate the lived experience of family caregivers for a variety of forms of dementia. It may even be appropriate to create slightly different versions of the program based on the diagnosis of the person with dementia, which could contribute to improved acceptability.

#### **Directions for Future Research**

The data for this study can be used in multiple future analyses. Since the present study demonstrated improvement in psychological flexibility and each of its subscales over time, future analyses should explore whether changes in psychological flexibility moderated or mediated changes in other outcomes. This is consistent with Pearlin et al.'s (1990) conceptualization of coping as potentially mediating or moderating the stress process, and with the nature of psychological flexibility as the mechanism of change within ACT (Hayes et al., 2013). The qualitative data can be further analyzed to attend to within-person patterns of change and stability, as well as interviews with participants who did not complete the program. This analysis is important to better understand the impact of the program at a

within-person level and to understand potential reasons why participants did not complete the program.

The current study suggests multiple avenues for additional studies. In using longitudinal mixed methods research, the study lays the foundation for future program evaluation of the next iteration of ACT for Caregivers. Integrating qualitative and quantitative information provides a holistic understanding of participants' experiences of change through the intervention, and thus should continue. In particular, future work should include qualitative assessment of change at multiple time points for all outcome variables to allow for fully longitudinal mixed methods research (Schumacher et al., 2021).

This study constitutes the first known application of DQA to a mixed methods context, and results are promising (Fife & Gossner, 2024). DQA allowed for a comprehensive integration of quantitative results with qualitative results by organizing results according to a well established conceptual framework (Pearlin et al., 1990), while also allowing for flexibility in integrating additional constructs that were not originally anticipated (e.g., person-centered care). Future mixed methods evaluation research should consider using DQA as a useful methodology.

Additionally, future research should compare different versions of ACT for Caregivers (the original, the current one, and a shortened one that does not include the choice point) to allow for examination of the active ingredients of the intervention and to determine the impact of dosage and content on participant outcomes.

In the present study, most participants were caring for someone with Alzheimer's disease or someone who was undiagnosed. This limited our ability to examine whether the influence of the program was moderated by diagnosis of the person with dementia. In light of

the meaningful differences in disease symptom profiles and progression, future research should collect samples that include care receivers with a variety of diagnoses and directly compare intervention effectiveness.

#### Limitations

The present study has multiple strengths, including evaluating outcomes over time with both quantitative and qualitative data, using advanced statistical modeling techniques, and using a conceptual framework that allows for the integration of quantitative and qualitative data. At the same time, several limitations of the current study require that results be interpreted with caution. First, although the design included a randomized controlled trial, the lag between the waitlist and treatment conditions was only one time point (from pre-test to post-test). The present analyses pooled data from participants in the treatment and waitlist conditions at all three time points to maximize power. This inhibits the ability to conclude that participants' improvements were directly caused by the program.

Second, multilevel modeling allowed for modelling of random intercepts for each outcome; however, there were insufficient participants and time points to model both random intercepts and random slopes. This is an important limitation to consider, since it required that the rate of change be the same for all participants in the model. Future research should include more participants and an additional time point to allow for modelling both random intercepts and random slopes.

Third, although there was acceptable retention in the present study, there was some attrition, with participants decreasing from 113 at pre-test to 84 at post-test and 80 at followup. Despite the present study being potentially underpowered, the study found significant improvement for all outcomes over time. Nevertheless, independent samples t-tests suggests that participants who did not complete the post-test had worse baseline scores on BPSD stress reaction, depressive symptoms, quality of life, and psychological flexibility than participants who did complete the post-test. Thus, improvement found in the study may have been due to a selection effect. This is consistent with other research that suggests more distressed individuals are more likely to drop out early from therapy (Lippke et al., 2021; Mitchell et al., 2023). Future research with intent-to-treat models is necessary to examine the effectiveness of the program for highly stressed caregivers.

Fourth, despite efforts to recruit participants through national networks of caregivers, the present study was heavily biased towards White, female caregivers. This may limit the generalizability of results. Future research with more diverse samples is necessary in order to understand whether program effectiveness is influenced by sociodemographic variables.

