Burden and Well-Being: The Same Coin or Related Currency?¹

Jon C. Stuckey, Ph.D.² Marcia M. Neundorfer, Ph.D., R.N.² Kathleen A. Smyth, Ph.D.³

RUNNING HEAD: Burden and Well-Being

¹ An earlier version of this paper was presented at the 47th Annual Meeting of the Gerontological Society of America in Atlanta, Georgia

- ² Alzheimer Center, University Hospitals of Cleveland and Case Western Reserve University, Cleveland, Ohio
- ³ Alzheimer Center, University Hospitals of Cleveland and Case Western Reserve University
 Department of Epidemiology and Biostatistics, Case Western Reserve University, Cleveland, Ohio

Burden and Well-Being: The Same Coin or Related Currency?

<u>Abstract</u>

To examine whether caregiver burden and general well-being are opposite sides of the same coin or distinct constructs, we compared burden (in physical, mental, financial, and social domains) and well-being (in the same domains, but with separate objective and subjective measures). The domains of burden and well-being were examined first as correlates of one another, second as correlates of antecedents in the caregiving situation, and finally, as predictors of likelihood to institutionalize. We conclude that burden and well-being are not opposite sides of the same coin, but rather related currency, each useful for tapping unique facets of the caregiving experience.

KEY WORDS: Caregivers, Alzheimer's disease, Measurement

Introduction

Over the past decade, caregiving has emerged as a dominant focus of research in gerontology. However, Pearlin and Zarit (1993) maintain that more study is needed to fully comprehend the societal consequences of an increasing caregiver population. Specifically, they call for research that is more methodologically sophisticated in order to understand the complexities of the caregiving experience. To this end, clarification of the concept of caregiver burden is needed. George and Gwyther (1986) argue that caregiver burden and general well-being are actually opposite sides of the same coin and note three distinct advantages of general well-being measures over caregiver burden measures: first, unlike burden, the well-being of caregivers and non-caregivers can be compared; second, burden confounds caregiving (cause) with its impact (effect) and well-being does not; third, while burden measures are often composite scores, well-being is usually measured in specific domains (e.g., physical, mental, financial, social). Although acknowledging the difficulties presented by the absence of a uniform definition of burden, Montgomery (1989) argues that the concept of caregiver burden differs from well-being in that burden has a specific referent, the caregiving role. As such, burden is likely to be more sensitive a measure than well-being to the effects of caregiving. Whether or not this is true remains an empirical question, as does the question of the overlap between burden and well-being.

Stull, Kosloski, and Kercher (1994) recently addressed both questions, thus renewing the debate on whether measures of burden provide more information about the impact of caregiving than do measures of well-being. Stull, et al. found that their burden measures were, in general, more strongly correlated than well-being measures with antecedent variables (e.g., care recipient ADL scores) and with caregiving outcomes (e.g., recency of considering nursing home placement). Based on these findings, they agree with Montgomery and argue against discarding burden as an unnecessary or redundant construct.

In an editorial response, George (1994) applauds the work of Stull and colleagues as the first empirical comparison of burden and well-being measures. She asks, however, "what was really measured?", noting two methodological weaknesses. First, the mental health domain, where caregivers most consistently experience negative effects (Schulz, Visintainer, & Williamson, 1990), was not measured in the Stull, et al. study. Second, the three well-being measures included relatively objective items (except for one subjective item on physical health), while the three burden measures were subjective. Although the distinction between what is a subjective or an objective indicator can be debated, especially when both are based on self-report, objective measures generally are verifiable by others (e.g., number of doctor visits); subjective measures are based on personal perceptions (e.g., rating one's own health). George reports that she and her colleagues have consistently found that subjectively measured well-being correlates more strongly than objectively measured well-being with caregiving outcomes (e.g., use of services, institutionalization). Therefore, the relationships between measures of burden and well-being reported by Stull, et al. may be true differences, differences between subjective and objective measures, or a combination of both. The purpose of this paper is to respond

to George's call for empirical comparisons of both subjective and objective measures of well-being with measures of burden across multiple domains. Consequently, our analysis includes three concepts (burden, subjective well-being, objective well-being), each assessed in four domains (physical health, mental health, financial resources, social resources), leading to twelve measures. Each of these measures is described in detail below.

