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# Caregiving Choice and Emotional Stress among Cancer Caregivers

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## Abstract

Caring for a relative or friend with cancer may be highly demanding and emotionally burdensome. Theory suggests that personal characteristics of a caregiver may contribute directly to a caregiver's emotional health. An underexplored variable is a caregiver's perception of choice in providing care to a relative or friend. Thus, this study sought to characterize perceived choice in providing care among family cancer caregivers and examine its association with emotional stress. This study is a secondary analysis of cross-sectional telephone interviews of 1,247 family caregivers, which included 104 cancer caregivers. The findings indicated that a high majority of cancer caregivers expressed elevated emotional stress. Most caregivers perceived themselves to have had a choice in providing care; however, a perceived lack of choice in providing care was significantly associated with greater emotional stress. Assessing clinical and policy-related strategies for alleviating concerns related to choice may be of value in the cancer context.

### Keywords

Caregiving; stress; cancer; caregiver; choice

Family caregiving refers to unpaid care provided to a relative or friend due to illness, disease, or disability. Caregivers commonly communicate with health care professionals, offer emotional support, manage pain or medications, and assist with daily life tasks, such as housekeeping and transportation (Coristine, Crooks, Grunfeld, Stonebridge, & Christie, 2003; IOM, 2008). Nearly a quarter of adults in the U.S. provide family care to another adult, and cancer is proving to be a primary reason for such care (National Alliance for Caregiving, 2009). As many Americans assume the cancer caregiving role, it is important to explore the potential adverse consequences of such a role and contributing factors.

## Cancer Caregiver Stress and Caregiving Choice

A growing body of literature suggests that cancer caregiving is physically and emotionally taxing (Coristine, et al., 2003). Indeed, following Alzheimer's disease (AD), cancer was reported as the second most frequently reported reason for providing family care among caregivers providing high intensity or burdensome care (National Alliance for Caregiving,

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2009). Similarly, another analysis indicated that cancer and dementia caregivers reported the highest levels of physical burden and psychological distress compared to other contexts, including diabetes and frail elderly caregiving (Kim & Schulz, 2008). Heightened anxious and depressive symptoms are also evident among cancer caregivers (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005), sometimes at levels even greater than reported by patients themselves (Hodges & Humphris, 2009; Longacre, Ridge, Burtness, Galloway, & Fang, 2012; Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004). Heightened emotional burden is shown to place caregivers at risk for poorer health outcomes, including decreased immune function and greater risk for cardiovascular disease (Damjanovic et al., 2007; Redwine et al., 2004; Schulz & Beach, 1999).

Sherwood and colleagues' mind-body framework of caregiving stress suggests that disease characteristics may prompt psycho-behavioral and biologic responses in caregivers, which may then lead to changes in overall physical health. In this same model, personal characteristics of caregivers are also suggested to lead directly to caregiver psycho-behavioral responses or moderate the relationship between care recipient disease characteristics and caregiver psycho-behavioral responses (Sherwood et al., 2008). Related research shows that greater objective burden or care intensity (i.e., providing a high number of hours of care and assistance with a higher number of functional deficits) as well as subjective burden (i.e., the perception of caregiving as straining) are associated with higher levels of caregiver anxiety, depressive symptoms, and emotional stress (Cannuscio et al., 2002; Grunfeld et al., 2004; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Palos et al., 2011). Further, caregiver characteristics, such as non-Hispanic white race, female gender, poor self-rated health, and residence in the same household as the care recipient, have also been shown to be associated with greater caregiver emotional stress (Dunkin & Anderson-Hanley, 1998; Etters, Goodall, & Harrison, 2008; National Alliance for Caregiving & AARP, 2004; Yee & Schulz, 2000).

In addition to these key variables, an often overlooked caregiver characteristic is a caregiver's perception of choice in providing family care. In qualitative studies, some cancer caregivers have reported little or no choice in taking on the caregiving role (Wennman-Larsen & Tishelman, 2002). Similarly, among adults caring for a parent with multiple sclerosis, almost one-third reported no or little choice in assuming caregiving responsibilities for their parent (Pakenham & Bursnall, 2006). Perceived lack of choice may be due to a variety of reasons, including the nature of the caregiver-care recipient relationship, financial barriers, or a lack of available support services (Arksey & Glendinning, 2007). However, regardless of the reason, caregivers who perceive having little choice in taking on the caregiving role report greater emotional stress and poorer adjustment (National Alliance for Caregiving & AARP, 2004; Pakenham, Chiu, Bursnall, & Cannon, 2007; Winter, Bouldin, & Andresen, 2010). In contrast, greater perceived choice is often associated with higher levels of life satisfaction and positive affect (Pakenham, et al., 2007).

