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# The Role Of Employment Status, Work Disruption, Leisure, And Resources In The Mental Health Of Dementia Caregiving Daughters

Lisa Jones Ficker  
*Wayne State University*

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**THE ROLE OF EMPLOYMENT STATUS, WORK DISRUPTION,  
LEISURE, AND RESOURCES IN THE  
MENTAL HEALTH OF DEMENTIA CAREGIVING DAUGHTERS**

by

**LISA J. FICKER**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2010

MAJOR: PSYCHOLOGY (Clinical)

Approved by:

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Advisor

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Date

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## DEDICATION

This dissertation is dedicated to my husband Steve and my children Grace, Andrew, and Elizabeth who have been a source of patient and enthusiastic support through the years. I would also like to dedicate this dissertation to my mother Joy Oliver and my father Frederic Jones who planted the seeds of desire for achievement so long ago and helped nurture them to fruition.

## ACKNOWLEDGMENTS

I would like to acknowledge my dissertation advisor Peter Lichtenberg whose consistent and unfailing support of my career has always inspired me to reach for my best. I would also like to acknowledge and thank Daniel Paulson and Joy Oliver for their contributions to the completion of this dissertation. Last, but certainly not least, I would also like to thank the members of the Institute of Gerontology faculty and my colleagues at the IOG research laboratory, who have greatly enriched my graduate training.

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## CHAPTER 1

### Introduction

An extensive body of literature aimed at understanding the stress and coping process of dementia caregivers has identified employment as a role strain that increases caregiver stress and burden. Studies of informal non-dementia caregivers, however, have often produced different findings. Combining work and caregiving, these studies have found, does not inevitably increase role strain (Maaik G.H., Dautzenberg, et al., 2000). It can have both positive and negative consequences (Scharlach, 1994; Stoller & Pugliesi, 1989). Largely unexplored is the relationship between level of employment and work disruption due to caregiving within the context of lifestyle factors (e.g., finances and leisure) and caregiver mental health.

The role of employee may protect dementia daughter caregivers from depression by preventing role engulfment and providing financial resources that enhance lifestyle. However, full-time work may increase conflicts with a demanding caregiving schedule and be associated with less personal time, despite the economic advantages. In turn, disruption of work may be experienced either as a frustration, a relief, or a combination thereof. How the caregiver experiences the work disruption will likely be influenced by the sociodemographic context of the caregiving, specific changes in lifestyle related to reduction or loss of work, and the importance of her career to her own identity and mental health.

In considering lifestyle changes for caregivers, the role of pleasant events, e.g., engagement in leisure activities, is hypothesized to be of key importance in helping

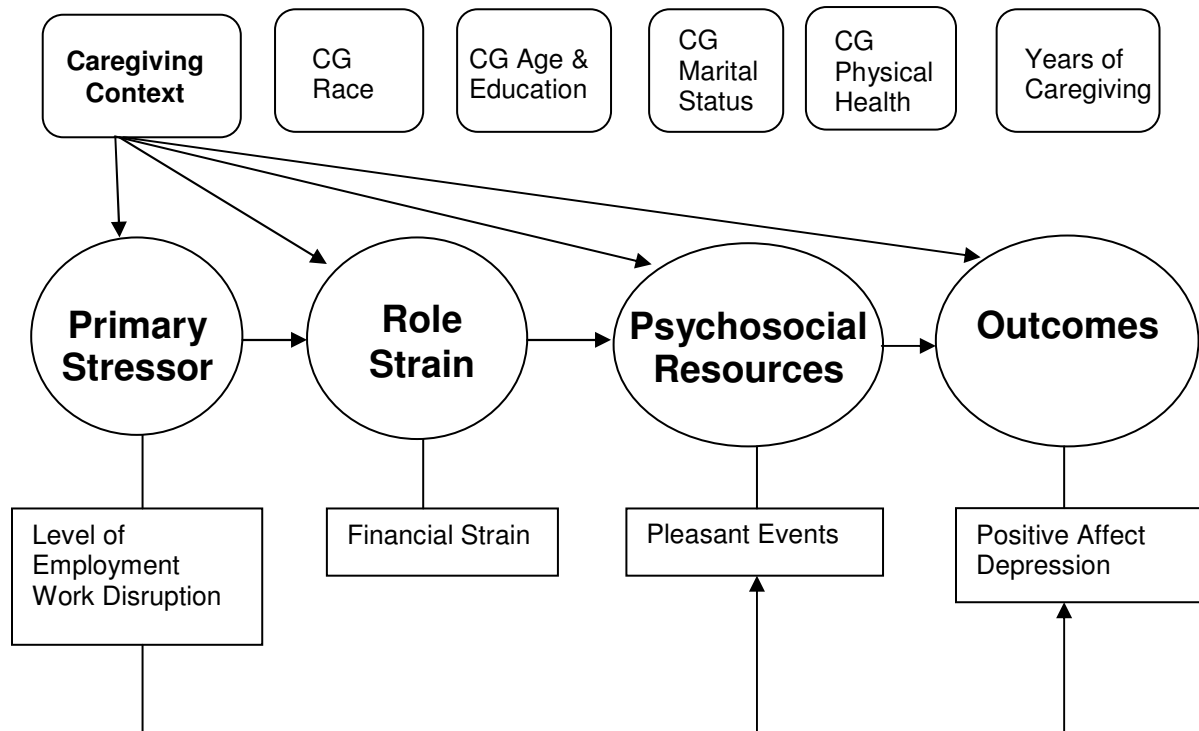


caregivers achieve and maintain mental health. Behavioral models of depression emphasize the importance of pleasant events (Lewinsohn, 1974) and encourage caregivers to engage in leisure pursuits during respite time as a given in caregiving interventions (Coon, et al., 2003). This balance between caregiving and leisure is important so that the caregiver can appreciate the positive aspects of being a caregiver and avoid depression. The current study seeks to examine two things: (1) the context of work in caregiving and how work disruption is related to the mental health of caregiving daughters and (2) a hypothesized mechanism, i.e., how work and work disruption are related to financial resources and engagement in pleasant events.

Dementia caregiving daughters are particularly vulnerable to conflict between work and caregiving, which can disrupt their careers. In a study comparing dementia vs. non-dementia caregivers, Ory and colleagues (1999) found that dementia caregivers were more likely to report disruptions in employment and higher levels of financial hardship than non-dementia caregivers. It should also be noted that being employed and experiencing work disruption are not evenly distributed among dementia caregivers; they occur more frequently among adult daughter caregivers, who are less likely to be retired than many spousal caregivers (Covinsky, et al., 2001). In addition, caregiving has been found to be more stressful when it is “off time” (i.e., occurring at a younger age), normally a time when adult caregiving daughters already have competing role demands (wife, mother, employee) in middle age (Christensen, Stephens, & Townsend, 1998; Seltzer & Li, 1996).

The traditional stress process model developed by Pearlin and colleagues (1990) for caregivers conceptualizes four domains: the background and context of stress, the

stressors, the mediators of stress, and the manifestations or outcomes of stress. Utilizing this model, the present study will consider employment and work disruption as primary stressors, financial strain as a role strain related to work disruption, and leisure activities (e.g., pursuit of hobbies, going out to have fun) as psychosocial resources. The outcome variables are caregiver mental health outcomes: positive and negative affect. See Figure 1 for an overview of how these variables fit into Pearlin's traditional stress process model (1990).

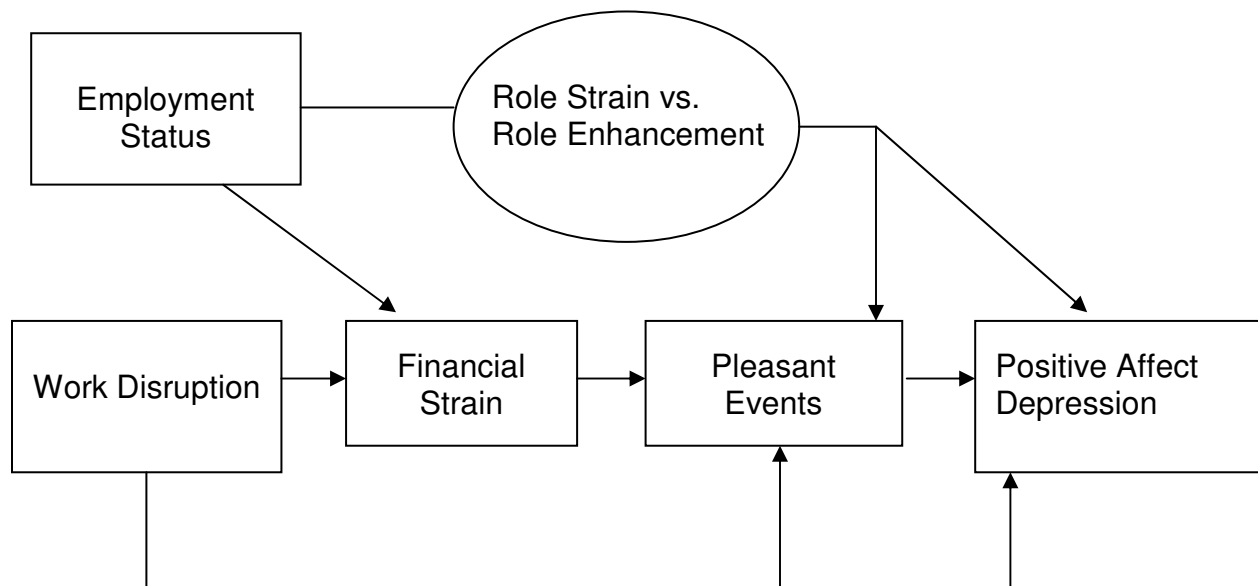


*Figure 1.* Working model for how employment, work disruption, and financial strain fit into the traditional stress process model, based on a reinterpretation, by Hilgeman and colleagues (2009), of a stress process model originally conceptualized by Pearlin and colleagues (1990).

Note: CR = Care Recipient; CG = caregiver.

Each latent construct that comprises caregiving context is defined by a circle with its indicator in a rectangle below it. Caregiver factors (race, age, education, number of chronic health conditions, and years caring for the care recipient) are depicted in boxes to improve readability of the model.

The present study seeks to contribute to an understanding of how and for whom employment is either stressful and/or rewarding by examining sociodemographic characteristics associated with employment, work disruption, and engagement in leisure activities. Because work disruption is conceptualized as a loss of (or reduction in) a potentially important role, it will likely be directly associated with increased feelings of frustration and sadness that will manifest as a direct relationship to caregiver mental health. However, work disruption may also have an indirect relationship with mental health of caregivers via reductions in financial resources and less engagement in leisure activities.



*Figure 2.* Model of how employment and work disruption may influence caregiver participation in pleasant events and mental health outcomes

### *Background of Caregiving Research*

In 1979, Fengler and Goodrich called attention to the predicament of spouses of disabled elderly men, describing them as the “hidden patients” because the role as caregiver had placed them at risk for negative physical, emotional, and social outcomes. From this initial call to awareness, a plethora of research about various aspects of the caregiving experience has developed. During the 1980s, caregiver burden became a popular research topic, and burden interviews (e.g., Zarit Burden Interview) were developed that summed multiple domains of stressors (e.g., finances, physical health, mental health, social activities) into a single burden score (Zarit, et al., 1980; George, 1994). This presumed that caregiving stressors and caregiving distress were inextricably linked or, at the least, that the presence of a greater number of stressors would inevitably lead to greater burden.

Subsequent measures of stress became more sophisticated and delineations were made between the various dimensions of stressors (objective vs. subjective), and it was found that they had differing correlates and shared a surprisingly small amount of variance (12%) (Montgomery, Gonyea, & Hooyman, 1985). Another intriguing finding was that the needs of the patient did not have a strong or consistent relationship to the level of stress reported by the caregiver (George & Gwyther, 1986). As a natural development, rationales were developed for the need to distinguish between caregiver burdens and caregiver sources of well-being, such as resources, finances and social support (George & Gwyther, 1986). Thus began the initial awareness that there could be positive aspects of the caregiving experience, and that caregivers did not experience

a “subtraction” of well-being in the same amount as they experienced the “addition” of distress from burden (George & Gwyther, 1986).

Caregiving research was growing in complexity, and it was in this atmosphere that Pearlin and colleagues (1990) developed and published the conceptual model of the stress of Alzheimer’s caregivers. Previously, caregiving research was generalized to include caregivers of different types and levels of care (“frail” elders, disabled elders, and informal caregiving). With Pearlin’s model, however, there was a recognition that under the severe and chronic stress that the presence of a dementia syndrome in the care recipient brings, “caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an extraordinary and unequally distributed burden” that can lead to a “profound restructuring of the established relationship” (Pearlin, Mullan, Semple, & Skaff, 1990, p. 583).

Pearlin’s model comprises four domains, each of which is made up of multiple components: a) the background and context of stress (e.g., SES, length of care, relationship to patient), b) the stressors, divided into two categories: *primary stressors* (e.g., care recipient cognitive status, ADLs, IADLs) and *secondary role strains* (e.g., economic problems), c) the mediators of stress (e.g., coping strategies and social support), and d) the outcomes or manifestations of stress (e.g., depression, deterioration of physical health, yielding of role). Pearlin designated stressors as “primary” and “secondary,” not because one type of stressor was more important than another, but because he perceived an intrinsic difference in their origins. Primary stressors, Pearlin pointed out, arise directly from the needs and demands of the patient and generally tend

to increase in severity over time. Pearlin conceptualized the root of secondary stressors to be in roles and activities outside the caregiving situation, such as constriction of social life. He included “intrapsychic strains” as secondary stressors and conceptualized them in both global (mastery and self-esteem) and situational dimensions (loss of self, role captivity, gain). Interestingly, each of Pearlin’s four domains was thought to be related to and having an influence on the other three domains, as well as being directly related to caregiver outcomes.

Pearlin and his colleagues (1990) stressed that no one component of the model is more or less important than another, and they observed that the background and context variables are “too frequently gathered and then used only as statistical controls while looking at relationships among other conditions” (p. 584). Indeed, characteristics such as age, relationship to patient, race, and health form the context of the caregiving experience.

It should be noted that the research of Pearlin and other social scientists was conducted primarily with middle-class Caucasians, mixed samples of spouses, daughters, and other caregivers. More recently, caregiving researchers have re-emphasized the context of caregiving, particularly with regard to variables that vary between different ethnic, socio-economic, and various other subgroups within the larger population of caregivers. In their review of 30 empirical studies, Yee and Shulz (2000) found that female caregivers are at greater risk for psychiatric morbidity, particularly depression, than male caregivers and their non-caregiving counterparts. Female caregivers also provided caregiving for a longer period of time, and they reported

greater role strain and conflict with work than male caregivers do (Yee, & Schulz, 2000), which makes them a distinct group with whom to utilize the stress and coping model.

### *Caregiving Daughters: A Unique Population and Context*

When Harper and Lund (1990) wanted to identify specific variables that could explain different levels of burden among caregivers, they proposed that caregiver gender, relationship to patient, and residential location of the patient (same house, community, or institution) are the major considerations. Their results supported this proposition. Adult daughters who lived with dementia patients had the highest burden scores when compared to wives or husbands of dementia patients who co-resided or whose spouse resided in a nursing home. Harper and Lund's data did not examine why this is so, but it is reasonable to assume that social and routine disruptions entailed in either moving in with the parent with dementia or having that parent move in with them played a role. The national dataset utilized for the present study included only caregiving daughters who resided with their care recipient, that is, a highly stressed population.

Witnessing the progressive disease process of dementia that Alzheimer's patients experience is difficult for any caregiver; it constitutes not just a loss for an adult child, but a role reversal. The adult daughter is losing a dominant figure in her life, a role model on whom she has relied in times of need, distress, or when seeking advice. Unlike a spouse, for whom the cultural prescriptions of "til death do you part" and "in sickness and in health" provide the context of the relationship, the adult child often has not contemplated a life in which her parent is dependent upon her (Pohl, Boyd, & Given, 1997). Moreover, becoming a caregiver may have been unexpected and thus

experienced as “off time” (Pearlin, Menaghan, Lieberman, Mullan, 1981). Thus, a parent’s need for intensive caregiving may interrupt a daughter’s pursuit of her own personal, familial, and occupational goals and may alter both the structure of her life and her sense of self.

