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Dementia caregiving characteristics, elder impairment, and caregiver strain and burden

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Dementia caregiving characteristics, elder impairment, and caregiver strain and burden

by

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A thesis submitted to the graduate faculty

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TABLE OF CONTENTS

LIST OF FIGURES	iii
LIST OF TABLES	iv
ABSTRACT	v
CHAPTER 1: GENERAL INTRODUCTION	1
CHAPTER 2: REVIEW OF LITERATURE	3
CHAPTER 3: METHODS AND PROCEDURE	22
CHAPTER 4: RESULTS	31
CHAPTER 5: DISCUSSION	45
REFERENCES CITED	54
APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVED LETTER	63
APPENDIX B: CAREGIVER CHARACTERISTICS	64
APPENDIX C: BURDEN INTERVIEW	65
APPENDIX D: CAREGIVER STRAIN INDEX	68
APPENDIX E: ELDER IMPAIRMENT SCALE	70
ACKNOWLEDGEMENTS	72

LIST OF FIGURES

Figure 1. Caregiver Burden and Strain Model	20
Figure 2. Participant Flow Chart After Obtained Caregiver Subsample	23
Figure 3. Relationship Between Perceived Elder Impairment and Caregiver Burden Mediated by Caregiver Strain	44

LIST OF TABLES

Table 1. Demographics of the Caregiver	24
Table 2. Relationship Status Differences in Perceived Elder Impairment, Burden, and Strain	32
Table 3. Age Differences in Perceived Elder Impairment, Burden, and Strain	34
Table 4. Work Status Differences in Perceived Elder Impairment, Burden, and Strain	36
Table 5. Gender Differences in Perceived Elder Impairment, Burden, and Strain	37
Table 6. Correlations for Elder Impairment, Burden, and Strain	39
Table 7. Predictors of Caregiver Burden	40
Table 8. Predictors of Caregiver Strain	41
Table 9. Predictors of Caregiver Characteristics on Perceived Elder Impairment	42

ABSTRACT

This study assessed the influence of caregiver characteristics on perceived elder impairment, caregiver burden, and caregiver strain in a study of 292 dementia caregivers in Iowa. Hierarchical regression analyses evaluated caregiver characteristics as predictors of perceived elder impairment, caregiver strain, and caregiver burden. Caregiver characteristics played little role in predicting perceived elder impairment, caregiver strain, or caregiver burden. However, the perceived level of elder impairment in the care recipient was highly associated with feelings of caregiver burden and strain. Caregiver strain also significantly mediated the relationship between elder impairment and caregiver burden. Future research should look more closely at specific types of elder impairment and the relationship between elder impairment, strain, and burden.

CHAPTER 1. GENERAL INTRODUCTION

The prevalence of Alzheimer's disease and related dementias is staggering. Currently, every 70 seconds someone is diagnosed with Alzheimer's disease and this number is projected to increase to every 33 seconds by 2050 (Mebane-Sims, 2009). With the estimated prevalence of dementia expected to increase significantly, the number of family caregivers that need to provide assistance to loved ones will coincide with the growing population of those afflicted with dementia. In fact, research by the National Alliance for Caregiving and the American Association of Retired Persons (1997) found that the bulk of caregiving will occur at home rather than in an institution.

Dementia is caused by damaged brain cells. Damaged brain cells influence memory and cognitive abilities (Mebane-Sims, 2009) and make it more difficult for those with dementia to use their memory and cognitive abilities properly. Although memory loss is the hallmark symptom of dementia, dementia and Alzheimer's disease can also cause problems with the ability to communicate needs and wishes, problems with judgment, confusion about place, as well as subtle or stark modifications in personality and behavior (Mebane-Sims, 2009). These behaviors may be so problematic that they influence the health of the caregiver. In fact, research by Son et al. (2007) found the more behavior problems there were, the poorer caregivers rated their health.

With so many people projected to develop dementia, it is important to understand if any caregiver characteristic (e.g., gender, age, relationship status, and employment status) influences the way caregivers rate the behaviors a person with dementia portrays. Understanding how caregiver characteristics are related to caregiver burden and strain is also

of importance, especially evaluating if there are different characteristics of the caregiver that are associated with higher levels of burden and strain. Caregivers may then better understand how their own role may affect levels of elder impairment, and their own feelings of burden and strain. Researchers may also gain new insight on which caregiver experiences greatest levels of burden and strain by assessing elder impairment in care recipients.

The purpose of this study is to find out which caregiver characteristics, if any, have an influence on the perception of elder impairment of the care recipient. Some caregiver characteristics (e.g., gender, age, relationship status, and employment status) may cause role strain for the caregiver, however, adding demented behaviors as another demand may increase feelings of role strain. Role strain in turn may have an impact on caregiver burden. With so many demands for the caregiver to keep up with and feelings of role strain, it seems likely that caregiver burden may occur.

CHAPTER 2. REVIEW OF LITERATURE

Literature Review

The literature on caregiving is reviewed below, beginning with differences between adult children and spouses as dementia caregivers. Gender differences between these two groups are also highlighted; specifically, the differences between husbands and wives, as well as between daughters and sons is discussed in the following section. The impact of work status on caregivers is also explored. In addition, the age of the caregiver is mentioned, as there are differences between young, middle-aged, and older caregivers. The last section of the literature review focuses on dementia behaviors, both agitated and aggressive. This section will summarize some of the common behaviors caregivers face when engaged in their caregiving role. Before moving directly to the literature review, a review of theories related to caregiving is covered.

Theoretical Background

Previous research has used role strain theory to provide a context for how caregivers deal with the many demands they are presented with (Gaugler, Zarit & Pearlin, 2003; Goode, 1960; Mui, 1992; Pearlin & McKean Skaff 1996). Although there are many roles that individuals must fulfill, role strain sets in when individuals have a hard time fulfilling all roles. In other words, there are too many demands placed on individuals and they cannot meet the requirements of all of their duties (Goode, 1960). This theory may help explain why caregivers have feelings of burden and strain, as they often have many roles to maintain.

During caregiving, a significant amount of time and attention is devoted to the care recipient. For caregivers who have outside employment, families of their own, and social lives, caregivers may worry about how they will keep up with all of the demands placed upon

them. Likewise, worries about obligations and not enough time spent engaged in each role create feelings of role strain (Goode, 1960). Adult children may experience role strain more often as they are commonly dealing with a combination of demands such as family, work, and caregiving. Adult children often have to take time away from their other roles to keep up with the demands of caregiving. Managing the additional demands of caregiving often leads to role strain (Aneshensel, Pearlin, & Schuler, 1993). Although Goode (1960) was one of the first to discuss role strain, more researchers have recently touched on this theory as well. Pearlin, McKean, and Skaff (1996) also noted that a dementia caregiver would likely feel role strain in trying to keep up with the demands of caregiving, other obligations, and the feeling of loss as a result of the care recipient's diminished status. Providing more assistance to the care recipient, such as with activities of daily living, as well as dealing with behavioral problems, can also lead to higher levels of reported role overload (i.e., holding too many roles) and role captivity (i.e., holding an unwanted role) (Robertson, Zarit, Duncan, Rovine, & Femia, 2007).

Secondary stressors may also occur as a result of an unexpected role, such as that of a caregiver. As the demands on caregivers increase and their time devoted to caregiving increases, secondary stressors such as financial problems due to lack of time spent working as a result of caregiving can occur. The secondary stressors that emerge as a result of caregiving can have a negative impact on the health of caregivers (Pearlin, Schieman, Fazio, & Meersman, 2005). As adult children and spouses are likely at different places in life and experience different kinds of stressors and demands, exploring the variation between these two types of caregivers is necessary. By looking at caregivers through this theoretical lens,

role theory would suggest caregivers have too many roles and obligations to fulfill which can cause feelings of caregiver strain.

Adult Children and Spousal Caregivers

Although research has noted vast differences between adult children and spouses as caregivers, research is still not conclusive on whether or not either type of caregiving relationship is more beneficial for the caregiver or person receiving care. The general relationships between an adult child and a parent and the relationship between spouses are quite different even without the added problems of dementia. It seems expected that when Alzheimer's disease or dementia appears, there would be differences in how the spouse not afflicted with dementia and adult children would deal with the onset of such symptoms and develop a caregiving relationship.

Interestingly, Van Den Wijngaart, Vernooij-Dassen, and Felling (2007) found that although having a spouse with dementia who may be more withdrawn, passive, or uncommunicative in itself was not problematic, the simple fact that the spousal relationship had now forever changed was quite troublesome and difficult for spouses to deal with. Spouses may no longer be able to reflect on their past memories and lives together. The non-afflicted spouse may no longer be able to rely on their spouses for advice or discussion, which in turn changes the marital relationship dramatically for some. In order to supplement the lack of communication that may have once been present in the marital relationship, Jansson, Nordberg, and Grafstrom (2001) noted that physical displays of affection such as a hug or pat on the back helped to fill that void.

Contrary to the notion that lack of companionship rather than behavior problems leads to an unsatisfactory caregiving relationship, other researchers have noted that increased

behavioral problems were related to an increase in depressive symptoms as well as increased feelings of distance in the relationship (Bookwala & Schulz, 2000).

Looking at gender roles within a spousal caregiving relationship and exploring costs and rewards within a social exchange theory context, Raschick and Ingersoll-Dayton (2004) found wives who were caring for a husband with dementia were less likely to report feeling rewarded as a result of taking care of their spouse if the wives felt a lack of companionship or connection with their spouse. However, wives who felt a sense of companionship were more likely to report feeling rewarded as a caregiver. This change in feeling was only reported in wives, as the level of companionship experienced by husbands and adult children did not seem to affect their feeling of reward as a caregiver (Raschick & Ingersoll-Dayton). Some caregivers may be able to overcome some of their lonely feelings by continuing to display affection to their spouse. Which spouse develops dementia may also have an impact on how the husbands or wives deal with their new caregiving role.

Research by Hayes, Boylstein, and Zimmerman (2009) indicates that husbands seem to detect less of a change in the marital relationship than wives when the wife experiences dementia. Women viewed themselves as more of a caregiver than wife, whereas men still regarded their wife as their spousal partner and not a care recipient. However, when wives dealt with a husband's dementia, they were more likely to report a change, especially in regard to physical and sexual closeness. Yet, over time both husbands and wives reported a significant change in their relationship in regard to intimacy as the other spouse progressed through the stages of dementia.