Caregiving choice has not been extensively studied among cancer caregivers even though more individuals will likely need to step into the cancer caregiving role over the next several decades. Due to a projected increase in the U.S. elderly population, a corresponding increase in cancer diagnoses is anticipated. Through 2030, 1.6 million older individuals (i.e., 65 or older) are estimated to be diagnosed with cancer, which will represent a 67% increase from 2010 (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). Further, a variety of factors are anticipated to shift the burden of care onto family caregivers, including a move toward more outpatient cancer care, advances in home-care technologies, and financial constraints (e.g., the cost of financing home aides).

A subset of caregivers may voluntarily choose to provide care, while others might be called upon to assume a caregiving role out of necessity (Burridge, Winch, & Clavarino, 2007). In discussing the concept of reluctance to care, Burridge and colleagues (Burridge, et al., 2007) propose that caregiver and care recipient factors influence caregiving reluctance. Thus, this study sought to characterize perceptions of choice in providing care among cancer caregivers, and, building on Sherwood and colleagues' model of caregiving stress (Sherwood, et al., 2008), examine the association of perceived choice in caregiving with emotional stress. The primary research question is as follows: Is caregiving choice associated with emotional stress among caregivers providing care to relatives or friends with cancer? Based on findings from other care contexts (National Alliance for Caregiving & AARP, 2004; Pakenham, et al., 2007; Schulz et al., 2012), it was hypothesized that a perceived lack of choice in providing care among cancer caregivers would be independently associated with greater emotional stress. Findings may allow for targeting subgroups of cancer caregivers with low perceived choice who are at risk for poor outcomes.

## Method

### Data Source and Sample

This study is a secondary analysis of a sample of 1,247 family caregivers identified through a survey of 6,139 adults in the U.S. (NAC/AARP, 2005). These data were collected by Belden, Russonello, and Stewart in 2003 for a report on caregiving in the U.S. by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP). Cross-sectional interviews were conducted via telephone. The national sample of 6,139 adults was acquired using random digit dialing (RDD) and targeted approaches. Targeted RDD was initiated to ensure that 200 interviews were performed for African American, Hispanic, and Asian American caregivers. Because targeted RDD did not result in an adequate number of Hispanic and Asian American caregiver interviews, Knowledge Networks was consulted to identify additional interviews. A sample of 1,247 caregivers was identified from the 6,139 adults. Caregivers were individuals age 18 or older living in the U.S. and providing one or more activities of daily living (ADL) or instrumental activities of daily living (IADL) for an adult (i.e., age 18 or older). A full description of the sampling technique is available in the NAC and AARP report entitled "Caregiving in the United States" (National Alliance for Caregiving & AARP, 2004). Of the 1,247 caregivers, 104 indicated that the primary reason for them providing care was cancer.

### Measures

The primary research question to be addressed is whether caregiving choice is associated with emotional stress among caregivers providing care to relatives or friends with cancer.

Potential covariates were also included based on prior literature (Cannuscio, et al., 2002; Dunkin & Anderson-Hanley, 1998; Etters, et al., 2008; Grunfeld, et al., 2004; Kim & Schulz, 2008; Nijboer, et al., 1999; Schulz, et al., 2012; Yee & Schulz, 2000). Covariates were comprised of caregiver demographic variables (gender, race/ethnicity, age, income, education level), caregiver self-reported health, duration of care, objective burden, assistance with IADs/ADLs, hours of care provided per week, AD co-morbidity, primary caregiver status, distance to care recipient, and care recipient's relationship to caregiver. These measures were included in the national survey conducted by the NAC and AARP (for more details, please see the report entitled “Caregiving in the U.S.”) (National Alliance for Caregiving & AARP, 2004) and are described below.

**Caregiving Choice—**Caregivers were asked about their perception of having choice in assuming the caregiving role: “Do you feel you had a choice in taking on this responsibility?” (yes or no).

