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**MEASURING THE EXPERIENCE AND PERCEPTION OF SUFFERING**

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## ABSTRACT

**Purpose of the study:** Assess psychometric properties of scales developed to assess experience and perception of physical, psychological, and existential suffering in older individuals.

**Design and Methods:** Scales were administered to three populations of older persons and/or their family caregivers: individuals with Alzheimer's disease (AD) and their family caregivers (N=105 dyads); married couples in which one partner had osteoarthritis (N=53 dyads); and African American and Hispanic caregivers of care recipients with AD (N=121). Care recipients rated their own suffering while caregivers provided ratings of perceived suffering of their respective care recipients. In addition, quality of life, health, and functional status data were collected from all respondents via structured in-person interviews.

**Results:** Three scales showed high levels of internal consistency, test-retest reliability, and convergent and discriminant validity. The scales were able to discriminate differences in suffering as a function of type of disease, demonstrated high intra- and moderately high inter-person correlations, and exhibited predicted patterns of association between each type of suffering and indicators of quality of life, health status, and caregiver outcomes of depression and burden.

**Implications:** Suffering is an important but understudied domain. This paper provides valuable tools for assessing the experience and perception of suffering in humans.

Key Words: Alzheimer's disease, caregiving, quality of life

## INTRODUCTION

The nature of and reasons for human suffering have been the subject of scholarly writings for millennia. Many important questions can be asked about suffering, including why do people suffer, how is it experienced and expressed by individuals, and how is it perceived and responded to by individuals exposed to suffering of others? The experience of suffering has received increasing attention in the medical and health care literature (Cassell, 2004; Ferrell & Coyle, 2008; Schulz et al., 2007), and in several recent papers we have focused attention on the interpersonal effects of suffering to make the case that exposure to suffering is an important and understudied pathway that explains some of the psychological and physical consequences of caregiving (Schulz et al., 2007; Schulz et al., 2009; Schulz et al., 2008; Monin & Schulz, 2009; Monin et al., 2010). Despite these recent advances, scientific study of the experience, expression, and interpersonal effects of suffering remains an important unexplored research endeavor, in part because we have lacked good measures of suffering in humans. The goal of this article is to present measures of suffering that can be used to assess both the experience and perception of suffering.

Researchers interested in end-of-life care have been at the forefront in developing methods to assess various components of suffering. Notable examples include simple, direct questions such as “Are you suffering?” (Cassell, 1999, 2004) and scales that emphasize physical symptoms, such as the Edmonton Symptom Assessment system (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991), and measures of pain behavior (Keefe et al., 2003; Wilson et al., 2004). Other researchers have included indices of psychological, spiritual, and social feelings along with measurement of physical symptoms (e.g., Ferrell, Grant, Dean, Funk, & Ly, 1996; Idler et al., 2003; McClain, Rosenfeld, & Breitbart, 2003). Still others have taken a more clinical approach, asking health care providers to rate patient attributes such as calmness, screaming, pain, and stability of general medical condition, and their overall impression of the patient’s level of suffering (Aminoff & Adunsky, 2004). Taken together, existing conceptual and measurement perspectives on suffering indicate consensus around four common themes. First, suffering is a holistic construct with multiple dimensions (Monin & Schulz, 2009). Second, suffering includes psychological distress, such as depression and anxiety, along with feelings of lack of control.

Third, physical symptoms, such as pain, nausea, and difficulty breathing, are a key feature of suffering. Fourth, suffering has an existential or spiritual dimension which includes loss or impairment of inner harmony and meaning and purpose of life. Using this framework as a guide, an interdisciplinary team of investigators and clinicians identified existing instruments in each of the three domains—physical, psychological, and existential—in order to identify or generate conceptually distinct items that might be used to measure suffering. Our goal was to compile a comprehensive set of non-overlapping items that captured key features of each domain. For two of the domains—psychological and existential suffering—both positively and negatively stated items were chosen. Based on this review, we developed three scales that assess the three domains of suffering: physical, psychological, and existential suffering. The scales can be used to rate both the experience and the perception of suffering.

Our view is that suffering is independent of illness attributes such as disability and that individuals automatically make appraisals about the magnitude of suffering based on an algorithm that incorporates the three key dimensions of suffering. This holistic appraisal is an important final pathway to understanding the interpersonal effects of suffering and is different from approaches that treat factors such as psychological distress and pain separately. The mechanisms linking the expression of suffering and individual response to the suffering of others include cognitive empathy, mimicry, and conditioned responding (see Monin & Schulz, 2009, for a detailed discussion of these issues).