Moreover, the primary caregiving tasks involve assistance with tasks that the caregiver may not be able to perform independently, such as self-care tasks of bathing and grooming (ADLs) and cooking, shopping, and managing finances (IADLs). There is evidence that informal caregivers who have a filial relationship with care recipients vary in the tasks that they perform for their parent according to gender. Multiple studies have documented that women provide significantly more assistance than men (Finley, 1989; Jutras & Veilleux, 1991) and that daughters provide ADL assistance and help with household chores (e.g., cooking, cleaning) while sons tend to provide more help with transportation and finances (Horowitz, 1985; Kramer & Kipnis, 1995). In addition, there is evidence that sons who are caring for elderly parents receive more emotional and material assistance in these tasks from their wives than daughters receive from their husbands (George & Gwyther, 1986; Horowitz, 1985). Caregiving daughters, as opposed to sons, can be considered vulnerable to increases in ADL/IADL disability in their care recipients.

There is evidence that married daughter caregivers are less depressed than single, divorced, or widowed caregivers, which may be attributable to increased social support. Indeed, a study in 1995 found that married caregivers reported more social support and more help with caregiving tasks than unmarried caregivers, although they also reported more hours spent in caregiving (Brody, Litvin, Hoffman, & Kleban, 1995).



However, lifestyle differences in the ability to engage in leisure activities may or may not impact depression levels and are largely unexamined (Brody, Litvin, Albert, & Hoffman, 1994). On a number of important variables, married, widowed, divorced and never married daughters report similar experiences: levels of caregiver burden, caregiver mastery, and caregiver satisfaction are virtually the same (Brody, Litvin, Albert, & Hoffman, 1994).

Daughter caregivers who have never been married appear to be particularly vulnerable; they report less social support and more financial strain than married or previously married daughter caregivers (Brody, Litvin, Albert, & Hoffman, 1994). In the current study, we expect to see more vulnerability to negative outcomes among the single caregivers, particularly those who have never married. Likewise, married informal caregivers appear to be more likely to report disrupted employment than their unmarried counterparts, and this is likely related to the extra income that a spouse contributes to the household (Covinsky, et al., 2001).

In an examination of caregiver outcomes, the number of years a caregiver must provide care is also important to consider. Evidence has been found that the longer the duration of care, the poorer the caregiver's well-being (Skaff & Pearlin, 1992), a phenomenon known as the "wear and tear" hypothesis. Other researchers point out that the reverse is true as the caregiver learns to adapt to the demands of caregiving (Townsend et al., 1989), hence the "adaptation hypothesis." Our analyses will enable us to test the influence of this variable on the stress and process model as a whole and see if years of caregiving plays a definitive role for dementia caregiving daughters.

### *Employment, SES, and Caregiving*

The employment status of caregivers is often tied to other contextual variables, such as a caregiver's age, race, marital status, and physical health. For example, older caregivers are more likely to be retired, they may be more emotionally prepared to take on the role of caregiver, and they may want the sense of purpose inherent in caregiving. However, there is also evidence that the demands of caregiving are more stressful for physically frail older caregivers and that this risk increases with age and length of care, as the risk of developing physical health problems increases over time for both the caregiver and care recipient. Physical health problems in the caregiver coupled with ADL demands in the care recipient compound the demands of caregiving and complicate the balance between self-care and caregiving that every caregiver needs to maintain (Pinquart & Sorenson, 2003).

Likewise, the educational level of caregivers also is often tied to other contextual variables. Education confers benefits mostly to caregivers, but some increased risk as well. Educated caregivers are more likely to have access to and/or the skills to seek social services, support, and information that are critical to understanding and coping with both the dementia of a loved one and the need to balance self-care with the demands of caregiving. Less educated caregivers have a tendency to be less physically healthy, in general, as education can be used as a proxy for socio-economic status (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). However, highly educated caregiving daughters may be more invested in their careers and subsequently would be expected to experience employment as a role enhancer with disruption of employment as a loss, particularly for those who quit their jobs entirely.

Research on employment in caregiving has generally focused on daughters who provide informal care to parents who are not suffering from dementia. It has been found that employed women provide virtually the same amount of caregiving assistance to their parents as unemployed women, but employed women are more likely to pay for services for care recipients (Brody & Schoonover, 1986). Qualitative research on the experience of combining work with caring for an elder has found that although almost half (48%) of the sample reported less time and energy for caregiving, a majority of the sample (65%) noted increased financial resources as a benefit of employment (Scharlach, 1994). Interestingly, social benefits were also linked to employment while caregiving. A majority of the respondents (58%) reported an improved relationship with the care recipient as a direct benefit from working while caregiving. A small but significant group (10%) noted support from co-workers as important (Scharlach, 1994).

Many studies have used variables such as part-time employment, low income, and living with the care recipient as descriptor variables. A few studies have stressed the importance of a caregiver's employment and financial stress in understanding caregiver burden and have demonstrated a relationship of these variables to a caregiver's age, but have not linked it definitively to being a daughter caregiver (Montgomery, Gonyea, & Hooyman 1985; Sun, Hilgeman, Durkin, Allen, & Burgio, 2009). Indeed, variables such as "part-time employment" are presumed to represent role strains and "no employment" is presumed to represent an absence of role strain (Harper & Lund, 1990). While this may be true, another dimension of the caregiver's experience has not been taken into account and that is that "part-time employment" or "no employment" may represent a loss. Part-time work may have been the norm, as it

is for many active middle-aged mothers who are also caregiving daughters, and may provide benefits, such as protection from being engulfed in the role of caregiving (Sharlach, 1994).

In general, there appears to be more evidence for employment as a role enhancer than as a role strain among female caregivers. For female caregivers of non-dementing elders, feelings of mastery in the employee role are related to less depression and better health (Christensen, Stephens, & Townsend, 1998). Likewise, a longitudinal study of role changes among a nationally representative sample of middle-aged women providing care for a disabled person in their own household found that employment was protective for health limitations (Pavalko & Woodbury, 2000). In a study of parental caregiving, Penning (1998) found that combining parent care and paid work was associated with better emotional health. However, other studies have found that female caregivers who work, as opposed to their male counterparts, indicate that work conflicts with their caregiving responsibilities, thus creating role strain (Fredriksen, 1996).

When employment has been examined in the context of other roles (wife, mother, caregiver), one study found that role conflict is more problematic for daughter caregivers of cognitively impaired elders, particularly for caregivers with low status jobs, low income, and low education (Stephens, Townsend, Martire, & Druley, 2001). A similar study concludes that employment demands was the most significant predictor for role strain (Fredriksen-Goldsen & Farwell, 2005), which speaks to the importance of the role of employment for caregivers in general, especially for low SES daughter caregivers.

This dissertation seeks to shed light on the relationship of dementia parent caregiving and employment in the context of psychosocial characteristics (e.g., age, ethnicity, length of caregiving, education) and circumstances (e.g., full vs. part-time employment, physical health characteristics of the caregiver, and functional status of care recipient) associated with experiencing employment as primarily a role strain and/or role enhancement by comparing levels of engagement in leisure activities.

Differences in ethnicity cut across all of these variables, which is not surprising because ethnicity is often confounded with differences in socio-economic status. Minority caregivers, such as Latinas (Gallagher-Thompson, et al., 2003) and African Americans (Janevic & Connell, 2001), are more likely to be younger than Caucasian caregivers and less likely to be a spouse. Minority caregivers were less educated than their White non-Hispanic counterparts (Janevic & Connell, 2001). In addition, minority caregivers, particularly African Americans, reported consistently poorer health than Anglo caregivers, which was attributed to stresses outside of the caregiving situation, e.g., lack of access to services, poverty, and discrimination (Roff, et al., 2004; Dilworth-Anderson, Williams, & Gibson, 2002; Pinquart & Sörenson, 2005). Thus, minority caregivers' ability to incorporate respite activities (pleasant events) with caregiving responsibilities may be especially challenging.

African American caregivers comprise the largest ethnic group in the REACH sample of caregiving daughters because they engage in caregiving responsibilities at a younger age, e.g., as daughters rather than as spouses. A consistent finding about African American caregivers has been that they express more strongly held beliefs about the value of filial support (Pinquart & Sorenson, 2005; Connell & Gibson, 1997;

Dilworth-Anderson, Williams, & Gibson, 2002). Interestingly, more than one article found that strong feelings of familism or cultural identification have resulted in adverse health outcomes and were associated with less education (Dilworth-Anderson, Williams, & Gibson, 2002; Kim, Knight, & Flynn Longmire, 2007).

Although many studies reported that African American caregivers report less burden, particularly when caring for dementia patients (Pinquart & Sorenson, 2005, Dilworth-Anderson, Williams, & Gibson, 2002), relationship of caregiver perceptions of burden have been influenced by religiosity (Roff et al., 2004; Picot, Debanne, Namazi, & Wykle, 1997). Interestingly, one study found that the more educated an African American caregiver was, the less likely she was to perceive rewards in caregiving, a finding that holds for White caregivers as well (Picot, et al., 1997). Additionally, Black caregivers may express more unmet service needs than White caregivers (Connell & Gibson, 1997), and they are significantly less likely to be married (Picot, et al., 1997). When stress is measured in qualitative research, African American caregivers reported their burden as quite substantial (Fox, Hinton, & Levkoff, 1999; Dilworth-Anderson, Williams, & Gibson, 2002).

A longitudinal study of intra-group differences among African American caregivers found that few of the caregiving stressors typically used in caregiving research were significant in predicting health outcomes among African American caregivers, only the number of medical co-morbidities (Dilworth-Anderson, Williams, & Gibson, 2002). Another study by the same research team has found that better education among African American caregivers was associated with better physical health (Dilworth-Anderson, Goodwin, & Williams, 2004).

### *Work Disruption among Dementia Caregivers*

One of the paradoxes of caregiving stress is that it is not, to quote Pearlin, “the magnitude of the workload” that creates the potency of the stressor, but rather such experiences unique to dementia caregiving as “burnout” and “relational deprivation,” as the progression of the patient’s disease causes the relationship between caregiver and patient to be “strip[ped] ...of its former reciprocities” (Pearlin, Mullan, Semple, & Skaff, 1990, p. 587). As the caregiver’s time and energy are focused on providing care, social roles outside of the caregiving context are disrupted and caregiving displaces other activities, particularly work and leisure social activities. When this occurs, the caregiver may experience a loss of self such that she feels engulfed by her role as caregiver. This role engulfment is accompanied by increased depressive symptoms and, while it is considered more common among spouses, younger caregivers are also particularly vulnerable (Skaff & Pearlin, 1992).

When role engulfment occurs and a loss of self is experienced, caregivers focus on one role and that role becomes the only source for feedback about the self and sense of identity. According to Pearlin and colleagues, “the more limited the contacts and the fewer major roles of which one is an incumbent,” (1992, p. 657), the more immersed one is in caregiving. The greater this immersion, the more vulnerable one will be to stress outcomes, such as depression and poor health (Pearlin, 1990). In this context, work disruption is a factor that may make caregivers more vulnerable to role engulfment precisely because it is a measurement of change in an already established role, e.g., the role of employee.

Dementia caregivers are particularly vulnerable to the role strain of work-caregiving conflict that can disrupt careers. In a study comparing dementia vs. non-dementia caregivers, Ory and colleagues (1999) found that dementia caregivers were more likely to report disruptions in employment, such as having to take less demanding jobs, having to take early retirement, turning down a promotion, losing job benefits, and having to give up work entirely. Dementia caregivers also reported higher levels of financial hardship than nondementia caregivers.

More recent research has found, at least among informal caregivers, that daughters were more likely to reduce hours at work, particularly when they lived with the care recipient (Covinsky, et al., 2001). A large study conducted at 11 different sites (Covinsky, et al., 2001) found that 22% of the 2806 frail elders (a portion of whom had dementia) had at least one caregiver who either reduced the number of hours they worked or quit working to care for the patient (Covinsky, et al., 2001). They found that the “burden of reduced employment” was more likely to be incurred by the families of ethnic minorities and of patients with specific clinical characteristics, such as dementia and severe impairment.

Indeed, among informal caregivers, African American caregivers were 1.5 times more likely than their White counterparts to experience work disruption, and Latinas were found to be more likely than African Americans to reduce work hours and almost twice as likely as caregiving Whites to reduce work hours (Covinsky, et al., 2001). Latino families are very cohesive, and it has been suggested that they are more vulnerable to disruption within the family unit than to disruption of an individual caregiver’s lifestyle (Aranda & Knight, 1997). Therefore, the high rate of work disruption



may reflect the willingness of caregiving daughters to sacrifice personal goals for family members and it is hypothesized that Latinos and African Americans may vary in their pattern of engagement in leisure activities.

Another factor that likely relates to work disruption is the degree of impairment of the care recipient. Some ethnic differences have been noted in care recipients' level of disability. Minority caregivers in general were found to provide more hours of care per week and reported a larger number of caregiving tasks than Whites; these ethnic differences, however, may not reflect clinically significant differences despite being statistically significant (Pinquart & Sorenson, 2005). Nevertheless, African American dementia patients, and some studies suggest Latino patients as well, report a longer time in the community prior to nursing home admission and longer duration of illness than their White counterparts. Thus, minority patients may have longer periods of time during which they require caregiving services from their families (Janevic & Connell, 2001).

Based on this literature, we expect that ADL/IADL impairment may be related to work disruption, and there is some evidence that caregivers whose work is disrupted are providing care to recipients who have more ADL impairment than other informal caregivers (Covinsky, et al., 2001). In this case, dementia caregivers in general and ethnic dementia caregivers in particular are at risk, due to the duration of care. For those who provide care for many years, it may be more likely that care recipient disability is related to a reduction in the caregiver's psychosocial resources and/or pleasant events. As a reduction in social support or engagement in pleasant events occurs, caregiver depression will likely increase.

### *Lifestyle Changes from Work Disruption*

One of the most central questions in caregiving research then becomes *how* the caregiver restructures her life and balances the demands of caregiving activities with her own social and psychological needs. One way to capture the extent to which work disruption impacts a caregiver's life is to measure how it relates to changes in lifestyle and finances. A reduction in hours of work for a dementia caregiver can be conceptualized as a relief that reduces strain and allows for greater availability of time and energy for pleasant events, or it can be viewed as a loss that creates additional barriers to respite activities due to a loss of financial resources.

Similarly, financial strain caused by work disruption that is directly related to caregiving responsibilities or reduction of employment may elicit different emotional responses than financial strain that pre-exists and will outlast the experience of caregiving. Pre-existing financial strain may be accepted as a chronic life stress, while financial strain caused by life disruption could engender a wide range of feelings toward caregiving, such as feelings of loss of a preferred lifestyle, resentment of caregiving, and guilt. For this reason, a description of income (low vs. high) or employment (none vs. part-time vs. full-time) is not adequate to capture the impact a change in working schedule (the reduced ability or inability to work due to caregiving responsibilities) may have on the individual caregiver. When one analyzes these factors separately, using them merely as descriptors, and/or not considering all of the ways that they may impact a dementia caregiver's experience, one loses the contextual variability of changes arising solely from the dementia patient's need for care.

### *Leisure Activities and Caregiving*

Not many recent studies have included pleasant events or respite time as variables in overall considerations of how the stress process model applies to caregivers. Intervention studies with small samples have found that increasing pleasant events (time for socializing and recreation) has decreased depression in caregivers (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003) and is associated with lack of termination of caregiving responsibilities (Kasper, Steinbach, Andrews, 1994). Likewise, recent studies have found a strong relationship between a lack of pleasant events (activity restriction) and depression in small samples of dementia (Mausbach, Patterson, & Grant, 2008) and non-dementia caregivers (Stephens, Townsend, Martire, & Druley, 2001). These findings provide compelling evidence for Lewinsohn's behavioral models (Lewinsohn, 1974) and speak to the importance of balancing caregiving duties with leisure for the maintenance of mental health of caregivers.

One study examined relationship-to-patient differences, albeit in a small sample. Quayhagen and Quayhagen (1988) found that dementia caregivers differed in their reactions to respite time, defined as the number of hours a caregiver was free of caregiving responsibilities during each week (Quayhagen & Quayhagen, 1988). In this study, daughters were found to have the most positive reaction to respite time, wives were neutral, and husbands had negative reactions to respite time (Quayhagen & Quayhagen, 1988).

It was hypothesized that caregiving daughters may be able to engage with respite time more positively because they had less guilt about leaving the care recipient.