**Emotional Stress—**Emotional stress was assessed using the following item: “How emotionally stressful would you say caring for your relative/friend is/was for you?” Response options ranged from 1 (not at all stressful) to 5 (very stressful). As in previous research (Winter, et al., 2010), this variable was recoded into either low stress (responses 1-2) or moderate to high stress (responses 3-5).

**Duration of Care—**To assess how long caregivers provided care, caregivers were asked, “For how long have you been providing/did you provide help to your relative/friend? Response options included: occasionally, less than 6-months, 6-months to 1 year, 1 year through 4 years, 5-9 years, 10 or more years. Due to the modest sample size, duration of care was then categorized as follows: 1) occasional or less than 6-months, 2) 6-months to 1 year, 3) 1 year through 4 years, and 4) five or more years.

**Objective Burden—**A Level of Burden Index was used to classify objective burden or intensity of care from level one through level five. Level one reflects the lowest objective burden and level five comprises the heaviest objective burden. The Level of Burden Index is based the Type of Care Index (i.e., number of Instrumental Activities of Daily Living [IADL] tasks and Activities of Daily Living [ADL] tasks) and the Hours of Care Index (i.e., number of hours of care provided weekly). Both indexes are described in detail below. Caregivers at Level 1 on the Level of Burden Index perform no ADLs and perform few hours of care per week, while Level 5 caregivers perform at least two ADLs and provide more than 40 hours of care per week. This measure of objective burden and associated indexes were established by NAC and AARP based on literature detailing care intensity and has been used in prior research (National Alliance for Caregiving, 2009; National Alliance for Caregiving & AARP, 2004). Also due to the small sample size, responses were categorized as having low burden (levels 1-2) or moderate to high burden (levels 3-5) for the present analysis.

**Type of Care Index—**The Type of Care Index is based on the number of IADL tasks and the number of ADL tasks performed by a caregiver. To determine ADL, caregivers were read and asked the following, “I'm going to read a list of kinds of help, which might be provided to a person, if the person cannot do this by him or herself. For each, just tell me if you [provide/provided] this kind of help. [Do/Did] you help your friend or relative: Get in and out of beds and chairs; get dressed; get to and from the toilet; bathe or shower; dealing with incontinence or diapers; by feeding him or her; giving medicines, pills, or injections.” (Yes or no was required for each ADL task). To determine IADL assistance, caregivers were asked: [Do/Did] you provide help for your relative or friend with: Managing finances, such as paying bills, or filling out insurance claims; grocery shopping; housework, such as doing dishes, laundry, or straightening up; preparing meals; transportation, either by driving him or her, or helping your friend or relative get transportation; arranging or supervising services from an agency, such as nurses or aides?” (Yes or no was required for each IADL task). The Type of Care Index characterized caregivers whether they performed 1 IADL task and 0 ADL; 2 IADL task and 0 ADL; 1 ADL (with or without IADLs); or 2 or more ADLs (with or without IADLs).

**Hours of Care Index—**Caregivers were asked “About how many hours do/did you spend in an average week doing these things?” Responses were categorized as 0-8 hours; 9-20; 21-40; 41 or more hours.

**Co-occurring Alzheimer's Disease or Mental Confusion—**Caregivers were asked whether their relative or friend suffered from Alzheimer's disease or other mental confusion (yes or no).

**Demographics—**Caregiver demographic variables, including gender, race/ethnicity, age, income, and education level were assessed. Caregiver self-reported health was also assessed using the following item: “How would you describe your own health?” As in the NAC & AARP report (National Alliance for Caregiving & AARP, 2004), responses were indexed into three categories: excellent; very good/good; or, fair/poor.

**Primary Caregiver Status—**Caregivers were described as primary (i.e., provide most of care) or secondary (i.e., do not provide the most care but do provide some level of assistance) caregivers. Status was based on the following questions: 1) Has anyone else provided unpaid help to your (relative/friend) during the last 12-months? (Yes or no); 2) Who would you consider to be the person who provided/provides most of the unpaid care for your (relative/friend) (Self; someone else; we split it 50-50). Caregivers were considered primary caregivers if no one else provided unpaid help (question #1 “no” response) or if respondent provides most of the help (question #2 “self” response). Caregivers were considered secondary caregivers if someone else provides most of the unpaid help or split care (question #2 “someone else” or “split 50-50” responses).