Hayes et al. (2009) noted that although the impact of dementia can cause strain on a marriage, some spouses reported that they felt a strong connection to the spouse with

dementia and reported that they cherished their time with their spouse more than when dementia had not been present. Spouses in research by Hope, Kenne, Gedling, Fairburn, and Jacoby (1998) were found to be more devoted to caregiving than adult children. Spouses may be used to providing care and assistance to one another throughout their marriage and therefore aging and problems such as dementia may seem like just another hurdle to get through together (Hayes et al., 2009). In contrast, adult children may not be used to providing greater levels of assistance or support to their parents and as a result may feel like a “caregiver” at an earlier time than a spouse would. However, it is also possible that a spouse may feel that as dementia progresses, they are developing more of a parent-child relationship with their spouse. This scenario was more likely for women (Hayes et al., 2009).

Men were more likely to report feeling a close bond with their wife they were caring for than wives in the opposite situation (Bookwala & Schulz, 2000). Perhaps the quality of the relationship or the way in which the relationship is thought of can influence how successful the caregiving relationship turns out to be.

Although husbands and wives who were caring for one another did provide similar levels of assistance to one another, they were more likely to engage in different types of assistive roles (Bookwala & Schulz, 2000). For example, husbands were more likely to help their wives as necessary with eating and difficult household tasks. Wives on the other hand, were much more likely to run errands and do shopping types of chores. Although the difference between husbands and wives who helped their spouse with toileting and transferring was not significant, husbands were more likely to assist with these tasks (Bookwala & Schulz). In the study by Bookwala and Schulz, husbands did seem to be quite

engaged, however, they still managed to maintain outside social activities, whereas wives in a similar situation seemed to give up outside social obligations and focused solely on caregiving. Findings by Rudd, Viney, and Preston (1999) noted similar results, citing that female spousal caregivers reported greater feelings of sadness and isolation as well as anxiety than husbands caring for their wives. Rudd et al. (1999) also reported that men were more likely to keep up with their social activities and outings than women.

Women who were caring for spouses were also less likely to cease employment than if they were caring for their in-laws (Pavalko & Woodbury, 2000). At first glance this may seem unusual, but the authors noted that there may be financial reasons underlying the decision for wives to stay employed and be able to provide for their ailing husbands.

When spouses are deceased, no longer present in the home, or too ill themselves to provide assistance to the other ailing spouse, it often falls to daughters to pick up the caregiving role rather than sons (Laditka & Laditka, 2000). Adult children may feel as though they are beginning to parent their parents and find this new reality difficult to adjust to (Betts-Adams & Sanders, 2004). Research by Synder (2000) explained that in her research of adult daughters caring for aging mothers, the quality of the relationship between mother and daughter before caregiving was more likely to dictate feelings of either burden or satisfaction regardless of any other factor in the caregiving relationship. Synder (2000) and Lopez, Lopez-Arrieta, and Crespo (2005) also noted that the relationship between the caregivers and the person receiving care before caregiving occurred likely dictated how burdened or satisfied the caregiver felt when caregiving.

When adult children step in to engage in a caregiving role with their parents, they may have feelings of aversion to their new role. Adult children are more likely to portray

feelings of jealousy toward friends and family not caring for aging parents (Meuser & Martwit, 2001). Possible explanations for the negative feelings noted by Meuser and Marwit (2001) were that the need to step in and give care came as a surprise. Aging spouses may have anticipated that in the near future the need to provide caregiving assistance to their spouse was at least possible, however, adult children may never have considered this possibility and as a result had a difficult time adjusting to their new role. In fact, adult children were more likely to place their demented parent in nursing home care than spouses who were caregiving. Hope et al. (1998) also noted that younger caregivers, such as adult children, had a more difficult time dealing with their caregiver role, possibly as a result of many other obligations such as family and work. Regardless of their increased physical abilities as compared to the likely older spouses, younger caregivers did not seem to benefit from their youthfulness.

For aging parents who do not have daughters of their own, daughters-in-law are more likely than sons to provide care for their aging in-laws. However adult children are more likely to supply more assistance to their own parents rather than in-laws (Laditka & Laditka, 2000). Even when both parents are still alive, Laditka and Laditka found that daughters were more likely to provide occasional needed assistance than sons. When both caregiving daughters and sons are studied together, daughters are more likely to be affected emotionally by the caregiving role (Jansson, Grafstrom, & Winblad, 1997). Jansson et al. (1997) suggest that sons may distance themselves from the caregiving process and as a result become less affected emotionally.

Caregiving daughters were more likely to engage in a greater number of hours of caregiving for their parent than sons, as noted by Laditka and Laditka (2000). The difference

in hours is actually quite remarkable, considering that in their study, daughters provided 356.6 more mean hours annually to their parent than sons.

Husbands and wives tend to be less selfish caregivers to one another, whereas adult-children often have other competing demands for their time and attention and as a result make them less selfless in caregiving for an aging parent (Meuser & Martwit, 2001). As highlighted previously, there are many differences between spouse and adult-child caregivers. Husbands seem to fare the best in terms of maintaining activities outside of caregiving and becoming less anxious and depressed with their new role. Wives tend to immerse themselves in the caregiving role, but this may be to their detriment, as they often feel isolated and depressed with their circumstances. Wives also seem to have more difficulty adapting to changes in their husbands, whereas husbands are more accepting and less upset about such changes. Daughters may be more likely than sons to step in and provide caregiving for a parent than sons as a result of previously established gender roles (Mui, 1995).

The role of a caregiver may come as less of a surprise to spouses than adult children. Adult children may resent the role and have a more difficult time keeping up with the demands of caregiving. Adult children are more likely to still be engaged in the workforce as well as have their own families to care for. This study will look at the differences in how adult children and spouses rated levels of elder impairment in the care recipient as well as assessing differences in caregiver burden and strain between the two groups.

Working and Non-Working Caregivers

Caregivers who are forced to maintain not only a working life but a family life may also increasingly have to deal with a “third shift” as discussed by Doress-Worters (1994)

known as caring for aging relatives. Although men were not included in a study by Chorn-Dunham and Dietz (2003), women who were still engaged in the workforce felt a lot of pressure to keep up with the demands of both work and caregiving. It seems only natural that women who were navigating their way through work and caregiving often valued flexibility in their jobs and found this very beneficial in balancing their tasks. In fact, women who did not have flexibility in their jobs were more likely to seek a different type of employment that did allow flexibility to increase their chances of being successful caregivers.

Although Lee, Walker, and Shoup (2001) did not find significant differences between caregivers who were employed and caregiving and those who were only caregiving, caregivers who were still in the workforce had an increase in depressive symptoms as compared to those who were not working or non-caregivers who were only working. Again, Lee et al. mentioned the importance of employers being flexible and accommodating to their employees who are caregiving. Lopez et al. (2005) found that caregivers who worked outside of the home environment had less caregiving satisfaction than those caregivers who did not have outside employment. The authors speculated that the reason for this was too many demands were probably being placed on the caregivers and the caregivers may have felt a sense of role strain with caregiving and employment.

Some caregivers who are still working may not be giving themselves enough credit. Rosenthal, Hayward, Martin-Matthew, and Denton (2004), found that caregiving daughters who were still working managed to provide much of the same care when compared to caregiving daughters who were not working outside of the home, in terms of instrumental activities of daily living. The only instrumental activity of daily living that was found to be given more attention by non-working caregivers was in the area of banking and bill paying.

Regardless of whether or not the caregiving daughter was working, the needs of a parent who needed assistance were met. Although the needs were probably met in different ways, and perhaps some non-working caregiving daughters spent more time engaged in assisting with those needs, even adult daughters who were working managed to successfully assist their parent when it was necessary. Employment outside of the home did not appear to be detrimental to helping a parent with his or her caregiving needs (Rosenthal et al., 2004).

Although many women mentioned that keeping up with both work and caregiving was challenging, some women appreciated the chance to change directions and go to work to focus on things they needed to do there (Rosenthal et al., 2004). Some women also reported in the study by Rosenthal et al. that if they did not have the chance to leave for work they would feel very isolated and almost prisoner like. Similar results were noted in research by Rands (1997) who studied individuals in the workforce who were also managing caregiving. Unlike the research by Chorn-Dunham and Dietz (2003) who only used female participants, male caregivers also appreciated leaving the caregiving environment and working outside of the home. Again, Rands (1997) echoed the fact that employees appreciated understanding supervisors and flexibility at work. Other positive effects that come from continuing employment are steady income, sick leave, vacation, and sometimes flexibility (Pavalko & Woodbury, 2000).

There may in fact be a buffering effect of employment outside of the home on the health status of caregiving women. Women, who were employed outside of the home and caregiving, had fewer health declines than women who were only caregiving and did not work outside of the home (Pavalko & Woodbury, 2000). Even women who were not necessarily employed outside of the home but were quite social and active within their social

network, fared better than those caregivers who were not social. The less social caregivers were, the higher the rate of depressive symptoms (Cannuscio et al., 2004).

Many of the studies mentioned previously only looked at adult daughters in the workforce who were also caregiving. Therefore, more attention needs to be placed on sons as well. Research primarily has been conducted with caregivers in the workforce rather than retired or non-working caregivers. The research is very mixed regarding whether or not being employed outside of the home is beneficial, detrimental, or has minimal effects on the way caregivers manage their caregiving relationship. However, it appears that many factors such as flexibility, social networks, and understanding co-workers and supervisors may influence how caregivers balance their working world with their caregiving world. Interestingly, much of the research focused on how adult daughters balanced working, caregiving, and raising families. There was very little research indicating how adult sons managed such tasks if they were involved in all three. In this study, three different types of work status (employees, retirees, and housewives) will be compared in order to understand how each status influences the reported level of elder impairment in the care recipient and caregiver burden and strain.

Differences due to Caregiver Age

There seems to be little research that focuses on the differences between younger and older caregivers. Each group has unique challenges making their caregiving experience quite different from one another. Research has often overlooked this interesting component to caregiving. What is known is that the majority of dementia caregivers are middle aged to older adults. A report from the Alzheimer's Association and National Alliance for Caregiving (2004) found that 37 percent of caregivers were between the ages of 50 to 60

years old, and an additional 29 percent of caregivers were between the ages of 35 to 49.