Another explanation could be that the spouses of care recipients were so engulfed in the role of caregiving that they were temporarily unable to enjoy themselves outside of their role (Skaff & Pearlin, 1992), a hypothesis which is supported by findings of higher levels of depression among spouses of dementia patients than among other caregivers, (Yee & Schulz, 2000). It is important to remember that caregiving spouses usually do not experience residence changes for the sole purpose of caregiving and that their social lives have already included their care recipient. For caregiving daughters, life disruptions create delineation between pre- and post-caregiving lifestyles and, coupled with pleasant events, may be helpful in the avoidance of role engulfment (Skaff & Pearlin, 1992). It is consistent with the theory of role engulfment that, as the daughter caregiver engages in enjoyable activities, she has the opportunity to remind herself not only of her lifestyle, but also her identity before undertaking the caregiving role (Skaff & Pearlin, 1992).

Li and colleagues (1997) found evidence for this in an examination of various dimensions of social support (e.g., social participation, emotional support, and instrumental support) in a sample of mixed dementia and non-dementia caregivers. They found evidence that the type and amount of stress experienced differed according to who the caregiver was (daughter vs. spouse) (Li, Seltzer, & Greenberg, 1997). For both wives and daughters, emotional support lessened the perceived burden of behavior problems of the care recipient; daughters received an additional benefit in their ability to cope with ADL/IADL limitations. In addition, the principal effect of social participation, which includes the types of engagement currently being considered as “pleasant events,” was to buffer depression for daughters, but not for wives.

It is important to note that other than “quiet time for yourself” and perhaps “taking part in hobbies,” all of the pleasant events measured in this study are such that engaging in them will place the individual in social situations, e.g., “getting together with friends and family,” “doing fun things with other people,” “going out for meals,” and “attending church.” A qualitative study of dementia family caregivers found that the majority of caregivers (60%) reported that their relative’s illness affected their relationships with other people (Chenoweth & Spencer, 1986). “Friends no longer visited, families found themselves isolated, and caregivers often had to give up jobs, volunteer work, and leisure activities” (Chenoweth & Spencer, 1986, p. 270). An unexpected report from some family caregivers was that they described feeling tense and ill at ease around their friends and expressed concern that the care recipient’s behavior was embarrassing (Novak & Guest, 1989; Chenoweth & Spencer, 1986).

Nevertheless, friends have been rated as a particularly important source of emotional support for daughters caring for a parent with dementia while siblings are often considered a source of conflict (Suitor & Pillemer, 1993; Chenoweth & Spencer, 1986). Some caregivers have reported that their circle of friends changed completely when they lost connection to their work-related friends, which highlights the importance of work disruption as a variable of interest in caregiving research, particularly for caregivers who stop working entirely (Chenoweth & Spencer, 1986). Overall, there is evidence that caregivers are a socially vulnerable group who report needs for social support that increase over time and who frequently do not have their social needs met (Clipp & George, 1990). Caregiving daughters who have had to stop working or reduce

their hours at work, church, or other groups are hypothesized to be quite vulnerable to the consequences of having inadequate social support resources.

#### *Caregiver Outcomes: Positive Affect and Negative Affect*

Few studies of caregiving stress include measures of positive affect during the caregiving experience, e.g., the extent to which caregiving is an enriching and rewarding experience associated with personal growth and increased sense of purpose in life (Kramer, 1997). Thus measurement of this construct has not been standardized, a problem which Kramer highlighted in a review on the subject in 1997, and which appears to persist to the present day. Positive affect for caregiving has been measured as caregiving rewards, uplifts, sense of well-being, benefits, and satisfaction with the caregiving role (Kramer, 1997). Benefits of providing caregiving have been found for a wide range of caregivers, e.g., for caregivers of persons afflicted with AIDS, schizophrenia, traumatic brain injury, and a variety of physical illnesses (Kramer, 1997). More recently, caregivers have been found to be at decreased risk of mortality, a finding that highlights the importance of understanding the positive aspects of the caregiving experience (Brown, et al., 2009).

Recognition of positive aspects of dementia caregiving first appeared in qualitative studies, notably conducted with spouse caregivers (Motenko, 1989). Lawton and colleagues conducted a study utilizing a two-factor model of caregiving that included both positive and negative affect (1991). Their study is germane because the analyses were conducted separately for children and spouse caregivers, although the physical impairments of care recipients were mixed. For adult child caregivers, higher

levels of caregiving effort were associated with both greater burden and greater satisfaction with caregiving (Lawton, et al., 1991), and a related study found that this was especially true for African American caregivers (Lawton, Rajagopal, Broken, & Kleban, 1992).

More recent studies have echoed the finding that caregiving is a deeply rewarding activity for African Americans (Roff, et al., 2004; Tarlow, et al., 2004)., but these more recent analyses did not conduct separate analyses for daughter caregivers. In fact, one factor analytic study of positive aspects of caregiving that was focused on White non-Hispanic caregivers found that none of seven positive items loaded for Caucasian daughter caregivers, highlighting the importance of background contextual variables of race and relationship to patient in caregiving research.

Some studies have focused on the relationship between positive and negative affect among caregivers. Interestingly, caregivers who report high positive affect do not necessarily report low negative affect (symptoms of depression), and vice versa (Robertson, et al., 2007). It appears that the experience of feelings of discouragement and loss arising from caregiving are somewhat independent of feelings of growth and satisfaction that occur with caregiving. At the same time, caregivers who are able to experience positive affect during periods of stress are less susceptible to the downward spiral associated with clinical depression (Folkman & Moskowitz, 2000)

Multiple studies have reported that depression is a common finding among dementia caregivers, particularly those who are Caucasian, female, and wives of the care recipient (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Yee & Schulz, 2000, Connell & Gibson, 1997). This is not to say that other groups, such as daughters

and African Americans, are not at risk for depression while engaging in the dementia caregiving experience. Clyburn and colleagues (2000) stress the importance of “understanding the individualized and unique reactions to the caregiving experience that could be improved through a more ... rigorous assessment of how the predictors of caregiving related directly and indirectly to caregiver outcomes” (p. S4). The presence of informal help was one such mediator, as well as the ability to manage disturbing behavior, which is considered an explanatory factor in the African Americans’ reports of less depression in the caregiving context (Janevic & Connell, 2001). Sun and colleagues (2009) recently demonstrated that perceived financial stress (not objective income) is related to caregiver depression. However, it would have been a more contextually sensitive analysis if it were known whether the perceived financial distress was pre-existing or due to lifestyle changes associated with caregiving, such as work disruption.

Qualitative research has found that poor relationship quality and loss of intimacy in married couples, in which one is the caregiver and the other is a dementia patient, is related to depression and that a feeling of “loss of self” is also related to caregiver depression (Adams, McClendon, Smyth, 2008). It is proposed that a similar experience of “loss of self” may be experienced by dementia caregiving daughters who experience loss of work identity or disruption to their career path. Thus, the study of negative affect (e.g., symptoms of depression) will be richer and more contextualized in a study where employment and work disruption are included in the stress and coping model, particularly in the less studied group of African American, Latino, and Anglo American daughter dementia caregivers.



## CHAPTER 2

### Significance of the Study

According to estimates by the Alzheimer's Association for 2009, approximately five million Americans have Alzheimer's disease, the most common cause of dementia. The majority of those who have the disease (87%) are cared for by family members. Sixty percent of such caregivers are women and over half of all dementia caregivers (57%) are caring for a parent or parent-in-law. The average age of a dementia caregiver is 48 years old (2009 Alzheimer's Facts and Figures, Alzheimer's Association). The duration of caregiving is longer for dementia patients than for elders with other health concerns and, at any particular point in time, approximately one-third of dementia caregivers have been providing help for five years or longer, and 39% have been providing care for one to four years (2009 Alzheimer's Facts and Figures, Alzheimer's Association).

The expanding population of older adults indicates that research on dementia caregiving must remain a high priority. The U.S. Bureau of the Census has projected that the population of White non-Hispanic elders will double between 2000 and 2050 and that the population of African American elders will quadruple (Dilworth-Anderson, Williams, & Gibson, 2002). To avoid overwhelming available institutional and financial resources, it is imperative to determine how to best strengthen family members to avoid relinquishing the caregiver role prematurely and to encourage willingness in younger generations to support caregivers or assume caregiving roles themselves (Schultz & Quittner, 1998; Mui, 1992). A contextually sensitive study on the relationships between

employment status, work disruption and associated changes in resources and leisure is likely to be uniquely practical and theoretically useful.

Dementia caregivers experience chronic stress, which often places their mental and physical health in jeopardy (Gitlin, et al., 2003; 2009 Alzheimer's Facts and Figures, Alzheimer's Association). Specifically, they have been known to experience depression, physical health problems, poor self-care behaviors, and lack of engagement in social activities (Pinquart & Sörenson, 2005; Dura, Stukenberg, & Kiecolt-Glaser, 1990; Ory, et al., 1999). Moreover, some research has found that objective measures of patient impairment or amount of care provided are not necessarily the strongest predictors of caregiver depression or life satisfaction (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Goode, Haley, Roth, & Ford, 1998). Rather, caregiver outcomes are thought to be more closely related to caregiver characteristics, psychosocial resources, and ability to cope with the demands of caregiving (Haley, Levine, Brown, & Bartolucci, 1987; Haley, et al., 1996; Goode, Haley, Roth, & Ford, 1998).

The caregiver characteristics that have been found to influence a dementia caregiver's mental and physical health are gender (females are more depressed), age (younger caregivers are more depressed), ethnicity (Whites experience more burden and anxiety; African Americans have worse physical health and self-care), educational attainment (those with less than high school are more depressed), and quality of relationship with the dementia patient (those caregivers who maintain a sense of emotional closeness to the dementia patient are less depressed) (Covinsky, et al., 2003). Caregivers differ in how they adjust to the caregiver burden during the duration

of the caregiving experience; wives report feeling closer to the dementia care recipient over time while daughters feel less close and more burdened (Seltzer & Li, 1996).

One risk in caregiving research is to treat caregivers as a homogenous group when in reality the context of the caregiving experience varies widely (Harper & Lund, 1990). One way to examine the role that a particular context may play in caregiver outcome variables is to analyze samples in which certain characteristics, such as caregiver gender, relationship to patient, and residential location, are the same. This avoids the problem of “noncomparability of samples” that arises when researchers attempt to compare, for example, Black and White dementia caregivers without statistically controlling for relationship to patient (Janevic & Connell, 2001). In this way it is possible to examine the factors that impact caregiver burden, psychosocial resources, and outcome for a particular context by isolating this subgroup from a larger sample, e.g., daughter caregivers who live with the dementia patient.

There has not been an examination of a national multi-ethnic population of daughter caregivers in which work, changes in work due to caregiving, resources and leisure activities has been the focus. For example, younger dementia caregivers, usually middle-aged and more likely to be daughters than spouses, are 68% more likely than caregivers of other older people to reduce their working hours or quit work (2009 Alzheimer’s Facts and Figures, Alzheimer’s Association). At the same time, middle-aged caregiving women have reported having positive feelings towards employment, which has been related to a lower incidence of depression (Christensen, Stephens, & Townsend, 1998). There has been a gap in the literature regarding how employment and work disruptions may impact the mental health of dementia caregivers via

hypothesized reductions of psychosocial resources. This dissertation proposes to fill that gap for caregiving daughters who live with a parent with dementia.

### *Definition of terms*

*African American* refers to a person of African descent residing in the United States, or someone who self-identifies as such. It may be used interchangeably with the descriptor *Black*.

*European American* refers to a person of European descent residing in the United States for multiple generations. It may be used interchangeably with the descriptors *White non-Hispanic*, *Anglo American*, and *Caucasian*.

*Caregiver (CG)* refers to an individual who provides care for a frail elder. For the purposes of this dissertation, the term will refer to a person who provides assistance and care for an elder with dementia.

*Daughter* in this dissertation will include not only female children of an elder with dementia but also any other person with whom they have a filial relationship, e.g., step-daughter, daughter-in-law, or grand-daughter.

*Care recipient (CR)* refers to a frail elder who requires assistance with personal care tasks (activities of daily living or ADLs) such as grooming, bathing, dressing, and transferring on and off the toilet, and other basic tasks of daily living (instrumental activities of daily living or IADLs), such as cooking, shopping, bill paying, transportation. For purposes of this dissertation, the term will refer to a dementia patient who is the parent, step-parent, parent-in-law, or grandparent of the caregiver.

The terms “leisure activities” and “pleasant events” are used interchangeably.

## *Variables*

### *Caregiving Contextual Variables*

Caregiver Age  
 Caregiver Education  
 Caregiver Race  
 Caregiver Physical Health  
 Years of Caregiving

### *Primary Stressor Variables*

Caregiver Employment  
 Caregiver Work Disruption

### *Role Strain Variable*

Caregiver Perceived Financial Strain

### *Psychosocial Resource*

Pleasant Events

### *Caregiver Outcome Variables*

Positive Affect towards Caregiving  
 Caregiver Depression

## *Research Design*

This study is a cross-sectional design that extracts a specific group, daughter caregivers, from a dataset that gathered quantitative data from dementia caregivers at six research sites across the nation. The purpose of this study is to examine how employment, work disruption and subsequent financial strain affect caregiver's leisure

activities and mental health according to Pearlin's stress and coping model among dementia caregiving daughters. The purposes of this study are:

1. to explore the patterns and context of employment, work disruption, and mental health among dementia caregiving daughters;
2. to examine the patterns and context of engagement in leisure activities among dementia caregiving daughters according to employment status and work disruption;
3. to discover the context and extent to which work disruption influences mental health through hypothesized reductions in financial resources and leisure activities.

### *Specific Aims and Hypotheses*

*Specific Aim #1:* to understand the patterns and context of employment and work disruption among dementia caregiving daughters and to determine the extent to which work status and work disruption have direct relationships to the mental health of dementia caregiving daughters. See Figure 2 on the next page for hypothesized relationships between the variables.

*The first hypothesis for this aim* is that employment will be associated with younger, healthier caregivers who have been caring for less ADL impaired care recipients for a shorter amount of time.

*The second hypothesis for this aim* is that work disruption will be associated with minority caregivers with lower education and who are caring for more ADL impaired care recipients.

*The third hypothesis for this aim* is that employment status and work disruption will be associated with negative impacts on mental health.

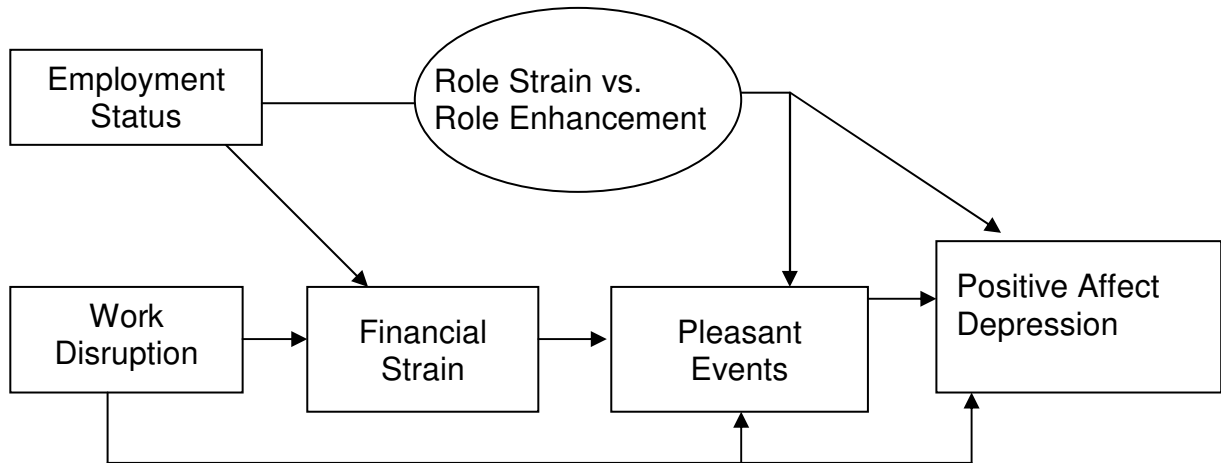


Figure 2. Model of how employment and work disruption may impact caregiver mental health in the stress and coping model

*Specific Aim #2:* to examine the patterns and context of engagement in leisure activities among dementia caregiving daughters according to employment status and work disruption and to determine if engaging in pleasant events has a relationship with caregiver mental health. See Figure 2 above for hypothesized relationships between the variables.

*The first hypothesis for this aim* is that married caregivers who are healthier and caring for less ADL impaired care recipients with more financial resources and less work responsibilities (e.g., part-time rather than full-time work) will display more engagement in leisure activities.