### The Current Study

We chose older samples with diagnosed cognitive or physical health problems in order to generate adequate variance on our suffering measures and to show differential suffering profiles as a function of different types of illness. To assess the validity of the scales, we examined: (1) differences in suffering as a function of type of disease; (2) intra- and inter-person correlations between the three measures of suffering; (3) the relationship between each type of suffering and a variety of psychosocial and health status indicators including quality of life and health status as well as the association with caregiver outcomes such as depression and burden when controlling for the functional disability of the care recipient.

Four types of predictions were tested. First, because pain is a prominent feature of osteoarthritis, we predicted higher levels of physical suffering in osteoarthritis care recipients when compared to individuals with AD. Second, we expected to find significant within person and between caregiver-care recipient associations for the three different suffering scales. Third, with respect to quality of life indicators, we predicted significant negative relationships between our suffering scales and measures of Quality of Life in Alzheimer's disease (QOL-AD) (Logsdon, Gibbons, McCurry, & Teri, 2002) and Dementia Quality of Life (DEMQOL) (Smith et al., 2007) in the two dementia samples. We also predicted that our suffering scales would be differentially associated with the physical and mental functioning dimensions of health-related quality of life (Short-Form-12 Health Survey[SF-12]) (Ware, Kosinski, & Keller, 1996) such that physical suffering is significantly associated with physical functioning while psychological and existential suffering are related to mental functioning of the SF-12. Finally, in as much as suffering is thought to be independent of functional disability and a determinant of caregiver outcomes such as depression and burden, we predicted that suffering would not be associated with functional disability and would be significantly associated with depression and burden in caregivers, after controlling for limitations in basic and instrumental activities of daily living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) and cognitive status of persons with AD.

## METHODS

### Description of the Scales, Instructions for Administration and Scoring

Three instruments were developed to assess each of the three domains of suffering: physical, psychological, and existential suffering (see Appendix 1). The physical symptoms scale consists of 9 items (e.g., pain, nausea, shortness of breath, dry mouth, lack of appetite, etc.). For each item the respondent is asked to indicate how often they experienced the symptom during the last 7 days (not at all=0; a little {a few days, 1-3}=1; quite a bit {most days, 4-6}=2; very often {every day}=3). For each symptom that is present, the respondent is also asked to indicate how much it bothered or distressed them (not at all, a little, quite a bit, very much). To calculate an index score, the items are dichotomized so that symptoms which are experienced "quite a bit" or "very often" are recoded as 1 and all others as zero. The index is then the sum of the recoded dichotomous items. Psychological symptoms are measured with 15 items (e.g., confident, afraid, irritable, depressed, cheerful,

hopeless, abandoned, etc.) using the same response options used with the physical symptoms scale, yielding scores from 0 (no psychological suffering) to 45 (high psychological suffering). Positive items are reverse scored. Follow-up questions assessing distress associated with psychological symptoms were not asked since many of the items are indicators of distress. Existential suffering is measured with 9 statements (I feel peaceful, My life has been a failure, I feel a sense of purpose in my life, Life is not worth living anymore, etc.). Respondents are asked to indicate how true each statement has been for them during the past 7 days (not at all=0, a little=1, somewhat=2, quite a bit=3, very much=4) yielding a score of 0 (no suffering) to 36 (high suffering). By changing the wording slightly, the scales can also be used to assess perceptions of suffering. Thus, to assess perceived physical suffering, the respondent is asked to indicate how often the target individual experienced each of the listed symptoms. We also assessed overall levels of suffering with a single item (“Please rate from 1 to 10 your suffering during the past week,” 1=“You have not suffered” and 10=“You suffered terribly”). The scales can be administered as either self-report instruments or by a trained interviewer.

#### Samples Used to Identify Psychometric Properties

Three different samples were used to establish the psychometric properties of the three scales (see Table 1). In Sample 1 (N=105 dyads) the scales were administered to both care recipients with Alzheimer’s disease and their family caregivers recruited in Pittsburgh, PA. Persons with AD and related disorders had a diagnosis based on medical records and/or report of family caregiver. Since we were interested in assessing both the experience and perception of suffering, care recipients provided self-reports of suffering, and caregivers were asked to rate the suffering of their relative with AD. Care recipients were screened to ensure that they were capable of providing reliable responses to the suffering items. Trained interviewers rated the ability of respondents with AD to reliably answer questions throughout the administration of a 30-minute structured interview and the Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) at the conclusion of the interview. Based on these ratings, MMSE scores, and analysis of responses to structured questions, it was determined that persons with dementia scoring less than 16 on the MMSE (N= 26) could not provide reliable responses, and their data were, therefore, not used in the care recipient self-report analyses. The second sample (N=53 dyads) consisted of older married couples also recruited in Pittsburgh, PA, in which one member of the dyad had osteoarthritis, and

