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Are Effort and Helpfulness Ratings of Session Activities Associated with Improved Outcomes in Web-Based Acceptance and Commitment Therapy (ACT) for Caregivers?

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ARE EFFORT AND HELPFULNESS RATINGS OF SESSION ACTIVITIES
ASSOCIATED WITH IMPROVED OUTCOMES IN WEB-BASED
ACCEPTANCE AND COMMITMENT THERAPY (ACT)
FOR CAREGIVERS?

by

Hannah R. Cragun

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

MASTER OF SCIENCE

in

Human Development and Family Studies

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2020
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ABSTRACT

Are Effort and Helpfulness Ratings of Session Activities Associated with Improved Outcomes in Web-based ACT for Caregivers?

By

Hannah R. Cragun, Master of Science

Utah State University, 2020

Major Professor: Elizabeth B. Fauth, Ph.D.
Department: Human Development and Family Studies

With increased prevalence of Alzheimer’s disease and related dementias, family caregivers are providing up to 10 years of unpaid care. Informal dementia caregivers are exposed to behavioral and psychological symptoms of dementia (BPSD) that are known to be associated with distress. In traditional face-to-face format, Acceptance and Commitment Therapy (ACT), an empirically validated subset of Cognitive Behavioral Therapy (CBT), has been shown to improve caregiver depressive symptoms, use of positive coping skills, and management of role demands. Because prior studies indicated that dementia caregivers face barriers to accessing traditional face-to-face therapy, online delivery of ACT may be helpful. In randomized control trials with non-caregiver populations, online ACT improves mental health indicators. Increases in caregiver wellbeing and in using ACT-related skills have also been found in the current project, which is the first known web-based ACT program for dementia caregivers. This thesis involves aspects of program evaluation on the ACT for Caregivers extant data. Forty-nine
caregivers successfully completed all 10 sessions and pre-, post-, and 4-week follow-up posttests. In sessions 2 through 10, caregivers were asked to rate if specific ACT skills from the prior session were helpful, and the effort they put into practicing those skills. I examined if the key outcomes—decreases in BPSD stress reactions—increases in progress towards valued-based living (a central goal of ACT) and continued use of ACT skills after program completion—were associated with the perceived helpfulness and reported effort of practicing ACT skills. Correlational analyses identified that effort and helpfulness were not significantly correlated with most of these outcomes. However, excerpts from the open-ended reflections on all sessions demonstrated comprehension of ACT concepts and everyday application of ACT skills, showing that future interventions should consider including evaluations on comprehension of ACT components and longer-term use of ACT skills post-program. Additionally, occasional concept refresher messages and suggestions of when to use ACT skills in different life contexts may be helpful in encouraging sustained use of ACT skills and continual improvements in dementia caregiver-specific outcomes.
PUBLIC ABSTRACT

Are Effort and Helpfulness Ratings of Session Activities Associated with Improved Outcomes in Web-based ACT for Caregivers?

Hannah R. Cragun

Family caregivers for people with dementia are providing care for up to ten years because people with dementia are living longer. This role can be demanding because the person with dementia can have behavioral and psychological symptoms that can be stressful for the caregiver to witness and manage. Acceptance and Commitment Therapy (ACT) in its traditional face-to-face format has strong scientific support in helping caregivers to be less depressed and better cope with the stress associated with taking care of their loved one. However, because caregiving is a time-demanding role, caregivers can struggle with accessing face-to-face therapy, making online ACT a flexible option. This study evaluated the first-known web-based ACT for caregivers. Previous data collected for this study showed that caregivers improved in their wellbeing and use of ACT-related skills. Caregivers completed 10 sessions that taught ACT concepts and skills, and for each session they reflected on how much effort they put into practicing the ACT skill from the previous session and how helpful they thought it was. This thesis investigated if those effort and helpfulness ratings were related to lower stress reactions to behavioral and psychological symptoms of dementia, increased values-based living (a central goal of ACT), and continual use of ACT skills after finishing the program. Findings indicated that effort and helpfulness ratings were not related to most outcomes, but caregivers did
put significant effort into the sessions and found them helpful. Suggestions are given for future programs to check for comprehension and use of ACT skills throughout the program and for refresher messages to be given after program completion.
I am grateful to Dr. Elizabeth Fauth for allowing me to work on the online ACT for Caregivers data set for this thesis research. I would like to express my gratitude to my committee members, Drs. Fauth, Schramm, and Liu for being so patient, supportive, and flexible throughout this entire process.

I am so thankful for my husband, my family, friends, and my master’s cohort for their encouragement, emotional support, celebration of milestones, and faith in me from the beginning in writing this document. Thank you for supporting me in my journey.

Hannah R. Cragun
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CHAPTER I
INTRODUCTION

Family caregiving is needed due to a rising prevalence in dementia diagnoses across the world, but especially in the U.S. (Kumar & Tsao, 2019). While caregiving can be a rewarding experience in general, dementia caregivers can face considerable difficulties in fulfilling their role, including declines in their own health, mental health, quality of life, and sometimes deterioration of the caregiver’s relationship with the family member with dementia (Fauth et al., 2012; Pearlin et al., 1990; Pinquart & Sörensen, 2004, 2007). Because the institutionalization of a family member with dementia is expensive and impacts both the mental health and relationship of the care receiver and the caregiver, psychoeducational interventions are sought to improve the caregiving experience for the benefit of both caregiver and care recipient (Qiu et al., 2019; Sörensen et al., 2002). However, caregiver interventions are typically delivered in a face-to-face format, making it difficult for them to attend given the demands of dementia care. For example, caregivers may have difficulties with transportation, they may not be able to leave their loved one unattended, or they may not have time balancing caregiving with other roles (Cuijpers, 1997; Levin et al., 2017a; Richards & Richardson, 2012). There is an increasing need for a home-delivered intervention that successfully addresses these barriers of access, helps alleviate the negative impacts of caregiving, and improves the quality of life of both caregiver and recipient.
Dementia: Prevalence and Needed Care

According to the World Health Organization (WHO, 2019), dementia is a classification of symptoms resulting from either diseases, injuries, or other health-related contributors to significant declines in cognitive functioning. Dementia is a non-normative phenomenon in the aging process, although advanced age puts people more at risk for dementia. It is accompanied by a notable and progressive loss of memory, attention-span, learning ability, understanding, speaking-ability, and logical reasoning, among other areas (WHO, 2019). Dementia has been diagnosed in over 50 million people globally, with projections of an additional ten million new diagnoses each year (WHO, 2019). Alzheimer’s disease is one of the most prevalent types of dementia, accounting for over 60 percent of cases (WHO, 2019). There is no current cure for dementia, but there are medications intended for slowing its progression and reducing the challenging behavioral and psychological symptoms that usually accompany the neurodegenerative syndrome (Cleveland Clinic, 2019; National Institute on Aging, 2019; National Institute of Neurological Disorders and Stroke [NINDS], 2019).

Because of the significant and continual increase in persons with dementia (PWD), greater resources for providing care are necessary, but many families cannot afford assisted-living and other institutionally based forms of support. Caregivers and care receivers often prefer care in their home and to avoid institutionalization (Grossman & Webb, 2016). In addition, because of advancements in modern medicine, those with Alzheimer’s disease or related dementias (ADRD) are living longer despite it being a terminal syndrome, living between three to over ten years post-diagnosis, depending on
the person’s age at dementia onset (National Institute on Aging, 2017), thus implicating the long-term involvement that becomes necessary of the caregiver. In 2018 alone, over 16 million family or peer caregivers were unpaid in providing 18.6 billion hours of care (Alzheimer’s Association, 2019).

**Demands of Caregiving**

While there are many rewarding and positive aspects of caregiving, it is a demanding role that requires more time intensive efforts if the relative has dementia. These efforts consist of assisting the care recipient in both instrumental functions of paying bills, cleaning, and grocery shopping, and also in more involved activities of daily living (ADL), including bathing, grooming, transferring from location-to-location, and managing the relative’s dementia symptoms and behavior, helping them to cope (Reinhard et al., 2008). According to the Stress Process Theory, caregivers have a unique configuration of demographic characteristics, available resources, and current economic situation that influence how they respond to stress and what kind of stressors are currently affecting them (Pearlin et al., 1990). The two primary stressors of caregiving include their relative’s dementia symptoms and behaviors and the residual effects of caregiving, including psychological processing and the strains of providing care (Pearlin et al., 1990).

Significant involvement in providing care in both ADL and instrumental activities can be challenging especially when the PWD is resistant to receiving the care due to confusion, depressive symptoms, impulsivity, and other behaviors caused by dementia (Reinhard et al., 2008). The most challenging symptoms to manage include aggression,
violence, and wandering (Cross et al., 2018; McIntyre & Reynolds, 2012), often becoming more frequent and intense as the dementia worsens (Lyketsos, 2015). Regardless if there are other family members nearby and available to help, the majority of responsibilities fall on one main caregiver, and there is usually disagreement between primary and secondary caregivers over the quality and type of assistance is being given to the relative (Reinhard et al., 2008). Consequently, caregivers often experience a burden that needs attention and alleviation through self-care, therapy, support groups, or assistance from other resources in order for them to have a more positive experience with their loved one during these last years of life. The Stress Process Theory has been the foundation for many caregiving interventions and continuously serves as a guide in showing how to improve the design and effectiveness of such interventions (Pearlin et al., 1990).

**Barriers and Needed Changes for Caregiving Interventions**

While interventions exist for improving mental health and caregiving outcomes, many caregivers face barriers of cost, transportation, scheduling, and adequate time for face-to-face therapy. A recent review of computer-based caregiving interventions has supported that online and tech-based components are effective and viably accessible for caregiver use (Godwin et al., 2013). However, none of these reviewed computer-based interventions for caregivers have incorporated Acceptance and Commitment Therapy (ACT). ACT is an empirically tested subset of Cognitive Behavioral Therapy (CBT) that is used to help clients cope with difficult thoughts and enable action according to one’s
values (Hayes et al., 2004). Traditionally, ACT is administered in face-to-face therapeutic sessions, and has been empirically demonstrated as effective in mitigating distress and other psychological effects experienced by those with mental illness and/or chronic health problems (Bethay et al., 2013; Blackledge & Hayes, 2006; Brinkborg et al., 2011). ACT has been shown to aid caregivers in positively coping with dementia symptoms and their internal distressing thoughts sometimes accompanying those symptoms (Márquez-González et al., 2010).

