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For many people, providing care for a seriously ill family member is a major life event that may disrupt their life and personal goals. Research has demonstrated the experience of such events is often associated with increased symptoms of depression, stress, and anxiety. Although many researchers have examined factors that influence this relation, few have explored it from a motivational perspective. Therefore, the goal of the present study was to examine the influence of self-regulatory processes and motivational orientation on the relations between burden (caregiver and objective burden) and psychological distress (defined as the experience of symptoms of depression, anxiety, and stress). Caregivers of adult family members diagnosed with cancer in the past three years were asked to complete a battery of questionnaires on psychological distress, caregiver burden, objective burden, goal adjustment and regulatory focus orientation. It was predicted that caregiver burden would partially mediate the relation between objective burden and caregiver psychological distress. Furthermore, based on the notion of regulatory fit, the strength of the relation between objective burden and caregiver burden would be greater for caregivers who tend to exhibit a *weaker* prevention focus than a *stronger* prevention focus. Lastly, it was hypothesized that the strength of the relation between caregiver burden and psychological distress would be greater for caregivers who report a greater *inability* to disengage from goals than caregivers who report a greater *ability* to disengage from goals. Results suggested that objective burden is associated with psychological distress through caregiver burden. Inconsistent with our hypotheses,

promotion focus, instead of prevention focus, moderated the relation between objective burden and caregiver burden. Lastly, findings suggest that an ability to disengage from goals alleviates symptoms of anxiety and stress, and an ability to reengage in goals alleviates symptoms of depressed mood.

A MOTIVATIONAL PERSPECTIVE ON CAREGIVER  
PSYCHOLOGICAL DISTRESS

by

Catherine Murphy Majestic

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Approved by

---

Committee Chair

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APPROVAL PAGE

This dissertation written by Catherine Murphy Majestic has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair \_\_\_\_\_  
Kari M. Eddington

Committee Members \_\_\_\_\_  
Elizabeth Van Horn

\_\_\_\_\_  
Rosemary Nelson-Gray

\_\_\_\_\_  
Arthur Anastopoulos

\_\_\_\_\_  
Date of Acceptance by Committee

\_\_\_\_\_  
Date of Final Oral Examination

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## CHAPTER I

### INTRODUCTION

As a result of recent medical advances, people with serious physical health problems are more frequently being cared for at home, oftentimes receiving care from family members or close friends (Cristine, Crooks, Grunfeld, Stonebridge & Christie, 2003). In 2010, an estimated 43.5 million adults adopted the caregiver role for family members 50 years old and over (Coughlin, 2010), and this number was expected to increase by 10 percent between the years 2010 and 2013 (Abutaleb, 2013). Furthermore, in 2012 there were an estimated 14 million new cases of cancer worldwide, and this number is expected to rise to 22 million annually over the next two decades (International Agency for Research on Cancer, 2014).

It is important to study family caregiver both from an economic and a public health policy standpoint. Recent reports have estimated that the economic value of care provided by family caregivers is \$450 billion a year (Feinberg, Reinhard, Houser, & Choula, 2011). Furthermore, adopting the role of caregiver for a physically ill family member may constitute a negative life event that can disrupt many aspects of the caregiver's life (Newman, 1997; Offerman, Schroevers, van der Velden, de Boer, & Pruyn, 2010). Not only do family caregivers have to cope with the devastating news of family members' deteriorating health, but they also have to face changes to their own life

style and personal goals as they make room for new responsibilities (e.g., driving care-recipients to appointments and assisting care-recipients with activities of daily life).

Research has shown that the experience of such events is often associated with a range of psychological problems, including increased symptoms of depression and anxiety; a diminished ability to concentrate; and feeling nervous, restless, fearful, and distressed (Grunfeld, 2004; Kim, Spiller & Hall, 2012; Puterman & Cadwell, 2008; Steel et al., 2011; Waldrop, 2007). However, while some individuals become overwhelmed with the caregiver role, others are able to find meaning and empowerment in it. For example, Cassidy (2012) found that caregivers who reported high benefit finding (i.e. acceptance of the changed life situations, empathy for others, appreciation for life, closer family ties, positive changes in self-perception, and reprioritization of values) also reported lower psychological distress. A critical question is why some people transition smoothly into the role of caregiver while others struggle with the adjustment and go on to develop psychological problems.

Researchers have identified numerous individual factors, such as objective burden and caregiver burden, that help explain differences in the impact of caregiving on psychological distress. Objective burden often refers to the tasks of caregiving which include, but are not limited to duration of care, hours spent per week providing care, number of caregiving tasks, and the care recipient's physical and cognitive impairments (Tsai, 2003). Caregiver burden, also termed subjective burden, is often defined as an individual's negative emotional reactions to caregiver demands (Brouwer et al., 2004; Patrick & Hayden, 1999; Sherwood, Given, Given & von Eye, 2005). Although these

and other individual factors have been examined, one topic that the current literature neglects is the impact of caregiving on the pursuit of personal goals (self-regulation).

### **Individual Factors that Influence Caregiver Distress**

Researchers have developed conceptual models to explain how internal and external factors related to the caregiver may influence individual differences in the experience of outcomes such as stress, depression, and anxiety (Pearlin, Mullan, Semple & Skaff, 1990; Roy, 1970; Tsai, 2003). While these models include numerous caregiver factors, they consistently suggest a significant influence of caregiver burden and objective burden on caregiver psychological distress. Furthermore, within the current literature, there appears to be a consensus on the directional influence of caregiver burden and objective burden on caregiver psychological distress. However, some researchers suggest the magnitude of caregiver burden and objective burden's impact on caregiver psychological distress can vary (Coristine, et al., 2003; Coughlin 2012; Huang, Musil, Zauszniewski & Wykle, 2006).

Prominent theories of caregiver stress and adjustment suggest a direct association between objective burden and caregiver psychological outcomes such as depression, anxiety, and stress (Pearlin, et al., 1990; Roy, 1970; Tsai, 2003). Specifically, the models predict that caregivers who maintain greater objective burden are likely to report more negative psychological symptoms. Although the literature appears to lack widely-used measures of objective burden (i.e. researchers appear to develop questionnaires that contain a checklist of tasks and responsibilities), research on objective burden consistently supports the models' predictions (Coristine, et al., 2003; Coughlin 2012;

Pinquart & Sörensen, 2004; Tsai 2003). Furthermore, some research suggests the impact of objective burden on caregiver psychological outcomes can vary based on the developmental stage of the illness and on the caregivers' social support (Coristine, et al., 2003; Coughlin 2012; Huang, et al., 2006). For example, Huang and colleagues have suggested that caregivers who have been providing care longer (i.e. care-recipient is further along in the disease progression) may experience fewer symptoms of depression because they are more experienced and have had time to adjust their goals and their expectations to the caregiver role. However, more than the developmental stage of the illness, this finding seems to suggest an importance in one's ability to adjust important personal goals in response to varying levels of objective burden.

Prominent theories of caregiver stress and adjustment, like those addressing objective burden, suggest a direct positive association between caregiver burden and psychological outcomes such as depression, anxiety, and stress (Pearlin, et al., 1990; Roy, 1970; Tsai, 2003;). Research on caregiver burden consistently supports the models' predictions in that individuals who report greater caregiver burden are likely to experience greater symptoms of depression and anxiety (González-Abraldes, Millán-Calenti, Lorenzo-López & Maseda, 2013; Grunfeld, et al., 2004; Lahaie, Earle & Heymann, 2013; Melo, Marco & Mendonça, 2011; Patrick & Hayden, 1999; Pinquart & Sörensen, 2004). Similar to the research on objective burden, some research in this area has suggested that the magnitude of caregiver burden's impact on caregiver

psychological outcomes can vary depending on factors such as the developmental stage of the illness (Grunfeld, et al., 2004), and relationship to the care-recipient (Lee, et al., 2013).

Theories of caregiver stress and adjustment have also suggested an association between caregiver burden and objective burden. For example, Tsai's theory of caregiver stress (2003) suggests a mediating role of caregiver burden on the relation between objective burden and the experience of psychological outcomes. Similarly, Pearlin and colleagues (1990) suggest a direct association between objective burden and caregiver burden in that individuals who experience greater objective burden are likely to report greater caregiver burden. Research seems to lend support for these theories' predictions. More specifically, Brouwer and colleagues (2004) found a positive association between objective burden and caregiver burden,  $r = .35, p < .01$ ; individuals who report greater objective burden (i.e., more time invested in caregiving demands) are likely to experience greater caregiver burden.

While prominent models within the caregiver literature provide some suggestions for moderating and mediating factors that may further explain caregiver outcomes, few have considered the impact of caregiving on the pursuit of personal goals, which could be an important factor in predicting psychological distress. As suggested earlier in this paper, caregiving constitutes a major life event, which may disrupt an individual's ability to pursue important personal goals. Broadly speaking, research on self-regulation examines the process of identifying and pursuing important personal goals. Furthermore, research has shown that stressful events (such as caregiving) can challenge and disrupt

effective self-regulation (Baumeister & Heatherton, 1996), leading to greater psychological distress. In light of these findings, it seems that individual differences in self-regulation may further explain variation in psychological distress as it relates to the caregiving role.

### **Self-Regulation and Emotion**

Models of self-regulation help explain how people set and maintain personal goals. However, each model attempts to explain this process through slightly different mechanisms. For example, Carver and Scheier (1996) define self-regulation as a “sense of goal directedness and reliance on feedback as a guide for altering the course of behavior” (pg. 2). They further suggest that people’s lives are comprised of goals and that behaving in a manner to attain these goals provides a sense of meaning (Scheier & Carver 2001). Conversely, Higgins’ Regulatory Focus Theory suggests individuals develop an inclination towards one regulatory orientation (prevention or promotion) based on aspects of social learning and cognition (Eddington, Majestic & Silvia, 2012; Higgins, 1997; Spiegel, Grant-Pillow & Higgins, 2004). Furthermore, this theory suggests individuals will experience differences in goal pursuit, emotion, and decision-making depending on their regulatory focus (Higgins, 1997).

#### **Carver and Scheier’s Model of Self-Regulation**

In their model of self-regulation, Carver and Scheier (1982) suggest the pursuit and the attainment of goals are part of a feedback loop. The feedback loop consists of four elements: an input function, a reference value, a comparator, and an output function. In their original model, Carver and Scheier (1982) proposed a *negative* feedback loop in



which the primary function is to reduce the discrepancy between individuals' current functioning and their desired goal. The result of this feedback loop was that individuals attempt to *approach* desired goals (Rasmussen, Wrosch, Scheier & Carver, 2006). Later, a *positive* feedback loop was proposed in which the primary function was to increase discrepancies between individuals' current functioning and their desired goal (Rasmussen, et al., 2006). As opposed to the *negative* feedback loop, the result of the *positive* feedback loop was that individuals try to *avoid* certain outcomes; the goal was one of *avoidance* rather than *approach*.

Despite differences in the goals of the two feedback loops (approach versus avoidance), the components are the same. The first component of the feedback loop is the *input*, or the perception of current behavior and functioning (Carver & Scheier, 1982, 1990). This perception is then compared to a *reference value* (i.e. a goal that is being used to drive behavior) through the use of a *comparator*. Next, if a discrepancy is perceived between individuals' current functioning and their goal (*reference value*), they perform behaviors (*output*), which impact their environment, indirectly adjusting the discrepancy (reducing for *negative* feedback loop, or increasing for *positive* feedback loop). In changing the environment and adjusting the discrepancy, individuals now have a new perception of their current functioning, which starts the feedback loop over again.

In addition to these components, Carver and Scheier (1982) also note the potential for *disturbances* to the feedback loop. *Disturbances* consist of anything outside of the feedback loop that can influence the individual's current state separately from the feedback loops' actions. Although *disturbances* often influence the system by increasing

discrepancies, they can also work to reduce discrepancies. For example, research now suggests that taking on the caregiver role serves as a disturbance (Offerman, et al., 2010), which may increase discrepancies between individuals' current state and their desired goal.

Carver and Scheier (1996) suggest goals must be important and attainable to the individual for effective self-regulation, but they recognize that disturbances happen and may impact an individual's ability to attain those goals. In these situations, effective self-regulation can persist or become ineffective. Carver and Scheier (1990) suggest that individuals will experience a disruption in their behavioral efforts when they encounter enough difficulty from a disturbance. Such disruptions give individuals a chance to re-evaluate their expectations for successful attainment of goals. Given that higher-level goals can be achieved through the achievement of numerous lower-level goals, the ability to shift or utilize different pathways to achieve the higher-level goal may prove effective. However, if an individual perceives disruptions to render goals temporarily or permanently unattainable, then the model suggests that effective self-regulation requires disengaging from the current goals (Carver & Scheier, 1990; Rasmussen, et al., 2006).