the other served as their caregiver, although the amount of care provided in this sample was minimal. Again, osteoarthritis patients provided self-reports of their suffering and their spouses rated the suffering of their partner with osteoarthritis. The third sample (N=121 caregivers) was recruited in Miami, FL and consisted of African American and Hispanic caregivers of individuals with AD who were enrolled in a caregiver intervention study. The latter samples enabled us to examine the psychometric properties of the scales for minority populations. For Hispanic caregivers, we translated all three scales into Spanish using established techniques for forward and backward translation.

## RESULTS

### Internal Consistency

Both the psychological and spiritual/existential suffering scales demonstrated very good internal consistency (see Table 2). Cronbach's alphas for both scales were .83 or higher for all samples with the exception of osteoarthritis patients who had an alpha of .77 for existential suffering. The KR-20 measure of internal consistency for the physical suffering index (.49 to .72 across the three samples) is lower than for the other scales, which is to be expected since it represents an index of physical symptoms that are not necessarily related to each other. We also calculated Cronbach's alphas separately for African American and Hispanic caregivers in the Miami sample and found them to be essentially the same as those of White AD caregivers in Pittsburgh, PA (see Table 3) with the exception of lower internal consistency for the physical suffering index reported by White AD caregivers. Because the internal consistency of the physical suffering index is a direct function of the number of physical symptoms reported, this difference may be attributed to differences in the levels of physical morbidity between the two samples.

### Test-Retest Reliability

To determine the test-retest reliability of the suffering scales, a randomly selected subsample of caregivers (N=14) and care recipients (N=14) in Sample 1 were administered the suffering measures twice, approximately 3-6 weeks apart. For care recipients, the following test-retest correlations were obtained: .88 ( $p < .001$ ) for physical symptoms; .53 ( $p < .05$ ) for psychological symptoms; and .76 ( $p < .01$ ) for existential symptoms. For caregivers, the test-retest correlations were: .76 ( $p < .01$ ) for physical symptoms; .84 ( $p < .001$ ) for

psychological symptoms; and .77 ( $p < .01$ ) for existential symptoms. These results suggest moderate to good stability of the suffering measures over a period of 3-6 weeks. Presumably, these correlations would have been higher had we been able to retest our study participants within the same week.

### Factor Analysis

As the construction of the three suffering scales and selection of items was based on theoretical and not empirical grounds, a confirmatory factor analysis (CFA) was performed to further validate the scales and assess the adequacy of the fit of the data to the conceptual model. The CFA was modeled using SEM with SAS<sup>®</sup> PROC CALIS and was conducted separately for both the caregiver and care recipient ratings of suffering to assess model fit in each. The CFA approach was guided by an assumption that the three factors representing the multiple dimensions of suffering are correlated while individual items load primarily on single latent factor.

A combined sample of caregiver ratings from the three studies ( $n = 279$ ) revealed the 3-factor model was adequate (RMSEA = .08). The two positively-stated items from the psychological suffering scale (“confident” and “cheerful”) cross-loaded on the latent existential factor and detracted the most from overall model fit. One of the physical suffering scale items, ‘confusion and difficulty concentrating’, also detracted from indices of fit due to its low but similar cross-loading on all three factors. Respecifying the model to allow for these cross-loadings between selected items and latent factors resulted in only modest improvements in the indices of model fit. Because this item captures a theoretically important dimension of suffering, we thought it inappropriate to eliminate it from our scale.

A second CFA was conducted in the combined sample of care recipients ( $n = 132$ , MMSE  $> 16$  for AD care recipients) to assess overall model fit to the data. Due to the subsamples being small and unequal in size, it was not possible to directly compare the differences in model fit between the combined care recipient and caregiver samples or between studies. However, the CFA conducted among the care recipients also revealed that one physical suffering scale item ‘confusion and difficulty concentrating’ weakly cross-loaded among the three factors and contributed the most to poorer fit. Overall, the indices of the initial model fit suggested that a 3-factor model fit among the care recipient responses is adequate to poor (RMSEA = .09), (GFI = .800) based on established criteria. When the model was respecified to account for the single physical suffering item, allowing it

to predict all three exogenous variables, the fit improved (RMSE = .08). As expected, the covariance among the three latent factors was high (range,  $r = -.49$  to  $r = -.76$ ) in both the caregiver and care recipient samples.