To my knowledge, no online ACT for caregivers has been disseminated in the research literature, but online ACT has been shown to reduce depressive symptoms and facilitate positive coping strategies in other populations (Lappalainen et al., 2015; Levin et al., 2017b). The current thesis builds upon the existing evaluation of “ACT for Caregivers” (N = 49; Fauth et al., 2020, which demonstrated improvements in caregivers across all measured outcomes. The current study examined if caregiver’s helpfulness and effort ratings of individual sessions, or of the sessions as a whole, are significantly associated with improvements in a care-specific outcome, in an ACT-specific outcome, and in continued use of ACT skills after sessions have ended.
CHAPTER II
LITERATURE REVIEW

Dementia Caregiver Stress

Family caregiving is a role characterized by the daily endeavors of assisting relatives whose ability to take care of themselves is limited or nonexistent (Pearlin et al., 1990), often requiring help with simple activities of daily living (ADL; NINDS, 2019). In conjunction with dementia becoming increasingly prevalent, the number of informal dementia caregivers that are unpaid family members is rising, which are typically spouses or adult offspring (Richardson et al., 2013). Caregiving can be a long-term responsibility for a family member, especially for care recipients with Alzheimer’s disease or related dementias (ADRD), which can require care for up to 10 years or more (National Institute on Aging, 2017). Due to the timing of the onset and development of dementia, eighty-six percent of informal ADRD caregivers assume this role and its responsibilities for at least a year, and 50 percent of those have been caregiving for at least four years (Alzheimer’s Association, 2019).

Due to the severity of the decline in mental functioning for people with ADRD (NINDS, 2019), caregivers of these PWD are three to four times more likely to assist them with activities of daily living (ADL) such as bathing or grooming, or other forms of personal care (Alzheimer’s Association, 2019). However, the PWD’s resistance to the care provided is more detrimental to caregivers’ well-being than providing significant support in ADL on its own (Fauth et al., 2016; Pearlin et al., 1990). With care recipients
exhibiting resistiveness to assistance, caregivers may experience increased role burden, role captivity—feelings of being trapped in their caregiving role, and depressive symptoms (Fauth et al., 2016; Pearlin et al., 1990).

Caregiver burden is the phenomenon described by caregivers as prolonged stress and frustration in multiple areas including emotional, mental, physical, social and financial (Butcher et al., 2001; Etters et al., 2008; Kasuya et al., 2000). On its own, being a family member of the person with dementia is correlated with experiencing greater caregiver burden (Annerstedt et al., 2000; de Vugt et al., 2005; Etters et al., 2008). Spousal caregivers reporting a high level of perceived burden and at least two caregiving tasks experienced reduced physical activity levels and heightened depressive symptoms (Nieboer et al., 1998). However, caregiver burden and stress are much more complex constructs that require more in-depth analysis of their potential causes, change over time, and relationship to caregiver outcomes.

The inception of the caregiving role seems to pose the most significant challenges on caregivers’ physical and mental health because of the difficulty of the role transition and its requiring of a family member to become severely disabled or ill. A large longitudinal, cross-national European study found that the transition into caregiving—especially if their spouse is the care receiver—is associated with and exacerbates physical and mental health problems for both male and female caregivers above age 50 (Uccheddu et al., 2019). The study also found that transitioning out of the caregiving role does not significantly improve those initially affected health indicators, except for some women, indicating that the caregiving experience has a significant long-term impact (Uccheddu et
Further, caregivers often experience an accumulation of other roles that compete for their time and attention. A quarter of dementia caregivers are still raising children of their own or are assisting in the care of their grandchildren, increasing the role burden and stress they already experience (Alzheimer’s Association, 2019). Others are subject to negative effects on their employment and income, whether in being forced to reduce the number of hours at work, taking time off, being tardy or leaving early, or sacrificing advancement opportunities due to their caregiving responsibilities (Alzheimer’s Association, 2019). Because of this accumulation of stress, caregivers’ time for leisure, self-care, and friendship pursuits is limited and sacrificed to keep up with their caregiving obligations (Pinquart & Sörensen, 2003; Zarit et al., 1980).

Those that perceive a lack of choice in becoming the caregiver for their loved one are more likely to experience greater caregiving burden and negative effects on mental health. Caregiver stress and negative mental and physical health indicators are associated with this feeling of obligation and lack of volition (Sayegh & Knight, 2011; Schulz et al., 2012). Care recipient’s health condition, emotions, and behaviors can also disrupt caregiver’s well-being. Health problems requiring more intensive care, including ADRD, in addition to longer years of caregiving (five or more) are significantly associated with perception of lack of choice (Schulz et al., 2012). Feelings of obligation may foster resentment and can result in potential harming of the care receiver and potentially elder abuse (MacNeil et al., 2010). Thus, there is a critical need for interventions that help improve caregiver well-being and subsequently care recipient health and safety.
Stress Process Theory

The Stress Process Model (Pearlin et al., 1990) describes how the dementia caregiving role can lead to outcomes such as increased depressive symptoms and poorer health outcomes. The model describes how caregivers’ demographic characteristics (e.g., age, gender, and ethnicity) and educational and economic statuses expose the caregiver to varying stressor types and intensities. These characteristics also influence resources that the caregiver can access and how stressors uniquely affect them. Within the model, there are two types of stressors: primary and secondary. Primary stressors include the PWD’s cognitive status, the BPSD, the volume of activities requiring daily assistance and the level of caregiving involvement needed to carry out those ADL. Primary stressors typically become more severe as the dementia progresses (Pearlin et al., 1990).

Primary stressors may be significant enough that they ripple into other stressors, also called secondary strains (Pearlin et al., 1990). Secondary strains either stem from the role’s effects on the caregiver’s life (i.e., role strains), or those that occur psychologically (i.e., intrapsychic strains). Role strains include things such as, family conflict emerging from discordant beliefs about care, decreased economic resources due to demands for caregiver’s time and/or cost of care, changes in caregivers’ involvement in social life or self-care, and others. Intrapsychic strains encompass the weakening or plateaued development of self-concept components, namely those of self-esteem and perceived levels of control, feeling of role captivity, loss of identity, self-efficacy (i.e., competence), and self-growth (Pearlin et al., 1990).

While these primary and secondary stressors may be prevalent for many ADRD
caregivers’, stressors are appraised differently among caregivers, yielding varying stress reactions even to the same stressor (Pearlin et al., 1990). Caregiver stress reactions are mediated by coping skills and the availability and use of social support (Bangerter et al., 2019). Coping skills involve attempts to change the situation, change the perceived meaning of the situation, or to directly mitigate the stress resulting from the situation. Social support constitutes direct instrumental assistance from others and/or emotional support derived from trustworthy others. The interaction of such mediating elements and resultant stress reactions can lead to different caregiving outcomes. Mediating variables are often the target of caregiver interventions (Pearlin et al., 1990). In fact, the Stress Process model is a common framework for caregiver interventions. While interventions for caregivers are discussed below, the next few sections will go beyond the Stress Process model and present literature on symptoms of dementia and subsequent caregiver stress.

**Mental and Physical Health Outcomes of Persons with Dementia**

PWD can be increasingly difficult because of their gradual changes in behaviors and emotions with the progression of cognitive decline. Dementia is marked by memory loss, confusion and difficulty in problem solving, speaking, maintaining attention span, judgment and decision-making, and simple daily tasks (National Institute on Aging, 2019; NINDS, 2019). Certain disorders that cause dementia-like symptoms can be treated, but the cognitive impairment associated with Alzheimer’s and other neurodegenerative dementias cannot be cured or reversed (National Institute on Aging, 2019; NINDS, 2019). Some medications can help manage specific symptoms, such as
hallucinations, delay worsening of the syndrome, and even temporarily sharpen remaining cognitive skills, but overall ADRD is a progressive disorder that can last years (Cleveland Clinic, 2019; NINDS, 2019). Because of these factors, caregivers often have to repeatedly answer questions, deal with lack of PWD recognition of relationship to caregiver or other family members, handle bills and grocery shopping, and maintain calmness with care recipient escalation.

BPSD are the noncognitive, externally observable symptoms in PWD that can make caregiving more difficult because of the PWD’s increased need for supervision and protection. Medical professionals sometimes refer to these as neuropsychiatric symptoms (NPS). While scales measuring BPSD and NPS may vary slightly in the items included, the constructs are the same for the most part. Therefore, in the current study, I will use the term BPSD. Behavioral and psychological symptoms of dementia include wandering, inappropriate comments, voice escalation, swearing, and aggression (Baharudin et al., 2019; Biernacki, 2007), apathy, depression, sleep disorders (e.g., insomnia, sleep apnea, restless leg syndrome), agitation or anxiety, reality-disconnecting psychosis (Geda et al., 2013; Lyketsos, 2015), changes in appetite, and poor behavioral inhibition (Cummings et al., 1994; Fauth & Gibbons, 2014; Kales et al., 2014). These symptoms tend to emerge in groups, rather than developing in isolation (Youn et al., 2011).

Being exposed to more intense BPSD is associated with increased caregiver stress, depressive symptoms, and caregiver burden (Aneshensel et al., 1995; Baharudin et al., 2019; Fauth & Gibbons, 2014; Gaugler et al., 2000; Rocca et al., 2010). High caregiver burden and distress risk the early institutionalization of the PWD and greater
potential for elder abuse (Seidel & Thyrian, 2019). As removal of exposure to BPSD is not always feasible, it is helpful that interventions not only target the most distressing BPSD, but most importantly aid in reducing caregivers’ stress reactions to such symptoms in general (Fauth & Gibbons, 2014).

**Risk and Protective Factors for Caregiver’s Wellbeing**

Prior research indicates that many caregivers’ physical and psychological symptoms can be mitigated, to some extent, by a positive relationship with their family member with dementia. Caregiver-care-recipient relationship quality and duration affects the absence of, development of, or severity of caregiver health problems, but can also have varying positive effects (Fauth et al., 2012). When caregiver’s health, quality of life, and well-being improve, this doubly benefits the care-recipients, suggestive of the dyadic nature of caregiver-care recipient health (Cross et al., 2018; Moyle et al., 2011; Quinn et al., 2019; Roach et al., 2016; Rosness et al., 2011). Further, institutionalization of the PWD can be delayed by improvement in that symbiotic health relationship (Cross et al., 2018; Rosness et al., 2011; Sommerlad et al., 2014). Additionally, involvement of other family members in both visiting the family member with dementia and helping in other care tasks lessens caregiver burden (Zarit et al., 1980) although help from other resources may not be readily available.

Caregivers’ use of effective coping skills is associated with their mental, social, and physical health and lower perceived stress and caregiver burden, showing the need for interventions to focus on improving mental health and behaviors, not just physical health indicators (Van Den Wijngaart et al., 2007). Mausbach et al. (2006) found that
caregiver maladaptive coping strategies including avoidant behavior served as a partial mediator in the relationship between BPSD and caregiver depressive symptomatology. However, caregivers who take time for self-care and personal interest activities have increased quality of life and decreased caregiver burden (Coen et al., 2002; Gonyea et al., 2005).