*The second hypothesis for this aim* is that less healthy caregivers whose work is disrupted and who care for more ADL impaired care recipients will have decreased participation in leisure activities.

*The third hypothesis for this aim* is that engagement in pleasant events will be associated with better mental health.

*Specific Aim #3:* to discover the context and extent to which work disruption influences caregiver mental health through hypothesized reductions in financial resources and leisure activities. See Figure 1 for hypothesized relationships between the variables.

*The hypothesis for this aim* is that work disruption and financial strain will be related to less engagement in leisure activities and that this will be associated with increased depression and less positive affect for caregiving in the context of the stress and coping model.

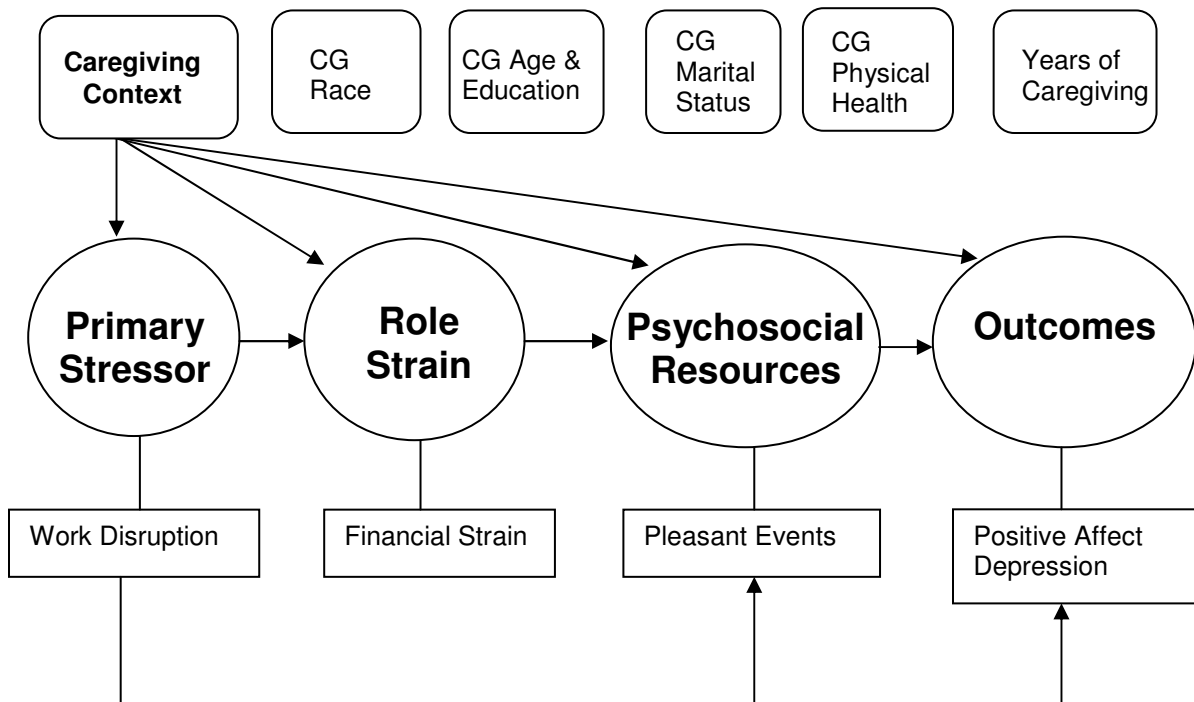


Figure 1. Stress and coping model for present study



## CHAPTER 3

### Method

#### *Participants*

Data were drawn from a secondary dataset obtained from the Interuniversity Consortium for Political and Social Research: the Resources for Enhancing Alzheimer's Caregiver's Health (REACH), 1996 – 2001 (Schulz, 2001). The REACH study was a multi-site research program sponsored by the National Institute of Aging (NIA) and the National Institute on Nursing Research (NINR) of the National Institutes of Health (Wisniewski, et al., 2003). Data were obtained from six sites, namely, Birmingham (AL) Boston (MA), Memphis (TN), Miami (FL), Palo Alto (CA), and Philadelphia (PA). The primary purpose of REACH was to conduct social and behavioral research on a variety of interventions in hopes of enhancing outcomes for family caregivers of patients suffering from Alzheimer's disease and related disorders. Because African American and minority family caregivers were often not included in research on family caregiving, a special effort was made to recruit minority candidates.

To be eligible for the REACH study, a participant had to be an adult caregiver at least 21 years of age who lived with and provided four or more hours of daily care to a family member suffering from impairment to at least two instrumental activities of daily living (IADL) or one activity of daily living (ADL) (Katz, Ford, Moskowitz, Jackson & Jaffe, 1963; Lawton & Brody, 1969). Care recipients needed to have either a diagnosis of Alzheimer's disease or related disorder (ADRD) or a recent Mini-Mental State Examination (MMSE) score less than or equal to 23 out of 30 (Folstein, Folstein & McHugh, 1975). In addition, the caregiver had to be in the caregiving role at least 6

months, to be reachable by telephone, and to be planning to stay in the area for the duration of the study (Wisniewski, et al., 2003). Exclusion criteria for care recipients were being bed bound and having an MMSE score of zero (Schulz, 2001). Also excluded from the Reach study were family caregivers who were involved in another caregiver intervention study, had an illness that would prevent them from participating for at least six months, were planning to move in the next six months, did not have a telephone, or did not speak the language required by the recruitment site (either English or Spanish) (Wisniewski, et al., 2003). For the purposes of the current study, only female caregivers who had a filial relationship with the care recipient, namely, daughters, step-daughters, daughters-in-law, and granddaughters were included in the study sample (n = 486).

### *Procedure*

In the current study participants were recruited from a variety of community sites, such as memory disorder clinics, primary care clinics, social service agencies and physician's offices. Potential participants were initially interviewed at each site using a common set of screening questions. After obtaining informed consent from those who were eligible, caregivers were administered the core battery of measures and then were randomly assigned to an intervention condition. All caregivers were read the questions of the core battery out loud in a one-on-one setting. Response cards were also provided to show respondents the choices for each question or set of questions (e.g., "never," "seldom," "sometimes," "often," "very often," "always"). Interventions were different at each site. The current project utilized only core battery interviews obtained

at baseline before any intervention occurred. Detailed information about the REACH study design and recruitment strategies was reported by Wisniewski and colleagues (2003).

### *Measures*

*Caregiver physical health.* Physical health burden of caregivers was assessed by asking caregivers “Do you currently have, or has a doctor told you that you have, any of the following health problems?” for seven chronic illness categories: arthritis, hypertension, heart condition (e.g., angina, heart attack, congestive heart failure, and atherosclerosis), chronic lung disease (e.g., asthma, emphysema), diabetes, cancer, and stroke. Next the caregivers were asked if they had experienced dizziness, headaches, or stomach/bowel problems in the last two weeks. All “yes” answers were given one point and the score was summed (Posner, Jette, Smith, & Miller, 1993).

*Care recipient characteristics.* In the current study, care recipient ADLs (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) were used to measure the objective stressors of the caregivers. There were seven items to assess ADLs that pertain to the care recipient’s ability to perform day-to-day personal care tasks such as grooming, bathing, dressing, and transferring on and off the toilet. If the caregivers reported that the care recipients needed help with the activity and that the caregiver provided the help, a score of 1 was given to that item. The more ADL tasks the caregiver provides for the care recipient, the higher their score on this scale.

*Work disruption.* The assessment of changes in employment began with the question: “Have you had to reduce the number of hours that you work in an average week in order to provide care to (Care Recipient)?” (note: interviewers were expected to

insert the name of the care recipient (CR) in the question and not repeat the formal term “care recipient”). If the caregiver responded in the affirmative, then the respondent was asked, “How many hours have you had to reduce per week?” and this time was recorded in hours. Next the caregiver was asked, “Did you stop working because of (CR)'s need for care?” Employment disruption was recorded as 1 if the caregiver reduced work less than or equal to the median number of hours, 2 if the caregiver reduced work more than the median number of hours, and 3 if the caregiver stopped working due to caregiving responsibilities.

*Financial strain.* Respondents were asked “How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is not difficult at all, not very difficult, somewhat difficult, or very difficult?” The choices provided on the response card were: “not difficult at all” (score = 0), “not very difficult” (score = 1), “somewhat difficult” (score = 2), and “very difficult” (score = 3). The higher the score, the greater the financial burden.

*Pleasant events.* Seven items were suggested by the REACH investigators to assess for pleasant activities that caregivers could be involved in, such as “having quiet time for yourself,” going out for meals,” “doing fun things with other people,” and “taking part in hobbies.” Each item was rated on a three-point scale from “not at all” (score = 0), “a little” (score = 1), to “a lot” (score = 2). Higher scores indicated greater participation in these leisure activities.

*Outcomes: caregiver positive affect and negative affect.* Positive affect was assessed using a measure that is a modified version of an instrument developed by Schulz and colleagues (1997), one of the principal investigators of the REACH study,

the Positive Aspects of Caregiving (PAC). PAC is an 11-item measure that assessed a caregiver's perception of the desirable aspects of providing care for the care recipient. Caregivers were asked to rate how much they agreed or disagreed with statements such as "Providing help to [Care Recipient] has made me feel useful," or "made me feel good about myself," or "enabled me to appreciate life more." Responses ranged from "disagree a lot" (score = 1) to "agree a lot" (score = 5) and higher scores indicate greater amount of positive affect towards caregiving. Psychometric Analyses of the PAC in the entire REACH sample (n = 1,229) resulted in a Cronbach's alpha of .88 (Tarlow, Wisniewski, Belle, Rupert, Ory, & Gallagher-Thompson, 2004).

Caregiver negative affect will be assessed using the Center for Epidemiological Studies – Depression (CES-D) measure (Radloff, 1977). The CES-D is a 20-item scale that asks the caregiver to rate the frequency of each symptom on a scale from "rarely" (score = 0) to "most of the time" (score =3). Examples of items include "I felt that I could not shake off the blues, even with help from my family and friends," "I felt that everything I did was an effort," as well as reverse coded items such as "I felt hopeful about the future." The higher the CES-D score, the more severe the depression. Although the CES-D cannot be used to diagnose depression, a score of 16 is generally viewed as being at risk for clinical depression; the average score of the entire REACH sample was 15.4 with a large standard deviation of 11.5 (Wisniewski, et al., 2003). For the REACH sample, Cronbach's alpha for the CES-D has been reported as .86 (Burgio, Stevens, Guy, Roth, & Haley, 2003).

## *Statistical Analyses*

### *Hypotheses #1*

The first set of hypotheses are

- 1) that employment will likely be associated with younger, healthier caregivers who have been caring for less impaired care recipients for a shorter amount of time;
- 2) that work disruption will be associated with minority caregivers with lower education who are caring for more impaired care recipients; and
- 3) that employment status and work disruption will be associated with direct negative impacts on mental health.

To analyze these initial hypotheses, a bivariate correlation analysis was conducted of all the variables (e.g., marital status, race, and employment will be dummy coded). Next the sample was divided between the caregivers who have experienced work disruption and those who have not and chi-square and one-way ANOVA analyses (with LSD post-hoc) was used to test for significant differences between caregivers of difference employment status on the variables of interest in the stress and coping model. Next, the caregivers were divided into three groups (disrupted work, employed with no disruption, and not employed) and chi-square and one-way ANOVA analyses were used to test for significant differences the variables of interest in the stress and coping model. Fisher's 'least significant difference' (LSD) post-hoc tests was used to

test for differences between groups when the ANOVA analysis yields a significant result. Specifically , one-way ANOVAS (with LSD post-hoc tests) was used to test for significant differences in demographics of age, education, physical health status, and years of caregiving. Chi-square analyses examined differences between race and marital status. A more conservative  $p$  value of .01 will be used to control for Type 1 error, although  $p$  values of .05 or .06 may be considered a trend.

### Hypotheses #2

The second set of hypotheses are:

1. that married caregivers who are healthier and caring for more functional care recipients with more financial resources and less work responsibilities (e.g., part-time rather than full-time work) will display more engagement in leisure activities;
2. that less healthy caregivers whose work is disrupted and who care for more impaired care recipients will likely have decreased participation in leisure activities; and
3. that engagement in leisure activities will be associated with better mental health.

A median split of leisure activities was done with Independent Samples  $t$ -tests and chi-square analyses performed on all relevant background variables to determine the characteristics associated with high leisure and low leisure activities. Caregivers who have experienced work disruption were examined separately from the caregivers who have not experienced work disruption and each was analyzed by employment status to separate the influence of work disruption and employment status on this

variable. Caregiver mental health variables were included in this analysis. A more conservative  $p$  value of .01 was used to control for Type 1 error, although  $p$  values of .05 or .06 may be considered a trend.

### Hypotheses #3

The final hypothesis is that work disruption and financial strain will be related to reduction in leisure activities which will be associated with increased depression and less positive affect for caregiving in the context of the stress and coping model.

Increased work disruption will likely be directly related to more negative affect and less positive affect and indirectly through reductions in financial resources and pleasant events. Path Analysis using LISREL 8.5 was conducted to determine if the path from work disruption is related to caregiver mental health in the hypothesized directions via reductions in financial resources and pleasant events. Two separate paths were used for each outcome variable, e.g., positive affect and negative affect. Because the path model did not display adequate fit, hierarchical regression analyses were performed with the mental health variable (positive affect or depression) with work disruption being entered as Step 1, financial strain as Step 2, and leisure activities as Step 3 and the mental health variables being the dependent variables. Background and control variables were added to further refine the model. A more conservative  $p$  value of .01 was used to control for Type 1 error, although  $p$  values of .05 or .06 may be considered a trend.





## CHAPTER 4

### Results

#### *Descriptives*

The sample is less than half White Non-Hispanic (44.9%) and roughly evenly divided between African American (29.8%) and Latino daughter caregivers (24.3%). The average age of the caregiving daughters is 51.8 years (SD = 10.09 years) with a range from 19 to 79 years. Approximately the same amount of caregivers was unmarried (53.6% are single, widowed, separated, or divorced) and married or living with a partner (46.4%) and most have some college education (63.7%). Average caregiver education is 13.1 years (SD = 2.5 years). No differences were found between ethnic groups (White vs. minority) for marital status (married vs. unmarried) ( $p > .05$ ), yet more specific analyses revealed that Latinos are more likely to be married and African American caregivers were more likely to be single ( $\chi^2 = 11.81$  (2,  $n = 480$ ),  $p < .01$ ).

Approximately one quarter of the sample was in the first year of caregiving and over half are in the first 3 years of caregiving (56.9%). The vast majority of the caregivers were daughters (91.4%), with 5.5% being daughters-in-law, and 3.1% granddaughters. Likewise, most caregivers were caring for their mothers, mothers-in-law, or grandmothers (85.2%), rather than their fathers, fathers-in-law, or grandfathers (14.8%). The median household income was \$30,000 to \$39,000, with a normal distribution across all categories. The care recipients' average age was 81.4 years (SD = 8.3 years) with the oldest care recipient being 101 years. All (100%) of the caregivers lived with the care recipients and in only 27.7% were the care recipient and caregiver

the only household residents. One-third of the sample (34.7%) had a household size of three persons and slightly more (37.6%) lived with more than three persons, with ten persons being the largest household size in the sample, including caregiver. The care recipients were quite impaired with the median number of ADL and IADL impairment was 4.0 and 7.0, respectively.

Quite a few differences were found between White and minority caregivers (e.g., African American and Latino are the represented ethnicities). Although there was no significant difference found in caregiver age, White caregiving daughters' care recipients were significantly older than minority caregivers' care recipients (82.5 years vs. 80.6 years for minorities,  $p < .01$ ). In addition, minority caregivers were significantly less educated (12.5 years of education vs. 13.7 years for Whites,  $p < .001$ ) and participated in caregiving duties for a longer amount of time (4.9 years vs. 3.7 years for Whites,  $p < .01$ ). Minority caregivers indicated more persons in the household (2.6 vs. 2.1 for Whites,  $p < .001$ ) and significantly more financial strain on a 5-point scale (2.17 vs. 2.61 for minorities,  $p < .001$ ).

### *Hypothesis #1*

The first set of hypotheses are:

- a) that employment will be associated with younger, healthier caregivers, who have been caring for less ADL impaired care recipients for a shorter amount of time;
- b) that work disruption will be associated with minority caregivers with lower education who are caring for more ADL impaired care recipients; and

- c) that employment status and work disruption will be associated with negative impacts on caregiver mental health.