### Convergent and Discriminant Validity

To assess the convergent and discriminant validity of the suffering scales, we examined intra- and inter-person correlations between the three measures of suffering, suffering profiles by disease state, and the relationship between each suffering indicator and a variety of quality of life and other health status indicators. These data are presented in Tables 4 and 5 and are summarized below.

Measures used to assess convergent and discriminant validity included several different indicators of quality of life including the QOL-AD (Logsdon et al., 2002) and DEMQOL (Smith et al., 2007) and the SF-12, a general health-related quality of life scale that yields summary scores for quality of life in two domains, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Functional status of persons with dementia (Samples 1 and 3) was measured using the MMSE and standard ADL/IADL instruments. Pain severity in osteoarthritis patients was measured using a standardized scale developed by von Korff and colleagues (von Korff, Ormel, Keefe, & Dworkin, 1992). To further assess the concurrent validity of the suffering measures, we also administered the 10-item version of the Center for Epidemiological Studies Depression Scale (Irwin, Artin, & Oxman, 1999) and the brief version of the Zarit Burden Inventory (Hébert, Bravo, & Preville, 2000).

*Suffering Profiles by Disease:* As predicted, caregiver and care recipient self-reports of physical suffering (see Tables 4 and 5) were significantly associated with caregiver and patient self-reports of pain intensity and physical co-morbidities among osteoarthritis patients (range  $r = .38$  to  $r = .59$ ,  $p < .001$ ). Though AD care recipients in Sample 1 rated their physical suffering significantly lower than the osteoarthritis patients (1.0 vs. 1.9,  $p < .01$ , see Table 2), ratings provided by caregivers were approximately equal on average to the osteoarthritis caregivers. AD caregivers in Sample 3 rated the care recipient's suffering significantly higher on all three scales than did caregivers in the other samples. This is consistent with the fact that the care recipients of these caregivers had a more advanced stage of dementia than the Pittsburgh care recipients.

*Intra- and Inter-person Associations of Suffering Scales:* All except one of the within person associations of the three suffering scales are statistically significant (see Tables 4 and 5). The one exception was the

relationship between physical suffering and existential suffering reported by osteoarthritis patients ( $r = .14$ ). The correlations between caregiver report and care recipient report using the same suffering scale are moderately high in both samples that collected these data (range  $r = .28$  to  $r = .62$ ,  $p$  values  $< .05$ ); however, note that caregiver ratings of care recipient suffering are consistently higher than care recipient self-report ratings (see Table 2). Both the within person and between person associations between psychological suffering and existential suffering are higher (range,  $r = .22$  to  $r = .78$ ) than associations between physical suffering and psychological or existential suffering (range,  $r = .03$  to  $r = .50$ ). Within person correlations between each of the suffering scales and the single item assessing overall suffering were consistently high; only one of 12 correlations examined did not reach statistical significance.

*Suffering and Quality of Life Indicators:* As shown in Table 4, each of the caregiver reported suffering measures is significantly negatively correlated with caregiver report of QOL-AD and DEMQOL (range,  $r = -.22$  to  $r = -.73$ , all  $p < 0.05$ ). A similar pattern of findings was obtained when examining the relationship between caregiver reports of suffering and care recipient reports of quality of life, with the one exception that existential suffering was not significantly associated with care recipient report of QOL-AD. Measures of psychological and physical and existential suffering were differentially correlated with the SF-12 health-related quality of life measure. As expected, only the physical suffering index is consistently negatively correlated with the SF-12 PCS score (range  $r = -.21$ ,  $p < .10$  to  $r = -.56$ ,  $p < .001$ ), while psychological and existential suffering are significantly correlated with SF-12 MCS ( $r = -.46$  and  $r = -.43$ ,  $p < .01$ ), but the latter finding was true only for Sample 2 (see Table 4). The within-person correlations between care-recipient SF-12 and each of the suffering indicators were very robust and negative with only 3 of 12 correlations not reaching statistical significance (see Table 5). In contrast, only 2 of 12 correlations between suffering scales and ADL/IADL status were significantly correlated (see Tables 4), suggesting that suffering is independent of functional status. For the osteoarthritis sample, measures of physical comorbidity and pain were also available. As expected, the largest correlations were found between patient reports of physical suffering and indicators of comorbidity and pain (see Tables 4 and 5).