**Interventions for Improving Caregiver Outcomes**

Interventions specific to reducing stress in dementia caregivers are abundant and well-studied. Respite services give caregivers a physical break from exposure to BPSD and providing ADL assistance (Bangerter et al., 2019; Lund et al., 2014; Zarit et al., 2017). Other interventions generally provide education about ADRD (Cho et al., 2016; Pot et al., 2019), build various coping skills, and provide resource referral. Specific examples of the most common approaches include support groups (Berwig et al., 2017; Friedman et al., 2018; Küçükgüçlü et al., 2018; Lauritzen et al., 2015, 2019; Simpson et al., 2018), individual counseling (Graßel et al., 2010; Jütten et al., 2018; Kaddour et al., 2019; Köhler et al., 2019), telephone based professional support (Corry et al., 2019), and family counseling (Gaugler et al., 2008; Mittelman & Bartels, 2014; Mittelman et al., 2007). While they vary, these approaches seek to lessen caregiver burden and strengthen health outcomes to delay institutionalization and improve the caregiving experience.

Caregiving interventions are most successful in reducing stress, depressive symptoms, and overall caregiver burden when they incorporate multiple treatment components rather than single-component interventions, including such components as education, counseling, and facilitating healthier or more effective coping strategies.
(Etters et al., 2008; Marriot et al., 2000). While female caregivers seem to benefit more from interventions (Etters et al., 2008) and caregiving stress is experienced differently across ethnic cultures (Janevic & Connel, 2001), interventions show wide applicability and success across cultures, ethnicities, education levels, socioeconomic status, and genders (Etters et al., 2008).

**Barriers to Face-to-Face Caregiver Interventions and Web-Based Solutions**

Even though traditional face-to-face interventions are effective, only one-third of qualified caregivers who are aware of intervention services utilize them, most of them waiting to seek help until after a crisis (Montgomery & Borgatta, 1989). Further, caregivers face obstacles to receiving face-to-face therapy and other interventions including the cost of therapy, time, transportation, lack of services in rural areas, waiting lists, scarcity of experienced professionals, or stigma (Cuijpers, 1997; Levin et al., 2017a, 2017b; Richards & Richardson, 2012). Thus, it is critical that interventions become more accessible, well-marketed, and professional.

There are various types of web-based interventions for improving caregivers’ well-being that have been empirically tested. Virtual support groups can benefit caregivers’ meaning-making, spiritual reflections, and peer support have on caregiver mental health and stress responses (Armstrong, 2019; Damianakis et al., 2018). Additional benefits of virtual support groups are currently being studied in their association in caregivers’ mental health, quality of life, and overall well-being (Parkinson
Education-based online training interventions focus on improving mental health indicators, relieving burden and stress responses, improving reactions to BPSD, and teaching coping skills and dementia awareness. However, they do not report any changes in quality of caregiving (Egan et al., 2018). Online individual counseling has emerged (a type of telehealth intervention), and shows promise in improving caregiving confidence, burden, responses to BPSD compared to a telephone-based control group (Williams et al., 2019). These findings suggest that web-based interventions are feasible and effective in enhancing positive caregiver outcomes, and caregivers who use them can benefit from them.

Therapy programs have become available online in order to treat a greater number of people who have difficulty in accessing traditional therapy. Online therapeutic treatment supplements current clientele’s face-to-face treatment with more resources when not physically present with their therapist. Online therapy is also attractive because it decreases the costs and time constraints that are often barriers to seeking therapeutic help and is especially beneficial for those on congested wait-lists (Levin et al., 2015), to those who face stigma, lack adequate transportation, live rurally, or cannot afford therapy (Petersen et al., 2019). Overall, caregivers can greatly benefit from online interventions because of their accessibility, low-cost, and schedule flexibility.

Recent studies suggest that internet-based psychotherapy is more effective at treating depression than traditional face-to-face psychotherapy alone (e.g., Berger et al., 2018). When coupled with in-person psychotherapy or any form of clinical guidance, online interventions are more effective in sustaining long-term benefits (Karyotaki et al.,
2018) and have higher retention rates (Richards & Richardson, 2012) than self-managed web-based treatment alone (Andersson & Cuijpers, 2009). Caregiving researchers have suggested that self-managed therapy would increase caregivers’ level of control over their experience in their role, thus sharpening their problem-solving skills in navigating care recipient behavioral episodes (Gallagher-Thompson et al., 2000; Pinquart & Sörensen, 2003). Such self-management is enabled by online psychological treatment (Lappalainen et al., 2015). Overall, combined guided therapy and internet-based therapy is most effective, but not always the most practical and feasible (Baumeister et al., 2014; Cuijpers et al., 2009; Newman et al., 2011; Webb et al., 2010).

Acceptance and Commitment Therapy

ACT stems from CBT but has different philosophical, theoretical, and methodical roots, as well as contrasting mechanisms for change (Hayes et al., 2012). ACT operates in the realm of Applied Behavioral Analysis (ABA; Harris, 2009), a method analyzing the function of behavior based on its context, lead-up of internal (psychological) and external (environmental) events, and both short-term and long-term consequences (Harris, 2009). For example, the thought “I feel stressed about an upcoming deadline” may precede the behavior of avoiding responsibilities by watching several hours of TV, which is effective short-term in distracting one from the stress but may result in poorer performance and more stress long-term (Harris, 2009). With this foundation, ACT helps an individual to recognize triggering thoughts and emotions, identify useful or avoidant behavior, and to engage in healthy behaviors with long-term benefits.
ACT is philosophically based in functional contextualism (Hayes, 1993), which further evaluates the workability of any thought, feeling, or behavior, recognizing that workability varies by context (Harris, 2009; Ruiz, 2010). This means that a thought is only dysfunctional depending on the situation in which it is considered (Harris, 2009). For example, experiencing the thought “I need to run away” is dysfunctional and unhelpful when experiencing stress resulting from a loved one exhibiting behavioral and psychological symptoms of dementia, but is extremely functional and helpful when a bear begins advancing quickly upon you in Yellowstone National Park. Thus, a thought should not be judged as positive or negative but needs to be evaluated for its utility and purpose (Harris, 2009). Functional contextualism posits that for behavior to be influenced, it needs to be explainable through contextual variables (Hayes, 1993; Ruiz, 2010), thus becoming essential in a therapy seeking to improve client cognition. Within ACT, this creates an environment where the client can employ new ways of thinking about their behavior (Hayes et al., 2011).

ACT is theoretically and methodically derived from Relational Frame Theory, or RFT (Ruiz, 2010), which describes humans’ trained ability to make cognitive relationships between objects, people, and events, including internal events such as thoughts and memories (Hayes et al., 2001). This involves mechanisms of language and cognition that train infants and children to create these relations, building a larger and more complex network over time. For instance, a mother at a supermarket may show her infant son a lemon and encourages him to repeat the word lemon, creating an association between an object, a sound, and word. Later at dinner, the mother may invite her son to
taste a lemon slice, and his reaction will be characterized by the word she teaches: *sour* and cemented in memory. As humans mature, their cognitive relations become second nature and subconscious (Harris, 2009), indicating that they become difficult to *unlearn*, and consequently influence behavior. ACT disentangles unhelpful relations by enabling client recognition of these learned thoughts and their inherent lack of power, giving the client a realization of power to act despite whatever events may occur (Hayes et al., 2012).

ACT focuses not on the truthfulness of thoughts, but on their *workability*, or the effectiveness of how the client navigates them, which navigation could be functional or dysfunctional. The overarching goal of ACT is to increase an individual’s *psychological flexibility*, which is achieved in an ongoing process where the client can stay connected with their inner experiences but chooses to see them as just thoughts that pass by, only allowing them to take greater shape when they are useful. Further, therapists train the client to act according to their own personally identified values regardless of their challenging thoughts, acknowledging that trying to avoid them only creates more mental pain (Hayes et al., 2012). Doing so empowers the client, giving them a potent sense of capability and purpose in life, enabling their pursuit of meaning and happiness (Twohig & Levin, 2017). With psychological flexibility, a person can successfully live a goal-oriented and values-based life even with the presence of mental illnesses (Hayes et al., 1996), or caring for someone who has them.

**ACT Behavioral Change Model**

The ACT Behavioral Change Model (see Appendix A) is a simple illustration for
identifying pathological processes of psychological inflexibility and their relevant ACT components for treating it. These components are divided into two processes: *mindfulness and acceptance* processes including components of acceptance, defusion, self as context, and being present; *commitment and behavior change*-oriented processes include identifying values and commitment to actions (Hayes et al., 2012; Twohig & Levin, 2017). The following sections will outline each process and the corresponding treatment component of the model in order to increase psychological flexibility.

**Experiential Avoidance and Acceptance**

Experiential avoidance is when individuals seek to avoid encounters with unpleasant experiences, including internal experiences (e.g., difficult thoughts or traumatic memories; Hayes et al., 1996, 2012). Avoidance becomes problematic when it impedes values-based living, causing more pain than the original thought or experience (Ruiz, 2010). Avoidant behaviors are correlated with increased levels of depression, anxiety, and other indicators of psychosocial dysfunction (Hayes et al., 2006), and exacerbate the impact that maladaptive coping skills, poor emotional regulation, and overthinking can have on stress (Kashdan et al., 2006). Conversely, “acceptance” decreases stress (Davis et al., 2015) and correspondingly combats avoidance through the acknowledgement and receptivity of a spectrum of internal experiences, refraining from trying to alter or avoid them. Acceptance requires a deliberate reorientation to be curious and explorative of one’s thoughts, emotions, and physiological responses without judgment, cognitive ruminating, or by locking onto one of these sensations (Hayes et al., 2012). This intentional behavior (Twohig & Levin, 2017) increases psychological
Fusion and Defusion

Cognitive fusion occurs when one believes that thoughts are factual (Hayes et al., 2011), constructing a constructed reality, shaping future interpretation of experiences (Hayes et al., 2012). Cognitive fusion amplifies chronic pain, depression, anxiety, and early onset mental health issues in youth and children (Addis & Jacobson, 1996; Greco et al., 2008; Wicksell et al., 2008) and is associated with lower quality of life (Fergus et al., 2012; Gillanders et al., 2014). The opposite is cognitive defusion, or the ability to view thoughts as distinct cognitive events on their own (i.e., “Thoughts are just thoughts”), without loaded meanings assigned to them (Romero et al., 2015; Twohig & Levin, 2017). Defusion helps the individual separate their thoughts from themselves and reality (e.g., “I notice that I am having the thought that___”), and creating a sense of control over thoughts through even subtle changes in cognitive language (e.g., “I want to go to the gym but I am tired” versus “I am tired and I am going to the gym”; Hayes et al., 2012, p. 987). Continually practicing cognitive defusion decreases how believable and distressing thoughts are, increasing psychological flexibility (Masuda et al., 2009).