In addition to providing a process model of goal pursuit, Carver and Scheier's model of self-regulation suggests a secondary feedback loop, which functions to explain emotional responses to goal pursuit (Carver & Scheier, 1990; Rasmussen, et al., 2006). In short, this secondary feedback system functions to check the progress of the initial feedback system's ability to achieve goal progress. When considering the negative, discrepancy-reducing feedback loops, Carver and Scheier suggest that better-than-

expected goal performance (i.e., the feedback loop reduces discrepancy faster) is associated with positive emotions such as eagerness and excitement. Additionally, they suggest that worse-than-expected goal performance (i.e., the feedback loop reduces discrepancy more slowly) results in negative emotions such as frustration and sadness. Conversely, Carver and Scheier suggest that effective functioning of the positive, discrepancy-enlarging loop results in positive emotions such as relief and contentment, and that ineffective functioning results in negative emotions such as fear and anxiety (Carver & Scheier, 2011). Finally, the model suggests that chronic negative mood, such as depression, is associated with an ineffective feedback loop (e.g. one that fails to make progress towards a goal) and inability of the individual to disengage from an unattainable goal (Carver & Scheier, 1990).

Research within the self-regulation literature seems to support Carver and Scheier's model of effective and ineffective goal pursuit. More specifically, studies have shown that effective goal pursuit provides individuals with a sense of purpose and meaning and has been found to be negatively associated with depression and negative affect (Emmons & King, 1988; Scheier & Carver 2001). However, as suggested by Carver and Scheier, disruptions such as a family member becoming seriously ill may make a personal goal temporarily unattainable, and may require individuals to make adjustments. An inability to disengage from unattainable goals has been found to be associated with more negative psychological distress (Scheier & Carver, 2001). On the other hand, disengaging from unattainable goals is adaptive because it reduces an individuals' chance of experiencing the negative emotions associated with goal failure

(Bailly, Joulain, Hervé, & Alaphilippe, 2011; Brandtstädter & Renner, 1990; Heyl, Wahl & Mollenkopf, 2007; Rasmussen, et al., 2006; Wrosch, Miller, Scheier & Brun de Pontet, 2007). Thus, further research is necessary to understand the impact of goal processes on psychological distress.

### **Higgins' Regulatory Focus Theory**

Taking a slightly different approach to studying self-regulation, Higgins' (1997) regulatory focus theory proposes an impact of self-regulation on both behavioral goal pursuit and the quality, intensity, and experience of emotional response. More specifically, the model suggests that aspects of cognition and social development influence an individual's inclination towards one of two distinct orientations of self-regulation (promotion or prevention) during their pursuit of a desired end-state (Eddington, Majestic & Silvia, 2012; Higgins, 1997; Spiegel, Grant-Pillow & Higgins, 2004).

The first orientation is nurturance-related regulation, which involves a *promotion focus*. Promotion focus is described using signal detection terms as a regulatory state that is concerned with minimizing errors of omission (i.e. missing an opportunity for improvement) and maximizing the presence of positive outcomes; it is concerned with attaining accomplishments and fulfilling aspirations (Higgins, 1997; Spiegel, et al., 2004). Conversely, the second orientation is security-related regulation, which involves a *prevention focus*. Prevention focus is described in signal detection terms as a regulatory state in which an individual is concerned with minimizing errors of commission (i.e.

doing something that turns out to be wrong) and maximizing the absence of negative outcomes; it is concerned with protection, responsibility, and obligation (Higgins, 1997; Spiegel, et al., 2004).

Higgins (1997) explains that regulatory focus is not only concerned with people's approach of pleasure and avoidance of pain, but also with the influence of regulatory focus on motivational outcomes, such as goal pursuit. In his theory of regulatory focus, Higgins proposes that depending on their present self-regulation orientation, people will work to reduce the amount of discrepancy between their current state and desired end state by utilizing a promotion focus (approaching matches) or a prevention focus (avoiding misses). This concept can often be seen in the type of personal goals an individual holds. For example, an individual utilizing a promotion orientation is more likely to have personal goals related to making good things happen such as exercising to stay healthy. Conversely, an individual utilizing a prevention orientation is more likely to have personal goals related to keeping bad things from happening such as exercising to keep prevent a heart attack.

Furthermore, it is suggested that goal attainment is more likely when one's orientation (promotion vs. prevention) matches the behavioral strategy needed for a task (Eddington, Majestic & Silvia, 2012; Higgins, et al., 2001). The matching of one's orientation to the behavioral strategy needed for a task is termed regulatory fit (Higgins et al, 1997). While the theory predicts that people may have a trait-like inclination towards one orientation or the other, it does not preclude the possibility that people can adapt to situational demands and utilize a motivational orientation that best fits the situation

(Haws, Dholakia & Bearden, 2010; Higgins, 1997; Higgins, Roney, Crowe & Hymes, 1994). For example, a prevention orientation may prove to be more successful in the caregiver role as people are likely to feel a sense of obligation and protection, and construe goals in a way that maximizing the absence of negative outcomes (i.e. not missing a doctor's appointments). Therefore, based on situational demands of caregiving, caregivers with an inclination towards a promotion orientation may benefit from utilizing a temporary prevention strategy.

Higgins also suggests that regulatory focus can explain variability in emotional experience and may moderate emotional intensity. Specifically, success with promotion-focused goals is associated with cheerfulness and pride, and failure is associated with disappointment and sadness. Alternatively, success with prevention-focused goals is associated with calmness and relief, and failure is associated with anxiety and fear (Eddington, Majestic & Silvia, 2012; Higgins, 1997). Lastly, some research has indicated that the strength of individuals' regulatory focus orientation influences the intensity of their emotional response (Higgins, 1997; Higgins, Shah & Friedman, 1997). For example, if a promotion focus matches the strategy required by a goal or task (termed regulatory fit), then a stronger promotion-focused orientation has been found to be associated with a stronger experience of cheerfulness-related emotions (Higgins et al, 1997). Similarly, if a prevention focus demonstrates regulatory fit, then a stronger prevention-focused orientation has been found to be associated with a stronger experience of relief-related emotions.

Overall, theories of self-regulation attempt to explain the motivational and emotional consequences of individual goal pursuit. Carver and Scheier (1982) suggest that individuals will pursue goals in a way that alters the discrepancy between their current state and desired end state (reduce discrepancy for *approach* orientation and increase discrepancy for *avoidance* orientation). Taking a different approach, Higgins' (1997) suggests goal attainment is more likely when an individual's orientation (promotion or prevention) fits the strategy needed for task completion. Furthermore, both theories suggest the emotional variability in response to goal failure or attainment is associated with an individual's regulatory orientation (Carver & Scheier, 1990; Carver & Scheier, 2011; Eddington, et al., 2011; Higgins, 1997; Rasmussen, et al., 2006)

### **Goals and Hypotheses**

Previous research within the caregiver literature has found a significant influence of internal and external caregiver factors (i.e. burden, gender, finances) on the experience of psychological outcomes such as stress, depression, and anxiety. Although research has examined the influence of several potential moderators and mediators, research is lacking on the role of personal goal pursuit and self-regulatory orientation on caregiver psychological distress (defined in this paper as a caregiver's experience of depression, anxiety, and stress) in caregivers of family members with physical health problems. One study has examined the impact of goal adjustment on the relation between caregiver burden and depression in caregivers of care-recipients with mental health problems (Wrosch, Amir & Miller, 2011). Results from this study indicated that caregivers who reported high caregiver burden and poorer goal adjustment exhibited an increase in

depressive symptoms. Additionally, other studies have examined the role of goal adjustment strategies in cancer patient populations and found that an ability to adjust goals is associated with fewer symptoms of depression and anxiety (Offerman, et al., 2010; Schroevers, Kraaij & Garnefski, 2008; Thompson, Stanton & Bower, 2013; Thompson, Woodward & Stanton, 2011; Zhu, et al., 2014).

Research on self-regulation has suggested that people gain meaning and purpose in life through identifying and attaining personal goals (Emmons & King, 1988; Scheier & Carver 2001). However, disruptions to goals, such as taking on the caregiver role, can challenge and even disrupt effective self-regulation, and such disruptions have been shown to be associated with more negative psychological distress, such as more symptoms of depression (Baumeister & Heatherton, 1996; Offerman et al., 2010; Rasmussen, et al., 2006; Scheier & Carver 2001; Wrosch, et al, 2007). Furthermore, as suggested by Higgins (1997), an individual's self-regulatory orientation is not only associated with the attainment of goals, but also the emotional response to goal pursuit. Taking on the caregiver role not only disrupts an individual's important personal goals, but is also comprised of new and unexpected tasks and goals. Given this information, gaining a better understanding of caregivers' pursuit of goals and emotional response to goals may further explain inconsistencies in caregiver psychological distress. Therefore, the goal of the present study was to examine the influence of self-regulatory processes and orientation on the relations between burden (caregiver and objective burden) and psychological distress (defined as the experience of symptoms of depression, anxiety, and stress).



The consensus within the caregiver literature is that objective burden (e.g. time spent in caregiver duties) and caregiver burden (subjective burden) are both positively associated with psychological distress. Adding to the understanding of these constructs, the literature further suggests a mediating effect of caregiver burden on the relationship between objective burden and psychological outcomes (Tsai, 2003). However, research on factors affecting the magnitude of the relationship between objective burden and caregiver burden is lacking. Based on Higgins' concept of regulatory fit, the association between objective burden and caregiver burden may be further explained by a caregiver's motivational orientation. More specifically, caregivers with an inclination towards a prevention focus are likely to focus on obligations and responsibilities, and they construe their goals in a way that minimizes negative outcomes. In the caregiver situation, a prevention orientation seems to "fit" the demands of the caregiver role (e.g. reminding care-recipients to take medication or making sure a care-recipient does not miss a treatment appointment). This "fit" increases the likelihood of goal attainment and decreases negative emotional responses (Higgins et al, 1997; Park, van Dyne & Ilgen, 2013). On the other hand, a promotion orientation presents less of an optimal "fit" with caregiver demands. Therefore, it was predicted that caregiver burden partially mediates the relation between objective burden and caregiver psychological distress. Additionally, it was predicted that the strength of the relation between objective burden and caregiver burden is greater for caregivers who tend to exhibit a *weaker* prevention focus than for caregivers who exhibit a *stronger* prevention focus.

Furthermore, as mentioned previously, research on caregiver burden suggests a positive association with psychological distress, in that individuals who report greater caregiver burden are likely to experience greater psychological distress (González-Abraldes, Millán-Calenti, Lorenzo-López & Maseda, 2013; Grunfeld, et al., 2004; Lahaie, Earle & Heymann, 2013; Melo, Marco & Mendonça, 2011; Patrick & Hayden, 1999; Pinguart & Sörensen, 2004). However, the caregiver literature also shows that while some caregivers become overwhelmed with the caregiving role, others are able to find meaning and empowerment in it (Cassidy, 2012). This suggests that the magnitude of the impact of caregiver burden on psychological distress may vary among caregivers. Thus, it was predicted that the ability to disengage from personal goals moderates the relation between caregiver burden and psychological distress. More specifically, it was predicted that the strength of the relation between caregiver burden and psychological distress is greater for caregivers who report a greater *inability* to disengage from goals than for caregivers who report a greater *ability* to disengage from goals.

To summarize, the hypotheses are as follows:

1. Caregiver burden will partially mediate the relation between objective burden and caregiver psychological distress.
2. The strength of the relation between objective burden and caregiver burden will be greater for caregivers who tend to exhibit a *weaker* prevention focus than for caregivers who exhibit a *stronger* prevention focus.

3. The strength of the relation between caregiver burden and psychological distress will be greater for caregivers who report a greater *inability* to disengage from goals than for caregivers who report a greater *ability* to disengage from goals.

## CHAPTER II

### METHOD

#### **Participants**

UNCG IRB approval was obtained to recruit through social media, from community organizations, and by word-of-mouth. Reciprocal approval was obtained from the Cone Cancer Clinical Research Coordinator to recruit in-person. One hundred five (105) adult caregivers (52.8 mean age in years, 65.7 percent female) of adult family members diagnosed with cancer were recruited from social media (Facebook, and Twitter), listservs, local support groups, the Durham Veteran Affairs Medical Center, and the Cone Cancer Center in Greensboro and Burlington, North Carolina. Recruitment took place between July 2014 and October 2015. Participants were entered into a raffle for a monetary reward for participating in the present study.

#### **Measures**

##### **Demographics**

In order to collect demographic information, participants were asked to report items such as their age, gender, ethnicity, race, education, employment status, and income. Participants were also asked about presence of social support, religious or spiritual involvement, and experience of prior mental health problems. Lastly, participants were also asked to report on the stage and severity of their family member's

diagnosis. To gain information about psychological health of the caregiver, participants were asked to respond to two questions: “Have you ever sought services for a psychological problem such as counseling, medication management, or psychiatric hospitalization,” and “Have you ever felt like you should seek treatment or has someone suggested you seek treatment for a psychological problem?” If the participant responded “yes” to either of these questions, they were asked to report what the mental health problems are and when the mental health problems were experienced, through the use of open ended questions.

For the purposes of this study, basic information about the presence of social support was obtained. More specifically, participants were asked two questions based on a 5-point scale (0=*none of the time*, 4=*all of the time*): “Can you count on others to provide you with emotional support (i.e. talk through difficult decisions, vent to, etc.),” and “Can you count on others help with daily demands.”