Fifth, although the semi-structured interview guide was intended to map onto quantitative outcomes, negative case participants suggest that some of the quantitative constructs may not have been fully explored in the interviews. Additionally, the qualitative interviews asked participants whether change had occurred "since beginning the program," so it was only possible to assess change from pre-test to follow-up, rather than from post-test to follow-up.

## Conclusion

Family caregivers for people with dementia are at risk for negative outcomes, including high levels of burden, depressive symptoms, anxiety symptoms, and suicidal ideation, and lower levels of positive aspects of caregiving and quality of life (Collins & Kishita, 2020; Contreras et al., 2021a; del-Pino-Casado et al., 2019; Quinn & Tomms, 2019). This study provides longitudinal mixed methods support for ACT for Caregivers as an online, self-guided intervention for family caregivers for people with dementia. ACT for Caregivers was condensed from 10 sessions down to 6 sessions and incorporated the choice point as a visual metaphor to tie different sessions together. Participants reported small to moderate improvement in all quantitative outcomes during the intervention that were sustained or increased from post-test to follow-up. The qualitative subsample reported meaningful improvement in burden, positive aspects of caregiving, quality of life, self-compassion, psychological flexibility, and their relationship with the care receiver. Negative case participants served to highlight areas for improvement in assessment in future studies, as well as potentially suggesting that the program may be most beneficial for caregivers who are early in the career of caregiving. Further research is needed to continue to refine and improve the ACT for Caregivers program.

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APPENDICES

# Appendix A. Additional Tables and Figures

## Table 1A

Mapping of Quantitative Measures and Qualitative Questions onto Mixed Constructs

Construct	Quantitative Measure	Qualitative Interview Questions
Burden	12-item [short] Zarit Caregiver Burden Interview (Bédard et al., 2001)	What parts of caregiving do you
Positive Aspects of Caregiving	Caregiving measure (Tarlow et al., 2004)	What parts of caregiving do you find most meaningful? Would you say that your ability to kind of focus on the meaningful parts of caregiving has changed at all since beginning ACT for Caregivers?
Quality of Life	1-item visual analogue scale (de Boer et al., 2004)	Taking the broadest view possible, how would you say that the ACT for Caregivers program has influenced your quality of life overall?
		Have you found that the way you treat yourself has changed since beginning the program?
		Looking back, how well do you feel the program addressed your needs as a caregiver?
Behavioral Awareness	5-item Behavioral Awareness subscale from compact measure (Francis et al., 2016)	When you are doing things that move you away from the things that matter to you and the person you want to be. We called these "away moves." To what degree do you feel like your ability to recognize when you are making away moves has changed since participating in ACT for Caregivers? When you recognize these away moves, what helps you to change course? (and follow-up questions)

(Francis et al., 2016)	thoughts, which we called unhooking. How useful has this been for you? Are there any particular techniques that have been useful for you?
	On stressful days, what do you do now to manage your stress, thoughts, and feelings? How is this different from what you did before beginning this program?
Valued Action 8-item Valued Action subscale from compact measure (Francis et al., 2016)	Since beginning the program, do you feel like you've been able to move towards the things that matter to you more regularly/intentionally? What has that experience been like? (and follow-up questions)

Note. All data was analyzed for the current study, and participants' responses were

categorized according to the sensitizing construct that they addressed, regardless of what

question they were responding to.

## Appendix B. Semi-Structured Interview Guide

## **Post-Test**

## **Experience of Caregiving**

To get started, I want to understand a little about your experiences with caregiving overall. Can you briefly give me just a little information about who you are caregiving for, how long you have been doing it, what caregiving looks like for you right now, and how much of your time you spend caregiving each week? What was your relationship like with the person you are caring for before you started caring for them? Are there other people involved in caring for your loved one (how much)?

- What parts of caregiving do you find most meaningful?
- What parts of caregiving do you find most challenging?
- As you've been learning how to be a caregiver, what has that process been like? How has your experience of caregiving changed over time?