Attachment to the Conceptualized Self and Self as Context

Cognitive fusion can occur in self-concept, resulting in an overidentification with self-defined narratives. Being fused to self-concept means perceiving that self-evaluations are literal, allowing negative evaluations to reinforce undesirable behavior and emotions (Twohig & Levin, 2017). The individual may avoid encountering
contradictions of their self-concept in an attempt to maintain stability of their sense of self (Hayes et al., 2012; Mendolia & Baker, 2008). For example, a client may accept many opportunities to serve others despite their time being spread thin, because of fear that by saying no, their self-concept of dependability would be threatened. Instead of trying to change fused self-concept, ACT helps clients take the perspective of a self-observer, or *self as context*. The client can then recognize that the mind is a safe space where self-evaluations always occur, and that internal mental events are not always truthful (Hayes, 1984; Twohig et al., 2019). This is also described as *noticing self* (Hayes, 1984), which considers others’ perspectives and is cultivated through mindfulness (Hayes et al., 2012). Mindfulness techniques are simple exercises that reorient a person to the present and surrounding stimuli, initially led by therapists or meditation experts but can be comfortably self-guided.

**Dominance of Past and Future or Being Present**

Fusion to past or future is a process of avoiding the “here and now,” marked by “attentional rigidity” (Hayes et al., 2012, p. 983). A person with anxiety can be fearful or uncertain of the future, while depression can encompass disappointment in and unhelpful reflection on the past. Psychological inflexibility is rampant in these two instances, because these mindsets dominate their well-being (Twohig et al., 2019) and hold them hostage to what is out of their control. Fusion to past or future can exacerbate the effects of post-traumatic stress and trauma but can be mitigated by mindfulness techniques (Engle, 2015). Mindfulness helps individuals shift their attention to the present, distance themselves from mental conflict and increase awareness of what is currently relevant and
in their control (Twohig & Levin, 2017). Mindfulness and being present are more effectively achieved by refraining from labeling or making weighted conclusions about thoughts (Valdez, 2016). By continually trying to be present, individuals are capable of focusing on their values and recommitting to them through action (Twohig & Levin, 2017).

**Lack of Values Clarity and Clarification of Values**

Changes in behavior are less likely to be effective and sustained long-term when the client is motivated by reducing feelings of guilt, which can result in avoidant behavior and increased guilt when behavior change efforts fail (Hayes et al., 2012). Values are meant to drive action even when thoughts and feelings do not currently align with what is important. Values are not feelings, actions or goals, but are what the client or individual deems as important in their life and that gives them a sense of purpose, regardless of the current state of their feelings or relationships. Lack of values clarity is the state of being unaware of or unmotivated by values due to their ambiguity and failure to focus on them.

ACT focuses on *values clarification*, or the process of identifying and solidifying what is most meaningful and significant to the client (Ruiz, 2010; Twohig & Levin, 2017). Valuing is a concerted effort, in which the client chooses what to value and when to choose value-based action over fear (Hayes et al., 2012; Twohig et al., 2019). “Values can motivate behavior even in the face of tremendous personal adversity” (Hayes et al., 2011, p. 297). It is crucial to note that the acceptance and defusion processes in the Behavioral Change Model must be at work in the client’s life *before* willingness to
connect their values to actions that facilitate behavior change occurs (Hayes et al., 2012; Twohig et al., 2019). In other words, if values are evident in motivating an individual’s actions, it is because other ACT processes and overall psychological flexibility have long been at work. When actions are paired with values in the individual’s mind, meaning is derived, individuals are more likely to act despite difficult mental events, and there is a greater likelihood of sustained behavioral change because of their commitment to those values (Twohig & Levin, 2017).

**Inaction and Committed Action**

The opposite of inaction and experiential avoidance is commitment, marked by actions becoming aligned with values. Following the ACT process of clarifying values, the client identifies the value associated with difficult actions and commits to doing them, even when challenging, uncomfortable, or feared circumstances arise (Ruiz 2010; Twohig et al., 2019). This commitment is manifest when behavior is continuously re-shifted to become a more consistent pattern of values-based living (Hayes et al., 2012). For example, a caregiver may be reluctant to spend time with their mom outside of assistance in activities of daily living due to a since-forgiven awkward quarrel, and consequently avoids every conversation with her for fear of it being brought up. However, the therapist has helped the caregiver identify that they value a close relationship with their mother, which encourages them to choose to engage in small-talk anyways with their mom because they are motivated by and committed to that value, even though their desire and feelings are not initially in agreement.
Acceptance and Commitment Therapy Empiricism and Interventions

ACT has been demonstrated in over 330 randomized controlled trails (RCTs) to be helpful in improving and treating psychological symptoms stemming from a wide spectrum of behavioral and mental health disorders and other common high-stress contexts and for various age groups (Association for Contextual Behavioral Science [ACBS], 2014; Ruiz, 2010). Examples of RCTs span groups with different challenges, include: social anxiety disorder (Hazavei & RobatMili, 2020), trichotillomania (Lee et al., 2020), mothers with children with autism (Salimi et al., 2019; Taghvaei et al., 2019), generalized anxiety disorder (Stefan et al., 2019), and many other applicable populations. In one study, psychological flexibility (i.e., practicing cognitive diffusion) served as a mediator in decreasing loneliness experienced by aging adults over 40 years old, and engagement in values-based living was a more powerful mediating mechanism for decreasing loneliness when paired with psychological flexibility (Frinking et al., 2019). This demonstrates the positive influence that ACT skills can have in individuals’ quality of life and psychosocial indicators, regardless of their challenges or stage in life.

Most ACT interventions have focused on singular groupings of psychological flexibility skills in ACT (e.g., mindful awareness vs. commitment to values), rather than the entirety of the ACT Behavioral Change Model. Additionally, most interventions have been laboratory-based studies (Petersen et al., 2019). Preliminary data has shown that combining all four components of ACT’s psychological flexibility model—rather than isolating certain ACT elements—into a holistic treatment intervention more positively affected psychosocial functioning and ACT skill retention pre- to posttest and during
long-term follow-up (Petersen et al., 2019). Consequently, it is important for ACT interventions to have a simple, holistic incorporation of the entire psychological flexibility model, especially because emotional needs and psychological symptoms may vary person to person, whom benefit differently from certain ACT concepts.

**Online-Based Acceptance and Commitment Therapy**

Online-based ACT has been shown to be most effective in decreasing depressive symptoms for individuals who are not severely depressed. These individuals would benefit most by supplementing online therapy to face-to-face therapy. Individuals who are severely depressed still reported benefitting from online ACT programs because of their new ACT skills that fuel positive coping with difficult thoughts and emotions (Lappalainen et al., 2015). In addition, online-based ACT can be useful for participants with long histories of depressive symptoms because of the behavioral change skills and overall increase in psychological flexibility (Lappalainen et al., 2015).

Previous online-based ACT programs to date have shown their ability to increase psychological flexibility, even if the treatment is self-guided (no additional face-to-face support) and short in duration (Lappalainen et al., 2015; Levin et al., 2017). Self-guided online ACT treatments have a far greater positive effect on psychosocial measures (i.e., depression, anxiety, psychological functioning, and general stress) than control groups and waitlist groups (Ivanova et al., 2016; Lappalainen et al., 2015; Ly et al., 2014). Web-based ACT is also compelling for organizations lacking adequately licensed mental health professionals, as the programs are simple to operate and administer (Lappalainen et al., 2015). Lack of funding creates barriers to administering cost-effective therapy and
research evaluating the effectiveness of a new therapy. Online ACT is appealing to researchers and organizations because of its feasibility in improving content with each new wave of research without requiring extensive funding (Levin et al., 2017).

Many studies of web-based ACT have suggested improvements to maximize the effectiveness of online interventions. Providing more text-based explanations, materials, and examples is needed to help caregivers internalize the different ACT skills and their varying techniques. Additionally, interactive computer applications that invite text-based responses potentially increase participant engagement more than smartphone applications do, although these computer applications can create strain by writing long-sentences and their difficult level of navigability between text boxes (Ivanova, 2016). Further, computers are not as integrated into daily life as smart phones are, suggesting a possible barrier to accessibility (Ly et al., 2014). Other online-ACT pilot studies had an overwhelming participant response in requesting that the sessions be shorter, implicating the possibility of greater retention over time and engagement (Lappalainen et al., 2015; Levin et al., 2017). Finally, it is essential for future interventions to include long-term follow-up data (in addition to the initial posttest), as previous studies implicated that certain ACT skills such as valued living take longer to master (Ly et al., 2014). The current intervention was mindful of these suggestions in its creation and implementation by examining the long-term effectiveness of the program at 4-week follow-up.

**Acceptance and Commitment Therapy for Caregivers**

Researchers of ADRD caregivers have called for interventions that will mitigate
the effect that negative thoughts have on intensifying stress and depressive symptoms (Chang, 1999; Pinquart & Sörensen, 2003). ACT offers a promising solution. The application of ACT to caregivers is fairly novel, with only one RCT published to date (reviewed in ACBS, 2014; Losada et al., 2015), while other research studies have used and evaluated more granular aspects of ACT and their effectiveness on improving caregiver’s emotional well-being and other mental health indicators (Davis et al., 2015; Losada et al., 2014; Romero-Moreno et al., 2015; Spira et al., 2007). In the aforementioned RCT comparing ACT to CBT, ACT was demonstrated as an equally efficacious treatment for caregivers of PWD in decreasing the hold of dysfunctional thoughts, depressive symptoms, and anxiety (Losada et al., 2015). Other empiricists also found that family caregivers of PWD have higher levels of distress associated with greater exhibition of avoidant behaviors (Losada et al., 2014; Spira et al., 2007). This indicates that ACT is well-suited in mitigating the difficult aspects of the caregiving role.

Many useful applications to caregivers have been found in studies researching granular components of ACT. For instance, commitment to one’s values was negatively associated with depressive symptoms and caregiver stress and positively associated with adaptive coping strategies and emotional acceptance (the opposite of experiential avoidance) in the caregiving experience (Romero-Moreno et al., 2017). Romero-Moreno et al. indicated the need for an intervention that helps caregivers to differentiate and balance their family-based values and their own personal values. Caregiving is a family-focused value that often overshadows personal values in day-to-day actions (e.g., self-care and social activities) and can increase anxiety because of the endless duties
associated with caregiving (Romero-Moreno et al., 2017). Qualitative studies have discovered that values, when applied to caregiving, enable healthy self-reflection and the ability to glean purpose and meaning from such reflection, thus fueling the positive aspects of caregiving (Cross et al., 2018). Making time for personal values-based actions may help caregivers find greater intrinsic motivation and internal locus of control in caregiving (Romero-Moreno et al., 2017), which are positively correlated with using helpful coping strategies and experiencing decreased stress in fulfilling caregiving duties (Contador et al., 2012).