Much is known about the differences between young and middle aged adults; however those differences are not often looked at in the context of a caregiving relationship. In fact, Levinson (1986) speaks of the many differences and transitions that occur in young adulthood through middle adulthood. Younger adults are experiencing many more events for the first time, including building a career and starting a family. Adults in middle adulthood may be ending phases in their lives and looking to younger generations to carry on their work and goals. Because individuals are at different points in their adult development, it is likely they have different opinions about caregiving and different priorities. With a movement for women to lead a more active role in the workplace as well as to postpone childbirth to an older age than previous generations, the growing number of adult children in the “sandwich generation” is expected to increase as baby boomers continue to age (Spillman & Pezzin, 2000).

Caregiver assistance with ADLs was found to differ by age group in research from the National Alliance for Caregiving and AARP (1997). The caregiver group aged 50-64 reported the highest level of burden on the Burden Index Scale. The heaviest burdened caregivers were caregivers who assisted with at least two or more ADLs and provided 40 or more hours of their time to the care recipient each week. The least burdened age group was those aged 35-49. Research by Stenberg-Nichols and Junk (1997) seems to agree with these findings, as they reported that adult children in their forties, followed by adult children in their fifties were most likely to be classified into the sandwich generation. As a result of this it seems likely that they would feel more burdened. Stenberg-Nichols et al. also pointed to the importance of identifying other resources, whether they were secondary caregivers,

government assistance, or employer support so that feelings of burden and stress may at least be alleviated in a small way.

In one of the few studies focusing on age in terms of caregiving, Dellmann-Jenkins, Blankemeyer, and Pinkard (2000) looked closely at younger adult caregivers providing care to a relative. The researchers studied both adult children and adult grandchildren, with the adult children more likely to be in their 30s and 40s, whereas the grandchildren were younger and more likely to be between the ages of 18-35. Although the study did not explore differences between younger versus middle-aged caregivers, there are still some general findings that can be inferred from the study that make younger caregivers different from middle-aged caregivers. Many of the caregivers in the study commented that they had increasingly less time for other social activities and dating relationships, with the adult grandchildren commenting on this loss more often. As indicated previously, the adult grandchildren in the study were younger than the adult children, thus making it more likely for the younger grandchildren to not be married or in a serious relationship. This can also be related to middle-aged adults who are often already married or have a long established relationship with a partner. The findings from adult grandchildren and children point toward differences that need to be studied between younger and middle-aged caregivers.

Yet another challenge younger caregivers had to deal with was working as well as tending to the needs of the person receiving care (Dellmann-Jenkins et al., 2000). Almost half of the participants in the Dellmann-Jenkins et al. study noted that their attendance at work had dropped since becoming a caregiver. Many caregivers noted that they could not afford to miss work or had just started a new job which looked down on so many absences so often. In contrast, it may be more likely that middle-aged caregivers already have a career

established or have been with their employer for a good number of years. A long-standing, excellent work record may lessen problems that an employer may have with frequent absences due to caregiving.

Although younger caregivers were not included in a study by Lima, Allen, Goldscheider, and Intrator (2006), older middle-aged caregivers, young-old adults, and older adults were compared in order to understand differences in their spousal caregiving roles and styles. Not surprisingly, the older middle-aged spousal caregivers, who were between the ages of fifty-two to sixty-four, were found to spend fewer hours caregiving than the young older adults and older adults. The older middle-aged caregivers had many more demands competing for their time and attention. For example, older middle-aged caregivers were more likely to have children that still needed tending, were more likely to have aging parents that needed assistance, and were more likely to be working a full-time job. However, after controlling for work status, there were no differences between the three different age categories. At least in this study, age of the caregiver did not seem to make a difference, but rather work status of the caregiver seemed to play the more dominant role. More research is needed in order to understand the role that age plays in caregiving. This study will assess the role a caregiver's age plays in how elder impairment is rated and the level of burden and strain felt by caregivers.

Dementia Aggressive and Agitated Behaviors

Those who are diagnosed with dementia often exhibit behaviors that are unique to the onset of dementia. For example, it is not uncommon for those suffering from dementia to experience changes in behavior, lack the ability to communicate or listen appropriately, have

confusion with orientation, as well as have deficiencies in judgment abilities (Mebane-Sims, 2009). Some behaviors may be more disruptive or problematic for caregivers than others.

Physical non-aggressive agitated behavior can often be seen in demented adults who wander, pace, have difficulty dressing themselves appropriately (understanding how to wear pants and shirts correctly), and engage in repetitive behavior (Cohen-Mansfield & Werner, 1999). Verbal non-aggressive agitation, on the other hand, includes verbal attention seeking, disruptive and or negative comments, and complaints (Cohen-Mansfield & Werner, 1999). Cohen-Mansfield (2009) found that physical aggression is often more disruptive in nature than verbal aggression, and aggression that occurs more frequently of either type can often be more disruptive. As depression increased for those exhibiting verbal disruptive behaviors, so did the disruptive behaviors (Cohen-Mansfield & Libin, 2004).

Aggressive behavior is often exhibited when caregivers are in close proximity, such as when assisting with toileting, bathing, and other hygiene matters (Zeller et al., 2009). Demented individuals may need more assistance with activities of daily living described above. Isaksson, Astrom, Sandman and Karlsson (2008) reported that demented adults who displayed aggressive or violent behavior also required more assistance with ADLs than did other demented adults who did not display aggression or violence. Cohen-Mansfield and Libin (2004) found similar results when looking at demented adults who displayed agitated rather than aggressive behaviors. Demented individuals who displayed more agitation also required more assistance with ADLs. Agitated behaviors were also more likely to coincide with decreased cognitive capacity (Cohen-Mansfield & Werner, 1999). Behaviors such as wandering and pacing are more likely to occur when a demented adult is in good health but in the later stages of dementia (Cohen-Mansfield & Werner, 1999). Although an older adult

may be in good health physically and engages in physical non-aggressive behaviors such as wandering, their decreased mental capacity can make wandering or pacing unsafe.

Demented individuals may use aggression as a type of defense mechanism in order to try to prevent caregivers from doing something they do not wish them to do. Other stressors that may result in aggressive behaviors include events such as the death or move of a family member (Zeller et al., 2009).

Although it may seem intuitive, caregivers who made an effort to respect the mood of the demented person, waited for the person to indicate they were comfortable with certain activities, and respected the demented person's wishes perceived decreased aggressive behavior in the care recipient (Zeller et al., 2009). Much of the literature was based on residents in nursing homes, and many at-home caregivers might benefit from the experiences of staff in nursing homes.

The gender of the demented person may also play a role in frequency or type of aggression. Men were more likely than women to display aggressive behavior in a study that looked at violent behavior in nursing homes (Isaksson et al., 2008). However, Cohen-Mansfield and Libin (2004) noted that women tended to display more verbal aggression than men. Further research is needed to see if there are gender differences in agitation and aggression.

Much of the research discussing agitated and aggressive behaviors is conducted within the context of a nursing home. It is important to study in-home caregiving situations as well, as the environment is quite different from a nursing home and may have an impact on what behaviors are displayed by demented individuals. Also, in-home caregivers likely have less support staff on hand to help when a demented individual becomes agitated or

aggressive. In nursing home care, a different staff member may be able to calm the resident down; however, in at-home situations there is often only one primary caregiver. Managing difficult behaviors may not be easy and may put the caregiver who experiences more of these behaviors at an increased risk for burden, as some researchers noted the relationship between behavioral problems and burden (Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001; Perren, Schmid, & Wettstein, 2006; & Majerovitz, 2001). In this study, the relationship between the rated level of elder impairment and its influence on caregiver burden and strain will be analyzed.

Caregiver Burden and Strain

The relationship between caregiver and care recipient has been found to be a significant predictor of burden in some studies and not predictive in others. Hayslip, Han, and Anderson (2008) noted that the relationship between caregiver and care recipient as well as the age of the caregiver can make a difference in the level of burden. Specifically, Hayslip et al. reported that adult children perceived more burden than spouses and younger caregivers perceived more burden than older caregivers. Opposite findings from Andren and Elmstal (2008) noted that the highest levels of burden occurred in spousal caregivers.

However, in contrast to these findings, Campbell et al. (2008) noted that neither caregiver age nor the relationship between caregiver and care recipient were predictive of caregiver burden. Other researchers have noted that the greatest influence on caregiver burden was the caregiver's feeling of role captivity (Campbell et al). The quality of the relationship between caregiver and care recipient was the most predictive of whether or not the caregiver perceived feelings of burden (Andren & Elmstal, 2008). Specifically, the closer the caregiver and care recipient were, the higher level of perceived burden the

caregiver reported. In this study, caregiver burden and caregiver strain will be looked at as two different outcome variables. The influence caregiver characteristics have on burden and strain will be analyzed separately to explore if caregiver characteristics are more likely to be predictive of one or the other.

Research Hypotheses

The caregiver burden and strain model (Figure 1) suggests caregiver characteristics directly predict caregiver burden and strain (path a), and indirectly through elder impairment (path b and c). Furthermore, caregiver characteristics may moderate the relationship between elder impairment and caregiver burden and strain (path d). Caregiver characteristics predicting elder impairment is not viewed as a causal relationship. Instead, it is hypothesized that because caregivers have different characteristics they will perceive elder impairment differently.