## **Overall Changes**

- I am interested in hearing your overall experience with ACT for Caregivers. Before I ask you any questions that might get you thinking about specific things, would you please give me your overall opinion of ACT for Caregivers?
- Can you please tell me the most helpful things you learned from ACT for Caregivers?
- Broadly speaking, in what ways has what you learned from ACT for Caregivers influenced your caregiving? What about other areas of your life?

## **Process-Based Questions**

• One of the focuses of the program was on helping you move towards what matters to you, even with difficult thoughts and feelings. Do you feel like you've been able to

move towards the things that matter to you more regularly/intentionally? What has that experience been like? [if not mentioned, can you give an example?]

- Can you describe some things you have done since beginning the program to move towards what you care about?
- What do you think has gone in to you being able to move towards what matters to you?
  - Probe: Part of the program involved you connecting with your values.
     How useful has this been for you?
  - Probe: Were there any activities or metaphors that have helped you to do this?
- Another focus of the program was identifying times when you are doing things that move you away from the person you want to be and the things that matter to you. We called these "away moves." To what degree do you feel like your ability to recognize when you are making away moves has changed by participating in ACT for Caregivers? When you recognize these away moves, what helps you to change course?
  - Probe: What effect did learning about this have on your actions? How has this impacted your life overall?
  - Probe: Can you share an example of what this has looked like?
- Another focus of the program was helping you take a step back from thoughts, which we called unhooking. How useful has this been for you? Are there any particular techniques that have been useful for you?

- If so, can you describe a time when you were able to use these techniques and it was helpful?
- Caregiving can be very meaningful, and there are still many difficult days, with plenty of stressful thoughts and feelings. Think about one of these difficult days.
  - On these stressful days, what do you do now to manage your stress, thoughts, and feelings? How is this different from what you did before beginning this program?
  - Have you found that the way you treat yourself has changed since beginning the program?
  - Taking the biggest perspective possible, how would you say that the program influenced your quality of life overall?

## Acceptability

- Did you engage with ACT for Caregivers primarily by phone or by computer?
  - How much time would you guess you spent on each session? Was this about the level of time and effort that you expected?
  - How manageable was it to complete the program within 30 days?
  - How well did the program meet your current needs as a caregiver?
  - What was your process like for engaging with the sessions? For example, did you take notes, do sessions at a particular time of day, etc.
    - What strategies did you use to try to remember what you were learning? Are there any skills that you continue to practice? Can you share an example?

- Were there any portions of the program that seemed unhelpful or confusing?
   Is there anything that you would change about the program?
- Did you encounter any barriers or obstacles to doing the program?
  - If so, how did you overcome those?

## Other

- Did you use the Education Library or mindfulness activities we provided? If so, did you find any of those materials particularly helpful? Were there things you wanted to know about that were not available in the Education Library?
- In addition to this program, are there other resources that you have been using, such as community classes, support groups, therapy, or religious groups?
  - If so, how well do you feel this program dovetailed with these other resources?
- Would you recommend this program to other caregivers? Why?
  - Follow-up: Are there any specific people who you think could benefit from this program? Please pass along the study information to them.
- If you were giving advice to another caregiver who was about to start this program, what advice would you give them to help them get the most out of it?

### Follow-up

### **Experience of Caregiving**

First I wanted to just get a little bit more information about caregiving overall for you right now. So between now and the last time we talked, has caregiving changed at all for you as far as the amount or the type of caregiving that's required? What does caregiving look like right now? Are any people newly involved, or has the involvement of other people changed at all?

- As you've been learning how to be a caregiver, what has that process been like? How has your experience of caregiving changed over time?
- What parts of caregiving do you find most meaningful? Would you say that your ability to kind of focus on the meaningful parts of caregiving has changed at all since beginning ACT for Caregivers?
- What parts of caregiving do you find most challenging? Has the way you navigate the challenges of caregiving changed since beginning ACT for Caregivers?