### **Depression Anxiety Stress Scales – 21**

Participants were asked to complete the Depression Anxiety Stress Scales-21 (Antony, Bieling, Cox, Enns & Swinson, 1998) as a measure of caregiver psychological distress (the experience of symptoms of depression, anxiety and stress). The scale contains 21 questions in which participants were asked to indicate how they felt over the past week, based on a 4-point scale (0=*did not apply to me at all*, 1=*applied to me to some degree, or some of the time*, 2=*applied to me to a considerable degree, or a good part of the time*, 3=*applied to me very much, or most of the time*). Some examples of questions on the scale are: “I found it hard to wind down,” “I felt down-hearted and

blue,” and “I felt close to panic.” The purpose of the scale is to measure the level of symptoms of depression, anxiety and stress an individual is experiencing and therefore is comprised of three subscales. Items are summed and multiplied by two to obtain a total score in each subscale. Scores on the DASS-21 subscales range from 0 to 42 and suggest varying levels of depression, anxiety, and depression from “normal” to extremely severe” with higher scores indicating greater symptom severity. In addition to subscales, a composite score was created by converting the subscales into Z-scores and then averaging the Z-scores. Results from this study indicated good internal consistency of the DASS-21 depression (Cronbach’s  $\alpha = .88$ ), anxiety (Cronbach’s  $\alpha = .81$ ), and stress (Cronbach’s  $\alpha = .88$ ) subscales, and high internal consistency for the total measure (Cronbach’s  $\alpha = .94$ ).

### **Zarit Burden Interview**

The Zarit Burden Interview (Zarit, Reever & Back-Peterson, 1980) was used to measure caregiver (subjective) burden. The scale contains 22 items and asked participants to describe how they feel as a result of the demands of caregiving, based on a 5 point scale (0=*never*, 1=*rarely*, 2=*sometimes*, 3=*quite frequently*, 4=*nearly always*). Some examples of questions on this scale are, “Do you feel you could do a better job in caring for your relative,” “Do you feel that your social life has suffered because you are caring for your relative,” and “Do you feel strained when you are around your relative?” Items are summed to obtain a total score. Scores range from 0 to 88 and suggest varying levels of subjective burden from “little or no burden” to “severe burden” with higher

scores indicating greater subjective burden. Similar to previous research, results of this study indicated that the measure has high internal consistency (Cronbach's  $\alpha = .94$ ).

### **Objective Burden**

An adapted version of the Clinical Care Task (van Ryn, et al., 2011) was used to measure caregiver objective burden. The measure contains 23 items and asks participants to report whether or not they have helped their care-recipient with tasks associated with four domains: activities of daily living, instrumental activities of daily living, clinical care tasks, and care recipient's treatment. In addition to collecting information on the number of tasks completed, the measure asks participants to estimate total time spent engaged in these activities. To do so, the following questions were asked, "Thinking about all the care you provide to your Care Recipient due to his or her illness, on average, on how many days a week do you provide care" and "On a typical day, about how many hours do you provide some care to your Care Recipient due to his or her illness?" While this measure includes both qualitative and quantitative information, for the purposes of this study, total time engaged in caregiving tasks was used to measure objective burden.

### **Goal Adjustment Scale**

Participants were asked to complete the Goal Adjustment Scale (Wrosch, Scheier, Miller, Schulz & Carver, 2003b) to measure individual differences in goal adjustment. Given that this is a general measure of goal adjustment; participants were asked to answer the questionnaire keeping in mind recent changes due to taking on the caregiver role. The scale contains 10 items and asked participants to indicate how they typically react when personal goals become unattainable, based on a 5-point scale (1=*strongly disagree*,

3=*neutral*, 5=*strongly agree*). Examples of questions on this scale include: “I start working on other new goals,” “It is easy for me to reduce my effort towards the goal,” and “I stay committed to the goal for a long time; I can’t let it go.” Items are summed (negative items are reverse coded prior to summation) to obtain a total goal disengagement score and a total goal reengagement score. Lower scores on either subscale indicate poor goal adjustment. Results from this study suggest that both subscales are internally consistent (Cronbach’s  $\alpha = .70$  and  $.84$  for disengagement and reengagement, respectively).

### **Regulatory Focus Questionnaire**

The Regulatory Focus Questionnaire (Higgins, et al., 2001) was used to measure participants’ self-regulatory (promotion or prevention) orientation. The scale contains 11 items, which are rated on a 5-point scale from 1 (*never or seldom*) to 5 (*very often*). Examples of questions from this scale include: “Not being careful enough has gotten me into trouble at times” and “I feel like I have made progress toward being successful in my life.” Subscale items are summed (negative items are reverse coded prior to summation) to obtain scores for prevention focus and promotion focus with high scores indicating stronger focus. The prevention subscale will be used for study analysis. Consistent with previous research, the prevention scale demonstrated acceptable internal consistency for this study (Cronbach’s  $\alpha = .80$ ). Conversely, the promotion scale for this study demonstrates low yet acceptable internal consistency (Cronbach’s  $\alpha = .63$ ).



## **Procedures**

Caregivers of adults diagnosed with cancer within the past 3 years were eligible to participate in the present study. In order to make the study easily accessible to participants, study questionnaires were uploaded on the online survey software, Qualtrics. Furthermore, paper copies of the questionnaire were made available to participants at on-site locations at Cone Hospital in Greensboro and Burlington, North Carolina. To participate in the study, interested caregivers provided informed consent and either logged on to the online survey and began answering demographics questions or completed the paper questionnaire packet. After completing the demographics questions, participants answered a series of questions about the number and amount of time spent engaged in caregiving tasks, the perceived burden of caregiving, their pursuit of goals and mood. Paper questionnaires were placed in a sealed envelope and returned directly to the principal investigator after completion.

## CHAPTER III

### RESULTS

#### **Participant Characteristics**

From the original sample of 105 family caregivers, 3 were excluded due to incomplete data. Of the remaining sample of 102 caregivers, 67.6% were women, 75.5% identified as White or European American, and the average age was 52.81 years old ( $SD = 15.17$ ). The majority of caregivers in the sample were primary caregivers (70.6%), who lived with the care-recipient (66.7%), did not have paid assistance (e.g., in-home nurse, 90.2%) but could count on others to help with daily demands at least once a week (49%). Caregivers in this study either worked full-time (42.2%) or were not working (43.1%), had a household income of over 50,000 (48.9%), and pursued at least some college (66.6%). Overall, the study caregivers reported being able to count on others for emotional support at least some of the time (76.5%) and considered themselves to be spiritual or religious (86.3%). The majority of caregivers denied previous mental health care (69.6%) or a need for mental health care (70.6%). The stage of the family member's diagnosis ranged from stage 1 to incurable with the majority of care-recipients in stage 4 (50.5%). The majority of participants were collected from the Cone Cancer Centers (67.7%). See Table 1 (Appendix A) for more information.

### **Tests of Normality**

Assumptions of normality were met as indicated by linear Q-Q plots. Additionally, all variables included in the following analyses were examined for skewness and kurtosis, and all but the anxiety subscale<sup>1</sup> of the DASS-21 were determined to be acceptable (skewness between -0.57 and 1.58, kurtosis between -.0102 and 2.30). No significant outliers were found. Descriptive statistics of included variables are shown in Table 2.

### **Associations and Group Differences**

Correlation analyses were run to examine the relation between study variables (see Table 3). Notably, there was a positive correlation between objective burden and caregiver burden, indicating that caregivers who reported greater objective burden also reported greater caregiver burden,  $r = .35, p < .01$ . Furthermore, there was a strong positive correlation between psychological distress and caregiver burden, suggesting that caregivers who reported more perceived burden also reported greater psychological distress,  $r = .77, p < .01$ .

While the variable for psychological distress was not separated into its subscales for the main study hypotheses, correlation analyses were also run for the subscales. Strong positive correlations were found between caregiver burden and all three subscales, suggesting that caregivers who reported greater caregiver burden also experienced greater stress,  $r = .75, p < .01$ , depression,  $r = .75, p < .01$ , and anxiety,  $r = .62, p < .01$ .

Independent-samples t-tests were conducted to determine if there were significant differences in study variables by employment status, income, ethnicity, caregiver status,

engagement in previous psychological services, and gender. No significant differences were found among study variables by employment status, income, ethnicity, caregiver status. However, results did show a significant difference between gender on psychological distress,  $t(80.20) = -2.86, p < .01$ , and caregiver burden,  $t(77.65) = -3.86, p < .001$ . Female caregivers reported more distress ( $M = 0.15, SD = 0.97$ ) than male caregivers ( $M = -0.34, SD = 0.71$ ). Additionally, female caregivers reported greater caregiver burden ( $M = 24.35, SD = 15.75$ ) than male caregivers ( $M = 13.48, SD = 11.52$ ). Results also demonstrated significant differences between caregivers who have engaged in psychological services and those who have not engaged in psychological services, with the former group reporting greater psychological distress,  $t(41.50) = 2.62, p < .05$ , and caregiver burden,  $t(43.05) = 2.14, p < .05$ . Caregivers who have engaged in psychological services reported more distress ( $M = 0.41, SD = 1.02$ ) than caregivers who have not engaged in psychological services ( $M = -0.16, SD = 0.82$ ). Additionally, caregivers who have engaged in psychological services reported greater caregiver burden ( $M = 26.50, SD = 16.86$ ) than caregivers who have not engaged in psychological services ( $M = 18.80, SD = 14.16$ ).

### **Data Analytic Strategy**

Based on the results of the correlation analyses, tests for multicollinearity among the predictor variables were examined prior to data analysis using the collinearity diagnostic test in SPSS 21. The results indicated low levels of multicollinearity (objective burden  $VIF = 1.14$ , caregiver burden  $VIF = 1.20$ , goal adjustment  $VIF = 1.09$ , prevention focus  $VIF = 1.03$ ). To determine whether our sample size of 102 maintained

sufficient power, G\*power was utilized to run a post-hoc power analysis using a small effect size, .15, and an alpha of .05. Based on this analysis, the study demonstrated appropriate power at 0.91. The PROCESS macro model 4 was used to test the mediation hypothesis, and the PROCESS macro 1 was used to test moderation analyses (Hayes, 2013). Results were reported using unstandardized coefficients (Hayes, 2013).

### **Mediation Analyses**

To examine the mediating effect of caregiver burden on the relation between objective burden and psychological distress (hypothesis 1, Figure 1, Appendix A), PROCESS macro 4 was conducted. Results suggested that objective burden indirectly impacts caregivers' experience of psychological distress through caregiver burden (Table 4, Appendix A). More specifically, caregivers who reported greater objective burden experienced greater caregiver (subjective) burden,  $b = 0.10$ ,  $t(91) = 3.51$ ,  $p < .001$  (path *a*), and caregivers who reported greater caregiver burden, in turn, experienced greater psychological distress,  $b = 0.05$ ,  $t(90) = 11.05$ ,  $p < .01$  (path *b*). Additionally, a bias-corrected bootstrap confidence interval for the indirect effect of objective burden on psychological distress,  $b = 0.27$  (path *ab*), based on 10,000 bootstrap samples was above zero (0.126 to 0.429), providing further evidence for the mediating effect of caregiver burden on the relation between objective burden and psychological distress. This represents a large indirect effect of objective burden on psychological distress,  $k^2 = 0.34$  with 95% CI [.170, .501]. However, results did not illustrate that objective burden directly influenced caregivers' psychological distress,  $b = 0.00$ ,  $t(91) = 1.81$ ,  $p = .07$  (path *c*). While some mediation analyses are contingent on this direct effect being significant

(Baron & Kenny, 1986), more recent methods suggest that mediation can exist in the absence of this direct effect (Hayes, 2013; MacKinnon & Fairchild, 2009).

### **Prevention Focus**

To examine the influence of a caregiver's level of prevention focus on the strength of the relation between objective burden and caregiver burden, the PROCESS macro model 1 (Hayes, 2013) was conducted (hypothesis 2, Figure 2, Appendix A). It was expected that caregivers with a greater prevention focus will be more likely to report lower caregiver burden following higher levels of objective burden than lower levels of objective burden. Results (see Table 5, Appendix A) indicate a significant main effect of objective burden,  $b = 0.11$ ,  $t(88) = 3.34$ ,  $p < .001$ ) on level of caregiver burden. However, prevention focus was not found to moderate the relation between objective burden and caregiver burden.

### **Goal Adjustment**

To examine the influence of a caregiver's goal disengagement on the strength of the relation between caregiver burden and psychological distress, the PROCESS macro model 1 (Hayes, 2013) was conducted (hypothesis 3, Figure 3, Appendix A). Specifically, we expected that caregivers who report a greater ability to disengage from goals will report lower psychological distress following higher levels of caregiver burden. Results (see Table 6, Appendix A) indicated a significant main effect of caregiver burden,  $b = 0.04$ ,  $t(90) = 10.68$ ,  $p < .001$ , suggesting that higher levels of caregiver burden are associated with greater psychological distress. While there is not a significant main effect of goal disengagement, the results approached significance for the interaction

between one's ability to disengage from goals and caregiver burden,  $b = -0.00$ ,  $t(90) = -1.78$ ,  $p = .077$ . Specifically, caregivers who report a greater ability to disengage from goals when caregiver burden is high are more likely to experience greater psychological distress.