*Bivariate relationships for Hypothesis #1 (a)*

Correlations between all the study variables are found in Table 1. In partial support for the first hypothesis, employment was associated with being younger ( $r = -.25, p < .001$ ) and a trend to be healthier ( $r = -.11, p < .05$ ). In addition, employed caregivers are significantly more likely to be better educated ( $r = -.18, p < .001$ ) and experience less financial strain ( $r = -.12, p < .01$ ). However, bivariate relationships between employment status and the study variables required that employment be dummy coded (e.g., 0 = unemployed, 1 = employed). In the process, the group of unemployed caregivers, e.g., homemakers, retirees, and unemployed, are grouped together and differences between these groups are lost. Therefore, a series of Chi Square (for categorical variables) and one-way ANOVAS (for continuous variables) was run to examine differences in the demographics and caregiving context by employment status (see Tables 2 and 3) to answer the first hypothesis in the set more thoroughly.

Table 1.

Correlations among Study Variables for Caregiving Daughters (n = 486)

	Employ	Work Disrupt	\$ Strain	Leisure	PA	Dep	Race	CGAge	Years CGing	CR ADLs	CG Health	CG Educ
Employed	-											
Work Disruption	-.84***	-										
Financial Strain	-.12**	.18***	-									
Leisure	.06	-.05	-.20***	-								
Positive Affect	.02	.04	.13**	.17***	-							
Depression	-.16***	.19**	.26***	-.35***	-.17***	-						
CG Race	.01	-.01	.21**	.06	.26***	.04	-					
CG Age	-.25***	.13*	-.11*	-.02	-.08	-.11*	-.07	-				
Years CG	.02	.01	.06	.05	.06	.02	.13**	.09*	-			
CR ADLs	-.05	.11	.12**	-.21***	.13**	.19***	.09*	.06	.14**	-		
CG Hlth Problems	-.11*	.09	.17***	-.18***	-.08	.48***	-.04	-.05	.01	.08	-	
CG Educ.	-.18***	-.13*	-.15***	-.13**	-.17***	-.12**	-.24***	-.16**	-.21***	-.10*	-.02	-
CG Marital	-.04	-.07	-.10*	.06	.01	-.04	.01	-.04	-.04	.01	.03	.01

Note: CG=Caregiver, CR=Care Recipient. Race, marital, and employment are dummy coded (0 = White, single, unemployed)

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

Table 2.

Caregiver Sociodemographic Characteristics by Employment Status MINUS DISRUPTED WORKERS

	Full-Time <sup>a</sup>	Part-Time <sup>b</sup>	Homemaker <sup>c</sup>	Retired <sup>d</sup>	Unemployed <sup>e</sup>	$\chi^2$ or <i>F</i> test
Caregiver Characteristic	(n = 118)	(n = 25)	(n = 59)	(n = 49)	(n = 37)	(n = 289)
<b>CAREGIVER AGE</b>						<b>21.37***</b>
Mean age	49.24	51.92	50.95	62.96	51.82	<b>(D &gt; A, B, C, E)</b>
<b>MARITAL STATUS</b>	n (expected count)		n (expected count)			<b>32.95***</b>
Married/Live With	52 (59) -	14 (13)	48 (30) +	20 (25) -	11 (17) -	<b>(C &gt; A, D, E)</b>
Single/Widow/Divorced	66 (59) +	11 (12)	11 (29) -	29 (24) +	26 (19)+	<b>(A, D, E &gt; C)</b>
<b>RACE</b>	n (expected count)		n (expected count)			15.12 ( <i>p</i> = .057)
White	51 (53)	10 (11)	32 (26) +	18 (22)	19 (17)	(> C)
African American	36 (36)	9 (8)	10 (18) -	24 (15) +	8 (11)	(D > C)
Latina	30 (28)	6 (6)	16 (14)	7 (12) -	10 (9)	(> D)
<b>EDUCATION</b>						<b>3.05*</b>
Mean	13.39	13.24	12.02	12.61	13.05	<b>(A, B &gt; C)</b>

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001; + or - indicates more or less, respectively than predicted by null hypothesis  
3 participants did not disclose race and 1 participant did not disclose marital status.

Table 3.

Caregiving Context Characteristics by Employment Status MINUS DISRUPTED WORKERS

	Full-Time <sup>a</sup>	Part-Time <sup>b</sup>	Homemaker <sup>c</sup>	Retired <sup>d</sup>	Unemployed <sup>e</sup>	$\chi^2$ or <i>F</i> test
CG Context Characteristic	(n = 118)	(n = 25)	(n = 59)	(n = 49)	(n = 37)	(n = 289)
<b>AGE OF CARE RECIPIENT</b>						<b>5.41***</b>
Mean age	79.97	80.52	80.42	85.69	82.61	<b>(D &gt; A, B, C,)</b>
<b>ADL IMPAIRMENT OF CARE RECIPIENT</b>						0.61
Mean ADLs	3.77	3.72	4.05	4.12	3.42	n.s.
<b>YEARS OF CAREGIVING</b>						0.48
Mean # of years	4.51	5.00	3.83	4.00	3.87	n.s.
<b>PHYSICAL HEALTH OF CAREGIVER</b>						<b>5.68***</b>
Mean # Conditions	2.10	1.68	2.63	2.51	3.32	<b>(C &gt; A*,B*)</b> <b>(E &gt; A***,B***,D*)</b>
<b>HOUSEHOLD SIZE (EXCLUDING CAREGIVER)</b>						<b>7.35***</b>
Mean # of people	2.45	2.36	3.07	1.92	1.97	<b>(C &gt; A, B, D, E)</b>
<b>INCOME</b>						<b>10.24***</b>
Mean Category	5.50	4.28	4.54	2.94	3.18	<b>(A &gt; B*,C*,D***E***)</b> <b>(B &gt; D*) (C &gt; D**,E*)</b>

\*p &lt; .05, \*\*p&lt;.01, \*\*\*p&lt;.001

*Employment Status: Demographic and Caregiving Context Analysis*

Only the caregivers who did not report disrupted work were considered for the employment status analysis because it would be impossible to differentiate the impact of employment vs. work disruption if the groups were combined. Of the 486 filial caregivers in the sample, 197 (41%) reported that they have reduced hours (105 caregivers) or quit working (92 caregivers) due to caregiving responsibilities. The disrupted workers were fairly evenly distributed in all the employment categories, e.g., part-time workers, homemakers, retired, etc. Approximately, one-third or more of each of these groups experienced work disruption due to caregiving that required them to reduce their hours or quit working altogether: full-time workers (n = 58, 33.0%), part-time workers (n = 47, 65.3%), homemakers (n = 32, 35.2%), retirees (n = 30, 38.0%), and even the unemployed (n = 30, 44.1%).

Of the remaining 289 caregiving daughters, approximately half (n = 143, 49.5%) were employed (118 full-time and 25 part-time) and the rest of the sample identified as homemakers (n = 59, 20.4%), retired (n = 49, 17.0%), or unemployed (n = 38, 13.1%). See Table 2 for details of caregiver demographics broken down into five employment status groups: full-time employees (n = 118), part-time employees (n = 25), homemakers (n = 59), retirees (n = 49), and the unemployed (n = 38).

Not surprisingly, retired caregivers were on average about 10 years older (61.6 years on average) than other employment status groups, i.e., employed caregivers average age was 49.24 years ( $F = 21.73, p < .001$ ). Regarding marital status, housewives were significantly more likely to be married and the full-time workers, retirees, and unemployed were significantly more likely to be single ( $\chi^2 = 32.95, p <$



.001). There was a trend for White non-Hispanic caregivers to be housewives, African American caregivers to be retired rather than homemakers, and Latina caregivers were less likely to be retired ( $\chi^2 = 15.12, p = .057$ ). Education also displayed a trend for employed caregivers being significantly better educated (13.31 years for combined full-time and part-time workers) than the homemaker caregiver groups (12.02 years) ( $F = 3.05, p < .05$ ).

Caregiving context variable details by employment status can be found in Table 3. Not surprisingly, the retired caregivers had care recipients who were significantly older (85.7 years) compared to the employed (80.2 years), unemployed (82.6 years) or homemaker group (80.4 years) ( $F = 5.41, p < .001$ ). However, the employment status groups did not differ significantly in the level of ADL impairment of the care recipient and the years of caregiving provided.

There was a trend for caregiving housewives to have more physical health problems than the full-time working (LSD = .62,  $p = .02$ ) and the part-time working (LSD = .95,  $p = .02$ ) caregivers and for unemployed caregivers had more health problems than retired caregivers (LSD = .81,  $p = .03$ ); however, the unemployed were also found to have significantly more health problems than part-time employed (LSD = 1.31,  $p < .001$ ) and full-time employed (LSD = 1.67,  $p < .001$ ) caregivers ( $F = 5.68, p < .001$ ). The homemakers were found to have significantly more people living in the household (3.07) than those who are employed full-time or part-time (2.4), are retired (1.92), or unemployed (1.97) ( $F = 7.35, p < .001$ ). The caregivers who were employed full-time, part-time, or homemakers who are likely reliant on a spouse's salary, had significantly higher income than the retired and unemployed groups ( $F = 10.24, p < .001$ ).

### *Hypothesis 1(a) Summary*

In summary, employed caregivers were significantly younger than retired caregivers, but the employed were not any younger than the unemployed or homemaker caregivers. Employed caregivers were healthier than unemployed caregivers and there was a trend for them to be healthier and better educated than homemaker caregivers. Employed caregivers provided care for a similar amount of time as non-employed or retired caregiving daughters, and their care recipients were no different in terms of level of impairment than the care recipients of the three other groups of caregivers, i.e., homemakers, retirees, and the unemployed. African American caregivers were more likely to be retired than homemakers; Latina caregivers were less likely to identify as retired.

### *Bivariate relationships for Hypothesis #1(b)*

Correlations between level of work disruption and the other variables in the study are found in Table 1. A trend was shown for level of work disruption to be associated with caregiver educational level ( $r = -.25, p < .05$ ). Little evidence is shown for work disruption being related to minority status and increased ADL impairment in the care recipient, however, work disruption was unsurprisingly related to financial strain ( $r = .18, p < .001$ ).

### *Work Disruption: Demographics and Caregiving Context Analysis*

A series of chi-square (for categorical variables) and one-way ANOVAS (for continuous variables) were run to examine differences in the demographics and

caregiving context by work disruption. The three groups being compared were: caregivers whose work was disrupted by caregiving and had to reduce hours or quit work altogether ( $n = 197$ ), caregivers whose work schedule has remained unchanged ( $n = 143$ ), and caregivers who were not employed prior to taking on caregiving responsibilities ( $n = 146$ ).

There was a trend for the unemployed group, which included the retired caregivers, to be younger than those caregivers who were employed or reported employment disrupted ( $F = 3.91, p < .05$ ), but there was no significant difference in age between the employed and those whose employment was disrupted. Likewise, the caregivers who were employed or had disrupted work were both more educated than the not working group ( $F = 5.8, p < .01$ ). Caregivers with disrupted employment also displayed a trend to be single and the caregivers who were not working displayed a trend to be married ( $\chi^2 = 6.46, p < .05$ ). There were no significant differences between the three levels of employment for the number of years spent caregiving or in ethnicity. This was true whether the racial groups were run separately (White vs. African American vs. Latino) or if they were coded dichotomously (White vs. Minority status). Unsurprisingly, employed caregivers reported significantly higher income than the disrupted workers or unemployed groups ( $F = 13.47, p < .001$ ).

Additional variables of interest in the stress and coping model were analyzed and are reported in Table 5. No differences were found between the disrupted, employed, and not employed groups in level of ADL impairment of the care recipient, mean number of leisure activities, or positive affect for caregiving. However, there were differences in the number of health conditions of the caregivers among these groups

and the not employed caregivers reported the most chronic health conditions ( $F = 7.96$ ,  $p < .001$ ). The not-employed had significantly more health problems than the employed caregivers (LSD = .816,  $p < .001$ ) with a trend to have more than the disrupted workers (LSD = .437,  $p = .02$ ). A trend was also found for caregivers with work disruption to have more physical health conditions than the employed group (LSD = .379,  $p = .02$ ).

### *Hypothesis 1(b) Summary*

To summarize, contrary to hypothesis, caregivers who experienced work disruption were virtually the same age, ethnicity, and education level as those who did not experience work disruption. However, both employed caregivers and those who experienced work disruption were significantly younger and better educated than those caregivers who were not employed, e.g., retirees, homemakers, and unemployed. Caregivers with disrupted work were somewhat more likely than the employed group to be single, tended to have more physical health problems, and not surprisingly, were in a significantly lower income category than the employed caregivers.

Table 4.

Stress and Coping Variables by Employment Status MINUS DISRUPTED WORKERS

	Full-Time <sup>a</sup>	Part-Time <sup>b</sup>	Homemaker <sup>c</sup>	Retired <sup>d</sup>	Unemployed <sup>e</sup>	$\chi^2$ or <i>F</i> test
CG Context Characteristic	(n = 118)	(n = 25)	(n = 59)	(n = 49)	(n = 37)	(n = 289)
FINANCIAL STRAIN						<b>2.91*</b>
Financial Strain	2.12	2.68	2.39	2.39	2.61	<b>(B &gt; A)(E &gt; A)</b>
PSYCHOSOCIAL RESOURCE						1.59
Mean Leisure Activities	5.97	6.76	6.19	5.14	5.37	n.s.
POSITIVE AFFECT FOR CAREGIVING						2.27, ( <i>p</i> = .063)
Mean Positive Affect	42.16	41.96	41.37	41.15	36.59	(A**,B*,C*,D* > E)
DEPRESSION						<b>7.34***</b>
Mean Depression	12.48	15.32	17.78	13.06	23.05	<b>(C &gt; A**,D*,E*) (E &gt; A***,B**,C*,D***)</b>
Clinical Depression						<b>21.87***</b>
% Below Cut-Off <sup>1</sup>	103 (98)	21 (21)	49 (49)	45 (41) +	22 (31) -	<b>(A, D &gt; E)</b>
% Above Cut-Off <sup>1</sup>	15 (20) -	4 (4)	10 (10)	4 (8) -	16 (6) +	<b>(E &gt; A, D)</b>

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001; + or - indicates more or less, respectively than predicted by null hypothesis

<sup>1</sup> Cut-Off refers to the cut-off score for clinical depression

### *Bivariate relationships for Hypothesis #1(c)*

Correlations between level of work disruption and the other variables in the study are found in Table 1. The level of work disruption did not have a direct relationship with level of positive affect for caregiver, although it did have a significant relationship with depression ( $r = .19, p < .01$ ) in the expected direction.

### *Employment Status, Work Disruption and Mental Health*

For caregivers who did not report work disruption from caregiving, homemakers and the unemployed reported significantly more symptoms of depression ( $F = 7.34, p < .001$ ) than employed or retired caregivers. See Table 4 for details. Chi-square analyses were run to determine if employment status increased risk of scoring below or above the cut-off for depression (range 0 – 56, 28 is cut-off score for clinical depression on CES-D). Caregivers who are employed full-time and retired caregivers were the most likely to score below the cut-off for depression and the unemployed were the least likely ( $\chi^2 = 21.87, p < .001$ ). The unemployed were the most likely to score above the cut-off for depression.

Table 5 provides details of the analyses of the same variables for work disrupted vs. not disrupted caregiver comparisons. When the caregivers with work disruption were compared to the employed caregivers without disruption and the not employed caregivers, caregivers with work disruption were more likely to score above the cut-off for depression ( $n = 41$ , expected count for null hypothesis = 36.5) than employed caregivers ( $n = 19$ , expected count for null hypothesis = 26.5). However, these differences failed to reach significance ( $\chi^2 = 3.68, p = .159$ ). When the CES-D score

was used as a continuous variable, both the disrupted and not employed group had significantly higher depression scores ( $F = 5.99, p < .001$ ) than the employed group.

#### *Hypothesis 1(c) Summary*

To summarize, filial caregivers who had not experienced work disruption and identify as 'unemployed' or 'homemakers' were at risk of increased depression. In addition, the 'unemployed' group was at increased risk of having clinically significant levels of depression. Caregivers who experienced work disruption were also at significantly greater risk of experiencing symptoms of depression compared to those who remained employed without disruption.

Table 5.