#### **Overall Changes**

- It has been a while since you completed ACT for Caregivers. Before I ask you any questions that might get you thinking about specific things, would you please give me your overall opinion of ACT for Caregivers?
- Can you please tell me the most helpful things you learned from ACT for Caregivers?
- Broadly speaking, in what ways has what you learned from ACT for Caregivers influenced your caregiving? What about other areas of your life?
- Which portions of the program do you remember and find yourself using?
  - What effect has this had on your life?
- Have you shared any things you learned from the program with someone else? What

has that experience been like? Can you share an example?

#### **Process-Based Questions**

- One of the focuses of the program was on helping you move towards what matters to you, even with difficult thoughts and feelings. Since beginning the program, do you feel like you've been able to move towards the things that matter to you more regularly/intentionally? What has that experience been like?
  - Can you describe some things you have done since beginning the program to move towards what you care about?
  - What do you think has gone in to you being able to move towards what matters to you?
    - Probe: Part of the program involved you connecting with your values.
       How useful has this been for you?
    - Probe: Were there any activities or metaphors that have helped you to do this?
- Another focus of the program was identifying times when you are doing things that move you away from the things that matter to you and the person you want to be. We called these "away moves." To what degree do you feel like your ability to recognize when you are making away moves has changed since participating in ACT for Caregivers? When you recognize these away moves, what helps you to change course?
  - Probe: What effect has learning about this had on your actions? How has this impacted your life overall?
  - Probe: Can you share an example of what this has looked like?

- Another focus of the program was helping you take a step back from thoughts, which we called unhooking. How useful has this been for you? Are there any particular techniques that have been useful for you?
  - If so, can you describe a time when you were able to use these techniques and it was helpful?
- Caregiving can be very meaningful, and there are still many difficult days, with plenty of stressful thoughts and feelings. Think about one of these difficult days.
  - On these stressful days, what do you do now to manage your stress, thoughts, and feelings? How is this different from what you did before beginning this program?
  - Have you found that the way you treat yourself has changed since beginning the program?
  - Taking the broadest view possible, how would you say that the ACT for Caregivers program has influenced your quality of life overall?

## Acceptability

- What strategies did you use to try to remember what you learned from the program?
- Are there any skills you learned that you continue to practice? Can you share an example?
- Looking back, how well do you feel the program addressed your needs as a caregiver?

## Other

• In addition to this program, are there other resources that have been useful for you, such as community classes, support groups, therapy, or religious groups?

- Would you recommend this program to other caregivers? Why?
  - Follow-up: Are there any specific people who you think could benefit from this program? Please pass along the study information to them.
  - If you were giving advice to another caregiver who was about to start this program, what advice would you give them to help them get the most out of it?

# CURRICULUM VITAE

## Jacob Gossner

## **EDUCATION**

Ph.D.	
	Utah State University, <i>Anticipated August 2024</i> , Human Development and Family Studies
M.S.	5
	Texas Tech University, 2021, 4.0, Couple, Marriage, & Family Therapy
B.S.	
	Brigham Young University, 2019, 4.0, Family Sciences
GRE	
	331 Composite, 170 Verbal (99th percentile), 161 Quantitative (75th percentile),
	4.5 Analytical Writing (80 <sup>th</sup> percentile)

## PROFESSIONAL EXPERIENCE

# **Research Experience**

May 2022—Present	Research Assistant, Dr. Elizabeth Fauth, Human Development and Family Studies, Utah State University
Sept. 2021—Aug. 2022	Research Assistant, Dr. Ty Aller, Institute for Disability Research, Policy, and Practice, Utah State University
Jan. 2021—Aug. 2021	Research Assistant, Dr. Stephen Fife, Couple, Marriage, and Family Therapy, Texas Tech University
Nov. 2019—Aug. 2019	Research Assistant, Dr. Mark Butler, School of Family Life, Brigham Young University
Sept. 2018—Feb. 2019	Research Assistant, Professor Jini Roby, Social Work, Brigham Young University
Sept. 2018—Dec. 2018	Research Assistant, Dr. Sarah Coyne, School of Family Life, Brigham Young University
Statistical Trainings	6 6 5
May 2020	Introduction to SEM, 24 hours, Curran-Bauer Analytics
<b>Teaching Experience</b>	
Aug. 2022—May 2023	Instructor of Record, Jacob Gossner, HDFS 2400, Marriage and Family Relationships, Utah State University
Jan. 2024—May 2024	Teaching Assistant, Scot Allgood, HDFS 4260, Family Life Education Methods, Utah State University
Aug. 2023—Dec. 2023	Teaching Assistant, Sarah Tulane, HDFS 3130, Research Methods, Utah State University