In addition to conducting a moderation analysis, the PROCESS macro ran a simple slopes analysis which was used to further examine the association between caregiver burden and psychological distress at low ( $-1$  *SD* below the mean), moderate (mean), and high ( $+1$  *SD* above the mean) levels of goal disengagement. Results from each simple slopes test indicated a significant positive association between caregiver burden and psychological distress. Specifically, the experience of caregiver burden was slightly more related to greater psychological distress for low levels of goal disengagement,  $b = 0.05$ ,  $t(90) = 9.89$ ,  $p < .001$ , than for moderate levels,  $b = 0.04$ ,  $t(90) = 10.68$ ,  $p < .001$ , and high levels,  $b = 0.04$ ,  $t(90) = 5.60$ ,  $p < .001$ . This suggests that caregivers who reported a poorer ability to disengage from goals at high levels of caregiver burden tend to experience greater psychological distress than caregivers who reported a greater ability to disengage from goals (Figure 4, Appendix A).

Analyses were also run using the psychological distress subscales as the outcome variable given the above marginal significance. Results (See Table 7 – 9, Appendix A) did not illustrate a significant interaction effect for depression,  $b = 0.00$ ,  $t(90) = .35$ ,  $p = .73$ , but did for both anxiety and stress. Specifically, there was a significant main effect of caregiver burden on the experience of anxiety,  $b = 0.24$ ,  $t(90) = 6.70$ ,  $p < .001$ , suggesting that higher levels of caregiver burden are associated with higher anxiety.

Results also show a significant interaction effect,  $b = -0.03$ ,  $t(90) = -2.35$ ,  $p < .05$ , suggesting that caregivers who report a greater ability to disengage from goals when caregiver burden is high also report lower anxiety. Similarly, results from simple slopes tests indicated that the experience of caregiver burden was more strongly related to greater anxiety for low levels of goal disengagement  $b = 0.33$ ,  $t(90) = 37.20$ ,  $p < .001$ , than for moderate levels,  $b = 0.24$ ,  $t(90) = 6.70$ ,  $p < .001$ , and high levels,  $b = 0.16$ ,  $t(90) = 2.72$ ,  $p < .05$ . This finding suggests that caregivers who report a poorer ability to disengage from goals at high levels of caregiver burden are more likely to experience greater anxiety than caregivers who report a greater ability to disengage from goals (Figure 5, Appendix A).

Lastly, the PROCESS macro model 1 was conducted to examine the impact of ability to disengage from goals on the relationship between caregiver burden and stress. There was a significant main effect of caregiver burden on stress,  $b = 0.41$ ,  $t(90) = 10.13$ ,  $p < .001$ , suggesting that higher levels of caregiver burden are associated with greater self-report of stress. While results did not show a significant main effect of goal disengagement on stress, a significant interaction effect was found,  $b = -0.03$ ,  $t(90) = -2.43$ ,  $p < .05$ , suggesting that caregivers who report a greater ability to disengage from goals when caregiver burden is high experience lower levels of stress. Given the significant moderation, simple slopes analyses were examined. Similarly, results from simple slopes tests indicated that the experience of caregiver burden was more strongly related to greater stress for low levels of goal disengagement,  $b = 0.52$ ,  $t(90) = 9.97$ ,  $p < .001$ , than for moderate levels,  $b = 0.41$ ,  $t(90) = 10.13$ ,  $p < .001$ , and high levels,  $b = 0.31$ ,



$t(90) = 4.83, p < .01$ . This suggests that caregivers who reported a poorer ability to disengage from goals, at high levels of caregiver burden, are more likely to experience greater stress than caregivers who report a greater ability to disengage from goals (Figure 6, Appendix A).

### **Post-Hoc Analyses**

Based on the self-regulation literature, an interactive effect of prevention focus and objective burden on caregiver burden was expected; however, results did not support this hypothesis. In addition to prevention focus, Higgins (1997) also suggested a promotion orientation which focuses on minimizing missed opportunities for improvement and maximizing the presence of positive outcomes. Therefore, in order to further examine the impact of self-regulatory orientation on the relation between objective burden and caregiver burden, the PROCESS macro model 1 was conducted using promotion focus as a moderator (See Table 10, Appendix A). Results indicated a significant main effect of objective burden on caregiver burden,  $b = 0.10, t(88) = 3.38, p < .001$ , suggesting that higher levels of objective burden are associated with higher self-report of caregiver burden. Additionally, a significant interaction effect of promotion focus,  $b = 0.01, t(88) = 2.42, p < .05$  was found, suggesting that caregivers who report a stronger promotion focus when objective burden is high experience greater caregiver burden. Given the significant moderation, simple slopes analyses were examined. Results from simple slopes tests indicated that the experience of objective burden was more strongly related to greater caregiver burden for high levels of promotion focus,  $b = 0.15, t(88) = 3.98, p < .001$ , than for moderate levels,  $b = 0.10, t(88) = 3.38, p < .001$ , and

was not significant for low levels,  $b = 0.05$ ,  $t(88) = 1.53$ ,  $p = .13$ ). This suggests that caregivers who reported stronger promotion focus, at high levels of objective burden, are more likely to experience greater caregiver burden than caregivers who report a weaker promotion focus (Figure 7, Appendix A).

In addition to examining the impact of goal disengagement on psychological distress, researchers have suggested that an ability to reengage in new goals may reduce perceived stress (Wrosch, et al., 2003b) and depression (Offerman, et al., 2010; Wrosch, et al., 2011), and increase positive emotions (Wrosch, Scheier, & Miller, 2013). Therefore, the impact of goal reengagement on the relation between caregiver burden and depression was examined using the PROCESS macro model 1 (See Table 11, Appendix A, for full results). There was a significant main effect of caregiver burden on depression,  $b = 0.41$ ,  $t(89) = 10.06$ ,  $p < .001$ , suggesting that higher levels of caregiver burden are associated with greater self-report of depression. Study results did show a significant interaction effect of goal reengagement,  $b = -0.02$ ,  $t(89) = -1.96$ ,  $p = .05$ , suggesting that caregivers who report a greater ability to reengage in goals when caregiver burden is high experience lower levels of depression. Given the trend towards a significant moderation, simple slopes analyses were examined. Results from simple slopes tests indicated that the experience of caregiver burden was more strongly related to greater depression for low levels of goal reengagement,  $b = 0.48$ ,  $t(89) = 7.69$ ,  $p < .001$ , than for moderate levels,  $b = 0.41$ ,  $t(89) = 10.06$ ,  $p < .001$ , and high levels,  $b = 0.33$ ,  $t(89) = 7.14$ ,  $p < .001$ . This suggests that caregivers who reported a poorer ability to reengage

in goals, at high levels of caregiver burden, are more likely to experience greater depression than caregivers who report a greater ability to reengage in goals (Figure 8, Appendix A).

## CHAPTER IV

### DISCUSSION

Due to recent medical advances, more people are taking on the caregiving role for physically ill family members, potentially disrupting many aspects of the caregiver's life (Newman, 1997; Offerman, Schroevers, van der Velden, de Boer, & Pruyn, 2010) and resulting in a range of psychological problems for the caregivers, including symptoms of depression and anxiety; difficulties concentrating; and feeling nervous, restless, fearful, and distressed (Grunfeld, 2004; Kim, Spiller & Hall, 2012; Puterman & Cadwell, 2008; Waldrop, 2007). Researchers have consistently examined the influence of objective burden and caregiver burden on psychological distress; however, inconsistencies exist in the caregiver literature about the directional impact and strength of these variables on the experience of psychological distress. In an attempt to explain these inconsistencies, few studies have examined the role of motivational processes (goal pursuit and orientation) on the relation between burden (objective and caregiver) on psychological distress.

Therefore, the purpose of this study was threefold. The first aim was to provide supportive evidence for the mediating role of caregiver burden on the relation between objective burden and psychological distress. The second aim was to examine the impact of prevention focus on the relation between objective burden and caregiver burden. The final aim was to examine the impact of goal disengagement on the relation between caregiver burden and psychological distress. The major findings provide support for the

mediating effect of caregiver burden, and provide partial support for the interactive effect of goal adjustment and caregiver burden on psychological distress. Furthermore, while findings do not support the interactive effect of prevention focus and objective burden on caregiver burden, post-hoc analyses do support an interactive effect of promotion focus and objective burden on caregiver burden.

Previous research has illustrated a mediating effect of caregiver burden on the relation between objective burden and psychological distress (Tsai, 2003). Results from the present study further support this mediating effect. More specifically, although a main effect of objective burden on psychological distress was not found, a main effect of objective burden on caregiver burden, and subsequently a main effect of caregiver burden on psychological distress was found. This demonstrates that while objective burden does not directly impact psychological distress, it negatively impacts psychological distress through the experience of greater caregiver (perceived) burden. In our study, objective burden was measured by direct time spent engaged in caregiving tasks whereas caregiver burden was measured through the subjective experience of caregiving such as worry, frustration, and fear. Therefore, results from the present study suggest that it is not merely the amount of time caregiving demands take, but the perception of how demanding and burdensome these tasks are that negatively influence psychological distress.

Research has consistently shown an association between objective burden and caregiver burden; however, the magnitude of this relation is not completely understood. Thus, in an attempt to further shed light on this the relation, we examined the interacting

effect of prevention focus and objective burden on caregiver burden. Specifically, we predicted that at higher levels of objective burden, caregivers who report weaker prevention focus will experience greater caregiver burden. Results from the present study did not support our hypothesis. One explanation for this insignificant finding could be that people with a high prevention focus are more likely to take on the caregiver role to fill a sense of obligation. Upon further examination of our caregiver sample, average self-report of prevention focus was high ( $M = 19.01$ ) in comparison to previous research by Eddington and colleagues (2012) using a college samples ( $M = 3.98$ ). Therefore, potentially more interesting would be the impact of promotion focus on the relation between objective burden and caregiver burden. Post hoc analysis revealed that promotion focus does in fact moderate the relation between objective burden and caregiver burden. More specifically, at high levels of objective burden, caregivers with a stronger promotion were more likely to report greater caregiver burden than caregivers with lower promotion focus. This finding lends support to Higgins' (1997) concept of regulatory fit, in that caregivers with stronger promotion focus may represent a mismatch between their orientation and the strategy needed to accomplish goals associated with caregiver demands. Thus, caregivers with stronger promotion focus are more likely to experience dissatisfaction and disappointment (caregiver burden) in response to self-report of caregiver demands (objective burden).

As outlined above, based on the concept of regulatory fit, it was hypothesized that using a prevention orientation would “fit” the strategy needed to complete caregiver tasks, increasing the likelihood of goal attainment, and potentially reducing caregiver

burden. However, while our study might suggest that people with stronger prevention focus over-select for the caregiver role, this orientation does not appear to be significantly related to caregiver burden. Instead, a stronger promotion focus seems to represent a mismatch in the behavioral strategy needed for caregiving task, thus increasing caregiver burden at high levels of objective burden. For a hypothetical example, a caregiver with a prevention focus may feel an obligation to attend appointments and construe a goal, “I will take notes because it is my job not to miss anything the doctor says,” whereas a caregiver with a promotion focus may attend the same appointment but construe a goal in a way that provides a feeling of accomplishment, “I will take notes because it is my responsibility to aid my family’s understanding of the diagnosis and treatment.” The caregiver with a prevention focus may “fit” the behavioral strategy needed for the caregiving task and experience some relief (Higgins, 1997). However, this sense of relief may not outweigh the anxiety and fear of the family member’s diagnosis. In contrast, the caregiver with a promotion focus may be able to take notes but be unable to add to their family’s understanding. Not only may this caregiver be experiencing anxiety and fear related to the family member’s diagnosis but is likely to experience disappointment and sadness because they weren’t able to attain their goal; thereby increasing caregiver burden. Given this finding, health care providers may benefit from providing psychoeducation on how caregivers approach goals and how it impacts their experience of caregiver burden.

Finally, research has begun to suggest that having multiple roles (i.e. working, parenting, etc.) in addition to the caregiving role can negatively impact psychological

distress (Kim, Baker, Spiller, & Wellisch, 2006). Thus, the present study hypothesized an interactive effect of goal disengagement and caregiver burden on psychological distress. It should also be noted that study results demonstrated high positive correlations between the DASS-21 depression, anxiety, and stress subscales potentially suggesting poorer construct validity. However, research examining the factor structure of the DASS-21 with clinical populations suggests that the measure maintains good construct validity despite moderate to high intercorrelations (Nieuwenhuijsen, de Boer, Verbeek, Blonk & van Dijk, 2003; Page, Hooke & Morrison, 2007). Additionally, while a total score was initially utilized, use of the subscales provided more specific information about the experience of caregiver psychological distress. Therefore, the present study ran separate moderation analyses for all three subscales. Our findings suggest benefits of goal adjustment on reducing the experience of depression, stress, and anxiety in caregiver population. In particular, at high levels of caregiver burden, caregivers with greater ability to disengage from unattainable goals report fewer symptoms of stress and anxiety (but not depression).