Variables of Interest in Stress and Coping Model by Work Disruption

	Disrupted <sup>a</sup>	Employed <sup>b</sup>	Not Employed <sup>c</sup>	$\chi^2$ or <i>F</i> test
Characteristics	(n = 197, 41% of total)	(n = 143, 29%)	(n = 146, 30%)	(n = 486)
ADL IMPAIRMENT OF CARE RECIPIENT				0.62
Mean number of ADLs	4.05	3.76	3.91	n.s.
PHYSICAL HEALTH OF CAREGIVER				<b>7.96***</b>
Mean # chronic health conditions	2.33	1.95	2.77	<b>(C&gt;B*,A**)(A&gt;B*)</b>
FINANCIAL STRAIN				<b>3.9**</b>
Financial Strain (5 point scale)	2.53	2.22	2.45	<b>(A &gt; B)</b>
PSYCHOSOCIAL RESOURCE				0.85
Mean Leisure Activities	5.84	6.10	5.62	n.s.
POSITIVE AFFECT FOR CAREGIVING	42.22	42.13	40.07	2.15
DEPRESSION	16.48+	12.98-	17.57+	<b>5.99***</b>
				<b>(A, C &gt; B)</b>
	n (expected count)	n (expected count)		3.68
% Below Cut-Off for Depression	156 (161)	124 (117)	116 (119)	n.s.
% Above Cut-off for Depression	41 (37)	19 (26)	30 (27)	n.s.

\*p &lt; .05, \*\*p&lt;.01, \*\*\*p&lt;.001



## *Hypotheses 2*

The second set of hypotheses are:

- a) that caregivers who have not experienced work disruption, and who are healthier and caring for less ADL impaired care recipients with more financial resources and less work responsibilities (e.g., part-time rather than full-time work) will display more engagement in leisure activities;
- b) that less healthy caregivers whose work is disrupted and who care for more ADL impaired care recipients will likely have decreased participation in leisure activities; and
- c) that engagement in pleasant events will be associated with better mental health.

### *Bivariate relationships for Hypothesis 2 (a, b, c)*

The caregiver's ability to engage in pleasant events was associated with ADL impairment of care recipient ( $r = -.21, p < .001$ ) and the caregiver's number of physical health conditions ( $r = -.18, p < .001$ ). Education was also significantly correlated to pleasant events ( $r = -.13, p < .01$ ) in such a way that higher education indicated less engagement in leisure activities. Financial strain was also indicative of less engagement in pleasant events ( $r = -.21, p < .001$ ). There was no significant relationship between leisure and being an ethnic minority, being married, caregiver age, or years of caregiving in this analysis. However,

pleasant events did have a strong association with both positive affect ( $r = .17, p < .001$ ) and depression ( $r = -.35, p < .001$ ) in the expected directions.

### *Leisure Activities and Employment Status*

To examine the impact of work status on leisure activities, a series of chi-square and *t*-tests were run on caregivers (minus caregivers whose work was disrupted) to examine differences between caregivers who were above the median or below the median in leisure activities (range 1-13, median = 5.0). See Tables 6 and 7 for details.

When considering the likelihood that caregivers with no work disruption would be in a high leisure vs. low leisure group (divided according to a median split), employment status was not significant. Other variables that did not differ between the low leisure and high leisure groups were caregiver age, marital status, race, education, age of care recipient, duration of caregiving, income, and financial strain. Physical health problems in the caregiver were significantly related to low leisure ( $F = 2.70, p < .01$ ) and there was a trend for ADL impairment in care recipient to also be related to low leisure ( $F = 2.43, p < .05$ ).

### *Hypothesis 2(a) Summary*

Among caregivers who had not experienced work disruption, employment status did not affect whether their level of engagement in leisure activities was low or high. Caregiver physical health problems were significantly related to lower engagement in leisure activities with a trend for ADL impairment of the care recipient to do likewise. No other demographic or caregiving context variable

was related to low vs. high engagement in pleasant events for caregivers who had not experienced work disruption.

Table 6.

Caregiver Characteristics that Influence Engagement in Low Leisure (Role Strain) vs. High Leisure (Role Enhancements) in NON-DISRUPTED GROUP

Caregiver Characteristics	Low Leisure <sup>a</sup> (n = 154)	High Leisure <sup>b</sup> (n = 134)	$\chi^2$ or t-test (n = 288)
CAREGIVER AGE			.45
Mean age	52.69	52.16	n.s.
MARITAL STATUS	n (expected count)		.32
Single, never married	72 (76)	71 (67)	n.s.
Married or Living together	81 (78)	63 (67)	n.s.
RACE	n (expected count)		.78
White	66 (69)	64 (61)	n.s.
African American	46 (46)	41 (41)	n.s.
Latino	39 (36)	29 (32)	n.s.
EDUCATION			.62
Years of Education	13.0	12.86	n.s.
EMPLOYMENT	n (expected count)		7.02
Full-time	64 (63)	54 (55)	n.s.
Part-time	8 (13)	17 (12)	n.s.
Homemaker	29 (31)	29 (27)	n.s.
Retired	29 (26)	20 (23)	n.s.
Unemployed	24 (20)	14 (18)	n.s.

\*p < .05, \*\*p<.01, \*\*\*p<.001; NOTE: 1 participant was missing pleasant events total. 3 participants did not disclose race; Column for employment does not equal 154 due to rounding of expected count values.

Table 7.

Caregiving Context Characteristics that Influence Engagement in Low Leisure  
(Role Strain) vs. High Leisure (Role Enhancements) in NON-DISRUPTED  
GROUP

CG Context Characteristics	Low Leisure <sup>a</sup> (n = 154)	High Leisure <sup>b</sup>	$\chi^2$ or <i>t</i> -test (n = 288)
AGE OF CARE RECIPIENT			1.54
Mean Age of CR	82.06	80.63	n.s.
YEARS OF CAREGIVING			.43
Mean Years of Caregiving	4.34	4.11	n.s.
INCOME			0.22
Mean category	4.49	4.42	n.s.
FINANCIAL STRAIN			1.78
Financial Strain	2.43	2.22	n.s.
HOUSEHOLD SIZE (EXCLUDING CAREGIVER)			-.65
Mean # of People	2.37	2.47	n.s.
ADL IMPAIRMENT OF CARE RECIPIENT			<b>2.43*</b>
Mean number of ADLs	4.14	3.46	<b>Low Leisure</b>
PHYSICAL HEALTH OF CAREGIVER			<b>2.70**</b>
Mean # chronic health conditions	2.62	2.07	<b>Low Leisure</b>
POSITIVE AFFECT			-1.75
Positive Affect for Caregiving	40.07	42.16	n.s.
<b>DEPRESSION</b>			<b>5.09***</b>
<b>Negative Affect for Caregiving</b>	<b>18.44</b>	<b>11.64</b>	

\*p < .05, \*\*p<.01, \*\*\*p<.001 NOTE: 1 participant was missing pleasant events total.

### *Leisure Activities among Caregivers with Work Disruption*

For caregivers who had experienced work disruption, no differences were found in low vs. high leisure activities with regards to age, age of care recipient, years of caregiving, or income level. See Tables 8 and 9 for details. There were trends for those with high leisure to be married ( $\chi^2 = 3.68, p = .055$ ), an ethnic minority (African American or Latina) ( $\chi^2 = 6.41, p < .05$ ), and to have more persons in the household ( $t = -1.86, p = .06$ ). Employment status was significantly related to low vs. high leisure activities for caregivers who had experienced work disruption. Full-time workers and not employed workers were significantly more likely to be in the low leisure group and part-time workers and homemakers were significantly more likely to be in the high leisure group ( $F = 14.58, p < .01$ ). Retired workers were no more likely to be in the low or high leisure group compared to what would be expected by the null hypothesis.

Low leisure was also significantly associated with being more educated ( $F = 2.89, p < .01$ ) and a trend for being White ( $\chi^2 = 6.41, p < .05$ ). Other characteristics significantly related to low engagement in pleasant events were financial strain ( $t = 3.04, p < .01$ ), ADL impairment in care recipient ( $t = 3.52, p < .001$ ), and physical health of caregiver ( $t = 3.97, p < .001$ ).

### *Hypothesis 2(b) Summary*

For caregivers who experienced work disruption, low leisure activity engagement is associated with being better educated, working full-time or being unemployed, experiencing financial strain, poor health, and having a care recipient with high ADL impairment. There was also a trend for White caregivers

and those with fewer household members to be less engaged in leisure activities. Among caregivers with work disruption, high engagement in leisure was associated with working part-time, being a homemaker, and with a trend for being an ethnic minority living in a household with more members than the low leisure group.

### *Hypothesis 2(c) Summary*

Caregivers with low leisure activities reported more symptoms of depression ( $t = 5.35, p < .001$ ) and displayed a trend to report less positive feelings about caregiving ( $t = -2.01, p < .05$ ). See Table 9 for details. To summarize, high engagement in leisure activities was associated with less depression, and there was a trend toward more positive affect for caregiving among filial dementia caregivers.

Table 8.

Caregiver Characteristics that Influence Engagement in Low Leisure (Role Strain) vs. High Leisure (Role Enhancements) in DISRUPTED GROUP

	Low Leisure <sup>a</sup>	High Leisure <sup>b</sup>	$\chi^2$ or <i>t</i> -test
Caregiver Characteristics	(n = 100)	(n = 97)	(n = 197)
<b>CAREGIVER AGE</b>			-.10
Mean age	50.71	50.86	n.s.
<b>MARITAL STATUS</b>	n (expected count)		3.68 ( <i>p</i> = .055)
Single, never married	66 (59)	51 (58)	Low Leisure (Trend)
Married or Living together	34 (41)	46 (39)	High Leisure (Trnd)
<b>RACE</b>	n (expected count)		<b>6.41*</b>
White	52 (44) +	35 (44) -	<b>Low Leisure</b>
African American	26 (29) -	32 (29) +	<b>High Leisure</b>
Latino	19 (25) -	30 (25) +	<b>High Leisure</b>
<b>EDUCATION</b>			<b>2.89**</b>
Mean Years Education	13.74	12.81	<b>Low Leisure</b>
<b>EMPLOYMENT</b>	n (expected count)		<b>14.58**</b>
Full-time	33 (29) +	25 (29) -	<b>Low Leisure</b>
Part-time	19 (24) -	28 (23) +	<b>High Leisure</b>
Homemaker	11 (16) -	21 (16) +	<b>High Leisure</b>
Retired	14 (15)	16 (15)	n.s.
Unemployed	23 (15) +	7 (15) -	<b>Low Leisure</b>

\**p* < .05, \*\**p* < .01, \*\*\**p* < .001; + or - indicates more or less, respectively than predicted by null hypothesis; NOTE: 3 participants did not disclose race. Columns for employment does not equal total n's due to rounding of expected count values.

Table 9.

Caregiving Context Characteristics that Influence Engagement in Low Leisure (Role Strain) vs. High Leisure (Role Enhancements) in DISRUPTED GROUP

CG Context Characteristics	Low Leisure <sup>a</sup> (n = 100)	High Leisure <sup>b</sup>	$\chi^2$ or t-test (n = 197)
<b>AGE OF CARE RECIPIENT</b>			.14
Mean Age of CR	81.47	81.29	n.s.
<b>YEARS OF CAREGIVING</b>			-.42
Mean Years of Caregiving	4.23	4.98	n.s.
<b>INCOME</b>			0.39
Mean category	4.46	4.42	n.s.
<b>FINANCIAL STRAIN</b>			<b>3.04**</b>
Financial Strain	2.76	2.30	<b>Low Leisure</b>
<b>HOUSEHOLD SIZE (EXCLUDING CAREGIVER)</b>			-1.86 ( $p = .064$ )
Mean # of People	2.22	2.61	High Leisure (Trend)
<b>ADL IMPAIRMENT OF CARE RECIPIENT</b>			<b>3.52***</b>
Mean number of ADLs	4.61	3.47	<b>Low Leisure</b>
<b>PHYSICAL HEALTH OF CAREGIVER</b>			<b>3.97**</b>
Mean # chronic health conditions	2.69	1.96	<b>Low Leisure</b>
<b>POSITIVE AFFECT</b>			<b>-2.01*</b>
<b>Positive Affect for Caregiving</b>	<b>40.75</b>	<b>43.73</b>	
<b>DEPRESSION</b>			<b>5.35***</b>
<b>Negative Affect</b>	<b>20.71</b>	<b>12.12</b>	

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$



### *Hypothesis #3*

The final hypothesis is that work disruption and financial strain will be related to reduction in pleasant events and this will lead to increased depression and less positive affect for caregiving in the context of the stress and coping model.

### *Bivariate Relationships for Hypothesis #3*

Amount of work disruption was significantly correlated with financial strain ( $r = .18, p < .001$ ), which had a strong association with leisure activities ( $r = -.20, p < .001$ ). Leisure was in turn related to both positive affect and depression, as described above (see Hypothesis 2c Summary above for details), although neither work disruption nor financial strain demonstrated a direct relationship with positive affect for caregiving, as did depression.

As predicted by the literature, positive affect (PA) towards caregiving was significantly associated with being a minority ( $r = .26, p < .001$ ) and PA also had a negative association with education ( $r = -.17, p < .001$ ). Interestingly, those caregivers with the most positive affect were also more likely to have care recipients with more ADL impairments ( $r = .13, p < .01$ ), which previous research has found to be true for African American caregivers.

Symptoms of depression among filial caregivers were significantly positively related to chronic health conditions ( $r = .48, p < .001$ ), ADL impairment in care recipients ( $r = .19, p < .001$ ), and education ( $r = -.12, p < .01$ ). Not surprisingly, depression had a negative relationship with positive affect towards

caregiving ( $r = -.17, p < .001$ ) indicating that caregivers who experienced depression are least likely to experience positive feelings towards caregiving and vice versa.

#### *Analyses for Stress and Coping model for Work Disruption*

Two path analyses were conducted to determine the direct and indirect effects of level of work disruption, financial strain, pleasant events, and positive and negative affect (depression), respectively, in a sample of filial caregivers. Only those caregivers who provided information about the number of hours that their work was reduced were included ( $n = 313$ ). Additional hierarchical regression analyses were done with depression because the fit indices of the initial path analysis did not clearly demonstrate adequate fit.

#### *Positive Affect Analyses*

The model for predicting positive affect had a chi-square value that was not significant ( $\chi^2 = 3.08, p = 0.38$ ), indicating that the model should be retained over the independence model. NFI and CFI were good (.98 and .99, respectively), and the RMSEA (.01) was also good. The  $R^2$  for the positive affect outcome model was .032, indicating that 3.2% of the variance in positive affect was predicted by this model. The hypothesized path diagram with path coefficients and squared multiple correlations is shown in Figure 3. Of the 3 hypothesized paths in the structural model, all were significant. Work disruption exerted a direct effect on financial strain ( $\beta = 1.03, p < .001$ ) explaining 53% of the variance in financial strain.

Financial strain exerted a direct effect on pleasant events ( $\beta = -.63, p < .01$ ) explaining 1.3% of the variance in pleasant events. Leisure activities in turn exerted a direct effect on positive affect ( $\beta = 1.83, p < .001$ ), which explains 3.2 percent of the variance in caregivers report of positive feelings about caregiving.

Next, race was added to the model predicting positive affect to determine if it adds to the model's ability to predict positive affect towards caregiving. Race was chosen because it is the strongest predictor in the bivariate model and is correlated with the other variables that related to positive affect: education and ADL impairment in care recipient. This model for predictive positive affect had a chi-square value that was not significant ( $\chi^2 = 3.84, p = 0.28$ ), indicating that the model should be retained over the independence model. NFI and CFI were good (.98 and .99, respectively), and the RMSEA (.03) was also good. The  $R^2$  for the positive affect outcome model was .103, indicating that 10.3% of the variance in positive affect was predicted by this model.

The path diagram with path coefficients and squared multiple correlations is shown in Figure 4. Race did not have a direct effect on work disruption, however it exerted an indirect effect on positive affect through financial distress ( $\beta = .95, p = .003$ ), pleasant events ( $\beta = 5.44, p < .001$ ). Race also had a significant direct effect on positive affect ( $\beta = 112.61, p < .001$ ). The direction of these relationships indicates that although minority filial caregivers had more financial distress, they also had more pleasant events, and more positive affect than their White non-Hispanic counterparts. The model proved to be stable retaining the initial small but significant relationships of work disruption predicting positive affect through indirect

effects of financial distress and lessening of pleasant events, regardless of the race of the participant.

Figure 3.

Prediction of Positive Affect from Work Disruption, Financial Strain, and Pleasant Events.

