**SEPTEMBER 2002** 





#### About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.



#### About Benjamin Rose

Benjamin Rose, established in 1908, is a nonprofit organization whose mission is to improve the quality of life for older people, their families and their caregivers through community-based and residential care, research, education and advocacy.

The Margaret Blenkner Research Institute (MBRI) of Benjamin Rose is one of the oldest nonacademic research centers in the United States. Founded in 1961, the MBRI is internationally recognized for its applied gerontological research focusing on developing and evaluating services and model interventions for older adults and their family members. MBRI staff publish widely and many of these articles and books have helped shape the growing body of knowledge in gerontology.

Family Caregiver Alliance National Center on Caregiving 690 Market Street, Suite 600 San Francisco, CA 94104 (800) 445-8106 www.caregiver.org

In collaboration with
Benjamin Rose
The Margaret Blenkner Research Institute
850 Euclid Avenue, Suite 1100
Cleveland, Ohio 44114-3301
(216) 621-7201
www.benrose.org





#### **ACKNOWLEDGMENTS**

This resource inventory was compiled by Kathryn G. Kietzman, MSW, under the supervision of Lynn Friss Feinberg, MSW, deputy director, National Center on Caregiving at Family Caregiver Alliance. Critical guidance, input and support was provided throughout this project by Carol J. Whitlatch, PhD, member of FCA's Advisory Committee for its National Center on Caregiving and a senior research associate at Benjamin Rose, Cleveland, OH.

Sincere appreciation goes to Steve Czerniak at Family Caregiver Alliance for expert assistance with document preparation.

#### **TABLE OF CONTENTS**

Introduction	1
Why These Measures Have Been Selected for Inclusion	1
How To Use The Resource Inventory	2
How To Access Specific Measures	3
I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING	4
Burden	4
Coping	9
Grief/Loss	11
Guilt	12
Intimacy	12
Living Arrangements	
Mastery	
Other	13
Pain	14
Quality Of Life	15
Relationship Issues	17
Religiosity	
Rewards / Gains	
Rewards / Gains	21
Satisfaction	21
Self-Efficacy/Competency	23
Strain/Stress	24
General	24
Family	26
Relationship	26
Role	27
Social	27
Work-Related	27
II. CARE TASKS AND SKILLS	28
Activities And Tasks	28
Care Recipient Functional Level And Its Impact On Caregiver	29
Knowledge	32
III. CAREGIVER HEALTH	34
General	34
Mental Health – General	34
Affect/Mood	35
Anger	36
Anxiety	36
Depression	
Self-Esteem	38
Well-Being	39
Physical Health – General	
IV. FINANCIAL IMPACT OF CAREGIVING	

#### **TABLE OF CONTENTS (CONTINUED)**

V. CAREGIVER SOCIAL SUPPORT	43
General	43
Formal	44
Informal	44
VI. CAREGIVER VALUES AND PREFERENCES	47
Attitudes About Family/Caregiving Responsibility	47
Attitudes About Institutional Settings/Placement	48
Attitudes Toward Receiving Help	49
Cultural/Religious Beliefs	49
Decision Making	49
Perception Of Quality/Effectiveness Of Care	51
VII. MULTIDIMENSIONAL CAREGIVER MEASURES	53
1. Aspects Of The Caregiving Role	53
2. Caregiver Appraisal Measure	54
3. Caregiver Reaction Assessment	55
4. Caregiver Well-Being	56
5. Family Caregiving Factors Inventory	57
6. Finding Meaning Through Caregiving Scale	58
7. Mental Health Effects	59
8. Sense Of Competence Questionnaire	60
References	61
Major References Used To Compile Inventory	61
References For Specific Measures	62

#### INTRODUCTION

This inventory represents a select group of caregiver assessment measures specifically chosen for practical application by practitioners who work with family and informal caregivers of older persons and adults with disabilities. Our purpose in compiling this inventory is to provide a compendium of caregiver assessment measures that is practice-oriented, practical and applicable, and which conceptually addresses the multidimensional aspects of the caregiving experience. While every effort was made to assemble a group of measures that characterizes the broadest possible range of the caregiving experience, this inventory is not intended to represent an exhaustive collection of such measures

### WHY THESE MEASURES HAVE BEEN SELECTED FOR INCLUSION

All of the measures included in this inventory are applicable to the caregiver population and most were specifically designed for caregiver assessment. Measures that are not caregiver-specific are referenced as such. While demographic measures, e.g., age or education, are an essential component of any caregiver assessment, they are excluded from this inventory, both because they are widely available in the literature and because demographic measures may be more suitably designed to reflect the needs of the setting in which they are applied.

The measures were selected because they are:

- Practical and applicable to caregivers
- Previously applied, or could be applied, in practice settings
- Cited in the literature
- Reliable and/or valid

Reliability. "Reliability is a matter of whether a particular technique, applied repeatedly to the same object, would yield the same result each time." (Rubin & Babbie, 2001). Unless otherwise noted, the reliability of the measures included in this

inventory was assessed using Cronbach's  $\alpha$  (i.e., alpha) correlation coefficient to measure internal consistency (Cronbach, 1951). In general, reliability is considered good if  $\alpha$  is .70 or greater. For the purpose of this inventory, we have included some measures that fall slightly below this benchmark because the measure is unique and the specific construct is considered to be an important component of caregiver assessment.