Methods

SAMPLE

Participants in this study were family caregivers of persons with a diagnosis of Alzheimer's disease (AD) who were enrolled in the University Hospitals of Cleveland/Case Western Reserve University National Institute on Aging Alzheimer's Disease Research Center (ADRC). All care recipients met NINCDS-ADRDA criteria (McKhann, Drachman, Folstein, Katzman, Price, & Stadlan, 1984) for probable or possible AD, and were living in the community.

Caregivers were given two self-administered questionnaires at one of the care recipients' regularly scheduled visits to the ADRC. Of the 158 caregivers eligible for this study, 131 (83%) returned questionnaires. Two subjects were not included because of missing data, leaving a sample of 129 caregivers.

Table 1 provides a description of the sample. The 129 caregivers were mostly spouses (70%) and female (66%). Their mean age was 63.7 years. African Americans comprised 9% of the sample. The caregivers were, on average, fairly well-educated (55% had more than a high school education). Most of the caregivers (64%) were either retired or not working. The care recipients were also predominantly female (54%); their mean age was 72.6. The majority of care recipients were diagnosed with probable AD (84%). The remaining 16% were diagnosed with possible AD mixed with other disorders, mainly depression.

insert Table 1 about here

The present sample differs from that of Stull, et al. in two ways. First, our largest caregiving group was

spouses (70%); their largest group was daughters (57%), with only 8% wives and no husbands. Second, all our care recipients were demented; less than half of theirs had dementia.

MEASURES

The descriptions of measures used in this study, as well as sample alphas, means, and standard deviations, are listed in Table 2. Following Stull, et al., the measures are categorized into four types: 1) antecedent conditions (care recipient severity of dementia, and behavioral symptoms; we added caregiver/care recipient relationship and gender of the caregiver); 2) measures of burden (physical, mental, financial, social); 3) measures of well-being (physical, mental, financial, social) by two different strategies (subjective and objective) and; 4) final outcome (likelihood to institutionalize). Although our variables reflect content similar to those used by Stull, et al., it should be noted that our measures are not exactly the same as theirs.

insert Table 2 about here

Antecedent Conditions

Dementia severity was measured with the Clinical Dementia Rating (Hughes, Berg, Danziger, Coben, & Martin, 1982), a clinician's assessment of six dimensions of functioning (memory, orientation, judgment, community affairs, home and hobbies, and personal care) that are then combined for a rating from 0 (no dementia) to 5 (terminal dementia). Behavioral symptoms were assessed by the CERAD Behavioral Rating Scale for Dementia (BRSD; Tariot, et al., 1992). Caregivers were asked to indicate the frequency of 48 behavioral symptoms (e.g., restlessness, aggression, wandering, delusions) that may be present in persons with dementia. For the purposes of this study, total counts were obtained based on whether or not the symptom had occurred in the prior month.

Burden

Our measures of burden are caregivers' perceptions of the impact of caregiving on their lives, physically, mentally, financially, and socially. *Physical Burden* was measured by summing three items from a scale developed by Deimling, Bass, Townsend, & Noelker (1989); the alpha for physical burden is .89. Caregivers were asked to indicate on a four-point scale the extent to which they agreed with the following statements: "Because of caring for my relative, I am sick more often; I am bothered by more aches and pains; my health is worse now than what it was before." Higher scores indicate greater physical burden. *Mental Burden* was measured by three items from Deimling, et al. (1989); the alpha for mental burden is .83. Caregivers indicated on a four-point scale the extent to which caregiving had made them more nervous, more irritable, and more often down-hearted. Higher scores indicate greater mental burden. *Financial Burden* was measured by a single item on the perceived impact of caregiving on their total household income (Pearlin, Mullan, Semple, & Skaff, 1990). Higher scores reflect higher perceived financial burden. *Social Burden* was measured by a single item on the extent to which the caregivers had lost contact with others because of caring for their relative (Pearlin, et al., 1990). Higher scores mean more social burden.