Aug. 2021—May 2022	Teaching Assistant, Kevin Barlow, HDFS 4900, Prepracticum, Utah State University
May 2017—June 2017	Team Teacher and Teaching Assistant, Dr. Mark H. Butler, SFL 336, Theories in Family Perspective, Brigham Young University
Aug. 2017—Dec. 2017	Teaching Assistant, Drs. Larry Nelson and Sarah Coyne, SFL 200, The Eternal Family, Brigham Young University
<b>Clinical Experience</b>	
April 2022—Present	Family Services On-Call Therapist Church of Jesus Christ of Latter Day Saints, Logan, UT
Aug. 2020—July 2021	Children's Behavioral Health Clinic Student Therapist University Medical Center, Lubbock, TX
Sept. 2019—Dec. 2020	Marriage and Family Therapy Clinical Practicum Therapist Family Therapy Clinic, Texas Tech University, Lubbock, TX
Clinical Trainings	
March 2024	Externship in Emotionally Focused Therapy, ICEEFT Trainers Robert Allan and Senem Saydam
February 2024	Success in Vulnerability, 20 hours, Dr. George Faller & Dr. Ryan Rana
December 2023	Emotionally Focused Therapy for Difficult Couples, 16 hours, Dr. Sue Johnson
February 2023	ACT for Grief and Loss, 8 hours, Dr. Russ Harris
August 2022	Trauma-focused Acceptance and Commitment Therapy, 16 hours, Dr. Russ Harris
August 2022	Acceptance and Commitment Therapy for Depression and Anxiety, 16 hours, Dr. Russ Harris
May 2022	Focused Acceptance and Commitment Therapy, 16 hours, Drs. Kirk Strosahl and Patti Robbins
July 2020	Gottman Method Couples Therapy Level 2, 19 hours, Drs. John and Julie Gottman
June 2020	Gottman Method Couples Therapy Level 1, 11 hours, Drs. John and Julie Gottman
May 2020	Developing Skills in Using Emotionally Focused Therapy with Couples, 6 hours, Dr. Rebecca Jorgensen, UAMFT
October 2019	Trauma-Focused Cognitive Behavioral Therapy Web 2.0, 11 hours

# SCHOLARSHIP

# **Grants and Awards**

2023	William H. and Stella Young Griffiths Graduate Scholarship (\$2,000), Utah
	State University
	Margaret F. Anderson Scholarship (\$700), Utah State University-Institute
	for Disability Research, Policy, and Practice
2022	Leah D. Widtsoe Scholarship (\$1,200), Utah State University

2021	Human Development and Family Studies Department Graduate Scholarship (\$800), Utah State University Graduate Student Enhancement Award (\$3,000), Utah State University Out-of-state Tuition Waiver, Utah State University
	Texas Association for Marriage and Family Therapy (TAMFT) Master's
	Student Achievement Award, TAMFT
	Graduate Student Research Support Award (\$1,000), Texas Tech Graduate
	School
2020	Marriage and Family Therapy Clinic Scholarship Endowment (\$1,000), Texas
	Tech University Couple, Marriage, and Family Therapy Program
	Helen DeVitt Jones Graduate Fellowship (\$3,500), Texas Tech Graduate
	School
2016-2019	Full Tuition Annual Scholarship, Sum (\$26,990), Brigham Young University