Research within the motivational literature may provide an explanation for this insignificant result of goal disengagement on depression. In particular, while the ability to disengage from unattainable goals may reduce psychological distress (Carver & Scheier, 1990; Rasmussen, et al., 2006; Wrosch, et al., 2007), it may also have negative consequences such as increasing a sense of failure (Wrosch, et al., 2007). Therefore, researchers have begun to suggest that successful goal adjustment, in the face of unattainable goals, requires both goal disengagement and goal reengagement (Wrosch,



Scheier, Carver & Schulz, 2003a; Wrosch et al., 2003b). Specifically, individuals who are able to reengage in new goals experience more positive emotions (Schorroevers, Kraaij & Garnefski, 2008; Wrosch, Scheier, & Miller, 2013) and fewer depressive symptoms (Offerman et al., 2010; Wrosch, et al., 2011). Thus, post hoc analyses were run to examine the interactive effect of goal reengagement and caregiver burden on depression. Results were significant, suggesting that at high levels of caregiver burden, caregivers who report a greater ability to reengage in new goals experience fewer depressive symptoms than caregivers who report a weaker ability to reengage in new goals.

These results suggest that both goal disengagement and goal reengagement are important for family caregivers' psychological distress, but in different ways. Specifically, caregivers' ability to disengage from unattainable goals may help to reduce their experience of stress and anxiety, but ability to reengage in a new goal may work to reduce their experience of depressed mood. As discussed, taking on the caregiver role is associated with increased emotional, physical, and temporal demands which can come into conflict with prior personal goals. Therefore, in our sample, the ability to temporarily disengage from unattainable goals, or shift goals, may provide a sense of relief, reducing stress and anxiety associated with goal pursuit. However, these caregivers may still feel a sense of disappointment, sadness, and failure over not being able to maintain all goals. Thus, the ability to reengage in new goals may buffer against the negative consequences of goal disengagement by promoting a sense of success and accomplishment, decreasing depressed mood. For example, caregivers may be

reengaging in goals that are consistent with their values and may have initially felt hard to maintain after taking on the caregiving role such as “spending time with friends,” “starting work with a charitable cancer organization,” or “eating a healthy and well-balanced diet.” Based on these findings, psychological interventions geared towards increasing self-regulation abilities may reduce psychological distress in family caregivers. Health care providers working with family caregivers may benefit from providing psychoeducation to caregivers about the impact of goal adjustment and guide them to consider disengaging from unrealistic or unattainable goals and reengage in new goals that are consistent with their values, will promote positive emotion, and may increase their support network (e.g. “attending Sunday church services,” “reengaging in an old hobby”).

### **Limitations and Directions for Future Studies**

The present study is not without limitations. First, it is important to recognize that the cross-sectional nature of the study design prevents questions of causality from being answered. For example, goal disengagement and goal reengagement may reduce symptoms of depression, stress, and anxiety, but lower symptoms may also impact caregivers’ report of goal disengagement and goal reengagement. Recent longitudinal research by Zhu and colleagues (2015) on the role of goal adjustment in symptoms of depression and anxiety in cancer patients has found evidence that goal reengagement, but not disengagement, leads to decreasing symptoms of anxiety and depression. However, there continues to be a debate in the literature about the mechanisms underlying these goal adjustment abilities. More specifically, researchers question whether goal

disengagement and reengagement are equally beneficial to psychological functioning or whether they potentially enhance or deplete one another (Dunne, Wrosch & Miller, 2011; Eddington, et al., 2015; Thompson, Woodward & Stanton, 2011; Wrosch et al., 2003b; Zhu, Ranchor, van der Lee, et al., 2015). Could there something inherent about the caregiver role that benefits from both goal disengagement and goal reengagement? Future research may benefit from examining the causality of goal disengagement and reengagement on caregiver psychological functioning across disease progression. For example, as mentioned previously in this paper, researchers have suggested that caregivers who have been providing care longer may experience fewer symptoms of depression because they have had more time to adjust their personal goals and expectations (Huang, et al., 2006). Longitudinal research that follows caregivers from time of diagnosis to end of treatment may provide a unique opportunity to examine the causal relationship between individual differences in goal pursuit and psychological distress.

Given the limited research on self-regulatory processes and motivational orientation within the caregiver literature, this study aimed to obtain a broad understanding of how these constructs influence the experience of psychological distress in family caregivers of cancer patients. For this reason, we did not limit participation based on cancer diagnosis or stage of diagnosis. Thus, study results provided a foundational understanding of the impact of goal pursuit and motivational orientation on the cancer caregiver experience. Future research would benefit from examining these strategies by specific types of cancer or stage of cancer to gain a more complete

understanding of individual differences in the experience of cancer caregiving. For example, by limiting participation to stage of diagnosis, researchers may be able to determine whether the ability to adjust your personal goals is protective across all stages of diagnosis or potentially more impactful at specific stages. Knowing this information, health care providers can then be more discerning when providing resources for reducing psychological distress and caregiver burden.

Due to the nature of this study, we were unable to randomly select participants which may have resulted in a self-selection bias. Specifically, caregivers who felt too overwhelmed by the caregiving role may have opted out of the research study entirely. While caregivers in our sample reported a range in symptom severity, the majority of caregivers reported mild symptoms of depression, anxiety, and stress. Given that free-time may be scarce for caregivers, the time commitment associated with the present study may have further deterred more overwhelmed caregivers. In fact, caregivers who completed the present study frequently commented about the length of study questionnaires taking longer than anticipated; it took an average of 30 minutes to complete. Future studies may benefit from including briefer measures in an attempt to reach caregivers with greater psychological distress.

Lastly, the present study only assessed one aspect of goal pursuit. In particular, while we used a widely used, self-report, measure of goal adjustment, we did not assess for the presence and frequency of goal disturbances or collect data on caregivers' actual goals. Research has suggested that family caregivers of head and neck cancer patients experience goal disturbance and psychological distress (Offerman, et al., 2010).

However, by not assessing for goal disturbances, we cannot know whether the caregiver perceived their new role as a disturbance or whether the caregiver was experiencing additional disturbances that may be unrelated to their caregiver demands. Additionally, by not asking about specific goals and the perceived attainability of these goals we were only able to obtain general information about caregivers' goal processes. Future studies could extend our findings by collecting more comprehensive information about goal disturbances, and the content and attainability of personal goals.

### **Conclusion**

Despite these limitations, the present study adds to our understanding of factors associated with family caregivers' of cancer patients experience of burden (objective and caregiver) and psychological distress. Results further support research suggesting that objective burden influences psychological distress through the experience of caregiver (subjective) burden. Additionally, the present study advances our understanding of the role of goal processes and motivational orientation on burden and psychological distress. Specifically, caregivers with a stronger promotion focus are more likely to experience caregiver burden than caregivers with weaker promotion focus. Furthermore, a caregiver's ability to disengage from unattainable goals may decrease the experience of stress and anxiety, and the ability to reengage in goals may decrease the experience of depression. Further research is needed to determine the benefit of psychological interventions, such as self-system therapy (Strauman et al., 2006), in alleviating the

experience of stress, depression, and anxiety in family caregivers. However, this study provides preliminary evidence that learning different ways to approach goals and adjust goals may reduce psychological distress in family caregivers.

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## ENDNOTE

<sup>1</sup>The anxiety subscale was moderately skewed (2.58) and leptokurtic (9.19). Bootstrapping methods do not require assumptions of normality to be met (Russell & Dean, 2000). Therefore, transformations were not made to the data to preserve true values.

APPENDIX A  
TABLES AND FIGURES

Table 1. Caregiver Demographics

		Percentage
Gender	Male	31
	Female	68
	Did not answer	1
Age	<30	14
	30 – 50	24
	51 – 65	38
	> 65	25
	Did not answer	1
Race	American Indian or Alaska Native	0
	Asian	0
	Black or African American	22
	Native Hawaiian or Other Pacific Islander	1
	White or European American	76
	Other	1
	Other	1
	Did not answer	1
Education	Did not complete high school	3
	High school or GED	26
	Some college	30
	Bachelor’s degree	26
	Advanced graduate work	11
	Did not answer	5
History of Previous Psychological Services	Yes	28
	No	70
	Did not answer	28

Religious	Not at all	6
	Not really	6
	Somewhat	22
	Yes	8
	Very much so	57
# of separate caregiving experiences	1-2	62
	3-6	18
	7 or more	18
	Did not answer	3
Learned about study	Flyer from UNCG campus	4
	Flyer from hospital setting	64
	Flyer from health care provider	4
	Word of mouth	9
	Website or listserv	3
	Social media	4
	Other	13
Relationship to care-recipient	Spouse	14
	Child	5
	Parent	1
	Sibling	6
	Did not answer	75
	Unknown	11
Stage of Diagnosis	Stage 1	7
	Stage 2	20
	Stage 3	11
	Stage 4	43
	Extensive	2
	Incurable	2
	Did not answer	6

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Table 2. Descriptive Statistics of Study Variables

Variables	Mean	SD	Range	N
Age	52.81	15.17	19 – 82	101
Objective Burden	39.72	52.57	0 – 168	93
Caregiver Burden	20.95	15.28	0 – 74	100
Psychological Distress	0	.92	-.92 – 3.62	101
Goal Disengagement	11.93	3.48	4 – 20	95
Goal Reengagement	20.18	4.72	6 – 30	94
Prevention Focus	19.01	3.96	7 – 25	100
Promotion Focus	23.00	3.80	13 – 30	100
Depression	7.20	8.00	0 – 36	101
Anxiety	4.73	6.55	0 – 40	101
Stress	10.02	8.91	0 – 38	101

Table 3. Correlation Matrix of Study Variables

Variables	1	2	3	4	5	6	7	8	9	10
1. Psychological Distress	1.00									
2. Objective Burden	.19	1.00								
3. Caregiver Burden	.77**	.35**	1.00							
4. Goal Disengagement	-.18	-.17	-.17	1.00						
5. Goal Reengagement	-.06	.04	.01	.11	1.00					
6. Prevention Focus	-.09	-.02	.11	.02	-.02	1.00				
7. Promotion Focus	-.25**	-.02	.21*	-.05	.14	.29**	1.00			
8. Depression	.92**	.16	.75**	-.09	-.04	-.03	.28**	1.00		
9. Anxiety	.89**	.16	.62**	-.20*	-.10	-.08	-.17	.70**	1.00	
10. Stress	.93**	.20	.75**	-.20	-.03	-.13	-.25**	.82**	.74**	1.00

Note. \*p < .05, \*\*p < .01

Table 4. Mediation Analysis

		M (Caregiver Burden)			Y (Psychological Distress)			
		Coeff.	SE	<i>p</i>	Coeff.	SE	<i>p</i>	
X (Objective Burden)	<i>a</i>	0.101	0.03	< .001	<i>c'</i>	-0.00	.00	.23
M (Caregiver Burden)		—	—	—	<i>b</i>	0.05	.00	< .001
Constant	<i>i</i> <sub>1</sub>	17.69	1.90	< .001	<i>i</i> <sub>2</sub>	-0.95	0.11	< .001
		R <sup>2</sup> = 0.12 F(1, 91) = 12.30, <i>p</i> < .001			R <sup>2</sup> = 0.59 F(2, 90) = 64.92, <i>p</i> < .001			

Table 5. Prevention Focus and Objective Burden Regressed on Caregiver Burden

		Coeff.	SE	<i>t</i>	<i>p</i>
Intercept	$i_1$	21.684	1.549	14.002	< .001
Objective Burden (X)	$b_1$	0.105	0.032	3.345	< .001
Prevention Focus (M)	$b_2$	0.565	0.438	1.290	.201
Objective Burden X Prevention Focus (XM)	$b_3$	0.008	0.008	.903	.369
		$R^2 = 0.148$ MSE = 212.301 $F(3, 88) = 5.166, p < .01$			



Table 6. Goal Disengagement and Caregiver Burden Regressed on Psychological Distress

		Coeff.	<i>SE</i>	<i>t</i>	<i>p</i>
Intercept	$i_1$	-0.01	0.06	-0.08	.93
Caregiver Burden (X)	$b_1$	0.04	0.00	10.68	< .001
Goal Disengagement (M)	$b_2$	-0.02	0.02	-1.07	.29
Caregiver Burden X Goal Disengagement (XM)	$b_3$	-0.00	0.00	-1.78	.077
		$R^2 = 0.61$ $MSE = 0.36$ $F(3, 90) = 45.47, p < .001$			

Table 7. Goal Disengagement and Caregiver Burden Regressed on Depression

		Coeff.	<i>SE</i>	<i>t</i>	<i>p</i>
Intercept	$i_1$	7.35	0.58	12.64	< .001
Caregiver Burden (X)	$b_1$	0.41	0.04	10.44	< .001
Goal Disengagement (M)	$b_2$	0.09	0.17	0.53	.600
Caregiver Burden X Goal Disengagement (XM)	$b_3$	0.00	0.01	.35	.729
		$R^2 = 0.56$ $MSE = 30.87$ $F(3, 90) = 38.20, p < .001$			