Subjectively Measured Well-Being (SWB)

Physical SWB was measured by a single item asking caregivers to rate their physical health on a five-point scale, ranging from poor to excellent. Higher scores mean greater physical SWB. *Mental SWB* was measured by the CES-D Scale (Radloff, 1977), a commonly used self-report measure of depression, on which the caregivers were asked to indicate how often they had experienced symptoms of depression (alpha=.90). Higher scores indicate more depressive symptoms and, thereby, less mental SWB. *Financial SWB* was indicated by a single item rating how well the family finances worked out at the end of the month on a three-point scale from "not enough to make ends meet" to "some money left over." Higher scores mean more financial SWB. *Social SWB* was measured by asking respondents how satisfied they were with their overall amount of social activities. The possible answers on the four-point metric ranged from very unsatisfied to very satisfied. Higher scores indicate more social SWB.

Objectively Measured Well-Being (OWB)

Physical OWB was the caregiver's report of the number of visits to a doctor in the past six months. Higher scores imply lower physical OWB. *Mental OWB* was measured by asking caregivers the following question, based on the work of George and colleagues (Clipp & George, 1990; George & Gwyther, 1986): "To calm you down, to raise your spirits, or to help you sleep, are you currently taking any medications?" All medications identified were verified by a physician or nurse as psychotropic. Those taking psychotropic drugs are considered to have less mental OWB. *Financial OWB* was annual household income. Higher scores reflect more financial objective well-being. *Social OWB* was measured by six items from the Social Well-Being Index (Donald & Ware, 1982), including visits with friends and family, number of organizational memberships, degree of activity within organizations, and time spent on hobbies. Higher scores mean more social OWB. Test-retest data on social OWB were available for 54 of the 129 caregivers; the Pearson's r for time 1 and time 2 data is .79 (p≤.001).

Final Outcome

Likelihood to Institutionalize in a Nursing Home was measured by a series of seven questions on a desire to institutionalize scale designed to elicit how many steps had been taken toward nursing home placement (Pruchno, Michaels, & Potashnik, 1990). The alpha for the scale is .88. Higher scores are indicative of a greater likelihood to institutionalize the care recipient. Although other caregiving outcomes warrant examination, we selected likelihood to institutionalize because it was an outcome that could be compared to the results of Stull, et al.

Results

The data analyses proceeded in four steps. First, following Stull, et al., we examined the correlations between burden and well-being, but included not only the mental health domain, but also subjective and objective measures of well-being. Second, we correlated the antecedent variables with measures of burden and well-being. Third, we regressed likelihood to institutionalize on burden, subjective measures of well-being and objective measures of well-being across the three domains used by Stull and colleagues, and then added the mental health domain. Fourth, we correlated the antecedent variables with likelihood to institutionalize and entered those variables significantly correlated at the bivariate level into a regression equation predicting likelihood to institutionalize, along with those burden and well-being measures that were significant predictors in the initial regression equation.

Correlations of Burden and Well-Being Measures

Looking first at the correlations among the burden and well-being measures (see Table 3), we found significant correlations between all the burden measures and their corresponding well-being measures, both subjective and objective, with one exception (financial burden was not significantly correlated with financial SWB). Comparing our correlations for the physical and social domains with those of Stull, et al.'s, we found

the magnitude of the correlations to be the same. In the mental domain, which was not included in the Stull, et al. study, we found the highest of all correlations (.53 between mental burden and mental SWB, i.e., depression). These correlations between measures of burden and well-being, especially in the mental health domain, indicate that burden and well-being are indeed related, but not identical constructs.

insert Table 3 about here

In addition, we examined whether the subjective measures of well being were more strongly correlated with burden than the objective measures. In the physical health domain, the correlation of -.48 between physical burden and physical SWB was significantly higher than the correlation of .29 between physical burden and physical OWB ($p\leq.05$). In the mental health domain, the correlation of .53 between mental burden and mental SWB was significantly higher than .26 between mental burden and mental OWB ($p\leq.05$.) In the social and financial domains, differences between correlations of burden with SWB and OWB were not statistically significant. Therefore, in two of the four domains, subjective measures of well-being clearly had more conceptual overlap with burden than objective measures of well-being.