Additional scholarship on components of ACT in samples of dementia caregivers includes their search for rewarding aspects of their role and measuring how perceived rewards affects their valued living. For example, higher levels of anxiety and psychological inflexibility can negatively affect the caregiver’s ability to perceive rewards from their relationship with the PWD and their role overall (Henriksson et al., 2015). Cross and colleagues also demonstrated that when caregivers intentionally search for and glean rewards from the caregiver-care recipient relationship, this facilitates acceptance of their caregiving role, including the uncertain and quickly developing changes in their family member’s health (Cross et al., 2018; Lawrence et al., 2008). Thus, ACT skills can bidirectionally affect the positive aspects of caregiving.

**Online-Based ACT for Caregivers**

Until recently, web-based ACT had not been applied to caregivers of PWD, although other technologically delivered therapeutic treatments have effectively reached and improved outcomes for this population. Godwin et al. (2013) reviewed twenty-four
tech-based interventions for caregivers, including seven RCTs, and found common outcomes that caregivers react positively to, including: online skill building, support groups, and computer-facilitated education and which resulted in improved mental health symptoms, lighter caregiving burden, and increased competence and confidence in caregiving duties. While caregivers respond positively to online-delivered interventions, ACT was not the foundation of any of these online interventions.

In the past 3 years, Utah State University professors Fauth, Levin, and Novak (now at Auburn University) developed an online-based ACT intervention for ADRD caregivers, supported by USU Extension (ACT for Caregivers). The intervention includes ten self-guided online sessions that incorporate explanatory videos, stories and mindfulness training, while using interactive “fill in the blank,” dropdown menus, and other web-compatible activities to teach and foster ACT skills. It is self-guided, with no face-to-face interaction with researchers or clinicians, and participating caregivers are requested to complete approximately two sessions each week, which allows them time and flexibility to practice between each session in order to finish within the recommended (but not required) 6-week period. Caregivers are allowed to finish the sessions at their own pace but received email reminders if they had lags in progress (Fauth et al., 2020).

A systematic pre-post-follow-up design was implemented to test the program ($N = 49$). Fauth et al. (2020) used a repeated-measures ANOVA from the three time points, and results indicated that there were mean level changes made in all tested outcomes (measures of these outcomes that were included in the current thesis are described in
more detail in the methods section). Participants using online ACT for Caregivers reported decreases in depressive symptomatology \((F(1.72, 73.9) = 17.86, p = 0.00)\) and caregiver burden \((F(2, 82) = 5.77, p = 0.01)\). Stress reactions to BPSD decreased \((F(1.65, 64.15) = 9.12, p = 0.00)\), despite the frequency of these symptoms not changing significantly over time. Positive aspects of caregiving increased \((F(2, 86) = 10.31, p = 0.00)\). Quality of life increased \((F(2, 86) = 15.80, p = 0.00)\). Cognitive fusion decreased (as higher fusion is worse, lower is better) \((F(2, 86) = 9.09, p = 0.00)\) and psychological inflexibility decreased \((F(2, 86) = 6.12, p = 0.00; \text{for this scale, lower is better, representing more flexible thinking})\). Finally, progress toward values-based living increased \((F(2, 86) = 12.17, p = 0.00)\). Further, qualitative thematic analysis of the open-ended questions responses (Braun & Clarke, 2006) and coders of short open-ended usage and satisfaction questions found that ACT skills were correctly employed by participating caregivers. Specifically, mindfulness activities were reported as the most helpful, that the sessions were easily navigable despite session completion being obstructed by competitions for time in daily life. These outcomes indicate that online ACT for Caregivers is associated with improved ACT and caregiver-related outcomes over time (Fauth et al., 2020).

### The Current Study

Despite the initial analyses from ACT for Caregivers being completed, the current study aimed to examine other aspects of program evaluation not included in the already submitted paper. Thus, this thesis uses the ACT for Caregivers study data, but the
analyses conducted here are not included in the current submitted paper, and thus represent novel work.

The current study evaluated user experience and user engagement, including how much effort caregivers put into the various activities recommended and how thoughtful they perceived the activities to be. The current study explored how user engagement and experience affected program outcomes. In concert with other tech-based ACT interventions calling for the need to include all components of the ACT Behavioral Change Model (Ly et al., 2014), this study used the entire model to identify which session activities affected outcomes the most and which needed improvement, especially in facilitating long-term use of ACT skills after program completion.

The current study focused on two predictor variables and three outcomes. The two independent variables were chosen to evaluate the effect of participant’s effort on practicing ACT skills in between sessions and the perceived helpfulness of those practice activities. The three outcome variables were chosen because they reflected: (1) a key aspect of the caregiving experience that was expected to be most directly affected by ACT (reducing the stress reactions caregivers experience with BPSD), (2) an ACT-specific skill that encompasses one of the final skills gained: participant’s progress toward values-based living, and (3) caregivers’ continued use of ACT skills after sessions ended, which indicates mastery and everyday application of the concepts in the ACT Model of Behavioral Change, after exposure to ACT training has commenced.

In sum, the initial analyses of ACT for Caregivers (Fauth et al., 2020) suggest that users experienced improvements in both ACT-specific and caregiver-specific outcomes,
as well as in more global outcomes such as quality of life. Existing analyses have not identified if specific effort on sessions, and helpfulness of sessions, are associated with improvements in key caregiver outcomes and retention of ACT skills. Thus, this thesis examined whether ratings of effort or helpfulness of certain ACT for Caregivers sessions, or of the sessions as a whole, were associated with the reductions in BPSD stress reactions, increases in values-based living and/or the continued use of ACT skills after the program.

Drawing upon prior studies’ findings, it was hypothesized that greater self-reported effort on practicing ACT skills in between sessions would be associated with decreased stress reactions to BPSD, increased progress made toward values-based living, and greater use of ACT skills after the program (H1). Likewise, it was hypothesized that between-session practice activities that caregivers perceived as more helpful would be associated with decreased stress reactions to BPSD, improvement in progress towards values-based living, and greater use of ACT skills post-program (H2).

Finally, it was hypothesized that effort and helpfulness of individual sessions would be more highly correlated with the sustained use the sessions’ corresponding skills after the program sessions ended. Specifically, the mean level effort and helpfulness in sessions which taught the cognitive defusion skill (Sessions 5 and 6: noticing unpleasant thoughts and behavior), and the sessions which taught everyday mindfulness skills (Sessions 7 and 8), would be associated with greater use of these related skills after all sessions have been completed (H3).
CHAPTER III

METHODS

This study was part of a larger program evaluation of existing data from the web-based ACT for Caregivers intervention. This study will significantly contribute to the literature and applied field because to our knowledge, online ACT has yet to be applied to dementia caregivers, a population needing increased flexibility and navigability in obtaining treatment to support them in the potentially demanding role.

Sample

Initially, 160 caregivers completed the online consent form and pretest. One hundred-nineteen then began the online intervention by entering the program, watching the orientation video, and completing the first session. Fifty-one participants completed all ten sessions in addition to both posttests (at completion and 4-week follow-up), but there were two IDs with two entries on each ID, meaning IDs were mis assigned twice, or participants shared their ID with a non-participant to provide them access to the material. All data for those ID numbers were excluded because it was impossible to confidently distinguish between them, which yielded a final sample of $N = 49$. While this may seem like low rates of take-up and high levels of attrition, systematic reviews of online CBT suggest that web-based ACT for Caregivers is similar to other online therapy participation (Christensen et al., 2009; Kaltenthaler et al., 2008). As discussed in this review, take-up rates are hard to determine from published studies as they often leave out this information. Kaltenthaler et al. reported ranges of 3-75% dropout rates for online
CBT. Even face-to-face therapy experiences high levels of dropout, as self-help can be challenging (Carlbring et al., 2018).

**Procedures**

Participants self-selected from advertisements and contacted the project manager via email or phone. Eligibility required that the individual was caring for someone with ADRD or significant memory impairment that impacted their daily life and that they reported a score of at least 4 or higher on the question, “How distressed are you by this role?,” ranging from 0 (not at all) to 10 (extremely). Participants also had to be fluent in English and were willing and able to do self-help work on the internet. If determined eligible, they were invited by email to complete an online informed consent and pre-test. Upon completion of the informed consent and pre-test, the participant was contacted via email and provided with the link to the ACT for Caregivers website and with a unique sign-in ID.

Caregivers watched a brief orientation video and started session 1 at their convenience. There are ten online sessions, each requiring approximately 20 to 30 minutes to complete. In the orientation video and informed consent, participants were recommended to complete two sessions a week, with a few days in between for practicing the ACT skills taught from each prospective session, facilitating completion of the intervention within 5 weeks. While participants were welcome to work at their own pace, and circle back to prior sessions at their own discretion, a participant manager sent a reminder email if the participant appeared to have taken a longer break from the
program (at 2 weeks of inactivity). In conjunction with the skills taught in each session, there was an education library that participants had access to, found on the ACT for Caregivers website, that provides resources for dementia-related education. Resources include USU Extension Fact Sheets on dementia and Alzheimer’s disease, educational videos (approved by dementia researchers) on providing care, and other resources. Caregivers were asked to rate the helpfulness of each education material if they used it (not at all helpful, somewhat helpful, very helpful). Once the tenth session had been completed, the participant completed the posttest survey, and was contacted 4 weeks later via email with a link to a follow-up posttest. Participants were paid $50 if they completed the study. The participant manager was reachable via email and phone for assistance, if needed. Procedures were approved by the ethical review boards of Utah State University and the Utah Department of Health.

Measures

Independent Variables

Effort

At the beginning of each ACT session (starting with Session 2), participants were given a review statement on what the practice assignment was for the previous session (e.g., “The practice assignment for Session 1: Focusing on What Matters was to try to pay attention and identify things that matter to you”). The participant was then asked, “How much effort did you put into this activity?” with answers on a 6-point Likert scale ranging from 0 (I did not have an opportunity to practice this assignment) to 5 (a lot).
Helpfulness

The next question in the review section at the beginning of each module asked about the participant’s perception of utility that the practice assignment had. After being asked the question, “How helpful was it to practice focusing on what matters?,” participants responded using a 6-point Likert slider scale with answers ranging from 0 (not at all helpful) to 5 (very helpful).

Dependent Variables

The pre-, post-, and 4-week follow-up posttests measured eight different outcomes varying from depressive symptoms, caregiver burden, and quality of life. The current study only evaluated two of these variables’ pre to 4-week follow-up change scores in addition to a variable measured at both posttests, as described below.

Stress Reactions to BPSD

The variable “stress reactions to behavioral and psychological symptoms of dementia,” was evaluated using the 24-item Revised Memory and Behavior Problems Checklist developed by Teri and colleagues (1992; α = .84 for patient behavior and α = .90 for caregiver reaction). The scale is commonly included in studies of caregiver well-being and interventions and asks participants the extent to which they witnessed dementia symptoms exhibited by their relative and they respond with an answer of frequency. For example, the participant was prompted with the question “Being aggressive to others verbally,” and chose an option on a Likert-scale between 0 (never occurs), to 4 (occurs
daily or more often; Teri et al., 1992). If they reported any exposure to a symptom, they were followed up with a stress reaction question: “How much did this behavior bother you?,” and responded on a 6-point Likert scale ranging from 0 (not at all) to 4 (extremely), with an option for don’t know or N/A. A mean score of the RMBPC stress reactions was used, so that high scores indicate higher levels of stress appraised from BPSD (Teri et al., 1992).