**Distance to Care Recipient—**Distance to care recipient was assessed using the following item: “Does/did your (relative/friend) live in your household?” Responses were classified into the following three categories: Living with care recipient; living less than an hour away; living one hour or more from care recipient.

**Care Recipient's Relationship to Caregiver—**Caregiver were asked: What [is/was] this person's relationship to you? Responses were pre-coded open-ended and included:

spouse, mother, father, mother-in-law, father-in-law, son, daughter, brother, sister, brother-in-law, sister-in-law, grandmother, grandfather, grandparent-in-law, aunt/uncle, other relative, friend/relative/neighbor, companion/partner, cousin, don't know, refused. For this analysis, relationship was categorized according to: Spouse/companion; parent/grandparent (or in-law); sibling (or in-law); offspring; other relative; or non-relative.

### Statistical Analyses

The primary research question is as follows: Is caregiving choice (independent variable) associated with emotional stress (dependent variable) among caregivers providing care to relatives or friends with cancer? To examine this question, we first performed bivariate chi-square analyses to evaluate whether: 1) perceived choice is associated with any demographic or caregiving covariates; and 2) distress is associated with any demographic or caregiving covariates. Based on prior literature, covariates selected for analyses included demographics, duration of care, objective burden, assistance with IADs/ADLs, hours of care provided per week, AD co-morbidity, primary caregiver status, distance to care recipient, and care recipients relationship to caregiver (Cannuscio, et al., 2002; Dunkin & Anderson-Hanley, 1998; Etters, et al., 2008; Grunfeld, et al., 2004; Kim & Schulz, 2008; Nijboer, et al., 1999; Schulz, et al., 2012; Yee & Schulz, 2000). Next, logistic regression was performed to evaluate the primary research question. Model variables included potential covariates identified in the preliminary analyses. Variables in the logistic regression model were entered simultaneously. Data were analyzed using SPSS 19.

## Results

The cancer caregivers in this sample were generally middle-aged (mean age of 45 years, range 18-99) and female (65%). Most of the caregivers provided care to a parent or grandparent (or in-laws) (55.3%), and provided care for less than one year (58.7%). According to the objective Level of Burden Index (i.e., IADLs/ADLs and hours per week), cancer caregiving was highly burdensome or strenuous for a majority of these cancer caregivers (55% for levels 4 and 5 on the Level of Burden Index). Additional demographics and caregiving-related characteristics are presented in a previously published article (Longacre, 2013).

### Cancer Caregiver Perceived Choice and Emotional Stress

Almost 69% of cancer caregivers perceived that they had a choice in providing care. Perceived choice was not significantly associated with caregiver characteristics (e.g., demographics, primary caregiver status, distance, relationship type) or characteristics related to care (e.g., duration of care, objective burden, type of care (IADLs/ADLs), hours of care per week, co-occurring AD) in bivariate analyses (see Table 1).

Most of these cancer caregivers (69.2%) expressed that caregiving was moderately to very stressful (i.e., levels 3-5), with over a quarter (28%) of caregivers reporting caregiving as being very stressful (i.e., level 5). In bivariate analyses, no demographic variables were significantly associated with emotional stress among cancer caregivers. In addition to choice, objective burden and patient cooccurring mental confusion or AD were significantly associated with emotional stress among these cancer caregivers (see Table 2). A higher percentage of cancer caregivers with high objective burden (levels 3-5) (80.6%, n=67) described caregiving to be moderately to highly stressful than cancer caregivers with lower objective burden (levels 1-2) (48.5%, n=33), $\chi^2$ (1) = 10.857, p = 0.001. A higher proportion of caregivers caring for a cancer patient without co-occurring AD or mental confusion (71.7%, n=99) expressed heightened emotional stress compared with caregivers of cancer patients with co-occurring AD or mental confusion (20%, n=5), $\chi^2$(1) = 5.976, p = 0.030. The Type of Care Index (ADLs/IADLs) and Hours of Care Index, both of which comprise the Burden Index, were also significantly associated with emotional stress among the caregivers (see Table 2).

### Is caregiving choice associated with emotional stress among caregivers providing care to relatives or friends with cancer?