Next, we examined whether there was a generalized response across the domains reflected in the three constructs. To do this, based on Table 3, we calculated an average intercorrelation for all four burden measures, all four SWB measures, and all four OWB measures. We found that average intercorrelations were greater for burden (\mathbf{F} =.32), than for subjective well-being (\mathbf{F} =.19) and objective well-being (\mathbf{F} =.12). These findings suggest that burden may be a generalized response to caregiving, affecting multiple domains of caregivers' lives. On the other hand, the effect of caregiving on well-being, both subjective and objective, may be more domain-specific.

We also examined whether average intercorrelations were similar within domains. Again, based on Table 3, we calculated average intercorrelations among all three measures in the same domains (e.g., physical burden, physical SWB, physical OWB). We found that the average intercorrelations were indeed similar for physical health, mental health, and social resources, with values of .38, .35, and .39, respectively. The average intercorrelation within the financial domain was .19. Therefore, within three of the four domains, there is evidence of consistency across measures, supporting the argument that burden and well-being are overlapping constructs.

Correlations between Antecedents, Burden, Well-Being, and Likelihood to Institutionalize

In keeping with Stull, et al., we completed our bivariate analysis by correlating burden and well-being (subjective and objective) with antecedents (severity of dementia, frequency of problem behaviors, caregiver gender, and relationship), and a key outcome of caregiving, likelihood to institutionalize. As shown in Table 4, the caregiving situation variables were related primarily to burden rather than to well-being, either subjectively or objectively measured. Within the physical domain, burden was significantly related to caregiver gender (female), greater dementia severity, and greater frequency of behavioral problems. In contrast, physical well-being, either subjectively or objectively or objectively or objectively measured. Within the mental domain, burden was related to caregiver gender (female), and more behavioral problems. Mental SWB (depression) also was related to gender (female) and behavioral symptoms, but mental OWB (taking psychotropic medications) was not. In the financial domain, the only significant correlation was between OWB (higher income) and relationship (non-spouse). In the social domain, burden was related to greater dementia severity and more behavioral problems. None of the social well-being measures was related to any of the antecedent variables. These results indicate the greater sensitivity of the burden measures than well-being measures to the effects of the caregiving situation, with two exceptions: mental SWB (depression) and financial OWB (income).

insert Table 4 about here

Looking at the final outcome variable in Table 4, likelihood to institutionalize was related to relationship (being a non-spouse), greater dementia severity, and more behavioral problems. Likelihood to institutionalize

also was significantly related to physical burden, mental OWB, financial OWB, and social burden. Likelihood to institutionalize was not significantly related to any of the subjective well-being measures.

Burden and Well-Being as Predictors of Likelihood to Institutionalize

To compare burden and well-being as predictors of likelihood to institutionalize, we conducted initial ordinary least squares regression analyses, using all burden and well-being measures as predictors (see Equation A in Table 5). The significant predictors in the physical health domain were burden and SWB (better self-rating of health). The only predictor in the mental health domain was OWB (not taking psychotropic medications). No predictors were found in the financial resources domain, and social burden was the only predictor in the social resources domain. These results seem to indicate the greater predictive value of burden measures over well-being measures, a conclusion in congruence with the findings of Stull, et al.

insert Table 5 about here

We next included as predictors antecedent variables that had significant correlations with likelihood to institutionalize. As previously shown in Table 4, these were being a non-spouse (r=-.20, p≤.05), greater severity of dementia (r=.26, p≤.01), and more behavioral symptoms (r=.22, p≤.05). These variables were added to the institutionalization equation along with the significant predictors shown in Equation A in Table 5. In the final regression (Equation B in Table 5), significant predictors of likelihood to institutionalize were greater severity of dementia (β =.22, p≤.05), and mental OWB, i.e., not taking psychotropic drugs (β =-.26, p≤.01). Physical subjective well-being (β =.09) and social burden (β =.13) were no longer significant predictors. Being a non-spouse caregiver (β =-.14) and experiencing more physical burden (β =.18) approached, but did not reach, significance at the .05 alpha level. These results show the importance of the context of caregiving, specifically severity of the dementia and whether or not the caregiver is a spouse.

Further, they affirm the necessity, as George points out, of including the mental health domain for understanding the experience of caregiving.