#### Peer-Reviewed Journal Publications (Published, In Review, or In Preparation)

- Fife, S. T., & Gossner, J. G. (2024). Deductive qualitative analysis: Evaluating, expanding, and expanding theory. *International Journal of Qualitative Research Methods*. Advance online publication.
- Fauth, E. B., Novak, J. R., Gossner, J. D., Aller, T. B., Kelley, H., & Levin, M. E. (2024). Family caregivers' progress toward values moderates the associations between behavioral symptoms of dementia, caregiver burden, and depressive symptoms. *The International Journal of Aging and Human Development*. Advance online publication.
- Dokos, M., Schultz., R., Gossner, J. D., & Fauth, E. B. (2023). Supporting persons with dementia: Perspectives from Certified Nurse's Assistants. *Innovation in Aging*, 7(5). https://doi.org/10.1093/geroni/igad049
- Fife, S. T., Gossner, J. D., Theobald, A., Allen, E., Rivero, A., & Koehl, H. (2023). Couple healing from infidelity: A grounded theory study. *Journal of Social and Personal Relationships*, 40(12). https://doi.org/10.1177/02654075231177874
- **Gossner, J. D.**, Fife, S. T., & Butler, M. H. (2022). Couple healing from infidelity: A deductive qualitative analysis study. *Sexual and Relationship Therapy*, Advance online publication.
- Fife, S. T., Theobald, A. C., Gossner, J. D., White, K., & Yakum, B. (2022). Healing from infidelity for emerging adults: A grounded theory. *Journal of Social and Personal Relationships.* https://doi.org/10.1177/02654075211067441
- Gossner, J. D., Hitiura, A., & McPhee, D. (2021). Contextual therapy for couples who are primary caregivers for a parent(s) with Alzheimer's disease. *Contemporary Family Therapy*, *43*, 248-258. https://doi.org/10.1007/s10591-021-09576-8
- Butler, M. H., Gossner, J. D., Barham, C. C., Hansen, B. M. C., & Crawford, M. D. (2021). Discerning motivational interviewing through a spiritual lens—discovering a Christian MI archetype and native MI language. *Journal of Marital and Family Therapy*, 47(3), 767-784. https://doi-org.lib-e2.lib.ttu.edu/10.1111/jmft.12472
- Butler, M. H., Gossner, J. D., & Fife, S. T. (2021). Partners taking turns leaning in and leaning out: Trusting in the healing arc of attachment dynamics following betrayal. *Journal of Couple and Relationship Therapy*. https://doi.org/10.1080/15332691.2021.1926388

- **Gossner, J. D.**, Aller, T., Russo, R., Clay, N., & Fauth, E. B. (in review). Mental health literacy training for cooperative extension-based workers: A qualitative evaluation.
- Soloski, K., Jones, E., Gossner, J. D., Speer, J., Stephenson, T., & Luschin, E. (in review). Masculinity, femininity, and alcohol use: Examining moderation effects. Submitted to *Journal of Studies on Alcohol and Drugs*.
- **Gossner, J. D.**, Fauth, E. B., Aller, T. B., Hamilton, E., Novak, J. R., & Levin, M. E. (in preparation). Learning how to pause: Qualitative impact of online, self-guided Acceptance and Commitment Therapy for family caregivers for persons with dementia.