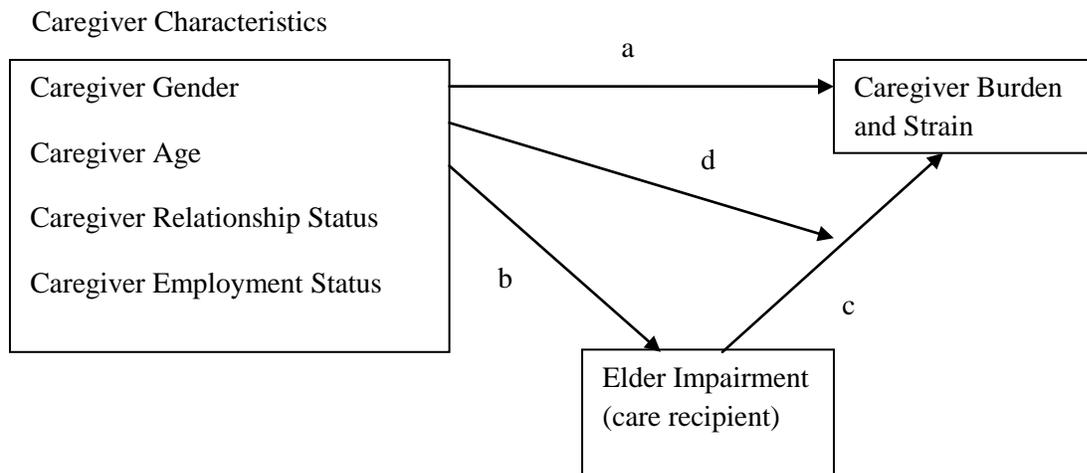


Figure 1. Caregiver burden and strain model

Based on the available literature regarding dementia caregiving, the following hypotheses are proposed:

1. Adult children will report more elder impairment than spousal caregivers. Due to the many demands placed on adult children (i.e., employment and their own family obligations), I predicted that adult children will perceive more elder impairment than spousal caregivers.
2. Younger/middle-aged caregivers and older aged caregivers will report more elder impairment than the oldest aged caregivers, with the younger/middle-aged caregivers reporting the greatest level of elder impairment.
3. The literature is mixed on whether or not outside employment hinders the abilities of the caregiver or provides them with a much needed escape from their caregiving role. This study will further investigate the influence of employment on caregiving.
4. Women will report more elder impairment and experience higher levels of burden and strain than men.
5. Caregivers who report more elder impairment will in turn report higher levels of burden and strain.
6. Elder impairment will be a mediator between caregiver characteristics and caregiver burden and strain.
7. Interaction effects will be explored: Does age interact with the elder impairment of the care recipient to influence burden and strain? Does employment status interact with elder impairment of the care recipient to influence burden and strain? Does relationship status interact with the elder impairment of the care recipient to influence burden and strain?

CHAPTER 3. METHODS AND PROCEDURE

Demographic information about the participants, the measures used, and the methods of data analysis are presented in the following sections.

Participants

Caregivers for individuals with Alzheimer's disease were asked to participate in a study about their caregiving relationship and experiences, including at-home caregivers and caregivers caring for someone in a facility. Participants were recruited from relatives of care recipients who had been given a probable diagnosis of dementia from the University of Iowa Hospitals and Clinics during 1987 and 1988. Caregivers were also selected from a mailing list from the Des Moines, Iowa chapter of the Alzheimer's Association. Participants were first approached via phone interviews during 1989 inquiring 1) if the person they were caring for had a probable dementia diagnosis from a physician, 2) if caregivers were currently caring for someone with such a diagnosis or recently had been, and 3) if the care recipient was still living. If potential participants indicated interest in the study, they were mailed questionnaires. Questionnaires were mailed to 625 caregivers, and a majority of caregivers responded (497 questionnaires were received, which was a 79.5 percent response rate).

Three hundred and ninety caregivers mailed back usable questionnaires. A subsample of the data (Figure 2) was used that included 292 caregivers who were either adult children or spousal caregivers and who were either retired, working, or housewives. One hundred and one were men and 191 were women (Table 1). The caregivers ranged in age from 34 to 89, with a mean age of 64.18 years. The majority of caregivers were spouses (63.4 percent), whereas 36.6 percent were adult children. About 12 percent of the sample

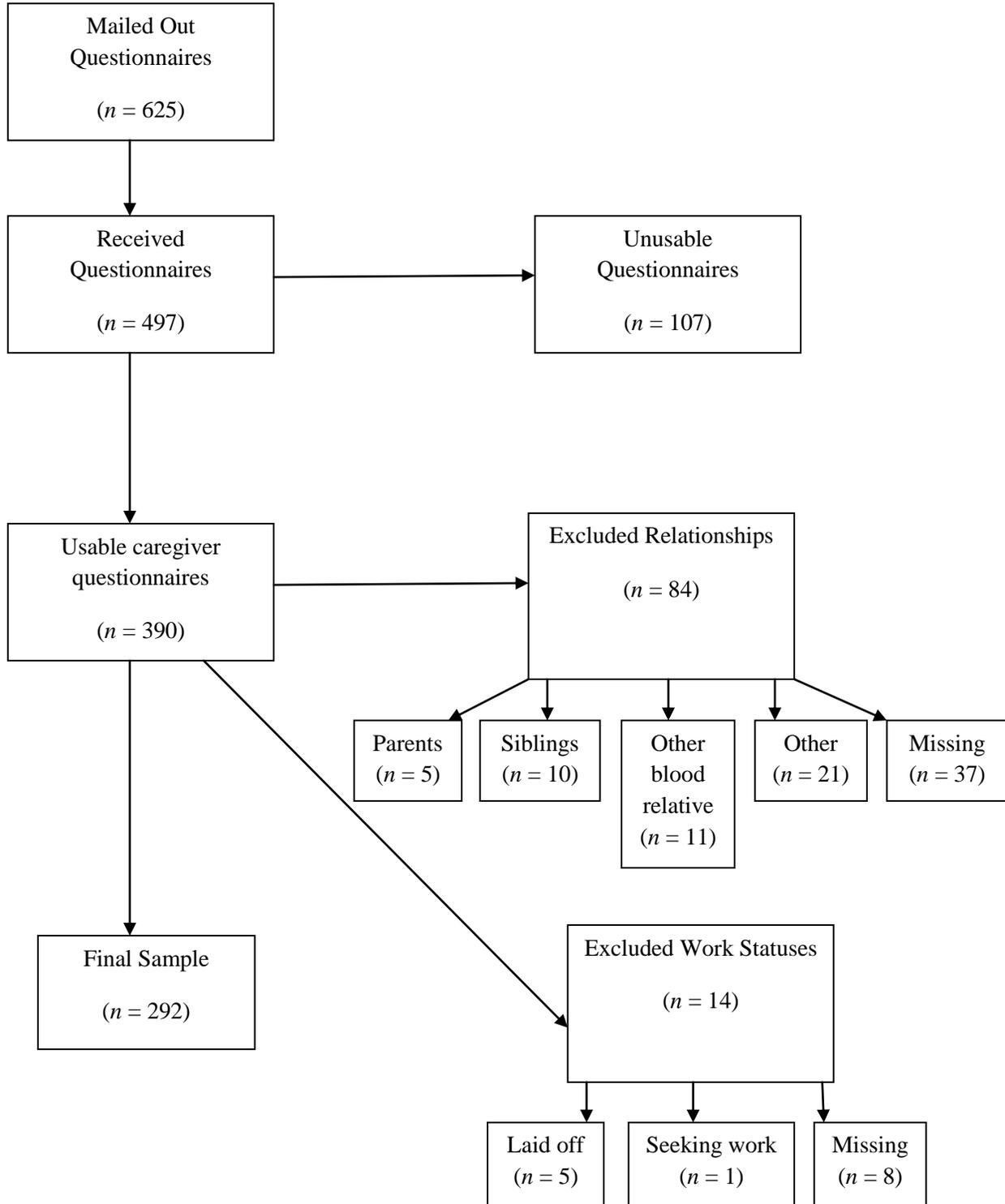


Figure 2. Participant flow chart after obtained caregiver subsample

Table 1

Demographics of the Caregiver

Category	<i>Frequency</i>	<i>Percent</i>
Gender		
1. Male	101	34.6
2. Female	191	65.4
Total	292	100.0
Age		
1. Young/Middle-Aged (34-59)	95	32.5
2. Older-Aged (60-72)	105	36.0
3. Oldest-Aged (73-89)	92	31.5
Total	292	100.0
Relationship to Care Recipient		
1. Spouse	185	63.4
2. Adult Child	107	36.6
Total	292	100.0

(table continues)

Table 1 (continued)

<i>Category</i>	<i>Frequency</i>	<i>Percent</i>
Highest Level of Education Completed		
1. Less than 12 years	36	12.3
2. 12 years	123	42.1
3. 13-14 years	56	19.2
4. 15 or more years	71	24.3
5. Missing	6	2.1
Total	292	100.0
Employment Status		
1. Working	100	34.2
2. Retired	139	47.6
3. Housewives	53	18.2
Total	292	100.0
Household Characteristics		
1. No additional persons in home	195	66.8
2. 1 additional person in home	62	21.2
3. 2 additional persons in home	13	4.5
4. 3+ additional persons in home	22	7.5
Total	292	100.0

had less than 12 years of education; another 42.1 percent completed high school, 19.2 percent went on to complete an additional one or two years of college, and 24.3 percent went on to finish three or more years of education after high school. Most caregivers in this study were retired (47.6), however, 34.2 percent of caregivers were employed. The majority of caregivers were also living alone as 66.8 percent of caregivers reported there were no other additional persons living in their home.

Comparing the excluded group (i.e., caregivers who were not adult children or spouses designated as working retired, or housewives) to the sample yielded no significant differences in gender between the two groups, $\chi^2(1, 384) = .74, p = .39$. Excluded caregivers were significantly more likely to be younger, $F(1, 384) = 6.27, p = .01$.

Mean comparisons did not show significant differences between the two groups on ratings of elder impairment, $F(1, 379) = 1.73, p = .19$ or caregiver burden, $F(1, 259) = 2.08, p = .15$. However, the two groups did differ significantly on ratings of caregiver strain, $F(1, 375) = 5.15, p < .05$ with the excluded sample rating lower levels of strain. Subscales “personal strain,” $F(1, 300) = .79, p = .38$ and “role strain,” $F(1, 323) = 3.18, p = .08$ were not significantly different in the two groups, although there was a trend indicating the excluded sample had lower levels of role strain.

Based on the total sample of 390 caregivers, showed caregivers caring for a care recipient in a home environment were significantly more likely to have higher levels of personal strain, $F(1, 296) = 5.94, p < .01$. There was also a trend indicating higher levels of burden, $F(1, 255) = 2.88, p = .09$ and role strain, $F(1, 315) = 3.50, p = .06$ in the at-home caregiver. Caregivers caring for a care recipient in an institution were significantly more

likely to rate higher levels of elder impairment, $F(1, 371) = 6.00, p < .05$. Caregiver strain did not yield any significant differences between groups, $F(1, 270) = 1.36, p = .24$

Measures

Questionnaires that were mailed back contained information concerning gender, relationship to the care recipient, age, education, and work status. The Caregiver Strain Index (Robinson, 1983), the Burden Interview questions (Zarit, Reever, & Bach-Peterson, 1980) and the Elder Impairment Scale (Poulshock & Deimling, 1984) were used to explore the relationship between caregiver characteristics, caregiver burden, caregiver strain, and elder impairment.