Discussion

Following the work of Stull, Kosloski, & Kercher (1994), we compared measures of burden and wellbeing first as correlates of one another, second as correlates of antecedent variables reflecting the caregiving situation, and finally, as predictors of likelihood to institutionalize. As George (1994) expected, subjective measures of well-being were more strongly correlated with burden measures than were objective measures of well-being, although only in the physical and mental health domains. We conclude that burden and wellbeing measures do indeed tap related, albeit not identical, content. Our data indicate that knowing something about the more global aspects of caregivers' lives (e.g., well-being) does, in fact, enhance our understanding of how caregivers perceive caregiving. Stull, et al. maintain that burden taps a unique aspect of caregiving not captured by general well-being. Had they included mental health well-being and more subjective measures in their study, they may have discovered more overlap between burden and well-being.

Although our antecedent measures were not identical to those of Stull, et al., we confirmed their finding that more burden than well-being measures were related to care recipient characteristics. This is not surprising given that burden measures are designed to be sensitive to caregiving specific demands, i.e., to involve an attributional process.

When comparing our findings with those of Stull, et al., differences in measurement must be remembered. Moreover, since many of our measures consisted of one indicator, errors in measurement may account for some of the relationship between variables. Also, there may be differences in reliability properties between the measures of burden and well-being. Finally, in terms of the outcome variable, likelihood to institutionalize, our measure represents actual steps ever taken toward nursing home placement; Stull, et al. use recency of considering placement. No doubt these two measures both represent some likelihood of nursing home placement, but the actual correspondence between them is not known.

With these caveats in mind, we compared our respective findings on whether burden or well-being measures were better predictors of likelihood to institutionalize. Our findings are similar in that, in both studies, physical and social burden were significant predictors. However, unlike Stull, et al., we found that physical subjective well-being (better self-rating of health) was also significantly related to likelihood to institutionalize. We suspect this discrepancy is due to differences in samples: Stull, et al.'s sample was mostly adult children, whereas ours was three-fourths spouses and one-fourth adult children. Subjective physical health might not have varied sufficiently in the adult children to exert an effect in the Stull, et al. study, as it did in ours. In the second regression (Equation B), when we controlled for relationship, subjective physical health was no longer a predictor, and being a non-spouse caregiver approached significance as a predictor. The initial correlation between physical SWB and likelihood to institutionalize appears to represent a spurious association that is removed when controlling for relationship. Moreover, in interpreting our multiple regression analyses, it should be noted that our burden measures, in general, are more strongly correlated with SWB than OWB. Consequently, where burden, SWB, and OWB are compared simultaneously, OWB may appear a more robust predictor simply due to the overlap between burden and SWB.

When we included mental well-being measures as predictors of likelihood to institutionalize, we confirmed the importance of mental health variables, but in an unexpected direction: <u>not</u> taking psychotropic drugs was a significant predictor of likelihood to institutionalize in both of our prediction equations. Further exploration showed that a small group of caregivers (n=14) reported taking psychotropic drugs. These caregivers were worse off than those not taking this type of medication on several of the burden and well-being measures. Psychotropic drug use was related to more physical burden (r=.22, p≤.01), lower self-rating of health (r=-.17, p≤.05), more doctor visits (r=.26, p≤.01), more mental burden (r=.26, p≤.01), and

greater depression (r=.27, p \leq .01). In addition, use of psychotropic medications was related to less caregiver confidence (r=.21, p \leq .05), as measured by Pearlin and colleagues (1990), and to more wishful thinking (r=.16, p \leq .10), as measured on the Pruchno and Resch (1989) coping subscale. It may be that psychotropic drug use inhibits the caregiver from taking the necessary steps toward placement. Or it may be that the caregivers are too emotionally distraught to take action toward placement. Whatever the reason, the fact that these few highly stressed caregivers either did not or could not take steps toward institutionalization requires further exploration.

Unlike Stull, et al.'s finding that financial burden was a significant predictor of likelihood to institutionalize, we did not find that any financial measures were predictors. This difference may be due to the fact that our measure of financial burden referred loss of income due to caregiving, whereas theirs included a feeling state (i.e., "I resent the extra cost of caring"). Perhaps these measures behaved differently because one focused on impact and the other on a feeling about impact. Indeed, researchers would be wise treat these as separate aspects of burden.