In unadjusted analyses among cancer caregivers, perceived choice in providing care was significantly associated with emotional stress, $\chi^2$(1)=5.17, p=0.023. A higher percentage of caregivers who perceived a lack of choice in providing care (84.4%, n=32) reported elevated emotional stress than caregivers who perceived they had a choice (62%, n=71). Controlling for patient co-occurring AD or mental confusion and objective burden, the association between perceived choice and caregiver emotional stress remained statistically significant (see Table 3). Further, the probability of expressing elevated stress was higher among caregivers expressing moderate to high objective burden (levels 3-5) compared with reporting with lower objective burden (levels 1-2), while the probability of elevated stress was lower among those caring for a patient experiencing AD or mental confusion compared with those not providing such care.

## Discussion

This study sought to characterize caregiving choice and explore its association with stress among a sample of cancer caregivers. These caregivers were middle-aged and primarily female. A majority of these caregivers were also caring for a parent or grandparent and lived outside of the patient's home, which differs from other studies in which a majority of the cancer caregivers were spouse-caregivers and were living with the patient (Osse, Vernooij-Dassen, Schade, & Grol, 2006; Schubart, Kinzie, & Farace, 2008).

Most of the caregivers in this study reported having had a choice in providing care. No significant associations were noted between caregiver or care characteristics and caregiving choice. Prior studies incorporating of caregivers providing care for diverse reasons noted differences in perceived choice by caregiver age, education, duration of care and care intensity (Schulz, et al., 2012; Winter, et al., 2010). The nature of the relationship between a caregiver and care recipient has also been noted as a significant factor in prior studies. Specifically, Winter and colleagues noted that caregivers without a choice most frequently reported being a child of the care recipient compared to any other type of relative (Winter, et al., 2010). It has been suggested that a sense of obligation may be strongest among spouse or adult child caregivers (Arksey & Glendinning, 2007; Schulz, et al., 2012). For example, feelings of “betrayal of marriage vows” may make spouses feel obligated to provide the necessary care, and, thus, spouse caregivers may then perceive less choice in caregiving roles (Arksey & Glendinning, 2007). Indeed, among a diverse sample of caregivers, those taking care of a spouse or parent were more likely to report not having a choice than those taking care of other relatives (Schulz, et al., 2012). Potential associations between choice and characteristics such as relationship type should continue to be explored among cancer caregivers.

Similar to other findings (Kim & Schulz, 2008; National Alliance for Caregiving, 2009), the majority of the cancer caregivers in this study reported elevated stress levels. Importantly, a lack of choice was a significant predictor of greater emotional stress. Given this finding, assessing a caregiver's perception of choice may be an effective method toward screening caregivers who might be at risk for poor mental health outcomes.

How to best discuss concerns of caregiving choice within the clinical context remains under-explored. Inherent with discussions of caregiving choice are considerations of privacy and cultural beliefs and values. Thus, such discussions may need to be approached delicately. Although the Institute of Medicine (IOM) has named family caregivers as a vital component of the health care team (IOM, 2008), the degree of integration of caregivers within clinical care continues to vary across contexts and institutions. Future research might benefit from exploring strategies for integrating caregivers and assuring that they are equipped and supported in providing care. A recent finding highlights the importance in recognizing pre-existing factors that may impact a caregiver's emotional response (Cipolletta, Shams, Tonello, & Pruneddu, 2013). Understanding how and why a caregiver arrives in a caregiving role may similarly be an important pre-existing factor.

The finding that a perceived lack of choice is associated with elevated stress among cancer caregivers may also have implications for policy making as policies can contribute to perceptions of choice. The Family and Medical Leave Act (FMLA) is a policy that may contribute to a caregiver's perception of having had a choice with regard to providing acute, short-term care. A caregiver may retain employment (unpaid) for up to 12 weeks to care for a seriously ill relative. Finding from this research might suggest bolstering support for such policies that allow caregivers to remain employed while providing care.