*Caregiver Depression and Burden:* We also examined the extent to which caregiver perception of suffering correlates with caregiver depression and burden. For caregiver ratings of care recipient suffering we

found significant associations between each suffering dimension and caregiver depression and burden among caregivers of persons with AD. Overall, psychological suffering was more strongly associated with caregiver burden than either existential suffering or physical suffering. Likewise, psychological suffering was more strongly associated with caregiver depression than the other two dimensions, and remained significant when all three suffering measures were included simultaneously and adjusting for ADL/IADL disability and caregiver demographics (results not shown). We also found significant associations between each suffering dimension as rated by the caregiver and caregiver depression in Sample 2. Only the care recipient's rating of physical suffering was strongly associated with caregiver burden in the osteoarthritis sample, measured in terms of the stress associated with assisting with IADL activities.

## DISCUSSION

The purpose of this brief report is to provide researchers and clinicians with tools for measuring the experience and perception of suffering in humans. We identify and present scales for three distinct domains of suffering and present data from three diverse samples demonstrating internal consistency, test-retest reliability, and convergent and discriminant validity. Internal consistency and patterns of association between the suffering scales and other psychosocial status indicators were similar for Whites and racial/ethnic minorities. This is important given the increasing number of minority older adults and caregivers and findings that there are differences among racial/ethnic groups in attitudes towards health and health management, patterns of caregiving, coping strategies, and distress. These scales can be used in combination or separately depending on the questions to be answered and the populations being studied. Our data indicate that even a single item assessing general suffering may be useful when opportunities for more intensive assessments are limited.

Why assess suffering? Suffering is a problem in life that affects everyone. All of us have had the experience of suffering directly as well as observing it in others. It is generally an aversive state and serves as a signal for action. Knowing in what way and how much a person is suffering is a requisite to addressing it. Health professionals have long been interested in assessing and addressing suffering in patients; as a result, many instruments are available to gauge patient suffering, although they tend to be disease specific and focus primarily on physical aspects of suffering. Our measures can be used with all individuals regardless of medical condition,

and in addition they assess psychological and existential components of suffering. Our measures can also be used with caregivers or other observers to assess perceptions of suffering in specific target individuals.

Our approach to suffering emphasizes both experiential and perceptual aspects of suffering. Suffering typically occurs in an interpersonal context and is shaped by and affects others exposed to it. In fact, our data shows strong associations between the experience and perception of suffering among individuals in close relationships. Our prior empirical research shows that being exposed to suffering of others is an important and unique source of distress. Consistent with this view, we show in this study that perceived care recipient suffering is associated with caregiver depression and burden, after controlling for the physical and cognitive functioning of the care recipient.

Our data also show that caregivers overestimate the magnitude of suffering of their care recipient. Caregivers report the perceived suffering of the care recipient to be almost twice as high as care recipient self-reports. If we assume self-reports to be the gold standard, these findings suggest that caregivers could benefit from a perceptual adjustment that brings their views of suffering in line with those of the care recipient. Our multi-dimensional approach to the measurement of suffering will enable intervention approaches to be tailored to the needs and experiences of the patient and caregiver.

One of the limitations of this research is that it is difficult to interpret the absolute levels of suffering reported by caregivers and care recipients included in this study because there are no normative data available on suffering in these samples. An immediate goal should be to collect data on the magnitude of suffering among populations with and without a variety of health conditions in order to better understand what normative levels of suffering are. Future research should then explore the role of key moderators of the experience of suffering as well as moderators of observer's perception of suffering, including gender, closeness and quality of the relationships, as well as individual differences in the ability to regulate individual's response to suffering. Another important question concerns the concordance between care recipients' and caregivers' assessment of care recipient suffering and how this affects caregiver and care recipient outcomes. A related question concerns understanding reasons for differences between caregivers and care recipients. Perhaps most important are studies that seek to identify methods for diminishing or eliminating suffering. Many strategies for treating physical signs

of suffering have been developed by cancer and palliative care researchers and clinicians (Hebert, Arnold, & Schulz, 2007), for example, but much less is known about how to treat psychological and existential suffering.