### **Professional Presentations (Peer-Reviewed)**

- Fife, S. T., & Gossner, J. D. (2023, September 22). Deductive qualitative analysis [workshop presentation]. Intervention Research in Systemic Family Therapy Annual Conference, Provo UT.
- Foster, K.\*, Gossner, J. D., Fauth, E. B., Juhasz, A., Aller, T. B. (2023, December 7). *Predicting dementia family caregivers' quality of life* [Poster presentation]. Undergraduate Research Symposium, Utah State University.
- Hamilton, E.\*, Gossner, J. D., Fauth, E. B., Juhasz, A., Aller, T. B. (2023, December 7).
   *Predicting burden of family caregivers for persons with dementia* [Poster presentation]. Undergraduate Research Symposium, Utah State University.
- **Gossner, J. D.,** Hamilton, E.\*, Aller, T. B., Fauth, E. B., Novak, J. R., & Levin, M. E. (2023, November 11). *Caregivers' reflections on an online, self-guided ACT intervention: A deductive qualitative analysis study* [Poster presentation]. National Council on Family Relations Annual Conference, digital conference.
- **Gossner, J. D.,** Fauth, E. B., Aller, T. B., & Levin, M. E. (2023, June 2). Brief, online ACT for caregivers: A longitudinal mixed methods study [poster presentation]. Mindfulness and Relationships Virtual Conference, digital conference.
- Gossner, J. D., Fauth, E. B., Levin, M. E., Novak, J. R., & Bradshaw, S. (2022, November 3). Caregiver depression and progress towards values: An autoregressive cross-lagged panel model [Poster presentation]. Gerontological Society of America Annual Conference.
- **Gossner, J. D.,** Clay, N.\*, Russo, R., Aller, T. B., & Fauth, E. B. (2022, May 12). *Becoming a mental health advocate: A qualitative case study program evaluation* [Poster presentation]. Utah Association for Marriage and Family Therapy Annual Conference.
- **Gossner, J. D.**, & Fauth, E. B. (2022, April 1). *Predicting quality of life of family caregivers for persons with dementia* [Poster presentation]. Utah Council on Family Relations Annual Conference.
- Fife, S. T., & Gossner, J. D. (2021, November 1-5). Deductive qualitative analysis: Evaluating, expanding, and expanding theory [Workshop presentation]. National Council on Family Relations Annual Conference, Theory Construction and Research Methodology, digital conference. (3 hrs @ 9 participants).
- Fife, S. T., Gossner, J. D., Theobald, A. C., Rivero, A. N., Allen, E., Koehl, H., & Harrell, J. (2021, November 1-5). *Couple healing from infidelity: A grounded theory of personal and relational healing* [Poster presentation]. National Council on Family Relations Annual Conference, digital conference.

- Gossner, J. D., Hitiura, A., McPhee, D. P., & Fauth, B. (2021, November 1-5). *Contextual therapy for couples who are primary caregivers for a parent(s) with Alzheimer's disease* [Paper presentation]. National Council on Family Relations Annual Conference, digital conference. (0.25 hrs @ 24 participants).
- **Gossner, J. D.,** & Fife, S. T. (2021, July 5-9). *Couple healing from infidelity: A deductive qualitative analysis study* [Paper presentation]. Thinking Qualitatively Annual Conference, digital conference. (0.25 hours)
- Fife, S. T., Gossner, J. D., Theobald, A. C., Rivero, A. N., Yakum, B. N., White, K. L., Harrell, J. B., Allen, E. E., Koehl, H. M., Silva, M. A., & Posadas Rivera, L. (2021, March 4-6). *Individual and relational healing from infidelity: Two grounded theories* [Workshop presentation]. Texas Association for Marriage and Family Therapy Annual Conference, digital conference. (1.5 hrs @ 100 participants)
- **Gossner, J. D.**, & Fife, S. T. (2021, March 4-6). *Couple healing from infidelity: A DQA study* [Poster presentation]. Texas Association for Marriage and Family Therapy Annual Conference, digital conference.
- Fife, S. T., Theobald, A. C., Gossner, J. D., White, K., & Yakum, B. (2020, November 4-13). *Individual and relational healing from infidelity: Two Grounded Theories* [Paper presentation]. National Council on Family Relations Annual Conference, digital conference. (1.5 hrs @ 60 participants)
- **Gossner, J. D.**, Sanders, D. M., Guzman, A. L. (2020, February 27-29). *Texas: Duty to warn* [Workshop presentation]. Texas Association for Marriage and Family Therapy Annual Conference, Houston, TX. (1.5 hrs. @ 33 participants)
- **Gossner, J. D.**, Fife, S. T., & Butler, M. H. (Accepted 2020 but not presented due to COVID-19). Couple healing from infidelity: A deductive qualitative analysis. Research discussion to be presented at the annual conference of the American Association for Marriage and Family Therapy, Orlando, FL.
- **Gossner, J. D.**, Butler, M. H., & Fife, S. T. (Accepted 2020 but not presented due to COVID-19). The arc of couple healing following infidelity: Non-parallel healing. Workshop to be presented at the annual conference of the American Association for Marriage and Family Therapy, Orlando, FL.
- \* denotes mentored student author