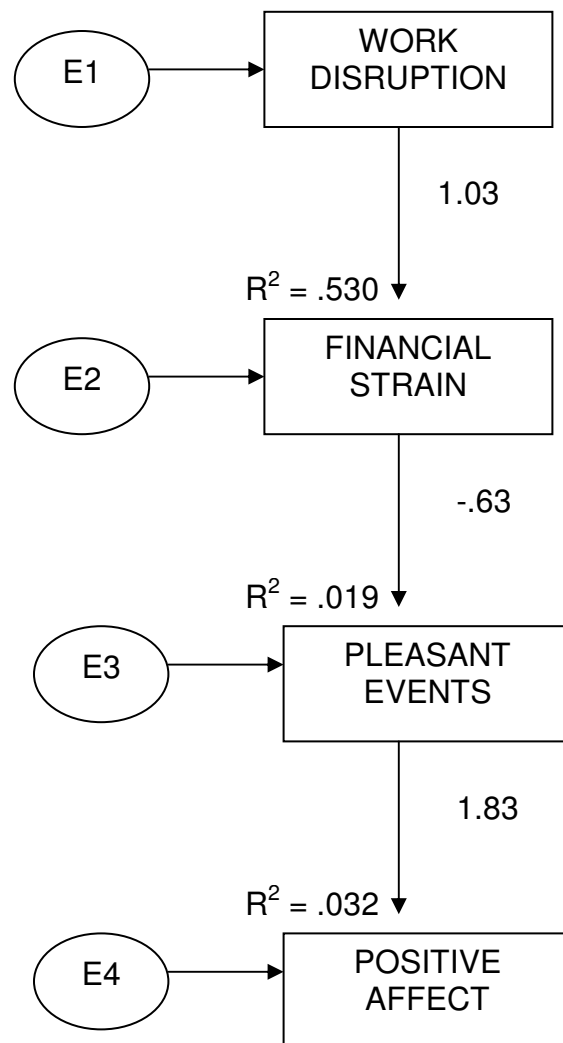
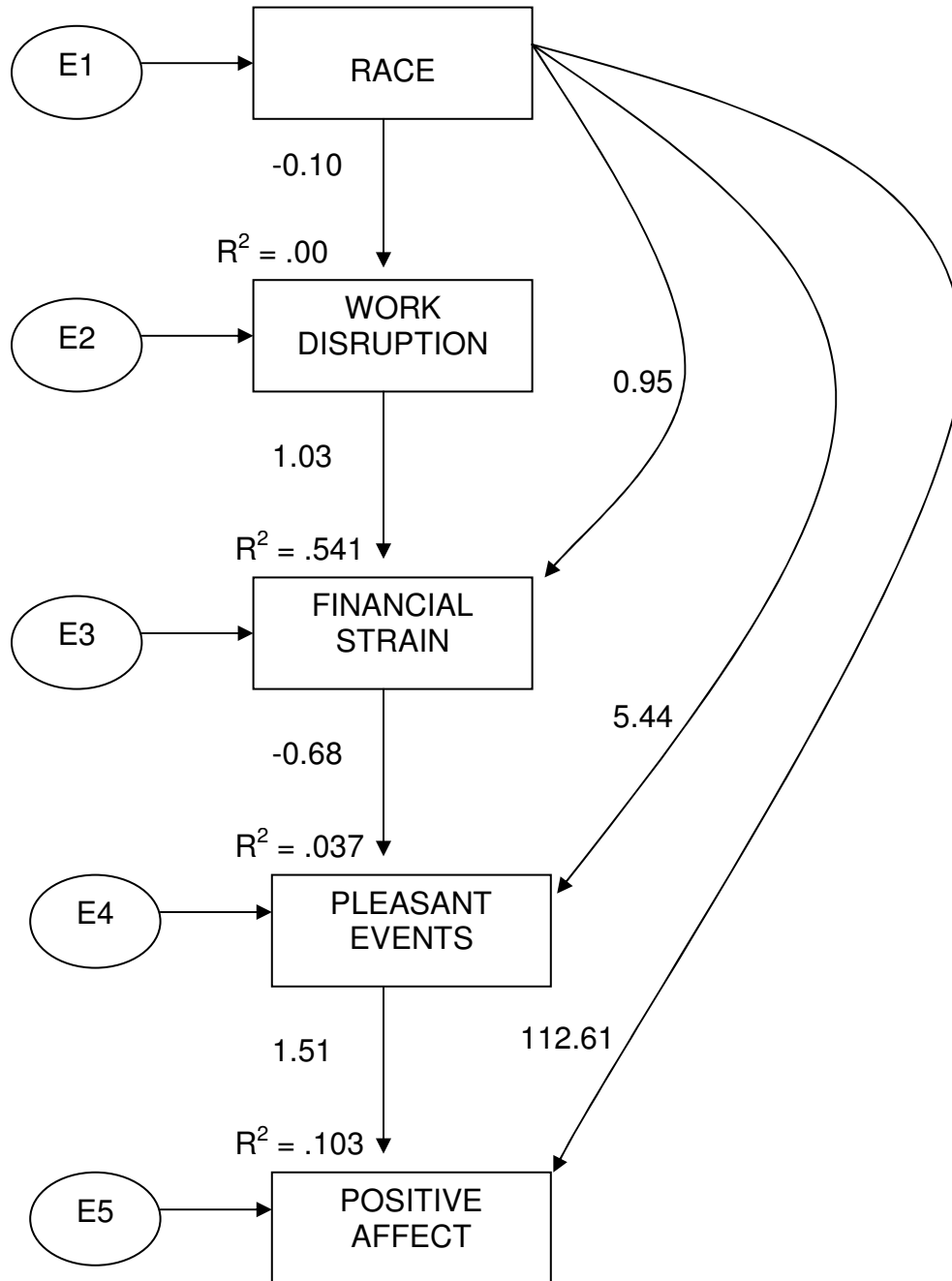


Figure 4.

Adding Race to Prediction of Positive Affect from Work Disruption, Financial Strain, and Pleasant Events.



### *Negative Affect Analyses*

The model for predicting negative affect had a chi-square value that was significant ( $\chi^2 = 21.34, p < .001$ ), which suggests poor fit. However, the critical value for N is 166, which is smaller than the actual sample size ( $n = 313$ ). In this case, the chi-square was likely significant because the sample is overpowered and this alone is not considered sufficient to reject the model. However, the NFI (.91) and CFI (.92) values were both barely greater than .90 and RMSEA (.138) was greater than .08, indicating that there is some doubt about whether this model adequately explains the relationships between the variables in this model.

The hypothesized path diagram with path coefficients and squared multiple correlations is shown in Figure 5. The  $R^2$  for the depression outcome model was .123, indicating that 12.3% of the variance in depression was predicted by this model. Of the 3 hypothesized paths in the structural model, all were significant. Work disruption exerted a direct effect on financial strain ( $\beta = 1.03, p < .001$ ) explaining 53% of the variance in financial strain. Financial strain exerted a direct effect on pleasant events ( $\beta = -.63, p < .01$ ) explaining 1.3% of the variance in pleasant events. Leisure activities in turn exerted a direct effect on depression ( $\beta = -4.61, p < .001$ ), which explains 12.3 percent of the variance in caregivers report of symptoms of depression.

Because this model displayed less than perfect fit, two hierarchical regression analyses were performed on depression to determine if the proposed model could explain a significant amount of variance in CES-D score (see Table 10 for details). Work Disruption (Step 1), Financial Strain (Step 2), and Leisure

Activities (Step 3) were the models tested. Work disruption alone accounted for 3.6% of the variance in depression ( $F = 11.82, p < .001$ ). When financial strain was added, both variables were able to account for 12.0% of the variance in depression ( $F = 30.27, p < .001$ ). When leisure activities were added, this simple model could explain 20.7% of the variance in depression ( $F = 34.86, p < .001$ ), an increase in nearly 9% of the variance.

Background variables were added from the stress and coping model to ascertain if the variables of work disruption, financial strain, and leisure activities could predict depression above and beyond caregiving context (see Table 11 for details). Caregiver race (dummy coded), age, years of caregiving, care recipient ADLs, caregiver health problems, education, and marital status were added to the model (Step One) and then the subsequent variables were added as described above.

Of the contextual variables, only two emerged as significant: care recipient ADLs and caregiver health problems, which explained 25.8% of the variance in depression ( $F = 15.54, p < .001$ ). These variables retained their significance when work disruption was added to the model and together explained 27.7% of the variance in depression ( $F = 8.12, p < .01$ ).

When financial strain was added, the significance of work disruption in the model was lowered to the .05 level, indicating partial mediation; however, CR ADLs and CG health problems retained their significance at the previous levels (.01 and .001, respectively). Adding financial strain significantly boosted the ability of the model to explain variance in depression to 30.5% ( $F = 12.23, p < .001$ ).

When leisure activities were added to the model, CR ADLs was fully mediated, and work disruption increased in significance to .01 level. The complete model explained 36.0% of the variance in depression ( $F = 26.67, p < .001$ ). The only variables that were significant were caregiver health problems ( $t = 7.83, p < .001$ ), work disruption ( $t = 2.44, p < .01$ ), financial strain ( $t = 2.46, p < .01$ ), and leisure activities ( $t = -5.16, p < .001$ ).

Subsequently, an additional path analysis was run adding caregiver physical health to the model to determine if the fit of the model would be increased. The second model for predicting depression had a chi-square value that was significant ( $\chi^2 = 13.12, p < .01$ ), which suggests poor fit. However, the critical value for N is 270, which is smaller than the actual sample size ( $n = 313$ ) indicating that the chi-square is significant due to large sample size and not necessarily lack of fit. The NFI (.96) and CFI (.97) values were improved compared to the initial model, however, RMSEA (.103) remained greater than .08, indicating that this model still has less than perfect fit.

The hypothesized path diagram with path coefficients and squared multiple correlations is shown in Figure 6. The  $R^2$  for the depression outcome model was .286, indicating that 28.6% of the variance in depression was predicted by this model. Physical health did not have a direct effect on work disruption, however it exerted an indirect effect through financial distress ( $\beta = .109, p < .001$ ), pleasant events ( $\beta = -.64, p < .01$ ) and depression ( $\beta = 19.73, p < .001$ ). The direction of these relationships indicates that filial caregivers with health problems had more financial distress, less leisure activities, and more depression than their healthier



counterparts. One key difference between the two depression models is that the path between financial strain and pleasant events was reduced to the level of a trend when physical health was added to the model ( $\beta = -.47, p = .07$ ). Thus, this model suggests that physical health and work disruption both predict depression through lessening of pleasant events, but that the physical health of the filial caregiver may play a greater role in caregiver engagement in leisure activities than financial strain.

### *Hypothesis 3 Summary*

These analyses support the hypothesis that work disruption leads to financial strain which reduces leisure activities in filial caregivers, which in turn produces lack of positive affect for caregiving and increased depression.

This model appears to be able to explain a small but significant amount of variance in positive affect and applies to both White non-Hispanic and ethnic minority caregivers (African American and Latina). However, race has a direct influence on engagement in leisure activities and positive affect, increasing both for minorities, above and beyond the influence of work disruption and financial strain.

This model can account for a large portion of the variance in depression; however, the role of financial strain in decreasing leisure activities appears to be diminished when physical health is added to the model. Although physical health is not directly related to work disruption, physical health problems in the caregiver are directly related to leisure activities and symptoms of depression, indicating that caregivers' health problems hold them back from participating in pleasant events to a greater degree than financial strain from work disruption.

Figure 5.

Prediction of Depression from Work Disruption, Financial Strain, and Pleasant Events.

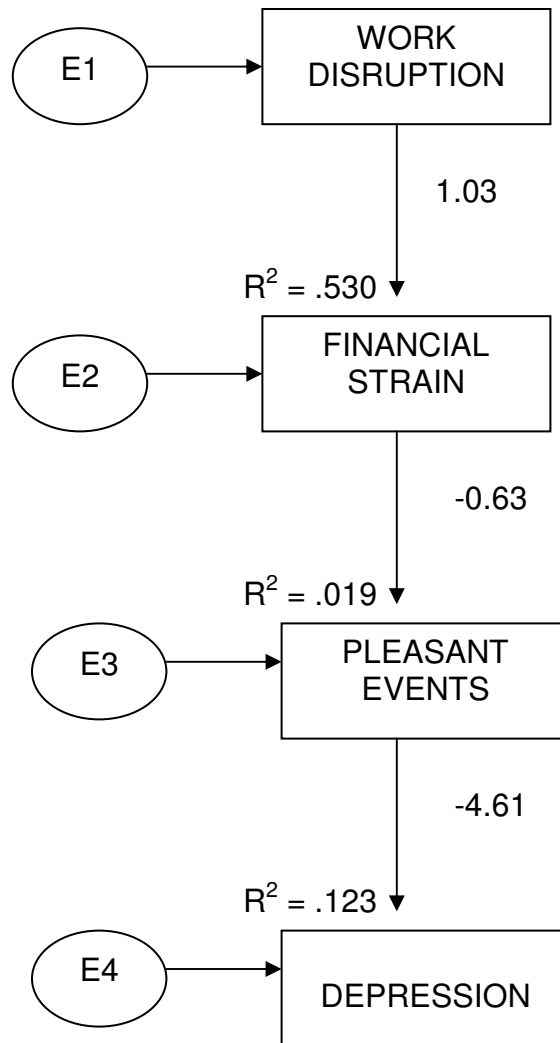


Table 10.

Hierarchical Regression Analysis for Study Variables Predicting Negative Affect (n = 319)

	Model 1			Model 2			Model 3		
	B	$\beta$	<i>t</i>	B	$\beta$	<i>t</i>	B	$\beta$	<i>t</i>
Work Disrupt	1.74	.19	3.44***	1.26	.14	2.55**	1.24	.13	2.64**
\$ Strain				3.30	.29	5.50***	2.69	.24	4.58***
Leisure Activity							-1.09	-.30	-5.91***
R <sup>2</sup>	.036			.120			.207		
F for R <sup>2</sup> change	11.82***			30.27***			34.86***		

\*p < .05, \*\*p<.01, \*\*\*p<=.001

Table 11.

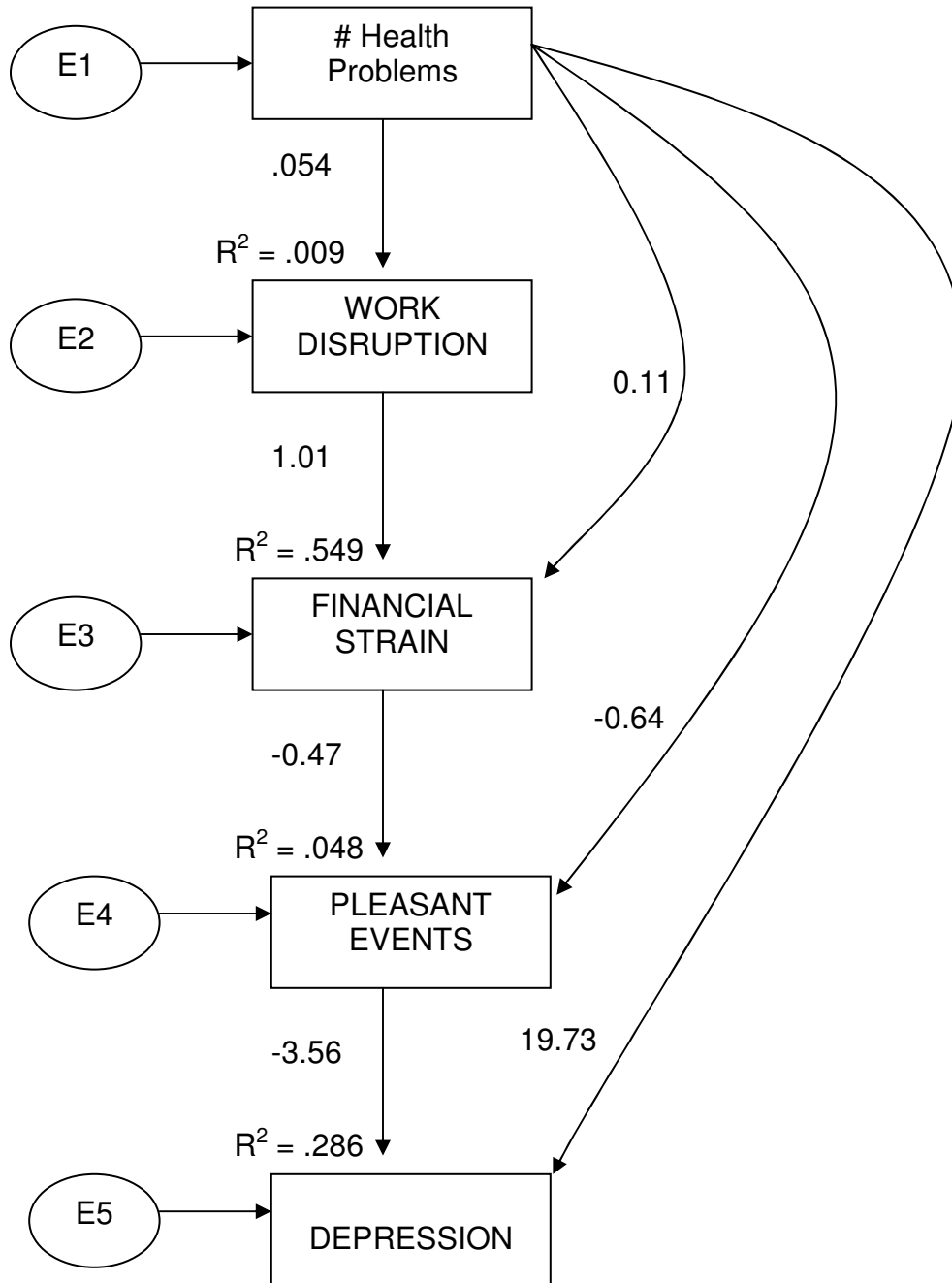
Additional Hierarchical Regression Analysis for Variables Predicting Negative Affect (n = 312).