Table 8. Goal Disengagement and Caregiver Burden Regressed on Anxiety

		Coeff.	<i>SE</i>	<i>t</i>	<i>p</i>
Intercept	$i_1$	4.61	0.54	8.49	< .001
Caregiver Burden (X)	$b_1$	0.24	0.04	6.70	< .001
Goal Disengagement (M)	$b_2$	-0.26	0.16	-1.61	.11
Caregiver Burden X Goal Disengagement (XM)	$b_3$	-0.03	0.01	-2.35	.02
		$R^2 = 0.42$ $MSE = 26.81$ $F(3, 90) = 22.17, p < .001$			

Table 9. Goal Disengagement and Caregiver Burden Regressed on Stress

		Coeff.	<i>SE</i>	<i>t</i>	<i>p</i>
Intercept	$i_1$	9.87	0.61	16.18	< .001
Caregiver Burden (X)	$b_1$	0.41	0.04	10.13	< .001
Goal Disengagement (M)	$b_2$	-0.28	0.18	-1.55	.13
Caregiver Burden X Goal Disengagement (XM)	$b_3$	-0.03	0.01	-2.43	.02
		$R^2 = 0.60$ MSE = 33.91 $F(3, 90) = 44.78, p < .001$			

Table 10. Promotion Focus and Objective Burden Regressed on Caregiver Burden

		Coeff.	SE	t	p
Intercept	$i_1$	21.67	1.51	14.37	< .001
Objective Burden (X)	$b_1$	0.10	0.03	3.38	< .001
Promotion Focus (M)	$b_2$	-0.86	0.35	-2.45	.02
Objective Burden X Promotion Focus (XM)	$b_3$	0.01	0.01	2.42	.02
		$R^2 = 0.19$ MSE = 201.51 $F(3, 88) = 8.43, p < .001$			

Table 11. Goal Reengagement and Caregiver Burden Regressed on Depression

		Coeff.	<i>SE</i>	<i>t</i>	<i>p</i>
Intercept	$i_1$	7.38	0.58	12.76	< .001
Caregiver Burden (X)	$b_1$	0.41	0.04	10.06	< .001
Goal Reengagement (M)	$b_2$	-0.12	0.11	-0.98	.29
Caregiver Burden X Goal reengagement (XM)	$b_3$	-0.02	0.01	-1.95	.05
		$R^2 = 0.58$ $MSE = 29.97$ $F(3, 89) = 34.52, p < .001$			

Figure 1. Hypothesis 1: Mediating Effect of Caregiver Burden on the Relation between Objective Burden and Psychological Distress

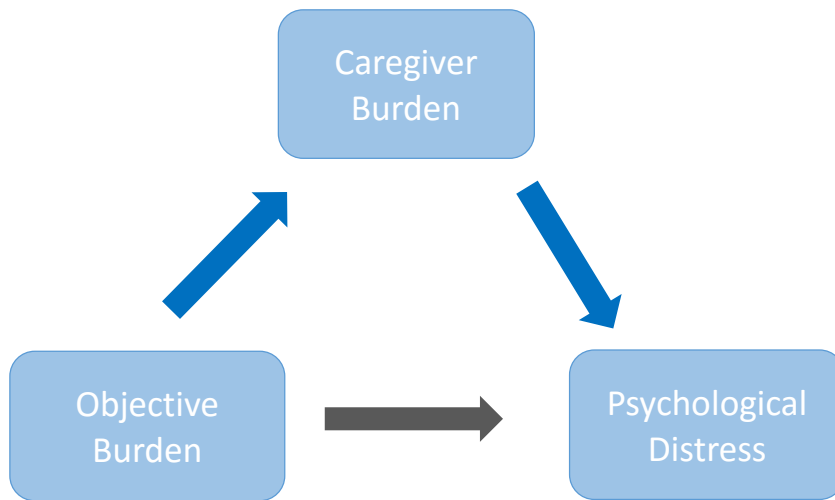


Figure 2. Hypothesis 2: Moderating Role of Prevention Focus on Relation between Objective Burden and Caregiver Burden

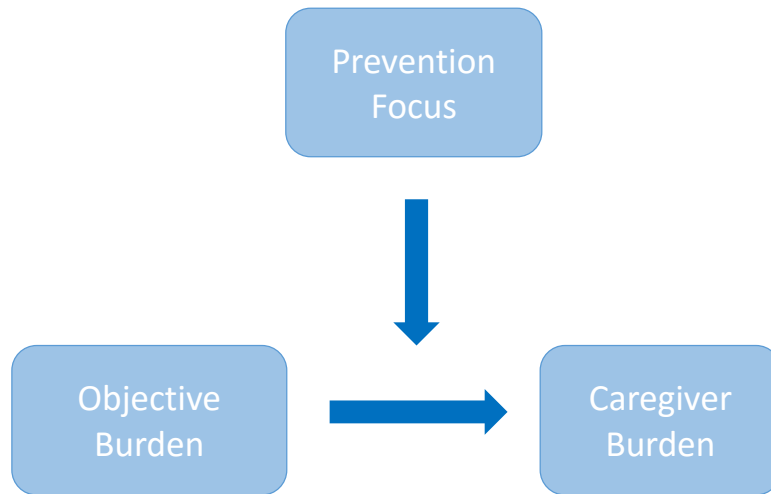




Figure 3. Hypothesis 3: Moderating Role of Goal Disengagement on the Relation between Caregiver Burden and Psychological Distress

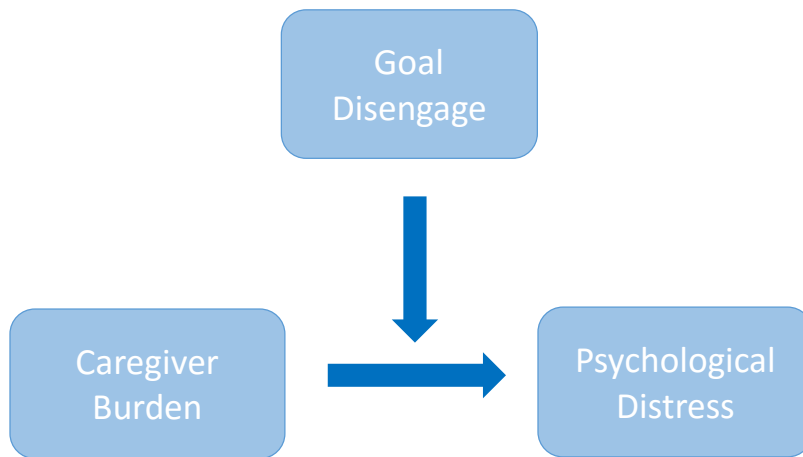


Figure 4. Interactive Effect of Goal Disengagement and Caregiver Burden on Psychological Distress

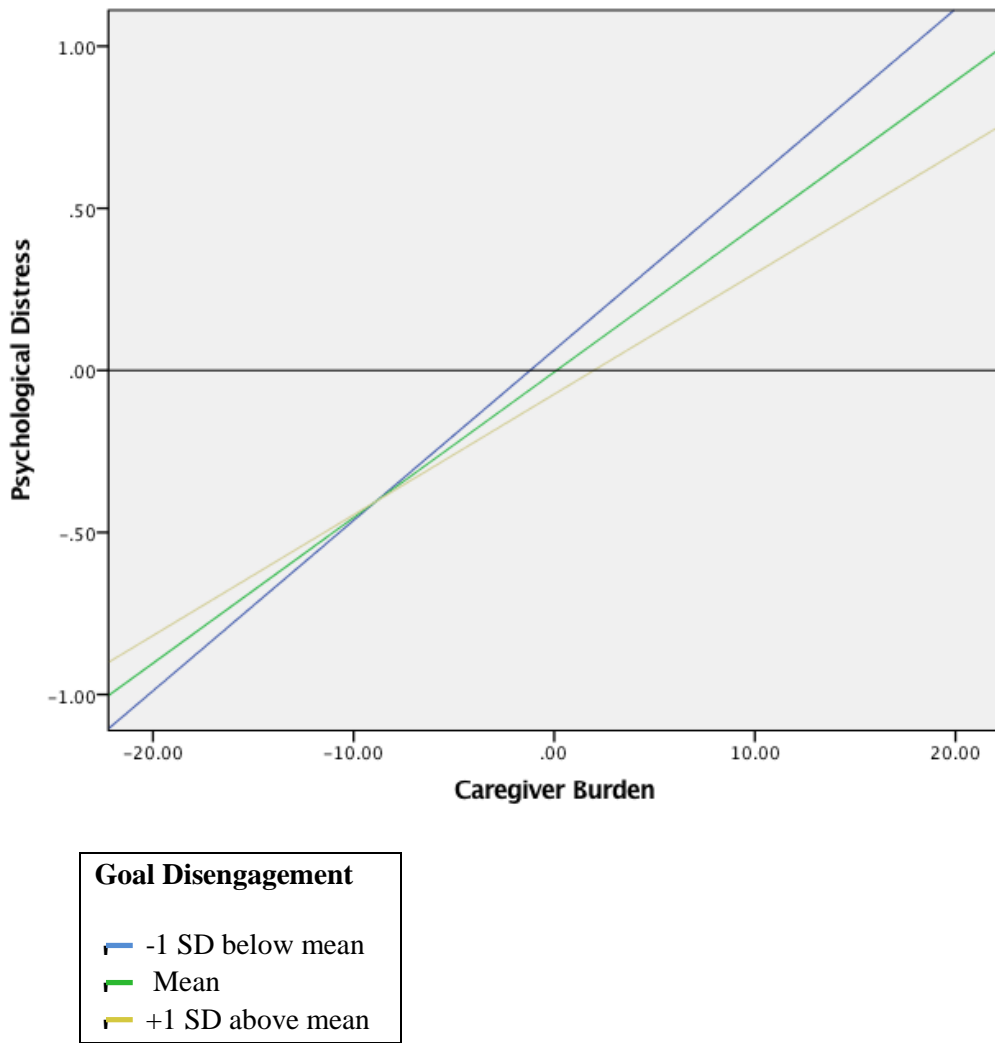


Figure 5. Interactive Effect of Goal Disengagement and Caregiver Burden on Anxiety

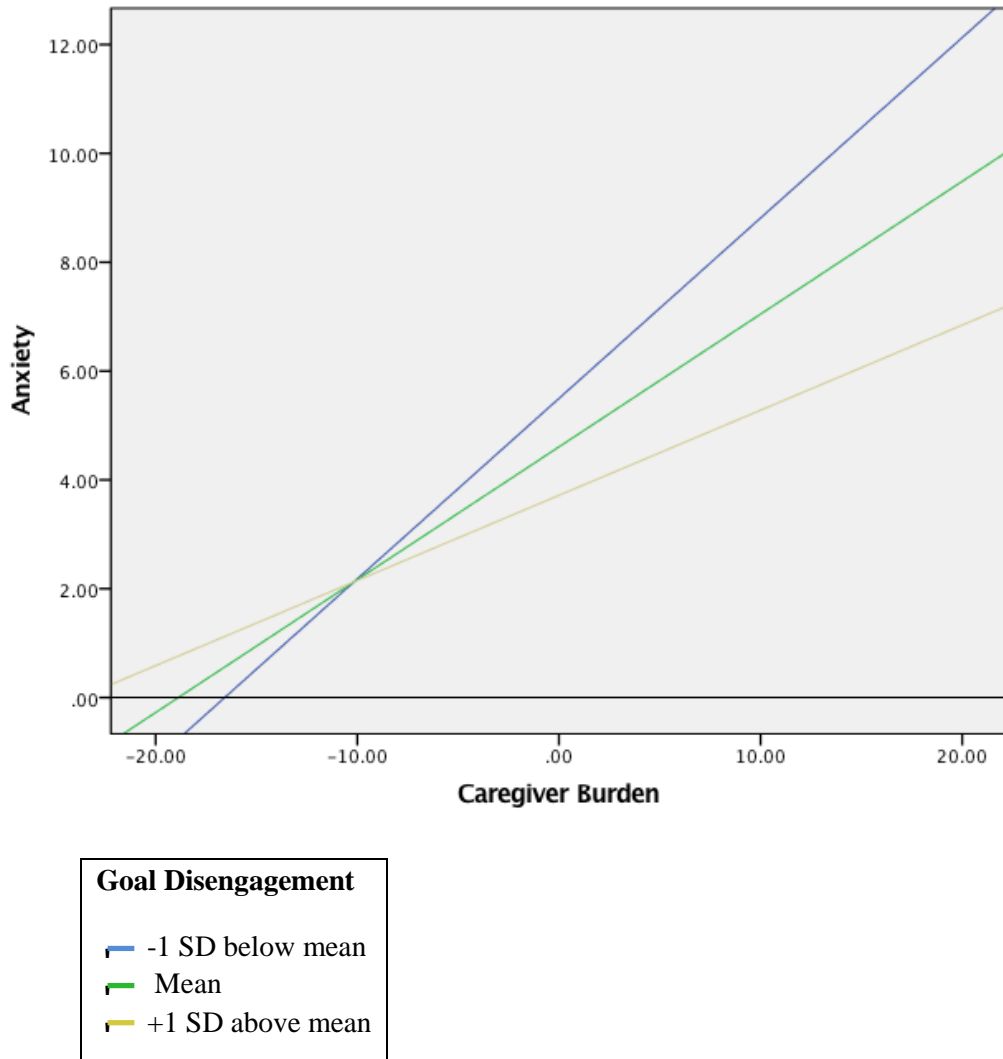


Figure 6. Interaction Effect of Goal Disengagement and Caregiver Burden on Stress