One of the most important findings of this research is the salience of contextual variables (e.g. caregiver/care recipient relationship and severity of dementia) for understanding caregiving in general and institutionalization in particular. Once relationship and severity of the care recipient's dementia were controlled, none of the burden measures and only one of the well-being measures (not taking psychotropic drugs) were predictors of likelihood to institutionalize at the .05 alpha level. This suggests that although burden and well-being both may be affected by caregiving, they do not contribute independently to ability or willingness to maintain the caregiving role. Our work supports the assertion by Stull, et al., which George reaffirms, that the choice of a measurement approach should be guided by the research question to be investigated. Neither caregiving-specific burden measures, nor global well-being measures, independent of each other, fully characterize the caregiving experience.

To conclude, we agree with Stull, et al. that dismissing burden as an unnecessary construct is unwarranted. Furthermore, our research affirms that well-being measures play an important role in understanding caregiving, particularly when researchers include the mental health domain and use separate subjective and objective measurement strategies. In turn, well-being measures can be used to guide policy decisions regarding services for caregivers. Placed within the context of the relationship of caregiver to care recipient and the severity of the care recipient's illness, burden and well-being measures are not opposite sides of the same coin, but related and useful currency.

Acknowledgments

Funding for this project was provided by NIA ADRC grant AG08012 (Peter J. Whitehouse, Principal Investigator). We wish to gratefully acknowledge the data management support and other assistance provided by Nancy Catalani, Rory Dick, Kimberly Gossett, Kathleen Horner, Linda Kresnye, Linda Rechlin, and Rebecca Simpson. Appreciation is also expressed to three anonymous reviewers who undoubtedly strengthened the article with thoughtful and insightful critique.

Corresponding Address: Jon C. Stuckey, Ph.D., Alzheimer Center, University Hospitals of Cleveland, 11100 Euclid Avenue, Cleveland, OH 44106-5000.

References

- Clipp, E. C., & George, L. K. (1990). Psychotropic drug use among caregivers of patients with dementia. Journal of the American Geriatric Society, 38, 227-235.
- Deimling, G. T., Bass, D. M., Townsend, A. L., & Noelker, L. S. (1989). Care-related stress: A comparison of spouse and adult-child caregivers in shared and separate households. <u>Journal of Aging and Health, 1</u>, 76-82.
- Donald, C. A., & Ware, J. E., Jr. (1982). <u>The quantification of social contacts and resources</u>. Santa Monica, CA: Rand.
- George, L. K. (1994). Caregiver burden and well-being: An elusive distinction. The Gerontologist, 34, 6-7.
- George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. <u>The Gerontologist, 26</u>, 253-259.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. British Journal of Psychiatry, 140, 566-572.
- McKhann, G., Drachman D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the auspices of the Department of Health and Human Services Task Force on Alzheimer's Disease. <u>Neurology</u>, 34, 939-944.
- Montgomery, R. J. V. (1989). Investigating caregiver burden. In K. S. Markides & C. L. Cooper (Eds.), Aging, stress, and health (pp. 201-218). New York: Wiley & Sons.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. <u>The Gerontologist</u>, 30, 583-594.

- Pearlin, L. I., & Zarit, S. H. (1993). Research into informal caregiving: Current perspectives and future directions. In S. H. Zarit, L. I. Pearlin, & K. W. Schaie (Eds.), <u>Caregiving systems: Informal and formal helpers</u> (pp. 155-167). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Pruchno, R. A., Michaels, J. E., & Potashnik, S. L. (1990). Predictors of institutionalization among Alzheimer Disease victims with caregiving spouses. Journals of Gerontology, 45, S259-266.
- Pruchno, R. A., & Resch, N. L. (1989). Mental health of caregiving spouses: Coping as mediator, moderator, or main effect? <u>Psychology and Aging, 4</u>, 454-463.
- Radloff, L. S. (1977). The CES-D Scale; A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.
- Schulz, R., Visintainer, P., & Williamson G. M. (1990). Psychiatric and physical morbidity effects of caregiving. <u>Journals of Gerontology</u>, 45, P181-191.
- Stull, D. E., Kosloski, K., & Kercher, K. (1994). Caregiver burden and generic well-being: Opposite sides of the same coin? <u>The Gerontologist</u>, 34, 88-94.
- Tariot, P. N., & the CERAD Behavioral Pathology Committee. (1992, November). CERAD Behavior Rating Scale for Dementia (BRSD). Paper presented at the annual meeting of the Gerontological Society of America, Washington, DC.