Caregiver Characteristics. Background information about the caregiver (Appendix B), was collected in order to describe the sample of participating caregivers. Demographic information about the caregiver included: Gender, age, household characteristics, relationship to the care recipient, highest level of education and attained work status.

Burden Interview. The Burden Interview is a tool that measures the level of burden caregivers feel as a result of the person they are caring for. However, three questions from the Zarit & Zarit (1983) scale were not included in the survey. Some items were deleted from the Burden Interview to reduce the time and energy caregivers spent on answering questionnaire items. Additionally, of the 19 questions that were used in the dataset, one of the questions was deleted because of a high rate of missing answers (“do you feel that you will be unable to provide care for much longer”), therefore, only 18 questions were used. Questions used in this data set can be found in Appendix C. Questions included items such as, “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?” and “Do you feel angry when you are around your

relative?” Scores for each question ranged from 0 (never) to 3 (nearly always). The higher the score, the higher the level of burden. The highest score possible was 72 and the lowest 0. Cronbach’s alpha for this study was computed and yielded a reliability score of .87. This compares to previous research findings of internal consistency at .91 (Gallagher, Rappaport, Benedict, Lovett, & Silven, 1985). Two subscales within the Burden Interview were personal strain ($\alpha = .75$) and role strain ($\alpha = .85$). Zarit and Zarit (1983;1990) found internal reliabilities of .80 for personal strain and .81 for role strain. The Burden Interview is still widely used today in the caregiving literature (e.g., Czaja et al., 2009; Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Yamamoto, Hayashino, Yamazaki, Takegami, & Fukuhara, 2009).

Caregiver Strain Index. The Caregiver Strain Index (CSI) measures level of strain among caregivers by asking if caregiving had required adjustments and changes (Robinson, 1983). All questions are located in Appendix D. Questions touch on multiple areas of strain including inconvenience (e.g., “caregiving has required changes in personal plans,” “caregiving has required emotional adjustments”). Caregivers answer “yes” or “no” to the questions. Scores range from 0 (answering no to all questions) to 13 (answering yes to all questions). A high score indicates a greater level of caregiver strain. Caregivers who score 7 or greater have a great deal of stress in their lives (Robinson). However, for this study, the Caregiver Strain Index was used with different answer choices to improve the psychometric properties of the scale. Answer choices “never,” “rarely,” “sometimes,” or “always” were used instead of “yes” or “no.” A high score still indicates a greater level of caregiver strain, as answering “always” to all questions would result in a score of 48 and answering “never” to all questions would result in a score of 0. Internal consistency of the CSI was calculated

using Cronbach's alpha. The scale was found to have a reliability level of .86 when all 13 questions were used (Robinson). However, in this study only 11 of the questions were used ($\alpha = .80$). One of the questions from the CSI was not included in the data set (i.e., "there have been demands on my time") and another item, "caregiving has required work adjustments" was deleted as a result of a high number of missing data. The highest score possible therefore was 33. The reliability of the scale remained the same after deleting the item. The Caregiver Strain Index is also still widely used and well known in the caregiving literature (e.g., Aggarwal, Liao, Christian, & Mosca, 2009; Bainbridge, Kruegar, Lohfield, & Brazil, 2009; Lee, 2009).

Elder Impairment. The Elder Impairment Scale measures both physical and mental impairment in the care recipient. The scale is located in Appendix E. Some examples include "Elder does things harmful to self and others" and "Elder interferes with caregiver and other household members" (Poulshock & Deimling, 1984). The four-option responses ranged from "never" (score of 0) to "always" (score of 3). Higher scores equal greater levels of elder impairment. The highest score possible was 69 and the lowest 0. The Elder Impairment Scale also had strong internal consistency ($r = .90$). The Elder Impairment Scale was developed over 20 years ago and is not often found in the caregiving literature.

Data Analysis

Before data analysis began, approval from the Iowa State Institutional Review Board was obtained (Appendix A). The data analysis first started with descriptive analyses. Descriptive statistics on mean differences, standard deviations, and frequencies were computed, comparing mean differences between men and women, adult children and spousal

caregivers, working, retired, and housewife caregivers, and younger/middle-aged, older-aged, and oldest-aged caregivers.

Mean Group Differences. Mean comparisons were analyzed using ANOVAs to explore if adult children and spousal caregivers had different scores on the Elder Impairment Scale, Burden Interview, and Caregiver Strain Index. Gender differences were also computed assessing whether or not being a male or female caregiver resulted in significantly different scores on the Elder Impairment Scale, Burden Interview, and Caregiver Strain Index. A one-way ANOVA was computed using the work status variable to evaluate if there were significant differences between a caregiver's work status. The age variable was grouped into three different categories in order to compute a one-way ANOVA. The ages were split into thirds with specific categories of young and middle aged (34-59 years of age), older aged (60-72 years of age), and oldest aged (73-89 years of age).

Blockwise Hierarchical Regression. Two separate blockwise hierarchical regression analyses were computed, with a total of three blocks in order to analyze which caregiver characteristics were predictors of burden and strain. Dummy coding was used to create three separate variables for work status (i.e., employees, housewives, and retirees). The retiree variable was not used due to high multicollinearity with the employee variable. Caregiver characteristics (i.e., gender, age, relationship status, employees, and housewives) were added in the first block, elder impairment was added to the second block by conducting the Aiken and West (1991) approach of using mean-centered values instead of raw values, and interaction terms were added separately to the third block (i.e., elder impairment x gender, elder impairment x age, elder impairment x relationship status, and elder impairment x work status).

CHAPTER 4. RESULTS

Findings from completed analyses using SPSS for Windows 18 are presented in this section. First mean group differences were computed, followed by bivariate correlations, and then by hierarchical multiple regression analyses to find out if any caregiver characteristics were predictive of burden and strain in the caregiver.

Mean Group Differences

On average, caregivers reported elder impairment of care recipients in midrange based on the reported scores. Caregiver strain levels, on average, were rated at mid-to high levels. Overall, levels of caregiver burden were also reported at midrange. The subscale role strain was also in midrange and personal strain was rated at mid-to high levels. When comparing the obtained mean scores to other data that have used the same scales, comparable mean scores on the Burden Interview were obtained (Hartke & King, 2003; Hashimoto, Yatabe, Kaneda, Honda, & Ikeda, 2009). However, other studies assessing the level of burden due to urinary incontinence have shown a much higher mean of 40 (Gotoh et al., 2009). Existing research using the Caregiver Strain Index has shown lower levels of caregiver strain (Blake, Lincoln, & Clarke, 2003; Aggarwal et al., 2009). Lower levels may be due to scaling differences between this study and previous research.

Hypothesis 1: Adult Children Will Report More Elder Impairment Than Spousal Caregivers

Spouses ($M = 31.24$) and adult children ($M = 32.04$) did not rate the care recipient significantly different from one another on the Elder Impairment Scale, $F(1, 283) = .31, p = .58$ (Table 2). Spouses ($M = 21.86$) and adult children ($M = 19.87$) did have significantly different scores on strain, $F(1,218) = 6.69, p \leq .01$, with spouses reporting higher levels

Table 2

Relationship Status Differences in Perceived Elder Impairment, Burden, and Strain

Variable	Spouse		Adult Child		<i>F</i>	Total	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Perceived Elder	31.24	11.89	32.04	11.26	.31	31.54	11.65
Impairment							
Caregiver Strain Index	21.86	5.59	19.87	5.47	6.69**	21.11	5.61
Burden Interview	24.75	9.99	24.41	8.73	.06	25.84	10.20
Burden Subscales							
Role Strain	8.29	4.32	7.48	4.17	2.13	7.98	4.27
Personal Strain	11.52	5.22	12.42	4.09	1.85	11.86	4.84

***p* ≤ .01.

of strain than adult children. However, Spouses ($M = 24.75$) and adult children ($M = 24.41$) did not have significantly different scores on burden, $F(1, 201) = .06, p = .81$. The subscale role strain, $F(1,246) = 2.13, p = .15$ did not yield any differences for spouses ($M = 8.29$) or adult children ($M = 7.48$), nor did the personal strain subscale, $F(1,229) = 1.85, p = .18$ for spouses ($M = 11.52$) or adult children ($M = 12.42$).

Hypothesis 2: Younger/Middle-Aged Caregivers and Older-Aged Caregivers Will Report More Elder Impairment Than the Oldest-Aged Caregivers, With the Younger/Middle-Aged Caregivers Reporting the Greatest Level of Elder Impairment

There were no significant differences between Young/Middle-Aged ($M = 32.68$), Older-Aged ($M = 31.23$), and Oldest-Aged ($M = 30.67$) on the Elder Impairment Scale, $F(2,282) = .73, p = .48$ (Table 3). Caregiver Strain was also not significantly different between Young/Middle-Aged ($M = 19.99$), Older-Aged ($M = 22.02$), and Oldest-Aged ($M = 21.25$), $F(2,217) = 2.70, p = .07$. However, there does seem to be a trend indicating that older caregivers perceive more strain. There were no significant differences between Young/Middle-Aged ($M = 24.53$), Older-Aged ($M = 25.87$), and Oldest-Aged ($M = 23.22$) on the Burden Interview, $F(2,200) = 1.26, p = .29$. The subscale of the Burden Interview, role strain did not show significantly different scores, $F(2,245) = 2.28, p = .12$ between Young/Middle-Aged ($M = 7.78$), Older-Aged ($M = 8.71$), and Oldest-Aged ($M = 7.34$) nor did the personal strain subscale, $F(2,228) = 2.42, p = .09$ between Young/Middle-Aged ($M = 12.57$), Older-Aged ($M = 11.98$), and Oldest-Aged ($M = 10.85$). However, there does seem to be a trend indicating that younger caregivers had higher levels of personal strain.