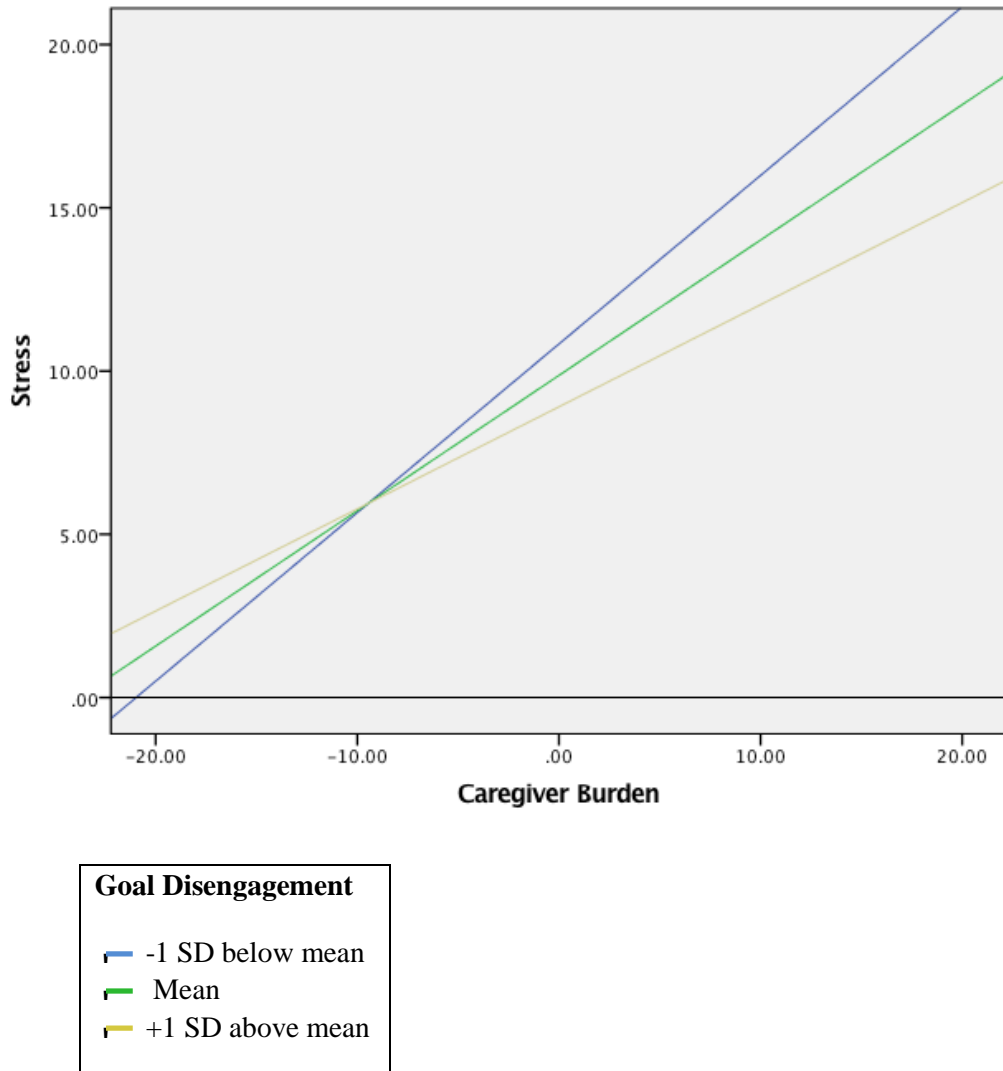


Figure 7. Interactive Effect on Promotion Focus and Objective Burden Regressed on Caregiver Burden

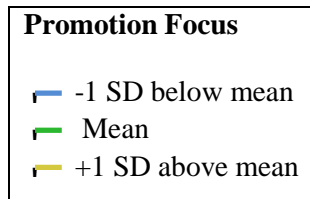
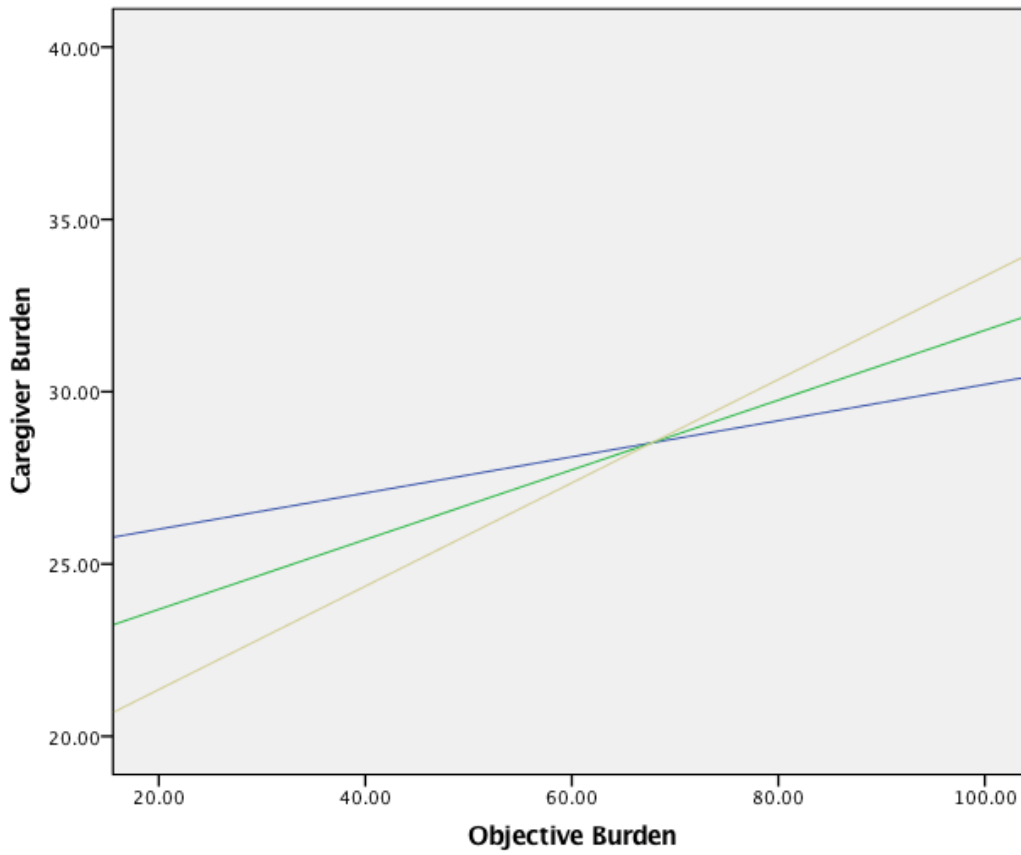
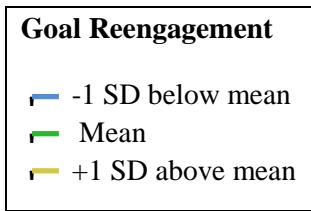
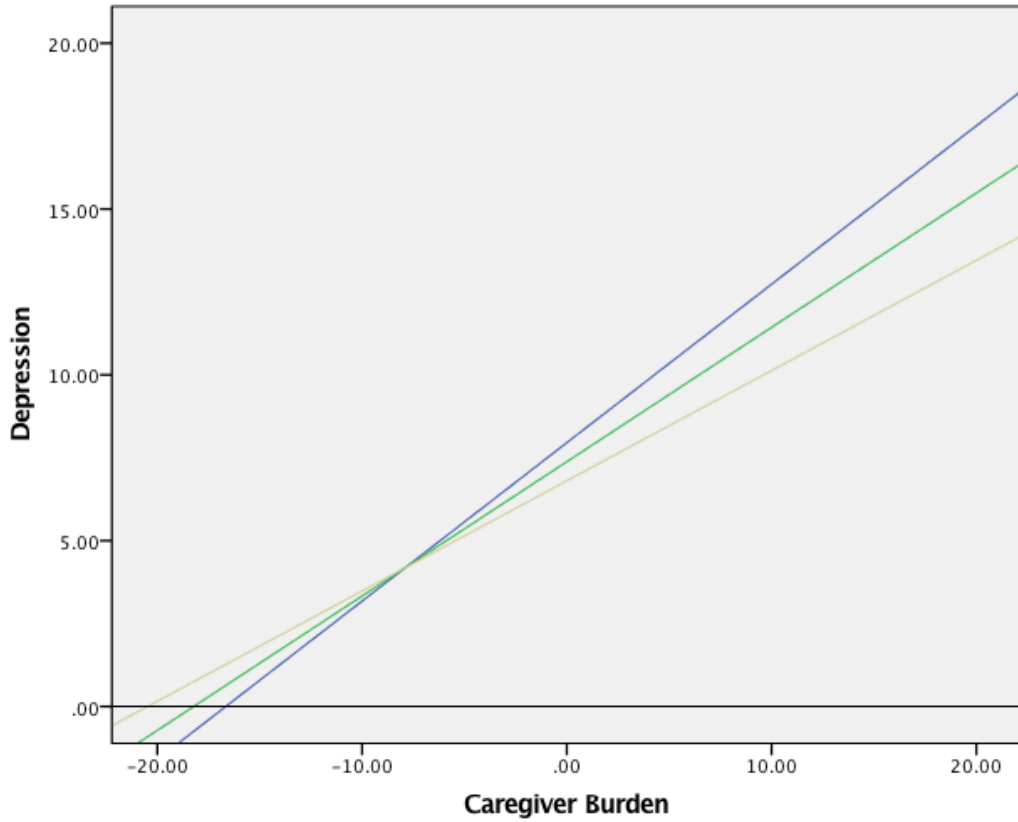


Figure 8. Interactive Effect of Goal Reengagement and Caregiver Burden on Depression



APPENDIX B  
CONSENT FORM

**UNIVERSITY OF NORTH CAROLINA AT GREENSBORO**  
**CONSENT TO ACT AS A HUMAN PARTICIPANT**

Project Title: A Motivational Perspective on Caregiver Psychological Adjustment

Principal Investigator and Faculty Advisor (if applicable): Catherine Majestic and Dr. Kari M. Eddington

**What are some general things you should know about research studies?**

You are being asked to take part in a research study. Your participation in the study is voluntary. You may choose not to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. There may not be any direct benefit to you for being in the research study. There also may be risks to being in research studies. If you choose not to be in the study or leave the study before it is done, it will not affect your relationship with the researcher or the University of North Carolina at Greensboro.

Details about this study are discussed in this consent form. It is important that you understand this information so that you can make an informed choice about being in this research study.

You may request a copy of this consent form for your records. If you have any questions about this study at any time, you should ask the researchers named in this consent form. Their contact information is below.

**What is the study about?**

This is a research project. Your participation is voluntary. This study is interested in examining how individual differences in goal pursuit are related to the experience of negative mood in caregivers of adult family members with cancer. Participation includes answering a series of questionnaires about your mood, experience of burden, and goal pursuit.

**Why are you asking me?**

You are being asked to participate because you are 18 years of age or older and are providing care to a family member who was diagnosed with cancer within the past three years.

**What will you ask me to do if I agree to be in the study?**

Once enrolled in the study, you will be asked to complete several questionnaires about your demographics, mood, experience of burden in the caregiving role, and goal pursuit. The questionnaires are expected to take 35 minutes.

**Is there any audio/video recording?**

There is no audio/video recording.

**What are the risks to me?**

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. The risk is no more than what most people would encounter in their daily lives. It is possible that some of the questions may temporarily make you feel upset or frustrated, but this effect is usually very mild and lasts only briefly. There is a slight risk of breach of confidentiality until the end of data collection, when the list of participant contact information will be destroyed. However, your responses to study questions will not be linked to your personal information, such as your email address or name.

If you would like to talk to someone about your feelings, there are professionals available who can assess your symptoms and, if necessary, recommend treatment options. We want to make you aware of some services that are available to you.

**Greensboro Area:**

UNCG Psychology Clinic: 336-334-5662

Tree of Life Counseling: 336-288-9190

Monarch: 336-676-6840

**Nationwide**

Association for Behavioral and Cognitive Therapies, Find a Therapist website: <http://www.abctcentral.org/xFAT/>"

**Caregiver Information and Support**

National Center on Caregiving: <https://www.caregiver.org>

If you have questions, want more information or have suggestions, please contact (Catherine Majestic or Dr. Kari M. Eddington) who may be reached at (336) 256-0059 or at [DTRPlab@uncg.edu](mailto:DTRPlab@uncg.edu)

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.