**Progress Toward Values-Based Living**

Participant’s “progress toward values-based living” was measured using the 10-item Valuing Questionnaire that has two subscales (Smout et al., 2014). The first subscale, “Making Progress Towards Values” contains prompts such as, “I worked towards my goals even if I didn’t feel motivated to,” which were measured on a 7-point Likert scale, ranging from 0 (not true at all) to 6 (completely true). The second subscale, “Obstructing Values,” includes prompts such as, “Difficult thoughts, feelings, or memories got in the way of what I really wanted to do,” also measured on a 7-point Likert scale, with answers ranging from 0 (not true at all) to 6 (completely true) (Smout et al., 2014). Past reliability and concurrent validity of the scale is high (α = .87 for Progress Scale, α = .88 for Obstruction Scale; Christie et al., 2017; Reilly et al., 2019; Smout et al., 2014). This measure is included in many ACT studies, either as a total score, or sub-scores. For the current study, the total score was used.

**Continued Use of ACT Skills from Program Completion to 4-Week Follow-Up**

Participant’s self-reported use of specific ACT strategies taught in the course was
assessed at program completion and 4-week follow-up. In the 10th and last session, these questions asked about use of ACT skills at program completion compared to before their study enrollment. At the 4-week follow-up, participants were asked to compare their use of ACT skills then to when the study ended 4-weeks prior. Change in use of the following five skills were evaluated: “noticing difficult thoughts and unpleasant behaviors”; “avoiding behaviors” (reverse coded); “identifying what matters to you”; “everyday mindfulness”; and “commit to what matters to you” (see Table 1 for corresponding sessions and the Appendix for Figures A1, A2, and A3). At the 4-week follow-up, these skills were evaluated through questions like: “Compare yourself now to when you last took this survey (about 4 weeks ago). Do you think you are able to (i.e.) ‘notice the presence of negative thoughts and unpleasant feelings’ more, less, or about the same?” Answers were inputted on a sliding scale 0 to 10, ranging from, 0 (I do this MUCH LESS now) and 10 (I do this MUCH MORE now). The current study focused on the 4-week follow-up data to identify if participants were continuing to use ACT skills after their initial post-program assessment, as most participants on average increased their use of ACT skills since completing online ACT for Caregivers. This was decided for evaluating program effectiveness long-term.

**Session 10 Reflections: Supportive Themes**

As part of the final module (Session 10), participants were asked to provide written answer responses in designated text boxes with prompts relating to reflections on each of the previous nine sessions. For example, the Session 3 prompt says, “Think about some away moves (avoidant behaviors) you have used in the past and write about how
Table 1

ACT Skills Taught in ACT for Caregivers Sessions as Related to the ACT Model for Behavior Change

<table>
<thead>
<tr>
<th>Session</th>
<th>Session title</th>
<th>ACT skill</th>
<th>ACT component</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Focusing on what matters</td>
<td>Identify what matters to you</td>
<td>Values clarity</td>
</tr>
<tr>
<td>2</td>
<td>Act to do what matters</td>
<td>Identify what matters to you</td>
<td>Commitment, taking action &amp; values clarity</td>
</tr>
<tr>
<td>3</td>
<td>Away moves</td>
<td>Notice avoiding behaviors</td>
<td>Acceptance, attention to present, commitment &amp; action</td>
</tr>
<tr>
<td>4</td>
<td>Letting go</td>
<td>Let go of avoiding behaviors</td>
<td>Commitment &amp; taking action</td>
</tr>
<tr>
<td>5</td>
<td>Noticing hooks</td>
<td>Notice thoughts and behavior</td>
<td>Cognitive defusion &amp; psychological flexibility</td>
</tr>
<tr>
<td>6</td>
<td>Getting unhooked</td>
<td>Notice thoughts and behavior</td>
<td>Cognitive defusion, self as context</td>
</tr>
<tr>
<td>7</td>
<td>Being present</td>
<td>Everyday mindfulness</td>
<td>Self as context &amp; mindfulness</td>
</tr>
<tr>
<td>8</td>
<td>Mindfulness</td>
<td>Everyday mindfulness</td>
<td>Self as context &amp; mindfulness</td>
</tr>
<tr>
<td>9</td>
<td>Making commitments</td>
<td>Commit to do what matters to you</td>
<td>Commitment &amp; values clarity</td>
</tr>
<tr>
<td>10</td>
<td>Moving forward</td>
<td>Overview of ACT skills</td>
<td>All</td>
</tr>
</tbody>
</table>

this intervention has changed your perception of these avoidance strategies.” The data collected in this section was not included in the correlational analysis, nor coded using systematic thematic analysis, but was used as supplemental information meant to provide context to participants’ responses to the posttest “Use of Act Skills” questions.

Analyses

Change scores (baseline scores minus 4-week follow-up scores) were created for the first two dependent variables (BPSD stress reactions, progress towards values-based
living) to determine associations between the independent variables (effort and perceived helpfulness of practice activities) and the extent of improvement on the outcomes in these indicated measures. Recall that prior analyses had already determined average improvements in all outcomes for this sample (Fauth et al., 2020). The third dependent variable was asked in the format of “to what extent you do this less, the same, or more,” thus no change scores were needed.

In preparing the independent variables, it should be noted that the Session 6 Perceived Helpfulness data was excluded from the study due to an error with Qualtrics. While the question was asked in the Session 6 reflection, the answers were not recorded for any participants, resulting in the inability to assess Session 6 helpfulness individually, and the inability to include this in the average across all session’s helpfulness. Session 7 had two practice sessions assessed, one asking about helpfulness and effort in the “Being Present” skill, and the other asking about helpfulness and effort in imagining thoughts as “Leaves on a Stream” (i.e., practicing mindfulness and being comfortable with thoughts as “just thoughts”). Thus, reported effort and perceived helpfulness for both session 7 practice activities were averaged to one effort and one helpfulness score.

Correlations were run between the independent variables (the individual session helpfulness and effort scores, and the mean helpfulness and effort across all sessions), with the dependent variables (change in BPSD stress, change in progress toward values-based living, and the continued use of ACT skills; the five skills individually and the mean across all five ACT skills). Initially, I planned to run regression models to determine the amount of variance explained by the individual sessions and across all
sessions in each outcome variable, by examining the model fit index $R^2$. Due to overall lack of statistically significant findings in bivariate correlations (see results), regression models were not pursued.

Finally, I reviewed the written responses to open-ended questions in Session 10 (at program completion), and I selected phrases or comments that provided supplemental context on participants’ perceived effort in the program and the helpfulness of practice skills embedded within. This was not a qualitative analysis (as this was not a mixed methods thesis), thus a systematic qualitative approach was not necessary. This review was merely to identify additional open-ended information that might serve as informative examples of the users’ experience with helpfulness or effort in sessions or skills.
CHAPTER IV
RESULTS

Preliminary Findings

Most participants in this sample were female, White (non-Hispanic), college graduates, spouses of the PWD, and living with the care recipient. Caregivers’ mean age was about 66 years, while care recipients’ mean age was approximately 82 (see Table 2).

Table 2

Sample Characteristics (N = 49)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>M</th>
<th>SD</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age (range 33-90)</td>
<td>66.6</td>
<td>10.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care receiver age (range 60-95)</td>
<td>81.7</td>
<td>7.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender: Female</td>
<td>80.0</td>
<td></td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>Kin relationship: Caring for spouse</td>
<td>53.1</td>
<td></td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Living with care receiver</td>
<td>59.2</td>
<td></td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Care receiver in assisted living</td>
<td>14.3</td>
<td></td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>93.9</td>
<td></td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino/Latina</td>
<td>2.0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2.0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Native American/Alaska Native</td>
<td>2.0</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Completed college</td>
<td>55.1</td>
<td></td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Currently working full-time</td>
<td>24.5</td>
<td></td>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

Overall, participants reported moderate effort in their between-session skill practices (M = 2.49, SD = .55). Participants reported higher effort on Session 9, (M = 2.61, SD = .98), expending marginally less effort mid-program, with Session 6 being the lowest reported (M = 2.38, SD = .94; see Table 3). A paired t-test compared the session
with the highest average effort rating (Session 9) and the lowest rating (Session 3) and the mean differences between the two were not statistically significant ($t(47) = -1.23, p = .21$). Thus, mean effort for individual sessions can be considered statistically similar to one another.

**Table 3**

*Average Effort Across All Sessions and of Individual Sessions*

<table>
<thead>
<tr>
<th>Session number</th>
<th>n</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>All sessions</td>
<td>49</td>
<td>2.49</td>
<td>.55</td>
</tr>
<tr>
<td>1</td>
<td>49</td>
<td>2.59</td>
<td>.86</td>
</tr>
<tr>
<td>2</td>
<td>49</td>
<td>2.51</td>
<td>.89</td>
</tr>
<tr>
<td>3</td>
<td>48</td>
<td>2.52</td>
<td>.97</td>
</tr>
<tr>
<td>4</td>
<td>49</td>
<td>2.50</td>
<td>.84</td>
</tr>
<tr>
<td>5</td>
<td>45</td>
<td>2.42</td>
<td>.84</td>
</tr>
<tr>
<td>6</td>
<td>48</td>
<td>2.38</td>
<td>.94</td>
</tr>
<tr>
<td>7*</td>
<td>48</td>
<td>2.40</td>
<td>.82</td>
</tr>
<tr>
<td>8</td>
<td>48</td>
<td>2.54</td>
<td>.87</td>
</tr>
<tr>
<td>9</td>
<td>49</td>
<td>2.61</td>
<td>.98</td>
</tr>
</tbody>
</table>

* Mean effort of both practice activities (“Being Present” and “Leaves on a Stream”) for Session 7.