## **Professional Presentations (Invited)**

- **Gossner, J. D.** (2024, February 23). Improving outcomes for family caregivers for people with dementia [lightning round presentation]. Human Development and Family Studies Graduate Student Research Colloquium, Utah State University.
- Gossner, J. D., Sanders, D. M., Guzman, A. L., & Brown, C. (2020, November 6). *Texas: Duty to warn* [Webinar workshop]. Texas Association for Marriage and Family Therapy Monthly Webinar, Houston, TX. (0.75 hrs. @ 85 participants)

### Professional Presentations (Non Peer-Reviewed Professional & Community Service

#### **Presentations**)

Gossner, J. D. (2024, February 27). Combating burden by embracing self-nourishing: Strategies from ACT and EFT. CCAMPIS, Utah State University (2 hours @ 14 participants).

- Gossner, J. D. (2023, October 13). ACT for Caregivers [in-person workshop]. USU Extension, Ogden, UT. (1 hrs @ 30 participants)
- Gossner, J. D. (2022, October 11). ACT for Caregivers [in-person workshop]. USU Extension, Ogden, UT. (1 hrs @ 50 participants)
- Gossner, J. D., & Rivero, A. N. (2019, November). *What is marriage and family therapy and why would you want to be one?* Coronado High School Mental Illness Class, Lubbock, TX (0.5 hrs. @ 25 participants)
- Butler, M. H., Butler, S. D., & Gossner, J. D. (2019, August). Helping members, spouses, and loved ones who struggle with pornography. Family Services Wellness Workshop (for ecclesiastical leaders, The Church of Jesus Christ of Latter-day Saints), Orem, UT. (1.5 hrs. @ 130 participants)

#### **Public Scholarship (Peer-reviewed)**

Gossner, J. D., Fauth, E. B., & Howard, T. (2022, October). Coping with grief and loss for agricultural producers. Extension. https://extension.usu.edu/agwellness/research/coping-with-grief-and-loss-for-ag-producers

- Gossner, J. D., Fauth, E. B., & Howard, T. (2022, October). Values: Helping agricultural producers find motivation by focusing on what matters. Extension. https://extension.usu.edu/agwellness/research/find-motivation-by-focusing-on-what-matters
- Gossner, J. D., Fauth, E. B., & Howard, T. (2022, September). Accepting uncomfortable emotions: Learning from car dashboards and manure. Extension. https://extension.usu.edu/agwellness/research/learning-from-car-dashboards-and-manure
- Gossner, J. D., Fauth, E. B., & Howard, T. (2022, September). Responding to financial stress for agricultural producers and couples. Extension. https://extension.usu.edu/agwellness/research/responding-to-financial-stress-for-ag-producers-and-couples
- Gossner, J. D., Fauth, E. B., & Howard, T. (2022, July). Unhooking and refocusing. Extension. https://extension.usu.edu/agwellness/research/managing-stress-foragricultural-producers

#### Public Scholarship (Non-Peer-reviewed)

- Fauth, E. B., Gossner, J. D., & Aller, T. (2022, Invited Issue). Takeaways from research on chronically stressed individuals: How dementia family caregivers' adaptation informs pandemic experiences. *Family Focus, Spring*.
- Gossner, J. D. (2019). The stories of depression. Family Connections: BYU School of Family Life Alumni Magazine, Spring, 19-20.
- Butler, M. H., Gossner, J. D., Boyd, H. R., Hilton, D. J., & Haupt, J. D. (2020, January 3). What is online porn teaching our children? MercatorNet [online]. Retrieved from https://www.mercatornet.com/mobile/view/what-is-online-porn-teaching-ourchildren/23162

# PROFESSIONAL ASSOCIATIONS

Member, Utah Association for Marriage and Family Therapy Member, Phi Kappa Phi Honor Society Roundtable Discussant, 2019 Wheatley Institute Roundtable on the Family