Table 3

Age Differences in Perceived Elder Impairment, Burden, and Strain

Variable	Young/Middle-Aged		Older-Aged		Oldest-Aged		<i>F</i>	Total	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Perceived Elder	32.68	10.49	31.23	12.88	30.67	11.34	.73	31.54	11.65
Impairment									
Caregiver Strain Index	19.99	5.55	22.02	5.10	21.25	6.20	2.70 ⁺	21.11	5.61
Burden Interview	24.53	9.30	25.87	9.42	23.22	9.84	1.26	24.62	9.52
Burden Subscales									
Role Strain	7.78	4.03	8.71	4.34	7.34	4.38	2.28	7.98	4.27
Personal Strain	12.57	4.43	11.98	4.96	10.85	5.06	2.42 ⁺	11.86	4.84

⁺ $p < .10$.

Hypothesis 3: Does Outside Employment Make Caregivers Experience Higher Levels of Burden and Strain or Lessen Feelings of Burden and Strain?

There were no significant differences between employed caregivers ($M = 32.33$), retired caregivers ($M = 31.11$), and housewives ($M = 31.12$) on the Elder Impairment Scale, $F(2, 282) = .35, p = .70$ (Table 4). No significant differences were found between employees ($M = 20.51$), retirees ($M = 21.59$), or housewives ($M = 21.17$), on the Caregiver Strain Index, $F(2, 217) = .84, p = .43$, nor between employees ($M = 24.35$), retirees ($M = 24.46$), and housewives ($M = 25.66$), on the Burden Interview measure, $F(2, 200) = .25, p = .78$. Again, there were no significant differences between employed caregivers ($M = 7.84$), retired caregivers ($M = 7.97$), or housewives ($M = 8.34$), on the Burden Interview subscale, role strain, $F(2, 245) = .20, p = .82$, nor between employed caregivers ($M = 12.26$), retired caregivers ($M = 11.37$), or housewives ($M = 12.20$), on the Burden Interview subscale, personal strain, $F(2, 228) = .92, p = .40$.

Hypothesis 4: Women Will Report More Elder Impairment and Experience Higher Levels of Burden and Strain Than Men

There were no significant differences between men ($M = 30.19$) and women ($M = 32.23$) on the Elder Impairment Scale, $F(290) = 1.99, p = .16$, and no significant differences between men ($M = 20.22$) and women ($M = 21.59$) on the Caregiver Strain Index, $F(1, 218) = 3.00, p = .09$ (Table 5). However, there does seem to be a trend indicating that women were more likely to have higher levels of caregiver strain. No significant differences were found between men ($M = 23.48$) and women ($M = 25.23$) on the Burden Interview, $F(290) = 1.58, p = .21$. No significant differences between men ($M = 7.39$) and women ($M = 8.31$) on the Caregiver Strain Index subscales role strain, $F(1, 246) = 2.69, p = .10$ and no significant

Table 4

Work Status Differences in Perceived Elder Impairment, Burden, and Strain

Variable	Employed		Retired		Housewife		<i>F</i>	Total	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Perceived Elder	32.33	11.32	31.11	11.97	31.12	11.55	.35	31.54	11.65
Impairment									
Caregiver Strain Index	20.51	5.43	21.59	5.74	21.17	5.69	.84	21.11	5.61
Burden Interview	24.35	9.13	24.46	9.63	25.66	10.32	.25	25.84	10.20
Burden Subscales									
Role Strain	7.84	4.08	7.97	4.67	8.34	3.53	.20	7.98	4.27
Personal Strain	12.26	4.60	11.37	4.85	12.20	5.31	.92	11.86	4.84

Table 5

Gender Differences in Perceived Elder Impairment, Burden, and Strain

Variable	Male		Female		<i>F</i>	Total	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>M</i>	<i>SD</i>
Perceived Elder	30.19	10.20	32.23	12.29	1.99	31.54	11.65
Impairment							
Caregiver Strain Index	20.22	5.36	21.59	5.70	3.00 ⁺	21.11	5.61
Burden Interview	23.48	9.63	25.23	9.43	1.58	25.84	10.20
Burden Subscales							
Role Strain	7.39	4.59	8.31	4.09	2.69	7.98	4.27
Personal Strain	11.55	4.59	12.01	4.97	.47	11.86	4.84

⁺ $p < .10$.

differences between men ($M = 11.55$) and women ($M = 12.01$) on personal strain, $F(290) = .47, p = .49$.

Correlations

Table 6 summarizes the bivariate correlations of all variables. There was a negative correlation between relationship status and caregiver strain. Caregivers who were spouses were more likely to have higher levels of caregiver strain than adult children $r(290) = -.17, p < .05$. The more elder impairment caregivers reported, the more caregiver strain was felt, $r(290) = .50, p < .01$; similarly, the more elder impairment reported, the more burdened caregivers felt, $r(290) = .55, p < .01$. The higher the level of caregiver strain, the higher the level of caregiver burden, $r(290) = .68, p < .01$.

Hypothesis 5: Caregivers Who Report More Elder Impairment Will in Turn Report Higher Levels of Burden

The Burden Interview and Caregiver Strain Index were both highly correlated with the Elder Impairment Scale ($p < .01$). Elder impairment also significantly predicted burden ($\beta = .55, p < .001$) and caregiver strain ($\beta = .55, p < .001$) in two separate multiple regressions after controlling for caregiver characteristics (Table 7 and 8).

Hypothesis 6: Elder Impairment will be a Mediator Between Caregiver Characteristics and Caregiver Burden and Strain

Caregiver characteristics did not significantly predict perceived elder impairment: gender ($\beta = .08, p = .22$), age ($\beta = -.15, p = .16$), relationship status ($\beta = -.06, p = .48$) or work status for employees ($\beta = -.03, p = .71$) or housewives ($\beta = -.05, p = .44$) (Table 9). Caregiver characteristics were not predictive of caregiver burden: gender ($\beta = .06, p = .39$),

Table 6

Correlations for Elder Impairment, Burden, and Strain

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Gender	1.00										
2. Age	-.17**	1.00									
3. Relationship Status	.06	-.72**	1.00								
4. Employees	.88	-.67**	.53**	1.00							
5. Retirees	-.23**	.63**	-.45**	-.69**	1.00						
6. Housewives	.29**	.01	-.06	-.34	-.45**	1.00					
7. Elder Impairment Scale	.08	-.09	.03	.05	-.03	-.02	1.00				
8. Caregiver Strain Index	.12	.12	-.17*	-.08	.08	.01	.50**	1.00			
9. Burden Interview	.09	-.07	-.01	-.02	-.01	.05	.55**	.68**	1.00		
Burden Subscales											
10. Role Strain	.10	-.04	-.09	-.03	-.00	.04	.52**	.67**	.86**	1.00	
11. Personal Strain	.05	-.16*	.09	.07	-.09	.03	.47**	.50**	.91**	.63**	1.00

* $p < .05$. ** $p < .01$.

Table 7

Predictors of Caregiver Burden (N = 202)

Predictor	Model 1				Model 2			ΔF^2	Model 3			
	<i>B</i>	<i>SE</i>	β	R^2	<i>B</i>	<i>SE</i>	β		<i>B</i>	<i>SE</i>	β	ΔF^2
Gender	1.29	1.50	.06	.02	.43	1.26	.02					
Age	-.15	.09	-.19		-.09	.08	-.11					
Relationship Status	-2.11	2.02	-.11		-1.45	1.69	-.07					
Employees	-1.98	2.14	-.10		-1.62	1.79	-.08					
Housewives	-.16	2.02	-.01		.55	1.69	.02					
Elder Impairment					.45	.05	.55***	83.75				
a. Sex x Elder Impairment									.00	.11	.01	.00
b. Age x Elder Impairment									.00	.00	-.04	.02
c. Relationship Status x Elder Impairment									-.09	.10	-.06	.69
d. Employees x Elder Impairment									.08	.11	.05	.51
e. Housewives x Elder Impairment									-.03	.14	-.01	.03

Note. Interaction terms were computed separately. *** $p < .001$.

Table 8

Predictors of Caregiver Strain (N = 217)

Predictor	Model 1				Model 2				Model 3			
	<i>B</i>	<i>SE</i>	β	R^2	<i>B</i>	<i>SE</i>	β	ΔF^2	<i>B</i>	<i>SE</i>	β	ΔF^2
Gender	1.72	.84	.15*	.05	1.26	.73	.11 ⁺					
Age	.02	.05	.05		.05	.05	.12					
Relationship Status	-1.85	1.13	-.16		-1.49	.97	-.13					
Employees	.19	1.20	.02		.39	1.03	.03					
Housewives	-.62	1.13	-.04		-.23	.97	-.02					
Elder Impairment					.24	.03	.55***	75.33				
a. Sex x Elder Impairment									.09	.07	.16	1.98
b. Age x Elder Impairment									.00	.00	.43	1.96
c. Relationship Status x Elder Impairment									-.11	.06	-.13 ⁺	3.47
d. Employees x Elder Impairment									-.02	.06	-.02	.07
e. Housewives x Elder Impairment									-.11	.08	-.10	2.29

Note. Interaction terms were computed separately. ⁺ $p < .10$. * $p < .05$. *** $p < .001$.

Table 9

Predictors of Caregiver Characteristics on Perceived Elder Impairment (N = 285)

Predictor	<i>B</i>	<i>SE</i>	β
Gender	1.90	1.54	.08
Age	-.13	.10	-.15
Relationship Status	-1.47	2.07	-.06
Employees	-.82	2.20	-.03
Housewives	-1.59	2.07	-.05
R ²	.02		

age ($\beta = -.19, p = .12$), relationship status ($\beta = -.11, p = .30$) or work status for employees ($\beta = -.10, p = .36$) or housewives ($\beta = -.01, p = .94$) (Table 7). Caregiver characteristics were not predictive of caregiver strain, with the exception of gender: gender ($\beta = .15, p = .04$), age ($\beta = .05, p = .69$), relationship status ($\beta = -.16, p = .10$) or work status for employees ($\beta = .02, p = .87$) or housewives ($\beta = -.04, p = .59$).

Elder Impairment did not mediate the relationship between caregiver characteristics and burden and strain, because the caregiver characteristics did not predict elder impairment (Table 9).