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**Table 1. Care Recipient and Caregiver Characteristics.**

Variable	Sample 1 <sup>a</sup>				Sample 2 <sup>b</sup>				Sample 3 <sup>c</sup>	
	Care Recipient		Caregiver		Care Recipient		Caregiver		Caregiver	
	N	%	N	%	N	%	N	%	N	%
<b>Gender</b>										
Female	42	40	86	82	26	50	26	49	98	81
Male	63	60	19	18	26	50	27	51	23	19
<b>Education</b>										
<High School	20	19	5	5	2	3.8	3	6	31	26
High School	29	28	25	24	12	23.1	11	21	22	18
More than HS	56	53	75	71	38	73.1	39	73	68	56
<b>Employment</b>										
Employed			33	31	12	23	15	38	44	37
Homemaker			21	20	6	11	4	7	16	13
Retired			45	43	32	60	32	60	46	38
Unemployed			6	6	2	4	2	4	14	12
<b>Race/Ethnicity</b>										
White	89	85	89	85	44	83	44	83		
AA	15	14	15	14	6	11	6	11	56	46
Other	1	1	1	1	2	4	3	6	9	7
Latino									56	46
<b>Income</b>										
<\$20,000			14	14			7	14	55	45
\$20,000–\$39,999			28	28			16	32	26	21
\$40,000–\$59,999			23	23			8	16	9	7

>\$60,000			35	35			19	38		25	21
CG relationship to											
Care Recipient											
Spouse			67	64			52	100		42	35
Son			4	4						8	7
Daughter			29	28						58	48
Other family			4	4						10	8
Friend			1	1						1	1
Other			67	64						2	2
Age											
(Mean, SD)	77.3	8.2	65.8	11.3	60.4	12.9	68.7	9.8	60.4	12.9	
(Median, IQR)	78	74-83	67	57-74	70	46-84	69	46-85	60	51-70	

- <sup>a</sup>. Sample 1= Community sample of persons with AD and their caregivers (N=105 dyads). Five caregivers refused to report their income.
- <sup>b</sup>. Sample 2 = Community sample of osteoarthritis patients and their spousal caregivers (n=53 couples). Three caregivers refused to report income and one care recipient refused to complete the entire questionnaire.
- <sup>c</sup>. Sample 3= Community sample of AD caregivers from Miami, FL (n=121). One caregiver missing for employment status, three refused to report income, two income was unknown, one had missing income.

**Table 2. Care Recipient Suffering Reported by Care Recipient and Caregiver: Descriptive Statistics**

CR Suffering Measure	Sample 1 <sup>a</sup>				Sample 2				Sample 3 <sup>b</sup>	
	Care Recipient		Caregiver		Care Recipient		Caregiver		Caregiver	
N	79		105		52		53		121	
Physical Suffering Index										
Cronbach's alpha <sup>c</sup>	.53		.49		.54		.72		.64	
Range	0-7		0-6		0-7		0-7		0-7	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All Care Recipients	1.0	1.3	2.0	1.4	1.9	1.5	1.9	1.9	2.6	1.8
MMSE less than 16			2.0	1.1					2.6	1.7
MMSE 16-23	0.8	1.0	2.0	1.6					2.6	2.1
MMSE 24-29	1.2	1.4	2.1	1.6					1.9	1.7
Psychological Suffering										
Cronbach's alpha	.86		.87		.87		.90		.89	
Range	0-32		1-38		0-24		0-27		0-37	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All Care Recipients	7.5	6.7	11.7	7.0	7.5	5.3	8.7	6.3	12.7	8.2
MMSE less than 16			13.1	8.1					12.8	8.4
MMSE 16-23	7.5	6.7	11.7	6.6					13.5	8.8
MMSE 24-29	7.8	5.8	10.9	6.6					9.7	7.9
Existential Suffering										
Cronbach's alpha	.85		.86		.77		.88		.83	
Range	0-28		0-33		0-20		0-24		0-36	

	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
All Care Recipients	6.2	5.9	11.6	6.6	7.4	5.0	9.4	6.5	12.0	7.1
MMSE less than 16			13.3	7.8					12.3	7.2
MMSE 16-23	6.2	5.9	10.5	5.9					12.1	6.8
MMSE 24-29	6.6	5.6	11.4	6.4					9.8	8.4

<sup>a</sup>The N for each MMSE group for Sample 1 caregivers are 26 for MMSE < 16, 37 for MMSE between 16 and 23, and 42 for MMSE greater than 24.

<sup>b</sup>The N for each MMSE group for Sample 3 caregivers are 82 for MMSE < 16, 25 for MMSE between 16 and 23, and 10 for MMSE greater than 24.

<sup>c</sup> For reliability of index, Cronbach's alpha is reported as equivalent to KR-20.

Sample 1= Community sample of persons with AD and their caregivers (n=105 dyads).