Participants reported that between-session practice assignments were helpful overall ($M = 3.65, SD = .54$). The data showed that the Session 9 practice assignment was overall the most helpful ($M = 3.97, SD = .97$), with earlier sessions being slightly less helpful (but still somewhat helpful; e.g., Session 3 $M = 3.42, SD = .97$; see Table 4). A paired samples $t$ test compared the session with the highest average helpfulness rating (Session 9) and the lowest rating (Session 6) and the mean differences between the two were statistically significant ($t(25) = -2.59, p = .02$), suggesting that Session 9 was rated as more helpful than Session 6 at a statistically significant level.
Table 4

Average Perceived Helpfulness of Individual Sessions and Across All Sessions

<table>
<thead>
<tr>
<th>Session number</th>
<th>n</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>All sessions</td>
<td>47</td>
<td>3.65</td>
<td>.54</td>
</tr>
<tr>
<td>1</td>
<td>37</td>
<td>3.54</td>
<td>.96</td>
</tr>
<tr>
<td>2</td>
<td>34</td>
<td>3.50</td>
<td>.75</td>
</tr>
<tr>
<td>3</td>
<td>33</td>
<td>3.42</td>
<td>.97</td>
</tr>
<tr>
<td>4</td>
<td>33</td>
<td>3.64</td>
<td>.74</td>
</tr>
<tr>
<td>5</td>
<td>39</td>
<td>3.62</td>
<td>.71</td>
</tr>
<tr>
<td>6</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>7^a</td>
<td>48</td>
<td>3.69</td>
<td>.77</td>
</tr>
<tr>
<td>8</td>
<td>37</td>
<td>3.84</td>
<td>.96</td>
</tr>
<tr>
<td>9</td>
<td>34</td>
<td>3.97</td>
<td>.97</td>
</tr>
</tbody>
</table>

Note. Session 6 had no data due to a Qualtrics error.

^a Mean perceived helpfulness of both practice activities ("Being Present" and "Leaves on a Stream") for Session 7.

The average change score for stress reactions to BPSD was .37 (SD = .58), while the average change score for progress towards values increased from -5.12 (SD = 7.61) at program completion to -4.37 (SD = 7.48) at 4-week follow-up (see Table 5).

Table 5

Average Change Scores of BPSD Stress Reactions and Progress Toward Values

<table>
<thead>
<tr>
<th>Change score variable (baseline minus 4-week follow-up)</th>
<th>n</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Δ BPSD stress reactions</td>
<td>46</td>
<td>.37</td>
<td>.58</td>
</tr>
<tr>
<td>Δ Progress toward values</td>
<td>49</td>
<td>-4.37</td>
<td>7.48</td>
</tr>
</tbody>
</table>
The ACT skills practiced the most at 4-week follow-up compared to program completion were “identify what matters” ($M = 7.37$, $SD = 1.75$), “everyday mindfulness” ($M = 7.49$, $SD = 1.71$), and “commit to what matters” ($M = 7.20$, $SD = 1.67$). The least practiced skill at 4-week follow-up was “avoidant behavior” (reverse coded, where higher is better; see Table 6).

**Table 6**

*Average Use of ACT Skills at 4-Week Follow-Up*

<table>
<thead>
<tr>
<th>ACT skill</th>
<th>n</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean use of all ACT skills</td>
<td>49</td>
<td>6.56</td>
<td>1.23</td>
</tr>
<tr>
<td>Notice unpleasant thoughts</td>
<td>49</td>
<td>6.69</td>
<td>2.17</td>
</tr>
<tr>
<td>Avoiding behavior (reverse)</td>
<td>49</td>
<td>4.06</td>
<td>2.18</td>
</tr>
<tr>
<td>Identify what matters</td>
<td>49</td>
<td>7.37</td>
<td>1.75</td>
</tr>
<tr>
<td>Everyday mindfulness</td>
<td>49</td>
<td>7.49</td>
<td>1.71</td>
</tr>
<tr>
<td>Commit to what matters</td>
<td>49</td>
<td>7.20</td>
<td>1.67</td>
</tr>
</tbody>
</table>

**Findings from Hypothesized Models**

Hypothesis 1 was not supported by effort data across all sessions. Average effort across all sessions was not correlated with any of the proposed outcomes: stress reactions to BPSD $r(47) = .16$, $p = .29$, progress toward values $r(47) = -.17$, $p = .26$, and continued use of ACT skills post-program $r(47) = .23$, $p = .12$. Hypothesis 2 was also not supported with helpfulness data across all sessions. Participant’s overall perceived helpfulness was not significantly correlated with change in BPSD stress reactions $r(42) = .13$, $p = .40$, change in progress towards values $r(45) = -.11$, $p = .46$ nor with continued use of ACT skills at 4-week follow-up $r(47) = .17$, $p = .24$ (see Table 7).
Table 7

Summary of Correlation Coefficients

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Dependent variables</th>
<th>Mean effort of all sessions</th>
<th>Mean helpfulness of all sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>p</td>
<td>r</td>
</tr>
<tr>
<td>Δ BPSD stress reactions</td>
<td></td>
<td></td>
<td>.16</td>
</tr>
<tr>
<td>Δ Progress towards values</td>
<td></td>
<td></td>
<td>-.17</td>
</tr>
<tr>
<td>Continued use of ACT skills</td>
<td></td>
<td></td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>.13</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-.11</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>.17</td>
</tr>
</tbody>
</table>

However, hypothesis 1 was partially supported by effort ratings from individual sessions. Specifically, individual session mean level effort ratings were not correlated with two of the proposed outcomes, albeit a few exceptions: Session 1 effort was correlated with change in BPSD stress reactions $r(44) = .35$, $p = .02$, and Session 9 effort was correlated with change in BPSD stress reactions, $r(44) = .32$, $p = .03$. None of the perceived helpfulness responses for individual sessions were correlated with change in BPSD stress reactions or in progress towards values (see Table 8), furthering lack of support for hypothesis 2.

Change in stress reactions to BPSD at 4-week follow-up was not correlated with progress towards values, $r(44) = -.27$, $p = .07$. Although some might consider this marginally significant ($p < .10$), an a priori decision was made to use .05 as the cutoff, thus marginal significance will not be interpreted. None of the ACT skills, nor overall use of ACT skills were significantly correlated with change in stress reactions to BPSD.

Some of the five individual ACT skills were significantly correlated with
Table 8

*Correlation Coefficients for Predictor Variables and Change Scores Outcome Variables*

<table>
<thead>
<tr>
<th>Session #</th>
<th>Independent variable</th>
<th>Δ BPSD stress reactions</th>
<th>Δ Progress toward values</th>
</tr>
</thead>
<tbody>
<tr>
<td>All (Mean)</td>
<td>Effort</td>
<td>.16</td>
<td>-.17</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.13</td>
<td>-.11</td>
</tr>
<tr>
<td>1</td>
<td>Effort</td>
<td>.35*</td>
<td>-.18</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.004</td>
<td>-.12</td>
</tr>
<tr>
<td>2</td>
<td>Effort</td>
<td>-.02</td>
<td>-.15</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.06</td>
<td>.05</td>
</tr>
<tr>
<td>3</td>
<td>Effort</td>
<td>.21</td>
<td>.17</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.33</td>
<td>.22</td>
</tr>
<tr>
<td>4</td>
<td>Effort</td>
<td>.09</td>
<td>-.27</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>-.11</td>
<td>-.04</td>
</tr>
<tr>
<td>5</td>
<td>Effort</td>
<td>.14</td>
<td>-.19</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.06</td>
<td>-.20</td>
</tr>
<tr>
<td>6</td>
<td>Effort</td>
<td>-.26</td>
<td>-.09</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>7</td>
<td>Effort</td>
<td>-.07</td>
<td>-.12</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>-.17</td>
<td>-.04</td>
</tr>
<tr>
<td>8</td>
<td>Effort</td>
<td>.10</td>
<td>.06</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.16</td>
<td>-.22</td>
</tr>
<tr>
<td>9</td>
<td>Effort</td>
<td>.32**</td>
<td>-.22</td>
</tr>
<tr>
<td></td>
<td>Helpfulness</td>
<td>.15</td>
<td>-.10</td>
</tr>
</tbody>
</table>

*Note.* Session 6 Helpfulness data were not recorded. While typically p values are included in correlation tables, there were only a few significant correlations.

* p = .02.

** p = .03, two-tailed.

individual session effort and helpfulness, while others were not (see Table 9). The first skill, “notice negative thoughts and unpleasant behaviors” was not significantly associated with overall effort, overall perceived helpfulness, nor any individual sessions for each predictor variable, showing insufficient evidence to support hypothesis 3. The
second skill, “avoidant behavior” (reverse coded, so higher is better) was not associated with overall effort and overall helpfulness across all sessions, nor with the average effort on individual sessions. However, “avoidant behavior” was negatively and significantly associated with perceived helpfulness of some individual sessions, including Session 2, $r(32) = -.41, p = .02$, Session 7 $r(46) = -.29, p = .05$, and Session 8 $r(35) = -.33, p = .05$.

The third skill, “identifying what matters” was significantly correlated with overall effort on all sessions $r(47) = .35, p = .02$, overall perceived helpfulness $r(45) = .36, p = .01$, and with average effort on Session 1 $r(47) = .45, p = .00$ and perceived helpfulness of Session 1 $r(35) = .36, p = .03$.

The fourth skill, “everyday mindfulness” was not significantly associated with average effort across all sessions, average perceived helpfulness across all sessions, nor individual session effort. While it was not associated with average effort and perceived helpfulness on sessions 7 or 8, which taught the “everyday mindfulness” skill (see Table 3), it was significantly associated with Session 4 perceived helpfulness $r(31) = .53, p = .00$. This also demonstrates insufficient support for hypothesis 3. The fifth ACT skill, “committing to what matters” was significantly associated with overall effort on all sessions $r(47) = .39, p = .01$ and overall perceived helpfulness across all sessions $r(45) = .40, p = .01$. It was not significantly associated with average effort for session 9 $r(47) = .14, p = .34$, which taught commitment. “Committing to what matters” was however significantly associated with Session 1 effort $r(47) = .38, p = .01$, and Session 9 perceived helpfulness $r(32) = .38, p = .03$ (see Table 9).
### Table 9

**Correlation Coefficients for Predictor Variables and Continued Use of ACT Skills After Session 10**

<table>
<thead>
<tr>
<th>Session</th>
<th>ACT practice activity</th>
<th>Mean of all skills</th>
<th>Notice thoughts &amp; behavior</th>
<th>Avoidant behavior (reversed)</th>
<th>Identify what matters</th>
<th>Everyday mindfulness</th>
<th>Commit to do what matters</th>
</tr>
</thead>
<tbody>
<tr>
<td>All (Mean)</td>
<td>All</td>
<td>Effort</td>
<td>.23</td>
<td>.07</td>
<td>-.18</td>
<td>.35*</td>
<td>.24</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Helpfulness</td>
<td>.17</td>
<td>.02</td>
<td>-.29</td>
<td>.36*</td>
<td>.21</td>
</tr>
<tr>
<td>1</td>
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</table>

*Note.* Correlations are bolded to signify that the skill was taught in that session. Session 6 Helpfulness data were not recorded. While typically *p* values are included in correlation tables, there were only a few significant correlations.

*p < .05.

**p < .01.
Contextual Comments from Open-Ended Questions

While the overall results from quantitative analyses could be interpreted that effort and helpfulness were not associated with improvements in the specified outcomes, this should not be interpreted that participants did not engage with the sessions or find the sessions helpful. In fact, the descriptive analyses in Tables 2 and 3 suggest that they were engaged with effort and found the sessions helpful. The open-ended responses give additional context as to what the caregivers found helpful, and what they were engaged in.