Variable	N = 129 Family Caregivers
Relationship	 43% Wives 27% Husbands 19% Daughters/Daughters-in-law 6% Sons 5% Other
Gender of Caregiver	66% Females 34% Males
Mean Age of Caregiver	63.7 (SD = 12.2; range 33 - 86)
Race of Caregiver	91% White 9% African American
Education of Caregiver	45% High School or less38% Attended or Completed College17% Post-Graduate
Employment	64% Retired/Unemployed 36% Working Full/Part Time
Gender of Care Recipient	54% Females 46% Males
Mean Age of Care Recipient	72.6 (SD = 7.8; range 52 - 87)
Diagnosis	84% Probable Alzheimer's disease 16% Possible Alzheimer's disease

Table 1. Demographic Profile

Table 2. Descriptions of Measures, Alphas, Means (<u>M</u>), and Standard Deviations (<u>SD</u>) (N=129)

Items	Alpha	M (SD)				
	•					
Antecedents						
Relationship 0 (non-spouse); 1 (spouse)	N/A					
Gender of Caregiver 0 (female); 1 (male)	N/A					
Dementia Severity Clinical Dementia Rating	N/A	1.6 (0.8)				
Scores: U (no dementia) to S (terminal dementia) Rehavioral Symptoms Count of symptoms on CER AD Rehavioral Rating Scale	N/A	126(64)				
Count of symptoms on CLAM D Denavioral Raung Scale	10/1	12.0 (0.1)				
Burden						
Physical Health Because of caring for your relative, you: are sick more often; are bothered by more aches and	.89	5.1 (2.0)				
pains; have health that is worse now than it was.						
Score: 1 (strongly disagree) to 4 (strongly agree)	02	77(00)				
Mental Health Because of caring for your relative, you: are more nervous; are more irritable; are more often	.85	1.7 (2.2)				
Score: 1 (strongly disagree) to 4 (strongly agree)						
Financial Resources Your total household income now compared to when you started caregiving.	N/A	3.4 (0.9)				
Score: 1 (much more now) to 5 (much less now)						
Social Resources Because of caring for your relative, you have lost contact with other people.	N/A	2.2 (0.8)				
Score: 1 (not at all) to 4 (completely)						
Subjective Well-Being (SWB)						
Physical Health Rate your physical health.	N/A	3.5 (1.0)				
Score: 1 (poor) to 5 (excellent) Montel Heelth CES D (0) item instrument of depression sumptome)	00	12.4(10.2)				
Score: 0 (less than 1 days)	.90	13.4 (10.2)				
Financial Resources How do your family finances work out at the end of the month?	N/A	2.5 (0.6)				
Score: 1 (not enough money) to 3 (money left over)						
Social Resources Overall satisfaction with your amount of social activities.	N/A	2.6 (0.8)				
Score: 1 (very unsatisfied) to 4 (very satisfied)						
Objective Well-Being (OWB)						
Physical Health Number of doctor visits in past 6 months	N/A	23(33)				
Score: number of visits	10/11	2.5 (5.5)				
Mental Health Taking medications to calm you down, lift your spirits, or help you sleep?	N/A	11% - yes				
Score: 0 (no) to 1 (yes)		89% - no				
Financial Resources Yearly household income from all sources.	N/A	4.9 (2.4)				
Score: 1 (less than 10K) to 10 (over 80K)	NI/A	20(0.8)				
Social Resources How many families do you visit with; now many friends do you have; now many organizations do you halong to how active are you in these argentizations; how often do you visit with friends;	N/A	2.0 (0.8)				
to you being to, now active are you in these organizations, now often do you visit with menus, how much time do you spend on hobbies						
Score: (recoded) 1 (fewer social resources) to 3 (greater social resources)						
Final Outcome: Likelihood to Institutionalize in a Nursing Home (NH)						
Have you; talked to family, talked to professionals, gotten the name of a NH, called a NH.	88	20(23)				
visited an NH: taken care recipient to visit NH: applied for placement	.00	2.0 (2.3)				
Score: 0 (no) to 1 (yes)						