Sample 2= Community sample of osteoarthritis patients and their spousal caregivers (n=53 couples).

Sample 3= Community sample of AD caregivers from Miami, FL (n=121).

MMSE = Mini-Mental State Exam

**Table 3. Reliability and Means of Suffering Measures Reported by Caregiver, by Race/Ethnicity of Caregiver**

	Index of Physical Suffering		Psychological Suffering		Spiritual/Existential Suffering	
African-American (N = 71)	.63		.90		.86	
White (N = 89)	.43		.87		.84	
Hispanic (N = 56)	.60		.85		.83	
	Mean <sup>a</sup>	SD	Mean	SD	Mean	SD
African-American (N = 71)	2.3	1.7	13.1	8.9	11.2	7.3
White (N = 89)	2.1	1.4	11.4	6.7	11.5	6.2
Hispanic (N = 56)	2.7	1.7	12.4	7.1	12.9	7.5

<sup>a</sup>. No statistically significant differences were found by race/ethnicity

**Table 4. Convergent and Discriminant Validity: Correlations between Caregiver (CG) Reports of Care Recipient (CR)****Suffering and other Psychosocial Factors**

Measure	Sample								
	1			2			3		
	Phys	Psych	Exist	Phys	Psych	Exist	Phys	Psych	Exist
<b>Phys</b>									
CR self-report	.32**	.13	.26*	.62**	.30*	.18			
CG report		.45**	.26*		.50**	.35*			
<b>Psych</b>									
CR self-report	.26*	.35**	.34**	.26	.41**	.40**			
CG report	.45**		.76**	.50**		.78**			
<b>Exist</b>									
CR self-report	.03	.22	.28*	-.04	.47**	.53**			
CG report	.26*	.76**		.35*	.78**				
<b>Physical co-morbidity</b>									
CR self-report				.49**	.29*	.35*			
CR MMSE	-.02	-.14	-.19				.002	.04	-.09
ADL help (CG report)	.16	.07	.03				.23*	.07	.24**
IADL help (CG report)	.09	.04	-.03				.09	.14	.17
CR self-report SF-12 (Mental)	-.11	-.20	-.13	-.23	-.46**	-.43**			
CR self-report SF-12 (Physical)	-.21	-.08	-.05	-.25	-.14	-.19			
<b>CR overall suffering</b>									
CR self-report	.06	.10	.17	.41**	.23	.17			
CG report	.34**	.58**	.46**	.60**	.53**	.41**			
<b>CR pain intensity</b>									
CR self-report				.43**	.20	.21			

CG report				.59**	.36**	.16			
CR IADL help received									
CG self-report				.18	-.02	.16			
CG report				-.002	.05	-.06			
QOL-AD									
CG self-report	-.23*	-.25*	-.14						
CG report	-.41**	-.43**	-.48**				-.39**	-.23*	-.22*
DEMQOL									
CG self-report	-.24*	-.35**	-.25*						
CG report	-.34**	-.73**	-.62**						
CG Depression (CESD-10)	.28**	.36**	.38**	.45**	.64**	.44**	.29**	.41**	.21*
CG Burden									
ZBI	.15	.35**	.28**				.31**	.41**	.33**
Stress with IADL Helping				.14	.23	.13			

Sample 1= Community sample of AD patients and their caregivers (n=105 dyads).

Sample 2= Community sample of osteoarthritis patients and their spousal caregivers (n=53 couples).

Sample 3= Community sample of AD caregivers from Miami, FL (n=121).

\*\*Correlation is significant at the 0.01 level (2-tailed).

\*Correlation is significant at the 0.05 level (2-tailed).

MMSE=Mini-Mental State Exam

ADL=Activities of Daily Living

IADL=Instrumental Activities of Daily Living

QoL-AD=Quality of Life in Dementia

DEMQOL=Dementia Quality of Life

ZBI = Zarit Burden Inventory

**Table 5. Convergent and Discriminant Validity: Correlations between Care Recipient Self-report of Suffering (Physical, Psychological, and Existential) and Other Psychosocial Factors**