Likewise, this finding may also have important implications for long term care policy. Long term care services may be required as a result of a prolonged illness, including cancer. Needed services may include homemaker services, home health aide services, adult day health services, assisted living care, and nursing home care. As a perceived lack of choice may be a result of an inability to afford long term care services for a family member, findings from this study support efforts toward developing a sustainable long-term care financing structure in the U.S. With the suspension of Community Living Assistance Services and Supports (CLASS) under the Affordable Care Act, services remain commonly financed via Medicare, Medicaid, out-of-pocket spending, or through long-term care insurance. Developing a structure that encourages the purchasing of long term care insurance for future need may ultimately be of benefit to family members with regard to caregiving choice. Alternatively, for those with an immediate need for services for a family member, tax credits for the out-of-pocket financing of cost effective services may be an incentive and provide relief to caregivers. Exploring reasons for a perceived lack of choice in future research would help to clarify which policies might contribute toward helping a caregiver feel as though he or she had a choice in providing care.

In addition to a lack of caregiving choice, adjusted analyses showed that heightened objective burden was also associated with elevated stress levels among the cancer caregivers. This also supports previous findings of a relationship between elevated objective burden and elevated stress among caregivers providing care for various reasons (Cannuscio, et al., 2002; Grunfeld, et al., 2004; National Alliance for Caregiving & AARP, 2004). The adjusted analysis also showed a lower likelihood of elevated stress among cancer caregivers providing care to patients with AD or mental confusion compared to caregivers providing care to patients without cognitive decline. This finding is in contrast to previous reports that indicate greater stress among caregivers for persons with dementia (Kim & Schulz, 2008; National Alliance for Caregiving, 2009). It is possible that these caregivers may have a unique perspective on caregiving in light of the patient's cognitive decline or may even experience a sense of relief or acceptance. However, it is important to note that this is speculative and based on a small sample of caregivers. Future research might consider issues of patient co-morbidity, particularly AD-related, and cancer caregiver stress among a larger sample.

This study has several limitations as the data were not originally collected to assess the relationship between perception of caregiving choice and emotional stress. A fuller representation of choice, including reasons for perceived lack of choice (e.g., lack of care alternative) as well as the point in which the caregiving is providing care (e.g., starting care at diagnosis, recurrence care), would have added greater context to the analysis. In addition to duration of care and objective burden, which incorporates patient IADL/ADL functioning and hours of care provided per week, the dataset did not include other potentially relevant clinical data (e.g., care recipient cancer stage). Additional limitations include the cross-sectional nature of the data, the modest number of cancer caregivers and the relatively low response rate of the original sample. However, for the increasing number of individuals who will be filling these roles in the coming years, these findings begin to illuminate key elements of such a role that may impact caregiver outcomes.

This study demonstrates the potential adverse consequences of a perceived lack of choice among cancer caregivers. Caregiver with poorer emotional health are shown to have poorer physical health outcomes as well as differential care recipient outcomes, including earlier nursing home placement or hospitalization (Brodaty, Gresham, & Luscombe, 1997; Brodaty, Mittelman, Gibson, Seeher, & Burns, 2009; Coehlo, Hooker, & Bowman, 2007; Hebert, Dubois, Wolfson, Chambers, & Cohen, 2001; Kesselring et al., 2001; Lang et al., 2010; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Porter et al., 2010; Pruchno, Michaels, & Potashnik, 1990; Yaffe et al., 2002). Thus, attending to choice in the clinical context and via policy initiatives may prove to benefit caregivers and, ultimately, care recipients.

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## Table 1

$\chi^2$ Analyses: Demographic and caregiving-related variables and caregiving choice.