	Model 1			Model 2			Model 3			Model 4		
	B	$\beta$	<i>t</i>	B	$\beta$	<i>t</i>	B	$\beta$	<i>t</i>	B	$\beta$	<i>t</i>
CG Race	1.22	.05	1.01	1.31	.06	1.10	.48	.02	.40	1.24	.05	1.07
CG Age	-.12	-.10	-1.92	-.14	-.11	-2.23*	-.11	-.09	-1.76	-.11	-.09	-1.09
Years CGing	-.03	-.01	-.24	-.02	-.01	-.12	-.03	-.01	-.28	.02	.01	.15
CR ADLs	.79	.16	3.22***	.72	.15	2.98**	.64	.13	2.66**	.41	.08	1.76
CG Hlth Probs	3.11	.45	9.17***	3.01	.44	8.94***	2.81	.41	8.34***	2.56	.37	7.83***
CG Education	-.35	-.07	-1.33	-.26	-.05	-.10	-.16	-.03	-.61	-.41	-.08	-1.60
CG Marital	-.90	-.04	-.79	-.69	-.03	-.61	-.30	-.01	-.27	.14	-.01	-.13
Work Disrupt				1.30	.14	2.85**	1.04	.11	2.29*	1.07	.12	2.44**
\$ Strain							2.04	.18	3.50***	1.41	.13	2.46**
Leisure										-.93	-.26	-5.16***
R <sup>2</sup>	.258			.277			.305			.360		
F for R <sup>2</sup> change	15.54***			8.12**			12.23***			26.67***		

\*p &lt; .05, \*\*p&lt;=.01, \*\*\*p&lt;=.001

Figure 6.

Adding Health to Prediction of Depression from Work Disruption, Financial Strain, and Pleasant Events.



## CHAPTER 5

### Discussion

Evidence was found that supports the importance of employment for dementia caregiving daughters who live with their care recipients. Those caregivers who were employed and whose work had not been disrupted by caregiving responsibilities were least vulnerable to depression and health problems. In contrast, the unemployed and homemakers were most vulnerable, despite being virtually the same age and having care recipients with similar levels of ADL impairment. It appears that employment plays a role in preventing role engulfment for these middle-aged filial caregivers since the difference in mental health between the employed and unemployed groups was not attributable to lack of participation in leisure activities. For homemakers, caregiver burnout is a particular risk because, in addition to their role as caregiver to a parent with dementia, they have significantly more household members to care for, most likely children.

The emotional benefits of employment, particularly for middle-aged caregivers, likely include the sense of identity and purpose work provides as well as the fact that work is a break from caregiving. Role theory provides a theoretical framework for understanding this phenomenon and posits that role identities are sources of existential meaning and behavioral guidance (Thotis, 1983; Simon, 1997 from diss). In support of this, one study found that women who combine caregiving with the multiple roles of spouse, parent, and employee, experience less distress than those with fewer roles (Dautzenberg, Kiederiks, Philipsen, & Tan, 1999) and our data support this idea. The caregivers with work disruption who had increased depression tended to be single.

However, the current study also indicates that employment alone may be a significant protective factor, regardless of marital status. It appears that middle-aged women who do not work, regardless of their status as parents or non-parents, may be at increased risk for depression when they take on the intensive role of caring for a parent with dementia.

It is somewhat counter intuitive, however, to cast employment as a “role enhancer,” rather than as a role strain. For example, some studies quoted by role theory enthusiasts have found that caregivers who work longer hours have a better sense of well-being than those who work less (Bainbridge, Cregan, & Kulik, 2006; Matire, Sepsens, & Atienza, 1997). It is important to note that these studies are epidemiological in nature to focus attention on policy decisions and are not necessarily designed to be of clinical utility. For example, one would not counsel distressed caregivers to work more hours in order to gain better well-being.

It is more likely that the caregivers who are able to work more hours are having a qualitatively different experience of caregiving than those whose work is disrupted by caregiving; for example, their experience is not necessarily defined by the length of care or ADL impairment of the care recipient. Certainly, there is a great deal of evidence that employment demands increase caregiver burden, create stress, and are related to less participation in social leisure activities (Fredriksen-Goldsen & Farwell, 2004; Glaser, Evandrou, Tomassini, 2006). In the caregiving literature, this is undoubtedly why employment is still often referred to as a role strain.

It is interesting that the retired caregivers are the only unemployed group that does not show increased symptoms of depression and they (along with the caregivers

employed full-time) are the group least likely to experience a clinical level of depression. According to the theory of role engulfment, these caregivers would be just as vulnerable to depression as the other non-employed caregivers. Additionally, the retired caregivers are just as likely to be in the low or high leisure group regardless of whether they chose retirement or were forced to retire due to caregiving responsibilities. These findings reflect the importance of age and stage of life when caring for a loved one: those who are retired or at or near retirement age are more likely to experience caregiving as expected and, according to Erikson's lifespan stages of development, to appreciate the generative aspects of this activity. Thus, our data confirm that caregiving that occurs off time is naturally more stressful and that employment status is a more useful demarcation of stress than relationship to the patient, even among a sample comprised of all filial caregivers.

In fact, for a dementia daughter caregiver, disruption of employment due to caregiving responsibilities may be considered a delineator between the role enhancement and role strain aspects of working. This type of work disruption had a high base rate, indicating how common this experience is among dementia caregivers. Over a third (41%) of the sample reported that they had reduced their hours at work or quit working due to caregiving responsibilities. Work disruption affected all employment status groups, e.g., 33.0% of full-time workers reported reducing their hours as did 35.2% of those who self-identified as homemakers but had been employed before caregiving began. Contrary to hypothesis and a previous study by Covinsky and colleagues (2001), caregivers who experienced work disruption were virtually the same age, ethnicity, and education level as those who did not experience work disruption and



they were involved in caregiving for virtually the same length of time. (Covinsky's sample was comprised of elders for caregivers, not necessarily dementia, and roughly a third of the caregivers lived with the care recipient.) In the current study, the care recipient's ADL impairment was not related to work disruption. Rather, disruption of work was directly related to financial strain, poor physical health, and increases in depressive symptoms. Of these three variables, it seems likely that financial strain and depression are consequences while physical health problems may be a contributing factor.

The current study's examination of the factors that are related to higher vs. lower engagement in pleasant events (leisure) shed additional light on the relationship of employment to lifestyle, caregiving context, and mental health. For caregivers who had not experienced work disruption, race, marital status, education, employment status did not influence leisure; only poor physical health and ADL impairment were related to low leisure activity, as was depression. However, for caregivers who had experienced work disruption, many more differences between the low vs. high leisure groups were found. Low participation in leisure activities was associated with being White (at the .05 level) and better educated, working full-time or being unemployed, and with financial strain, poor health, and greater ADL impairment of the care recipient. High leisure participation was associated with being African American or Latina, having less education, and with part-time employment, or being a homemaker. Moreover, for the disrupted workers, high leisure activity was associated with increased positive affect for caregiving and low leisure activity was related to depression.

These findings are intriguing because much has been made of ethnic minority caregivers, particularly African Americans, having more positive appraisals of and feelings towards caregiving, as well as experiencing less depression. Usually, this is attributed to their greater religiosity (Roff, et al., 2004). It appears that among caregivers experiencing work disruption, ethnic minorities, particularly those who are less educated, have a stronger tendency to maintain high levels of leisure activity than White non-Hispanic caregivers. Multiple studies have found that minority caregivers have more health problems but, to my knowledge, none has linked being a minority caregiver with the ability to integrate more leisure activities with caregiving, despite health challenges. Perhaps this speaks to a cultural flexibility that is part of African American and Latino lifestyles, despite increases in financial strain, at least among filial dementia caregiving daughters who live with their care recipients.

Physical health problems and the ADL impairment of the care recipients emerged as important variables related to low leisure participation for both sets of caregivers as well as being related to increased depression. This is not unexpected, based on previous research. It is paradoxical, however, that correlational analyses showed that ADL impairment was related to both increased positive affect and increased depression, despite having a clear negative relationship with pleasant events. This indicates that the mechanisms that lead to depression may affect caregivers in opposite ways depending on their context and that it is possible to have high positive affect for the caregiving experience while at the same time feeling depressed. In fact, for filial middle-aged caregivers whose lives are disrupted by caregiving and whose parent is functionally limited, it is likely normative.

Regression analyses for depression indicated that ADL impairment of the care recipient was moderated by physical health of the care recipient. Having more physical health problems was strongly associated with increased depression although physical health was not related to positive affect. Being a racial minority was associated with increased positive affect and did not appear to be directly related to employment status, although it did show a tendency to be related to increased pleasant events.

The final hypothesis of the study tested two path analytic models to predict positive affect and depression from a cascade of events that were hypothesized to begin with work disruption, followed by financial strain, and a decrease in leisure activity. The initial analyses of the study relied on null hypothesis significance testing (NHST), which is the methodology long popular with social scientists, but has certain limitations. Notably, statistical significance does not necessarily imply practical significance and that rejection of the null does not provide logical or strong support for the alternative (Rodgers, 2010). Therefore, it was decided to put this model to a more rigorous test.

This model appears to be able to explain a small but significant amount of variance in positive affect that is independent of racial identity. However, race has a direct influence on engagement in leisure activities and positive affect, increasing both for minorities, above and beyond work disruption and financial strain. Therefore, it is correct to say that there are other explanatory factors for high levels of positive affect of minority caregivers that lie outside of this model. Our data indicate that work disruption and financial strain play a role for some caregivers' decreases in positive affect, but other cultural factors outside of the caregiving context appear to ameliorate the negative effect

of these events. These cultural factors may also be related to high engagement of pleasant events, which our data should be explored in future studies.

The hypothesized model can account for a large portion of the variance in depression; however, the role of financial strain in decreasing leisure activities appears to be diminished when physical health is added to the model. Although physical health is not directly related to work disruption, physical health problems in the caregiver are directly related to leisure activities and symptoms of depression, indicating that caregiver health problems hold them back from participating in pleasant events to a greater degree than financial strain from work disruption. As suggested previously, it may be that physical health problems may be a determining in whether or not employment is disrupted in the first place.

Limitations to the present study are that 1) the data are not necessarily representative of the general population (i.e., reflect a non-random population of caregivers who responded to advertisements for caregiving research), and 2) that other factors that may play a role in the decision to reduce or stop working, such as available social support, level of religiosity of the caregiver, or sources of financial support other than employment were not considered. Longitudinal data would also be helpful to determine the effect that work disruption and physical health have on the ability of caregivers to respond to interventions designed to boost their respite/leisure activity participation.

Future studies may want to examine leisure activities more closely and carefully consider what caregiving contextual variables contribute to high engagement in leisure activities and what holds caregivers back. Certainly, our data indicate that financial strain

from work disruption is one such variable but that a caregiver's ability to maintain their own physical health is fundamentally important to their ability to retain their roles as caregiver and employee. Certainly, clinicians and medical professionals would benefit from understanding the link between work disruption and mental health problems, and important link between physical health problems and increased work disruption. It may be common for medical professionals to promote working less as a way to ease stress, but it may be that maintaining work, while finding more support for caregiving responsibilities and time for self-care, is in the best interest of a middle-aged caregiver's mental health.

Another important consideration is how an individual's racial identity affects their engagement in leisure events, particularly after work disruption occurs. Social flexibility and an ability to integrate caregiving responsibilities with social leisure activities are key and may be especially challenging for White non-Hispanic caregivers. Perhaps interventions that mix racial groups to share and learn about one another's lifestyles may promote such social flexibility.

These distinctions are important in designing interventions for caregivers in a variety of contexts and in acknowledging the challenge that work disruption represents for middle-aged parental dementia caregivers. Certainly, the results of this study show the importance of employment to middle-aged dementia daughter caregivers and suggest that clinical interventions designed to support caregivers in participating in the workplace while maintaining their own physical health are likely to succeed in having positive impacts on caregiver mental health and their ability to maintain their role of caregiver.

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**ABSTRACT****THE ROLE OF EMPLOYMENT STATUS, WORK DISRUPTION,  
LEISURE, AND RESOURCES IN THE  
MENTAL HEALTH OF DEMENTIA CAREGIVING DAUGHTERS**

by

**LISA J FICKER****December 2010****Advisor:** Dr. Peter Lichtenberg**Major:** Psychology (Clinical)**Degree:** Doctor of Philosophy

Employment has been consistently identified as a role strain among dementia caregivers. This study sought to examine the patterns and context of employment and work disruption among dementia caregiving daughters and learn the extent to which work disruption influences mental health through hypothesized reductions in financial resources and leisure activities. This study was a cross-sectional design that extracted data of 486 daughter caregivers from a dataset that gathered information from Caucasian, African American, and Latina dementia caregivers at six research sites across the nation.

Results indicated that caregiving daughters who were employed reported the lowest number of depressive symptoms and chronic health conditions. In contrast, the unemployed and homemakers were most vulnerable to mental and physical health problems, despite being virtually the same age, having care recipients with similar levels of ADL impairment, and similar levels of engagement in leisure activities as the employed caregivers. Work disruption

was directly related to financial strain, poor physical health, and increased depression. Work disruption had a relatively high base rate: 41% of sample reported that they had reduced or quit working due to caregiving responsibilities.

Path analyses found that work disruption, subsequent financial strain, and reduction in leisure activities explained a small but significant amount of variance in positive affect that was independent of racial identity. However, race had a direct influence on engagement in leisure activities and positive affect, increasing both for minorities, above and beyond work disruption and financial strain

The model accounted for a large portion of the variance in depression; however, the role of financial strain in decreasing leisure activities diminished when physical health was added to the model. Although physical health was not directly related to work disruption, health problems in the caregiver were directly related to leisure and symptoms of depression, indicating that caregiver health problems may prevent participating in pleasant events to a greater degree than financial strain from work disruption. This finding suggests that caregiver physical health problems may be an important factor in whether or not employment is disrupted in the first place.

**AUTOBIOGRAPHICAL STATEMENT**

LISA JONES FICKER

Lisa Jones Ficker is a graduate student in clinical psychology at Wayne State University and the 2010 recipient of the Department of Psychology's Norine Johnson Clinical Psychology Award. She received her Master's Degree in Psychology from Wayne State University and her Bachelor's Degree from Brigham Young University. Her research interests are lifespan developmental issues in families that focus on caregiving: adult daughters who care for parents with dementia, grandparents who become primary caregivers for their grandchildren, substance abuse among mothers during and after pregnancy and the effects of prenatal and postnatal drug and alcohol exposure on children. She is working as coordinator for the Lifespan Investigation of Family, Health and Environment (LIFHE) at the Merrill Palmer Skillman Institute for Children and Families, which is conducting research for and outreach to grandparents raising grandchildren. Previously, she was Lead Interventionist and Motivational Interviewer for the Fetal Alcohol Syndrome Prevention Project at the Detroit Department of Health and Wellness Promotion, funded by the Center for Disease Control.