Measure	Sample					
	1			2		
	Phys	Psych	Exist	Phys	Psych	Exist
CR Phys self-report		.51**	.49**		.41**	.14
CR Psych self-report			.60**			.69**
CR self-report physical co-morbidity				.52**	.18	.04
CR MMSE	.25*	.08	-.02			
ADL help (CG report)	-.02	.07	-.12			
IADL help (CG report)	-.07	-.12	-.21			
CR self-report SF-12 (Mental)	-.29**	-.56**	-.57**	-.27	-.73**	-.64**
CR self-report SF-12 (Physical)	-.38**	-.26**	-.29**	-.56**	-.14	.11
CR overall suffering						
CR self-report	.45**	.50**	.53**	.54**	.52**	.15
CG report	.22	.20	.19	.51**	.15	.09
CR pain intensity						
CR self-report				.57**	.42**	.06
CG report				.38**	.10	-.12
CR IADL help received						
CR self-report				.05	.01	.02
CG report				.22	.10	.03
QOL-AD						
CR self-report	-.38**	-.50**	-.59**			
CG report	-.20	-.16	-.10			

DEMQOL						
CR self-report	-.49**	-.73**	-.70**			
CG report	-.22*	-.32**	-.28*			
CG Depression (CESD-10)	.11	.20	.12	.14	.13	.34*
CG Burden						
ZBI	.05	.23*	.13			
Stress with IADL Helping				.39**	.17	.17

Sample 1= Community sample of AD patients and their caregivers (n=105 dyads).

Sample 2= Community sample of osteoarthritis patients and their spousal caregivers (n=53 couples).

\*\*Correlation is significant at the 0.01 level (2-tailed).

\*Correlation is significant at the 0.05 level (2-tailed).

MMSE=Mini-Mental State Exam

ADL=Activities of Daily Living

IADL=Instrumental Activities of Daily Living

QoL-AD=Quality of Life in Dementia

DEMQOL=Dementia Quality of Life

ZBI = Zarit Burden Inventory

**Appendix: Suffering Scales**

**EXPERIENCE OF SUFFERING**

**I WANT TO ASK YOU SOME QUESTIONS ABOUT HOW YOU HAVE BEEN FEELING OVER THE PAST WEEK.**

**Please indicate: (1) how often you experienced each of the following symptoms during the past 7 days; and (2) how much each symptom has bothered or distressed you.**

*Physical Symptoms:*

How often did you experience the following symptom?					How much did the following symptom bother or distress you?				
Symptom	Not at all	A little (a few days, 1-3)	Quite a bit (most days, 4-6)	Very often (every day)	Not at all	A little	Quite a bit	Very much	
1. Lack of energy/ fatigue	0	1	2	3	0	1	2	3	
2. Lack of appetite	0	1	2	3	0	1	2	3	
3. Pain	0	1	2	3	0	1	2	3	
4. Dry mouth	0	1	2	3	0	1	2	3	

5. Shortness of breath	0	1	2	3		0	1	2	3
6. Nausea	0	1	2	3		0	1	2	3
7. Difficulty sleeping	0	1	2	3		0	1	2	3
8. Constipation/ diarrhea	0	1	2	3		0	1	2	3
9. Confusion/ difficulty concentrating	0	1	2	3		0	1	2	3

*Psychological Symptoms:*

Please indicate how often you experienced the emotions listed below during the past 7 days.

How often did you experience the following emotions?	Not at all	A little/ a few days (1-3)	Quite a bit/ most days (4-6)	Very Often/ every day
1. Afraid	0	1	2	3
2. *Confident	0	1	2	3
3. Worried or anxious	0	1	2	3
4. Irritable	0	1	2	3
5. Depressed	0	1	2	3
6. *Cheerful	0	1	2	3
7. Hopeless	0	1	2	3
8. Sad, blue	0	1	2	3
9. Burden to others	0	1	2	3
10. Angry	0	1	2	3
11. Lonely	0	1	2	3

12.	Embarrassed about yourself	0	1	2	3
13.	Guilty	0	1	2	3
14.	Abandoned	0	1	2	3
15.	Rejected	0	1	2	3

\*positive items –reverse coding for total score

*Existential Symptoms:*

Please indicate how true each statement has been for you during the past 7 days.

Statement	Not at all	A little	Somewhat	Quite a bit	Very much
1. *I felt peaceful	0	1	2	3	4
2. *I had a reason for living	0	1	2	3	4
3. My life had been a failure	0	1	2	3	4
4. I had trouble feeling peace of mind	0	1	2	3	4
5. *I felt a sense of purpose in my life	0	1	2	3	4
6. *I felt a sense of harmony within myself	0	1	2	3	4
7. My life lacked meaning and purpose	0	1	2	3	4
8. *I know that whatever happens with my illness, things will be okay	0	1	2	3	4

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9. Life was not worth living	0	1	2	3	4
any more					

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\*positive items—reverse coding for total score