| Variable | N | No choice n (%) | $\chi^2$ (df) | P |
|---|---|---|---|---|
| **Duration of Care** | | | .52 (3) | .915 |
| Occasionally or less than 6-months | 37 | 12 (32.4%) | | |
| 6-months to 1 year | 24 | 6 (25%) | | |
| 1-4 years | 30 | 10 (33.3%) | | |
| 5 or more years | 10 | 3 (30%) | | |
| **Objective Burden** | | | 2.35 (1) | .125 |
| Moderate/High (levels 3-5) | 66 | 24 (36.4%) | | |
| Low (levels 1-2 | 33 | 7 (21.2%) | | |
| **Type of Care Index** | | | 3.46 (3) | .326 |
| 1 IADL/0 ADL | 4 | 0 (0%) | | |
| 1+ IADL/0 ADL | 26 | 6 (23.1%) | | |
| 1 ADL (with or without IADL) | 13 | 4 (30.8%) | | |
| 2+ ADL (with or without IADL) | 60 | 22 (36.7%) | | |
| **Hours of Care Index** | | | 2.29 (3) | .514 |
| 0-8 | 34 | 8 (23.5%) | | |
| 9-20 | 27 | 8 (29.6%) | | |
| 21-40 | 19 | 8 (42.1%) | | |
| 41 or more | 19 | 7 (36.8%) | | |
| **Care Recipient AD** | | | .30 (1) | .584 |
| Yes | 5 | 1 (20%) | | |
| No | 98 | 31 (31.6%) | | |
| **Caregiver gender** | | | .95 (1) | .329 |
| Female | 67 | 23 (34.3%) | | |
| Male | 36 | 9 (25%) | | |
| **Caregiver age** | | | 1.62 (3) | .655 |
| 18-34 | 26 | 9 (34.6%) | | |
| 35-49 | 40 | 12 (30%) | | |
| 50-64 | 29 | 10 (34.5%) | | |
| 65 or older | 8 | 1 (12.5%) | | |
| **Caregiver Race/ethnicity** | | | 6.38 (3) | .095 |
| White | 51 | 13 (25.5%) | | |
| Black | 11 | 7 (63.6%) | | |
| Hispanic | 21 | 6 (27.8%) | | |
| Asian | 18 | 5 (27.8%) | | |
| **Income** | | | 2.36 (3) | .501 |

| **Variable** | **N** | **No choice n (%)** | **$\chi^2$ (df)** | **P** |
|---|---|---|---|---|
| < $30,000 | 26 | 8 (30.8%) | | |
| $30,000-$49,000 | 24 | 10 (41.7%) | | |
| $50,000-$99,000 | 29 | 9 (31%) | | |
| $100,000 or more | 16 | 3 (18.8%) | | |
| **Caregiver Education** | | | 2.09 (2) | .352 |
| High school or less | 26 | 10 (38.5%) | | |
| Some college or technical college | 27 | 10 (37%) | | |
| College degree or higher | 49 | 12 (24.5%) | | |
| **Caregiver health** | | | 1.06 (2) | .588 |
| Excellent | 24 | 7 (29.2%) | | |
| Very good or good | 60 | 17 (28.3%) | | |
| Fair or poor | 17 | 7 (41.2%) | | |
| **Primary caregiver status** | | | 1.46 (1) | .227 |
| Primary | 47 | 18 (38.3%) | | |
| Secondary | 52 | 14 (26.9%) | | |
| **Distance to care recipient** | | | 2.44 (2) | .296 |
| In-home | 26 | 11 (42.3%) | | |
| Less than one hour away | 52 | 13 (25%) | | |
| One hour or more away | 25 | 8 (32%) | | |
| **Care Recipient Relationship to Caregiver** | | | 8.44 (5) | .134 |
| Spouse/companion | 9 | 4 (44.4%) | | |
| Parent/grandparent (or in-law) | 57 | 17 (29.8%) | | |
| Sibling (or in-law) | 10 | 5 (50%) | | |
| Offspring | 1 | 1 (100%) | | |
| Other relative | 7 | 3 (42.9% | | |
| Non-relative | 18 | 2 (11.1%) | | |

* $p < .05$

** $p < .01$

## Table 2

$\chi^2$ Analyses: Demographic and caregiving-related variables and emotional stress.