N/A Not Applicable

	Physical Health		Mental Health		Financial Resources			Social Resources				
	Burden	SWB	OWB	Burden	SWB	OWB	Burden	SWB	OWB	Burden	SWB	OWB
Physical Health												
Burden												
SWB	48***											
OWB	.29***	38***										
Mental Health												
Burden	.53***	21*	.12									
SWB	.41***	30***	.20*	.53***								
OWB	.22*	17*	.26**	.26**	.27**							
Financial Resources												
Burden	.21*	10	03	.17*	.23**	.10						
SWB	14	.13	.08	02	07	.00	14					
OWB	06	.24**	11	02	11	12	23**	.21*				
Social Resources												
Burden	.39***	22*	.06	.43***	.35***	.10	.21*	.06	06			
SWB	23**	.22*	18*	22*	33***	08	03	07	.10	35***		
OWB	25**	.16	05	16	23**	06	15	06	.15	29***	.52***	

Table 3. Zero-Order Correlation Coefficients of Measures of Burden, Subjective Well-Being (SWB),
and Objective Well-Being (OWB) by Domain (N=129)

<u>p</u> ≤ .05 <u>p</u> ≤ .01 *

**

*** <u>p</u> ≤ .001

		Likelihood to			
	Relationship ^a	Gender ^b	Dementia Severity	Behavioral Symptoms	Institutionalize
Physical					
Burden	01	26**	.20*	.20*	.18*
SWB	14	.14	09	.07	.09
OWB	05	02	09	.06	.06
Mental					
Burden	.07	24**	.12	.28**	.09
SWB	.14	26**	.16	.23*	.07
OWB	.01	14	01	.16	21*
Financial					
Burden	.14	13	.16	.08	.03
SWB	.16	.16	.00	.10	.06
OWB	30***	.10	02	.05	.21*
Social					
Burden	.15	09	.32***	.30***	.21*
OWB	02	.13	07	.00	.03
OWB	03	01	20*	06	.12
Likelihood to Institutionalize	20*	04	.26**	.22**	

Table 4. Zero-Order Correlations Between Antecedents, Burden, Subjective Well-Being (SWB), Objective Well-Being (OWB), and Likelihood to Institutionalize by Domain (N=129)

^a 0=non-spouse / 1=spouse * $\underline{p} \le .05$

^b 0=female / 1=male

** $\underline{p} \le .01$ *** $\underline{p} \le .001$

	Likelihood to Institutionalize				
	Equation A	Equation B	Stull, et al., 1994		
Adjusted R ²	.16	.19	N/R		
Physical					
Burden	.26*	.18+	.46*		
SWB	.21*	.09	.08		
OWB	.14	Х	Х		
Mental					
Burden	07	Х	Х		
SWB	.09	Х	Х		
OWB	27**	26**	Х		
Financial					
Burden	.03	Х	.19*		
SWB	.04	Х	Х		
OWB	.15	Х	.13		
Social					
Burden	.24*	.13	.38*		
SWB	.04	Х	Х		
OWB	.18	Х	.23*		
Antecedents					
Relationship ^a	Х	14+	Х		
Gender ^b	Х	Х	Х		
Dementia Severity	Х	.22*	Х		
Behavioral Symptoms	Х	.11	Х		

Table 5. Adjusted R² and Standardized Beta Coefficients of Measures of Burden, Subjective Well-Being (SWB), and Objective Well-Being (OWB) for Likelihood to Institutionalize (N=129)

0=non-spouse / 1=spouse 0=female / 1=male

J/R not reported

ζ not included in the equation

• <u>p</u>≤.10

<u>p</u>≤.05

Burden & Well-Being Page 23

** <u>p</u>≤.01

Burden & Well-Being Page 19

Burden & Well-Being Page 20