**Are there any benefits to society as a result of me taking part in this research?**

Taking on the role of caregiver for a physically ill family member can disrupt many aspects of the caregiver's life. By investigating caregivers' expectations and pursuit of goals after taking on the caregiver role, we may gain a better understanding of the experience of negative mood such as stress, anxiety and sadness.

**Are there any benefits to *me* for taking part in this research study?**

There are no direct benefits to participants in this study. Indirectly, participants may benefit from learning about psychological research. Broader benefits to the society may include improving researchers' understanding of why some individuals experience more negative psychological outcomes in response to caregiving as compared to others.

**Will I get paid for being in the study? Will it cost me anything?**

There is no cost involved in participating in this study. However, participants who complete the study will have the option to enter a drawing for the chance to receive a \$100 gift card. In order to enter the drawing, participants will be asked to provide their email address. One email address will be randomly selected out of all the email addresses received. Once the winner has been determined, the person will be contact through email to make arrangements for payment of a \$100 Amazon gift card.

**How will you keep my information confidential?**

All information obtained in this study is strictly confidential unless disclosure is required by law.

All electronic data obtained during the course of the research study will be stored on a password-protected site and will be accessed through a secure network on a password-protected computer. Email addresses of participants who choose to enter the random drawing will be stored on a password-protected spreadsheet, separate from study data, on a secure network. Email addresses will not be linked to your study responses and will only be used for the purposes of the optional drawing for a chance to receive a \$100 gift card. However, absolute confidentiality of data provided through the Internet cannot be guaranteed due to the limited protections of Internet access. Please be sure to close your browser when finished so no one will be able to see what you have been doing.

Paper questionnaires will not contain any identifying information. These questionnaires will be placed in a sealed envelope after completion and will be stored in a locked filing cabinet, in a secure office. The principal investigator will be the only research staff to view paper questionnaires.

**What if I want to leave the study?**

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

**What about new information/changes in the study?**

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

**Voluntary Consent by Participant:**

By completing this survey, you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By completing this survey, you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Catherine Majestic.

## APPENDIX C

### MEASURES

#### Study Questionnaire

Are you currently providing care to a family member diagnosed with cancer?

- Yes (1)
- No (2)

Was this family member diagnosed within the past three years?

- Yes (1)
- No (2)

***\*If you answered “no” this question, please stop completing the survey. Thank you for your time.***

How old are you?

\_\_\_\_\_

What country do you live in?

\_\_\_\_\_

What is your gender?

- Male (1)
- Female (2)
- Transgender (3)

What is your relationship to the care-recipient (member recently diagnosed)?

\_\_\_\_\_

What is the gender of the care-recipient?

- Male (1)
- Female (2)
- Transgender (3)

What is your race?

- American Indian or Alaska Native (1)
- Asian (2)
- Black or African American (3)
- Native Hawaiian or Other Pacific Islander (4)
- White or European American (5)
- Other (6)

What is your ethnicity?

- Hispanic or Latino (1)
- Not Hispanic or Latino (2)

What is your household income?

- Below 25,000 (1)
- 25,000 - 50,000 (2)
- 50,000 - 75,000 (3)
- 75,000 - 100,000 (4)
- 100,000 - 150,000 (5)
- Above 150,000 (6)
- Not sure/Would rather not report (7)

What is your current employment status?

- Full-time (1)
- Part-time (2)
- Unemployed (3)

Do you live with the care-recipient?

- Yes (1)
- No (2)

Do you have paid assistance to help with some caregiving tasks?

- Yes (1)
- No (2)

How many hours do you currently work per week?

- Unemployed (1)
- 10 to 20 hours (2)
- 20 to 30 hours (3)
- 30 to 40 hours (4)
- 40 to 50 hours (5)
- 50 to 60 hours (6)
- over 60 hours (7)

How many hours did you work per week prior to taking on the caregiving role?

- Unemployed (1)
- 10 to 20 hours (2)
- 20 to 30 hours (3)
- 30 to 40 hours (4)
- 40 to 50 hours (5)
- 50 to 60 hours (6)
- over 60 hours (7)

If employed, what do you do for work? If not employed, answer "NA."

D11 What is your highest educational level obtained?

- Did not complete high school (1)
- High school or GED (2)
- Some college (3)
- Bachelor's degree (4)
- Master's degree (5)
- Advanced graduate work or Ph.D. (6)

What month and year was your family member diagnosed with cancer?

---

What stage and severity is the care-recipient's cancer diagnosis?

---

Are you the primary caregiver?

- Yes (1)
- No (2)

How many months have you been providing care to the care-recipient?

---

How many separate times have you been a caregiver (includes formal and informal caregiving)?

- 1-2 (1)
- 3-4 (2)
- 5-6 (3)
- 6-7 (4)
- 8 or more (5)

How often can you count on others to provide you with emotional support (i.e. talk through difficult decisions, vent to, etc.)?

- Never (1)
- Rarely (2)
- Some of the time (3)
- Often (4)
- All of the time (5)

How often can you count on others help with daily demands?

- Never (1)
- Less than Once a Month (2)
- Once a Month (3)
- 2-3 Times a Month (4)
- Once a Week (5)
- 2-3 Times a Week (6)
- Daily (7)

Are you currently in a support group for caregivers?

- Yes (1)
- No (2)

If yes, how many support group meetings have you attended?

\_\_\_\_\_

\_\_\_\_\_

Do you consider yourself a religious or spiritual person?

- Not At All (1)
- (2)
- Somewhat (3)
- (4)
- Very much so (5)

Does your religious or spiritual involvement bring you support?

- Never (1)
- Rarely (2)
- Sometimes (3)
- Often (4)
- All of the Time (5)

Have you ever received any therapy or counseling for an emotional or psychological problem?

- Yes (1)
- No (2)

Have you ever felt like you should seek treatment or has someone suggested you seek treatment for a psychological problem?

- Yes (1)
- No (2)

If you have received therapy or counseling or felt that you should, what was it for? \_\_\_\_\_

Have you ever received a mental health diagnosis? And if so, please list.

\_\_\_\_\_

\_\_\_\_\_

Have you ever taken any medication for an emotional or psychological problem?

- Yes (1)
- No (2)

Please list the medication taken and length of time taken.

\_\_\_\_\_

\_\_\_\_\_

How did you hear about this study?

- Flyer and/or handout from UNCG campus
- Flyer and/or handout from hospital setting
- Flyer and/or handout from physician, psychologist, case worker, or other health care provider
- Word of mouth
- Website or listserv announcement
- Social media
- Other
- Experimetrix

## DASS -21

*INSTRUCTIONS: Please read each statement and click a number 0, 1, 2 or 3 that indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.*

I found it hard to wind down

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I was aware of dryness of my mouth

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I couldn't seem to experience any positive feeling at all

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I experience breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I found it difficult to work up the initiative to do things

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I tended to over-react to situations

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I experienced trembling (eg, in the hands)

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt that I was using a lot of nervous energy

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I was worried about situations in which I might panic and make a fool of myself

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt that I had nothing to look forward to

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I found myself getting agitated

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I found it difficult to relax

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt down-hearted and blue

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I was intolerant of anything that kept me from getting on with what I was doing

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)



I felt I was close to panic

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I was unable to become enthusiastic about anything

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt I wasn't worth much as a person

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt I was rather touchy

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt scared without any good reason

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

I felt that life was meaningless

- (0) Did not apply to me at all (0)
- (1) Applied to me to some degree, or some of the time (1)
- (2) Applied to me to a considerable degree, or a good part of the time (2)
- (3) Applied to me very much, or most of the time (3)

## Zarit

*INSTRUCTIONS: Please choose the response the best describes how you feel.*

Do you feel that your care-recipient asks for more help than he/she needs?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that because of the time you spend with your care-recipient that you don't have enough time for yourself?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel stressed between caring for your care-recipient and trying to meet other responsibilities for your family or work?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel embarrassed over your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel angry when you are around your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that your care-recipient currently affects your relationships with other family members or friends in a negative way?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Are you afraid what the future holds for your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel your care-recipient is dependent on you?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel strained when you are around your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel your health has suffered because of your involvement with your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that you don't have as much privacy as you would like because of your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that your social life has suffered because you are caring for your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel uncomfortable about having friends over because of your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that your care-recipient seems to expect you to take care of him/her as if you were the only one he/she could depend on?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that you don't have enough money to take care of your care-recipient in addition to the rest of your expenses?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that you will be unable to take care of your care-recipient much longer?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel that you have lost control of your life since your care-recipient's illness?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Nearly Always (4) Overall, how burdened do you feel in caring for your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you wish you could leave the care of your care-recipient to someone else?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel uncertain about what to do about your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel you should be doing more for your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)
- Nearly Always (4)

Do you feel you could do a better job caring for your care-recipient?

- Never (0)
- Rarely (1)
- Sometime (2)
- Quite Frequently (3)

## Objective Burden Measure

*INSTRUCTIONS: In the past two weeks, have you helped your care recipient with the following:*

	Yes (1)	No (2)	Not Needed (3)
<b>Get around inside (1)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Get around outside (2)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Eat (3)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Get in or out of bed (4)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Get dressed (5)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Bathe (6)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Get on or off the toilet (7)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Clean him or herself after s/he used the toilet (8)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Managed his or her money (9)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Made telephone calls for your Care Recipient (10)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Done housework you wouldn't normally do (11)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Washed laundry you wouldn't normally do (12)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Shopped for your Care Recipient's groceries (13)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Driven your Care Recipient to a doctor's office, clinic or hospital (14)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Had to do other chores and tasks your Care Recipient would normally do if he or she was not ill (15)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Help administer medicine to your Care Recipient (16)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Make a decision about whether your Care Recipient needed medication (17)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Keep track of or watch for side effects from you Care Recipient's treatment (18)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Spend time assisting your Care Recipient manage or control symptoms such as nausea/vomiting, fatigue or pain (19)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Change your Care Recipient's bandages (20)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Give oxygen, give a nebulizer treatment or perform chest percussions (21)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Decide whether to call a doctor (22)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Accompany your Care Recipient to treatments or doctor's appointments (23)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thinking about all the care you provide to your Care Recipient due to his or her illness, on average, on how many days a week do you provide care? \_\_\_\_\_

On a typical day, about how many hours do you provide some care to your Care Recipient due to his or her illness? \_\_\_\_\_

## Goal Adjustment Scale

*INSTRUCTIONS: During their lives people cannot always attain what they want and are sometimes forced to stop pursuing the goals they have set. We are interested in understanding how you usually react when this happens to you. Please indicate the extent to which you agree or disagree with each of the following statements, as it usually applies to you. If I have to stop pursuing an important goal in my life...*

	<b>Strongly Disagree (1)</b>	<b>Disagree (2)</b>	<b>Neutral (3)</b>	<b>Agree (4)</b>	<b>Strongly Agree (5)</b>
<b>It's easy for me to reduce my effort towards the goal. (1)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I convince myself that I have other meaningful goals to pursue. (2)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I stay committed to the goal for a long time; I can't let it go. (3)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I start working on other new goals. (4)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I think about other new goals to pursue. (5)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I find it difficult to stop trying to achieve the goal. (6)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I seek other meaningful goals. (7)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>It's easy for me to stop thinking about the goal and let it go. (8)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I tell myself that I have a number of other new goals to draw upon. (9)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>I put effort toward other meaningful goals. (10)</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Have you adjusted your personal goals given the caregiving role?

- Yes (1)
- No (2)

## Regulatory Focus Questionnaire

*INSTRUCTIONS: This set of questions asks you how frequently specific events actually occur or have occurred in your life. Please indicate your answer to each question by choosing the appropriate number.*

Compared to most people, are you typically unable to get what you want out of life?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very often (5)

Growing up, would you ever "cross the line" by doing things that your parents would not tolerate?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very often (5)

How often have you accomplished things that got you "psyched" to work even harder?

- Never or seldom (1)
- (2)
- A few times (3)
- (4)
- Many times (5)

Did you get on your parents' nerves often when you were growing up?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very often (5)

How often did you obey rules and regulations that were established by your parents?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Always (5)

Growing up, did you ever act in ways that your parents thought were objectionable?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very Often (5)

Do you often do well at different things that you try?

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very Often (5)

Not being careful enough has gotten me into trouble at times.

- Never or seldom (1)
- (2)
- Sometimes (3)
- (4)
- Very Often (5)

When it comes to achieving things that are important to me, I find that I don't perform as well as I ideally would like to do.

- Never true (1)
- (2)
- Sometimes true (3)
- (4)
- Very often true (5)

I feel like I have made progress toward being successful in my life.

- Certainly false (1)
- (2)
- (3)
- (4)
- Certainly true (5)

I have found very few hobbies or activities in my life that capture my interest or motivate me to put effort into them.

- Certainly false (1)
- (2)
- (3)
- (4)
- Certainly true (5)