| Variable | N | n (%) Elevated Stress | $\chi^2$(df) | P |
|---|---|---|---|---|
| **Caregiving choice**[*] | | | 5.17 (1) | .23 |
| No | 32 | 27 (84.4%) | | |
| Yes | 71 | 44 (62%) | | |
| **Duration of care** | | | 1.83 (3) | .608 |
| Occasionally or less than 6-months | 37 | 27 (73%) | | |
| 6-months to 1 year | 24 | 18 (75%) | | |
| 1-4 years | 30 | 20 (66.7%) | | |
| 5 or more years | 11 | 6 (54.5%) | | |
| **Objective Burden**[**] | | | 10.86 (1) | .001 |
| Moderate/High (levels 3-5) | 67 | 54 (80.6%) | | |
| Low (levels 1-2 | 33 | 16 (48.5%) | | |
| **Type of Care Index**[**] | | | 17.53 (3) | .001 |
| 1 IADL/0 ADL | 4 | 1 (25%) | | |
| 1+ IADL/0 ADL | 26 | 11 (42.3%) | | |
| 1 ADL (with or without IADL) | 13 | 10 (76.9%) | | |
| 2+ ADL (with or without IADL) | 61 | 50 (82%) | | |
| **Hours of Care Index**[**] | | | 16.68 (3) | .001 |
| 0-8 | 34 | 15 (44.1%) | | |
| 9-20 | 27 | 23 (85.2%) | | |
| 21-40 | 19 | 15 (78.9%) | | |
| 41 or more | 20 | 17 (85%) | | |
| **Care Recipient AD**[*] | | | 5.98 (1) | .030 |
| Yes | 5 | 1 (20%) | | |
| No | 99 | 71 (71.7%) | | |
| **Caregiver gender** | | | .74 (1) | .390 |
| Female | 68 | 49 (72.1%) | | |
| Male | 36 | 23 (63.9%) | | |
| **Caregiver age** | | | 2.31 (3) | .510 |
| 18-34 | 26 | 16 (61.5%) | | |
| 35-49 | 40 | 29 (72.5%) | | |
| 50-64 | 29 | 22 (75.9%) | | |
| 65 or older | 9 | 5 (55.6%) | | |
| **Caregiver race/ethnicity** | | | 2.94 (3) | .402 |

| **Variable** | **N** | **n (%) Elevated Stress** | **$\chi^2$(df)** | **P** |
|---|---|---|---|---|
| White | 52 | 39 (75%) | | |
| Black | 11 | 8 (72.7%) | | |
| Hispanic | 21 | 13 (61.9%) | | |
| Asian | 18 | 10 (55.6%) | | |
| **Income** | | | 1.85 (3) | .604 |
| < $30,000 | 27 | 19 (70.4%) | | |
| $30,000-$49,000 | 24 | 15 (62.5%) | | |
| $50,000-$99,000 | 29 | 23 (79.3%) | | |
| $100,000 or more | 16 | 11 (68.8%) | | |
| **Caregiver education** | | | .49 (2) | .781 |
| High school or less | 26 | 19 (73.1%) | | |
| Some college or technical college | 28 | 18 (64.3%) | | |
| College degree or higher | 49 | 34 (47.9%) | | |
| **Caregiver health** | | | 3.29 (2) | .193 |
| Excellent | 24 | 13 (54.2%) | | |
| Very good or good | 60 | 43 (71.7%) | | |
| Fair or poor | 18 | 14 (77.8%) | | |
| **Primary caregiver status** | | | .069 (1) | .793 |
| Primary | 48 | 33 (68.8%) | | |
| Secondary | 52 | 37 (71.2%) | | |
| **Distance to care recipient** | | | 2.91 (2) | .234 |
| In-home | 27 | 21 (77.8%) | | |
| Less than one hour away | 52 | 32 (61.5%) | | |
| One hour or more away | 25 | 19 (76%) | | |
| **Care recipient relationship to caregiver** | | | 5.66 (5) | .341 |
| Spouse/companion | 9 | 7 (77.8%) | | |
| Parent/grandparent (or in-law) | 57 | 40 (70.2%) | | |
| Sibling (or in-law) | 11 | 9 (81.8%) | | |
| Offspring | 1 | 1 (100%) | | |
| Other relative | 7 | 6 (85.7% | | |
| Non-relative | 18 | 9 (50%) | | |

[*] $p < .05$

[**] $p < .01$

## Table 3

Logistic Regression: Elevated Emotional Stress (levels 3-5) (n=99)

| Predictor | B | SE | Exp(B) | P | 95% CI |
|---|---|---|---|---|---|
| **Burden Level** | | | | | |
| Moderate/High (levels 3-5)** | 1.437 | .498 | 4.260 | .004 | 1.586-11.163 |
| Low (levels 1-2) | - | - | - | - | - |
| **AD or Mental Confusion** | | | | | |
| Yes* | −2.587 | 1.254 | .075 | .039 | .006-.878 |
| No | - | - | - | - | - |
| **Choice** | | | | | |
| No* | 1.308 | .628 | 3.699 | .037 | 1.080-12.671 |
| Yes | - | - | - | - | - |

[*] $p < .05$

[**] $p < .01$