Hypothesis 7: Interaction Effects Will Be Explored. A) Does Age Interact With the Elder Impairment of the Care Recipient to Influence Burden and Strain b) Does Employment Status Interact With Elder Impairment of the Care Recipient to Influence Burden and Strain c) Does

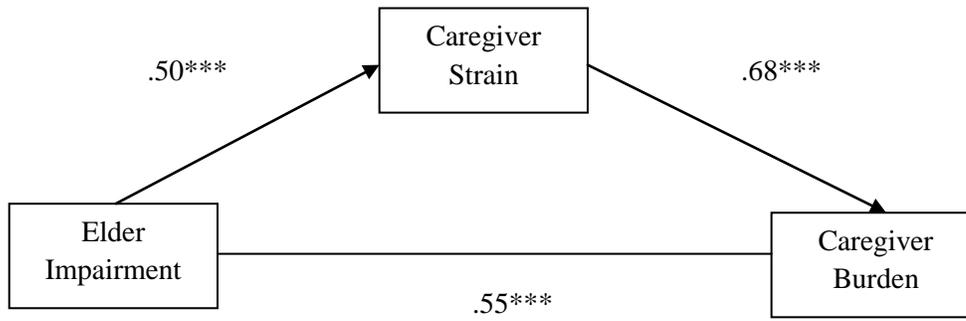
Relationship Status Interact With the Elder Impairment of the Care Recipient to Influence Burden and Strain?

None of the interaction terms, demographics paired with perceived elder impairment, were significant (Table 7 and 8).

Follow-Up Analyses

Caregiver characteristics did not seem to be predictive of perceived elder impairment or levels of burden or strain in the caregiver. It may be plausible that elder impairment leads to feelings of caregiver strain, and ultimately to caregiver burden. As a result, a follow-up test of mediation was computed (Figure 3). Results from the Sobel test (Baron & Kenny, 1986; Sobel, 1982) showed that caregiver strain was a significant mediator between elder impairment and caregiver burden ($p < .001$).

An additional analysis was computed to assess mean differences between the number of diseases spouses and adult children reported because of the differences found in the level of caregiver strain. Spouses ($M = 2.70$) reported a higher number of diseases, $F(1,260) = 17.30, p < .001$ since becoming a caregiver than adult children ($M = 1.54$). An analysis of covariance using number of diseases since becoming a caregiver showed there were still significant differences in caregiver strain after controlling for caregiver disease, $F(1,201) = 4.98, p < .05$. The indirect effect was calculated at .34.



*** $p < .001$.

Figure 3. Relationship between perceived elder impairment and caregiver burden mediated by caregiver strain

CHAPTER 5. DISCUSSION

The purpose of this study was to find out which caregiver characteristics (i.e., gender, age, relationship status, and work status) had an influence on perceived elder impairment, caregiver burden and strain. It seems most caregiver characteristics play little if any differentiating role in predicting caregiver burden and strain. The level of elder impairment appears to be most predictive in determining how strained and burdened caregivers feel, with more elder impairment causing higher levels of strain and burden. The most important findings from this study are: First, relationship status is the only caregiver characteristic that is predictive of caregiver strain, with spousal caregivers feeling more strained when compared to adult children. Second, the level of elder impairment in the care recipient is highly predictive of caregiver strain and burden and third, caregiver strain mediates the relationship between elder impairment and caregiver burden. A more in-depth discussion addressing the specific hypotheses is covered below.

Hypothesis 1: Adult Children Will Report More Elder Impairment Than Spousal Caregivers

Contrary to this hypothesis, there were no significant differences in how adult children and spouses rated the level of elder impairment of the care recipient they were providing care for. This hypothesis was stated as a result of adult children having many roles to play, with a higher number of roles than spousal caregivers. Adult children likely have their own families, may be in the workforce, and may also have to provide care to a loved one. Spouses on the other hand, were not hypothesized to have as many competing demands and thus less role strain, burden, and reported elder impairment of the person they were caring for. Research by Hayes et al. (2009) also pointed to the fact that some spouses felt a deep closeness to their spouse as a result of the caregiving relationship and were also more

devoted to that relationship than adult children (Hope et al., 1998). At least in this study, whether or not a caregiver was an adult child or a spouse did not seem to predict perceived elder impairment or caregiver burden. This is also contrary to research that has found spouses to have higher levels of burden than adult children (Andren & Elmstal, 2008). However, in this study spouses were significantly more likely to report higher levels of caregiver strain than adult children. It is possible that spouses felt high levels of role strain as their primary role changed from being a husband or wife to a caregiver. Even though the marital relationship remains, the intense change of the context of the relationship may be difficult for some caregivers, as the relationship is now more about caregiver and care recipient (Aneshensel et al., 1993). It is also plausible that spousal caregivers had higher levels of role strain because they are often in worse health than other caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Russo, Vitaliano, Brewer, Katon & Becker, 1995). Spousal caregivers may be managing their own health needs while trying to meet the needs of the care recipient.

A follow-up analysis, controlling for disease in the caregiver did not indicate that disease was the reason spouses had higher levels of caregiver strain. It is still possible that health of the caregiver did play a role in caregiver strain but was not found in this study due to limited health variables available to control for.

Hypothesis 2: Younger/Middle-Aged Caregivers and Older-Aged Caregivers Will Report More Elder Impairment Than the Oldest-Aged Caregivers, With the Younger/Middle-Aged Caregivers Reporting the Greatest Level of Elder Impairment

There were no significant differences on the rated level of elder impairment in the care recipient based on the three categories of age (young/middle-aged, older-aged, and the

oldest-aged). There were also no significant differences in caregiver burden depending on the age of the caregiver. These findings seem to agree with previous research by Campbell et al. (2008) who did not find significant differences in caregiver burden based on the age of the caregiver. Although there were no significant differences in how strained caregivers felt, there was a trend showing that older caregivers reported more strain. Older caregivers may have feelings of strain as a result of their own health issues and needs in addition to trying to be a caregiver and manage the issues the care recipient is facing. Interestingly, the burden subscale personal strain showed a trend indicating that the older the caregiver the less personal strain was felt. These findings seem to contradict one another. It may be that younger caregivers have higher levels of personal strain because questions on the personal strain subscale dealt more with feeling uncertain about what to do for the care recipient as well as feelings of resentment (e.g., anger, embarrassment about behavior, wishing someone else could be a caregiver). Perhaps younger caregivers had more resentment about being a caregiver and sometimes wished they had not been put in a caregiving situation. The other subscale, role strain, did not yield any significant differences based on caregiver age. More research is needed in order to understand how caregiver age may influence burden and strain, especially taking into account the existing health of the caregiver.

Hypothesis 3: Does Outside Employment Make Caregivers Experience Higher Levels of Burden and Strain or Lessen Feelings of Burden and Strain?

Whether or not a caregiver was employed, retired, or a housewife did not seem to make a difference on how burdened or strained the caregiver felt, nor did it make a difference in the reported level of elder impairment in the care recipient. More research is necessary when looking at the effects of employment on caregiving. Previous research has shown that

it depends on the type of employment caregivers engage in that influences how they feel about their caregiving situation (Chorn-Dunham & Dietz, 2003). Flexibility while being employed appears to be extremely important as caregivers who were working a flexible job enjoyed the change of pace from caregiving. Caregivers often changed jobs to something more flexible when caregiving began in order to manage their busy lives (Chorn-Dunham & Dietz). Employed caregivers in this study did not have higher levels on the burden or strain measures that asked questions related to feelings of strain, anxiousness, and losing control. Other research has also mentioned the protective effect working or volunteering can have on caregiver well-being by providing them with a productive and social outlet not necessarily achieved through caregiving (Rozario, Morrow-Howell, & Hinterlong, 2004). The importance of flexibility in volunteering and working was also mentioned as an area of importance for caregivers (Rozario et al.)

Hypothesis 4: Women Will Report More Elder Impairment and Experience Higher Levels of Burden and Strain Than Men

There were no significant gender differences on the level of perceived elder impairment of the care recipient they were caring for, nor on caregiver strain or burden. However, there was a trend showing that women were more likely to have higher levels of burden, although the difference between men and women was not statistically significant. This finding was also noted in the hierarchical regression of caregiver strain, where gender was a significant predictor. This trend seems similar to what other research has found, indicating that women have greater anxiety and sadness as a caregiver than men (Rudd et al., 1999). Hayes et al. (2009) also showed that wives were more likely than husbands to feel as though their marital relationship was changing due to dementia. It is possible that women in

this study felt more burdened because they felt they were more of a caregiver than wife and had difficulty dealing with this new reality. However, previous research has shown that women have higher levels of depression and anxiety than men (Leach, Christensen, Mackinnon, Windsor, & Butterworth, 2008), which may increase the likelihood of feelings of burden.

Hypothesis 5: Caregivers Who Report More Elder Impairment Will in Turn Report Higher Levels of Burden

The relationship between greater elder impairment and higher levels of burden and strain was highly significant. This finding is not particularly surprising as many other researchers have reported on the link between behavior problems and burden (Leinonen et al., 2002; Majerovitz, 2001; Perren et al., 2006). More research assessing the type of elder impairment or problem behavior the care recipient engages in may be helpful in suggesting interventions or support strategies to the caregiver to lessen feelings of burden and strain.

Hypothesis 6: Elder Impairment Will Be a Mediator Between Caregiver Characteristics and Caregiver Burden and Strain

Perceived elder impairment was not a mediator between the demographic characteristics of the caregiver and caregiver burden and strain. Results showed that caregiver demographic characteristics seemed to have less of an impact on caregiver burden and strain than previously thought. It is possible that elder impairment is a universal experience and that caregiver characteristics do not have an impact on the way a caregiver rates the level of elder impairment. Instead it appears that caregivers rate elder impairment quite similarly and that their age, relationship to the care recipient, gender, and work status do not affect this rating. It was previously thought that because caregivers were of different

ages, had different relationships, genders, and work statuses they would have had different perceptions about the level of impairment and in turn rate it differently because of their own caregiver characteristics.

It is also possible that other variables could have mediated the relationship between caregiver characteristics and caregiver burden and strain. Previous research has shown that the level of income in the caregiver influences feelings of burden, with lower levels of income associated with higher levels of burden (Evans, Wethington, Coleman, Worms, & Frongillo, 2008). Ethnicity of the caregiver, with a more diverse sample, may have also been an important caregiver characteristic, as previous research has shown that African American caregivers, compared to White caregivers, rate care recipient behavioral problems as less stressful (Haley et al., 1996). Additional caregiver characteristics that should be explored in the future include household size and the amount of help provided by caregivers.