Session 1 taught participants to work on identifying what matters most. Many participants reflected that it was helpful for them to do this, and made them want to be more patient, compassionate, have no regrets, and remember that they also have needs that matter. One participant said, “Meeting the needs of my mother matter greatly to me and not taking care of my needs made me feel deprived of my freedom. When I remember what matters most, I take time for myself as well as her and not feel guilty.” Overall, by focusing on their values and what matters, participants cited their desire to spend quality time and enjoy these last years of life with their loved one, rather than seeing caregiving as an endless to-do-list for a helpless person.

Session 2 focused on acting on what matters most. Participants showed effort in practicing this and cited that it was helpful to remember that they have control over their actions, even when they do not have control over anything else. Many caregivers talked about being able to let go of difficult emotions over those things they could not control. Another participant said, “I remembered that mom doesn’t know she’s bugging me!”
When I act miffed, it hurts her and me. When I let the things that bother run off me, then I can act on what matters rather than what doesn’t.” Overall, participants reported that they were better able to act on what they value rather than feeling guilty about something they “should” do, demonstrating a conscious decision to act on what matters to them and turn away from things that are far less important.

Session 3 taught participants to notice when they avoid difficult situations, accept their thoughts as just “thoughts” and not as reality, and face them directly. A participant reflected, “Taking things one day at a time and facing them head on allows me more relief and happiness. Rather than ignoring it or tackling it another day, I will face it and deal with it immediately, allowing the release of emotions or frustration.” Overall, most participants spoke about how addressing feelings and difficult topics is freeing and helps them feel better sooner, rather than feeling anxious or fearful over something they have been avoiding.

Session 4 continues the theme of confronting avoidant behavior, and participants showed that they put in effort to confront their difficult thoughts and emotions. Many cited that because of their avoidance, they would blame others, become easily hurt, say harsh words, disagree, and other harmful behaviors. One caregiver shared their experience of trying to control their emotions by avoiding some of the more frustrating dementia symptoms:

There are things I can’t change – I can’t stop what we now call “adventures at midnight” around here. I could let that be so disruptive and energetically draining… but now, it’s so much easier to have a light heart, be in the moment, take care of any needs, and then gently guide her back to bed. A plus: we now journal the adventures and the conversations and are grateful for each day.

Many participants spoke of how helpful it was to let go of their avoidant behavior,
highlighting how it helped rid them of guilt and resentment.

Session 5 helped caregivers to identify their mental “hooks,” or the thoughts that would ruminate and cause increased stress. Most participants revealed their main “hooks,” which would range from fear of failure to fear of life never changing for the better. A participant related, “My hook has always been I have so much to do and no time to do it.’ I have finally been able to let go and realize this is a thought and it is okay if I don’t always have the time. It will be there tomorrow, so no big deal.” Pinpointing their hooks aided caregivers to recognize their hold and shift their attention to reality, increasing their psychological flexibility and decreasing stress.

Session 6 taught various strategies for letting of their hooks. Many participants’ favorite was changing “but” to an “and,” with one caregiver adding that it “helps me remember that it’s OK to have challenging thoughts, but they are just thoughts and don’t have to stop me,” showing effective application of cognitive defusion.

Sessions 7 and 8 taught mindfulness strategies to help participants let go of their difficult thoughts and emotions to be able to continue their commitment on what matters. Participants showed continued effort in practicing these strategies:

I use this skill almost daily. When a thought comes into my mind that I don’t want, I visualize putting it on a leaf and watching it float down the stream. Even by watching the leaf in the stream, I notice my breathing slows down and I naturally begin to focus on things around me.

According to these reflections, mindfulness skills were applied in most caregivers’ everyday lives and were effective in reducing stress and anxiety.

Session 9 reviewed the ACT skills and concluded with a commitment to act on values. Participants cited how their commitment to being compassionate and more patient
usually involved taking time for self-care and social interactions to keep their commitments in other areas:

Because I am homebound most of the time, my goal was to make connections more often with different members of my family. This has been by telephone, FaceTime, text, and inviting them up to our house. Each of these efforts has helped me to feel less frustrated by my circumstances, to realize that it is a temporary stage, and thus I feel less discouraged.

This session reflection coupled with the others demonstrate that, while individual session measurements of effort and perceived helpfulness were not significantly correlated with outcomes, the excerpts still show themes of effortful everyday application of ACT skills and reports of their helpfulness in reducing stress and increasing values-based living.
CHAPTER V
DISCUSSION

The current study sought to examine aspects of web-based ACT for Caregivers user experience, specifically how much effort they put into activities between sessions and how helpful they found the sessions to be. Prior analyses of this sample (Fauth et al., 2020) had identified mean improvements over time in all measured outcomes. This study examined if the effort and helpfulness ratings were associated with the improvement in BPSD stress reactions, progress toward values, and the continued use of ACT skills after the sessions ended and 4-week follow-up data were collected. In general, findings did not suggest that effort and helpfulness ratings across all sessions were significantly associated with changes in BPSD stress reactions, progress toward values, and continued use of the ACT skills in general. For the most part, the individual session effort and helpfulness ratings did not significantly correlate with changes in stress reactions to BPSD and progress toward values, with a few noted exceptions. Given the large number of correlations that were conducted, these few individual associations should be interpreted with caution.

The hypotheses that effort and helpfulness would be associated with the improvements in BPSD stress reactions, progress toward values, and continued use of ACT skills were not fully supported, although average ratings of helpfulness and effort were moderate to high across all sessions. Likewise, the open-ended response data suggested that caregivers found the skill training and practice activities helpful, and that they put forth effort into them (e.g., “Squared breathing helps me center my mind…I take
more time each day to just look around me and notice things like the clouds and children” and “Breathing and leaves on a stream are helpful”). The lack of association also implies that there are one or more additional variables that affect participants’ resultant decrease in stress reactions to BPSD, increase in progress towards values, and continued use of ACT skills. The majority of the sample is college-educated, which might reflect an inclination to apply learning more readily than other populations.

Perhaps the improved outcome variables were influenced by participants’ overall understanding and integrated use of the ACT skills, not as much by how helpful they thought each practice activity was and whether they put in effort between sessions. It is evident that because these participants reached the end of the entire intervention and had been practicing these ACT skills over the course of several weeks, these skill training activities and sessions explaining their concepts were helpful and effective. This may be due to participants’ comprehension of ACT concepts and that ACT skills resonated with them, resulting in their likelihood to continually use them. Understanding and application of ACT concepts and skills may better explain the outcomes, because they reflect greater psychological flexibility and true learning.

This interpretation is supported by similar implications from other online ACT programs. One study encouraged researchers to continue using specific measurements of various aspects of psychological inflexibility and how its changes affect participant-related outcomes, because they may pinpoint components of the online intervention’s content needing revision for better understanding of the ACT Model of Behavioral Change and improvement of those outcomes (Levin et al., 2017b). Another study noted
that continual post-program suggestions of how to practice different skills, which suggestions were catered to check-in updates of emotions and thoughts resulted in greater ACT skill application (Levin et al., 2017a). These check-ins and catered suggestions identified which skills are best used for different life contexts and were associated with improved outcomes for those different contexts, including depressive symptoms (Levin et al., 2017a). Future updates of online ACT for Caregivers and other similar interventions can focus their measurements on comprehension of ACT concepts and use of ACT skills throughout and after program completion in addition to investigating further relationships associated with its successful application.

**Limitations**

There are several limitations that can be noted for the current study. For the original ACT for Caregivers study, a power analysis using effect sizes for changes in caregiver burden over time based on Sörensen et al.’s (2002) caregiver intervention meta-analysis data determined that a sample of 109 caregivers would be appropriate for the quantitative analysis that evaluated pre-to-post change in the main outcomes (depressive symptoms, caregiver burden, etc.). The current study’s sample ($N = 49$) is significantly lower and may affect generalizability to a larger dementia caregiver population. However, while the sample size may have been statistically underpowered, the sample was large enough to yield statistically significant findings across all outcome measures in the main analysis (Fauth et al., 2020). The $p$ values for changes over time in the main outcomes were all statistically significant, so power may not have been an issue, however it is possible that some of the associations between effort, helpfulness, and the chosen
outcomes would have been statistically significant with more power.

Further, the study participants were recruited in Utah, which has a large religious population, mostly of one Christian subgroup—The Church of Jesus Christ of Latter-day Saints. Many of the participants cited in their open-ended response data that their spirituality, prayer, and other religious aspects were a main component incorporated in their self-care and reframing of thoughts and behaviors (i.e., use of ACT skills). Such experiences may not be as generalizable to other caregivers.

Because of an error in Qualtrics, there was an absence of perceived helpfulness data for Session 6, which may have weakened the mean for perceived helpfulness for overall session practice activities and related correlates, compared to the mean of all session effort, which includes Session 6 effort data. Finally, all measures used self-report data, which could introduce bias and to the stress level of the BPSD reaction, or errors in accuracy of use of ACT skills and changes in living according to one’s values.

**Implications for Future Research**

Because there were improvements across all outcomes in the original study (Fauth et al., 2020), future studies could examine the association between effort and helpfulness ratings with other caregiver-specific outcomes, such as changes in caregiver burden or depressive symptoms. Future research could use person-centered analysis or qualitative analysis to identify significant associations between ACT-specific predictors and caregiver outcomes.

Web-based ACT for Caregivers and other interventions can use “concept-check” questions to evaluate understanding of ACT skills and their use at later rather than
helpfulness and effort evaluations. Further, concept-check questions should be used as a review at the end of the session in which the concept was taught and at the beginning of the following session before a new concept is taught. Possible refresher “booster sessions” to ACT concepts and skill strategies could be used after program completion to continue progress towards values-based living and encouragement of lessened stress responses to BPSD. Considering there were weaker correlations between certain sessions and their corresponding ACT skills, perhaps the program could sharpen its instruction on identifying what matters to help increase commitment to what matters, or values-based living.

In sum, and in concert with the pilot study’s previous findings, the current study of specific aspects of program evaluation showed that online ACT for caregivers is feasible, helpful, and can be applied in caregivers’ everyday lives. The web-based therapy promisingly affects caregiver-specific and ACT-specific outcomes long after program completion.
REFERENCES


Corry, M., Neenan, K., Brabyn, S., Sheaf, G., & Smith, V. (2019). Telephone interventions, delivered by healthcare professionals, for providing education and psychosocial support for informal caregivers of adults with diagnosed illnesses. *Cochrane Database of Systematic Reviews, 5* [online]. https://doi.org/10.1002/14651858.CD012533.pub2


APPENDIX

ACT PROCESSES EXPLAINED
Figure A1

The ACT Behavioral Change Model: Six Processes of Change

Figure A2

The Primary ACT Model of Psychopathology

Figure A3

*The Primary ACT Model of Treatment*