Hypothesis 7: Interaction Effects Were Explored. 1) Does Age Interact with Elder Impairment of the Care Recipient to Influence Burden and Strain 2) Does Work Status Interact With Elder Impairment of the Care Recipient to Influence Burden and Strain 3) Does Relationship Status Interact With Elder Impairment of the Care Recipient to Influence Burden and Strain?

The interactive effects of caregiver characteristics of the caregiver and elder impairment did not predict caregiver burden or strain. This again suggests that caregiver characteristics have less of an influence on caregiver burden and strain, even when looking at their combined interaction with elder impairment. Again, it was hypothesized that adult children and spouses would perceive elder impairment differently. However, it seems caregiver characteristics do not play a role in how caregivers rate elder impairment.

Caregiver Strain as a Mediator

As a result of caregiver characteristics having less of an effect on caregiver burden and strain but also taking into account the significant relationship among burden, strain, and elder impairment, a path analysis was computed assessing caregiver strain mediating the relationship between elder impairment and caregiver burden. Caregiver strain significantly mediated the relationship between elder impairment and caregiver burden. In other words, elder impairment is associated with caregiver strain, which in turn is associated with caregiver burden. These findings seem to indicate that elder impairment causes feelings of strain in caregivers, perhaps because some of the impairment is challenging and frustrating to deal with and that is why there is a relationship between elder impairment and caregiver burden. If elder impairment did not cause such high levels of caregiver strain, the rates of caregiver burden would be reduced.

Limitations

The limitations of this study include the measures used in the study. Only some of the questions were used from the Burden Interview and Caregiver Strain Index. The full intact scales were not used in this study. The demographic questions of the caregiver could also have been more specific, such as including the gender of the care recipient. As a result of this taking place in the Midwest it is likely that most caregivers who completed a questionnaire were White. Religious affiliation of the caregiver indicated that the large majority of caregivers classified themselves as “Protestant” showing religious diversity was not present in this study. This study is generalizable to other areas of the Midwest but not likely to the United States as a whole. Causality cannot be inferred because of the cross-sectional study design. Caregivers only answered questions about themselves and the care

recipient at one point in time and were not followed throughout the course of the caregiving experience.

Sample Comparisons. Looking at the living situation of care recipients showed caregivers caring for a care recipient had higher levels of burden, personal strain, and role strain than caregivers caring for a recipient in an institution. At-home caregivers likely have higher levels of stress as they are often dealing with the aspects of caregiving on their own rather than with a team of trained staff. Interestingly, caregivers did not rate their level of strain significantly different from one another. It is possible that caregivers caring for a care recipient in an institution still felt strained because they likely still had to make difficult decisions for the care recipient and perhaps still had to adjust their life in order to meet the needs of the care recipient. It does not appear to be unusual that caregivers caring for a care recipient in an institution rated the elder impairment of that person significantly higher than care recipients in an at-home situation. It seems likely that with the advancement of dementia, caregiving may be increasingly difficult at-home and institutionalization may be necessary.

Implications and Future Research

Future research needs to look more closely at the link between elder impairment and caregiver burden and strain. Understanding what types of impairments or behavioral problems are most difficult for caregivers to deal with may lead to successful development of intervention strategies. Clearly from this study, caregiver characteristics have less of an influence on caregiver burden and strain and seem to reflect a more universal experience rather than individual one. Interventions need to be developed that are specifically targeted at reducing caregiver strain as a result of elder impairment. Specific intervention strategies

targeted at assisting caregivers in coping with elder impairment and managing the stress from that impairment may lower feelings of caregiver strain and reduce levels of caregiver burden.

It is important for clinicians and researchers to understand that the caregiving experience seems to be more universal than it is different for caregivers. Targeted interventions for caregivers should note the strong relationship between elder impairment and caregiver burden and strain. Specific interventions addressing appropriate ways to manage elder impairment will be most helpful to caregivers and may lead to a reduction in burden and strain.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVED LETTER

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Institutional Review Board
Office for Responsible Research
Vice President for Research
1138 Pearson Hall
Ames, Iowa 50011-2207
515 294-4566
FAX 515 294-4267

DATE: December 1, 2009

TO: Melinda Heinz
96 LeBaron Hall

CC: Peter Martin
1085 Elm Hall

FROM: Office for Responsible Research

TITLE: **Dementia Caregiving Characteristics, Elder Impairment, and Caregiver Burden**

IRB ID: 09-558

Submission Type: New

Exemption Date: 30 November 2009

The project referenced above has undergone review by the Institutional Review Board (IRB) and has been declared exempt from the requirements of the human subject protections regulations as described in 45 CFR 46.101(b). The IRB determination of exemption means that:

- **You do not need to submit an application for annual continuing review.**
- **You must carry out the research as proposed in the IRB application**, including obtaining and documenting informed consent if you have stated in your application that you will do so or if required by the IRB.
- **Any modification of this research should be submitted to the IRB on a Continuing Review and/or Modification form, prior to making any changes**, to determine if the project still meets the federal criteria for exemption. If it is determined that exemption is no longer warranted, then an IRB proposal will need to be submitted and approved before proceeding with data collection.

Please be sure to **use only the approved study materials** in your research, including the **recruitment materials and informed consent documents that have the IRB approval stamp.**

Please note that you must submit all research involving human participants for review by the IRB. **Only the IRB may make the determination of exemption**, even if you conduct a study in the future that is exactly like this study.

APPENDIX C. BURDEN INTERVIEW

This set of questions concerns your reactions caregiving. Please read each statement below and indicate whether it represents your feelings about caregiving NEVER, RARELY, SOMETIMES, or ALWAYS. Circle the letter that corresponds to your answer.

	NEVER	RARELY	SOMETIMES	ALWAYS
1. Because of my involvement with the person I care for, I don't have enough time for myself.	N	R	S	A
2. I feel stressed between trying to give to the person I care for as well as to other family responsibilities, job, etc.	N	R	S	A
3. I feel that the present situation with the person I care for doesn't allow me as much privacy as I'd like.	N	R	S	A
4. I feel that my social life has suffered because of my involvement with the person I care for.	N	R	S	A
5. I feel uncomfortable when friends visit.	N	R	S	A
6. I feel that I don't have enough money to support the person I care for in addition to the rest of my expenses.	N	R	S	A
7. I feel embarrassed about the behavior of the person from whom I care.	N	R	S	A

8. I am afraid of what the future holds for the person for whom I provide care.	N	R	S	A
9. I feel that the person I care for is overly dependent.	N	R	S	A
10. I feel that I will be unable to provide care much longer.	N	R	S	A
11. I feel that I have lost control of my life since the person I care for became ill.	N	R	S	A
12. I feel burdened as a caregiver.	N	R	S	A
13. I feel angry towards the person I care for.	N	R	S	A
14. I feel that I don't do as much for the person I care for as I could or should.	N	R	S	A
15. I feel that the person I care for seems to expect me to take care of him/her as if I were the only one he/she could depend on.	N	R	S	A
16. I sometimes wish I could just leave caregiving to someone else.	N	R	S	A
17. I feel uncertain about what to do about the person I care for.	N	R	S	A
18. I feel strained in my relationship with the person I care for	N	R	S	A

19. I feel that the person I care
for makes more requests
than necessary.

N

R

S

A

APPENDIX D. CAREGIVER STRAIN INDEX

Below are a number of statements concerning ways in which caregiving can potentially influence other aspects of a caregiver's life. Please read each statement and indicate whether the situation or the feeling described has occurred to you NEVER, RARELY, SOMETIMES, or ALWAYS. Circle your responses.

	NEVER	RARELY	SOMETIMES	ALWAYS
1. My sleep has been disturbed as a result of caregiving (e.g., the person I care for wanders at night).	N	R	S	A
2. Caregiving is confining (e.g., helping restricts free time).	N	R	S	A
3. Caregiving has required family adjustments (e.g., because helping has disrupted routine).	N	R	S	A
4. Caregiving has required changes in personal plans (e.g., could not go on vacation).	N	R	S	A
5. Caregiving has required work adjustments (e.g., because of having to take time off).	N	R	S	A
6. Caregiving is a financial strain.	N	R	S	A
7. Caregiving is inconvenient (e.g., because helping takes so much time).	N	R	S	A
8. Caregiving is a physical strain (e.g., because of lifting in and out of a chair).	N	R	S	A

- | | | | | |
|--|---|---|---|---|
| 9. The behavior of the person I care for is upsetting (e.g., incontinence; he/she has trouble remembering things). | N | R | S | A |
| 10. Caregiving has required emotional adjustments (e.g., because of severe arguments). | N | R | S | A |
| 11. It is upsetting to find that the person I care for has changed so much from his/her former self. | N | R | S | A |
| 12. Caregiving has made me feel completely overwhelmed (e.g., because of concerns about how I will manage). | N | R | S | A |

APPENDIX E. ELDER IMPAIRMENT SCALE

The next set of questions concerns the behavior of the person for whom you provide care. Read each statement below. Please indicate how often each behavior occurs by circling one of the following answers: NEVER, RARELY, SOMETIMES, or ALWAYS.

	NEVER	RARELY	SOMETIMES	ALWAYS
1. Elder is interesting to talk to	N	R	S	A
2. Elder does things harmful to self and others.	N	R	S	A
3. Elder complains or criticizes things.	N	R	S	A
4. Elder is enjoyable to be with.	N	R	S	A
5. Elder repeats self.	N	R	S	A
6. Elder interferes with caregiver and other household members.	N	R	S	A
7. Elder is friendly and sociable toward people.	N	R	S	A
8. Elder talks or mumbles to self.	N	R	S	A
9. Elder fails to respect privacy.	N	R	S	A
10. Elder seems interested in things.	N	R	S	A
11. Elder has unrealistic fears.	N	R	S	A
12. Elder yells or swears at people.	N	R	S	A
13. Elder is cooperative.	N	R	S	A

14. Elder wanders inside the house.	N	R	S	A
15. Elder does embarrassing things.	N	R	S	A
16. Elder is clean or neat about self.	N	R	S	A
17. Elder hears or sees things that are not there.	N	R	S	A
18. Elder disrupts meals or makes them unpleasant.	N	R	S	A
19. Elder is appreciative or grateful for help.	N	R	S	A
20. Elder is forgetful.	N	R	S	A
21. Elder is withdrawn or unresponsive.	N	R	S	A
22. Elder physically strikes out at people.	N	R	S	A
23. Elder is confused.	N	R	S	A

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