Validity. Validity generally refers to "the extent to which an empirical measure adequately reflects the *real meaning* of the concept under consideration" (Rubin & Babbie, 2001). Validity is most typically determined by assessing convergent and/or discriminant validity as it is measured by Pearson's correlation coefficients. Other common measures of validity include construct, content, and face validity. Please note that validity has not yet been determined, or such determinations are not available, for some of the measures included in this inventory. For more in-depth information about both validity and reliability, the reader is encouraged to reference the Rubin and Babbie (2001) text cited above.

#### **HOW TO USE THE RESOURCE INVENTORY**

Conceptual organization. This inventory has been organized into six conceptual domains:

- 1) positive and negative effects of caregiving
- 2) care tasks and skills
- 3) caregiver health
- 4) financial impact of caregiving
- 5) caregiver social support
- 6) caregiver values and preferences

Individual constructs (e.g., burden or physical health) that fall within each of these domains are arranged alphabetically to make the inventory an easy-to-access and useful tool. The intention is to provide practitioners access to a wide range of measures from which they may generate assessment instruments appropriate and applicable to their practice setting.

Multidimensional measures that are comprised of more than one scale are presented in two ways. First, measures that assess the *same* construct (e.g., quality of life) are presented together. Second, measures that assess *different* constructs (e.g., mental health and informal social support) have been separated. Please note that all subscales separated from their original source are again presented in their original format at the end of the inven-

tory, in section VII entitled, "Multidimensional Measures." *Practical organization*. The resource inventory is tabled into seven columns that are labeled and defined as follows:

- **Measure:** Name of the measure as cited in the literature, presented in alphabetical order within each construct category.
- **Source:** Author(s) and year(s) of the published source(s), in chronological order from earliest to most recent source.
- Number of items: Number of items included in the measure;
   e.g., number of questions or statements.
- **Item responses:** Number and text of the response options that accompany items; e.g., 3-point scale: "never," "sometimes," or "always."
- Reliability: Cronbach's correlation coefficient (unless otherwise noted) is represented by α (alpha), typically .70 and higher.
   Reliability is categorized as "NAP", or, not applicable for those measures that *cannot* be appropriately assessed for reliability using this type of test (e.g., yes/no response options).
- Validity: Determination of validity by type (e.g., construct, convergent, or discriminant) is presented in this column. If a determination of validity is not available, validity is categorized as such; i.e., "NA" (not available).
- Description: Description of the measure, the construct it is meant to assess, and sample items, when available. Differences in the use of terminology, for example, care recipient or care receiver, may reflect regional and/or cultural differences and/or the preferences of the original author(s).

#### **HOW TO ACCESS SPECIFIC MEASURES**

Measures included in this inventory are drawn from published sources. Readers who are interested in obtaining a particular measure with appropriate instructions and scoring information, must first gain permission from the author or author's representative. Inclusion in this inventory does not imply that permission to use a copyrighted measure has been granted by the author. Please see reference list at the end of this inventory for author and publication information.

BURDEN			1			
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
Caregiver Burden Inventory     a) Time-     dependence     burden	Novak & Guest, 1989; Caserta et al., 1996	5	5-point scale: responses range from "not at all descriptive" to "very descriptive"	.85	construct	Measures caregiver burden due to restrictions on time. Items include statements such as, "I don't have a minute's break from my caregiving chores."
				1		
b) Develop- mental burden	Novak & Guest, 1989; Caserta et al., 1996	5	5-point scale: responses range from "not at all descriptive" to "very descriptive"	.8587	construct	Caregivers' feelings of being "off-time" in their development with respect to their peers is measured with this subscale. Statements include items like, "I expecte that things would be different at this poin in my life."
c) Physical burden	Novak & Guest, 1989; Caserta et al., 1996	4	5-point scale: responses range from "not at all descriptive" to "very descriptive"	.86	construct	Measures caregivers' feelings of chronic fatigue and damage to physical health with statements such as, "I'm not getting enough sleep" and "Caregiving has made me physically sick."
d) Social burden	Novak & Guest, 1989; Caserta et al., 1996	5	5-point scale: responses range from "not at all descriptive" to "very descriptive"	.6973	construct	Items such as, "I don't get along with other family members as well as I used to are used to measure caregivers' feelings of role conflict.
e) Emotional burden	Novak & Guest, 1989; Caserta et al., 1996	4	5-point scale: responses range from "not at all descriptive" to "very descriptive"	.7781	construct	Measures caregivers' negative feelings with statements like, "I feel embarrassed over my care receiver's behavior."

BURDEN						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Cost of Care Index  a) Personal and social restrictions	Kosberg & Cairl, 1986; Kosberg et al., 1990	4	4-point scale: responses range from "strongly disagree" to "strongly agree"	.91	NA	Measures limitations and restrictions due to accommodating the needs of the care recipient. Items include statements such as, "I feel that as a result of caring for my elderly relative I do not (will not) have time enough for myself."
b) Physical and	Kosberg & Cairl,		4-point scale: responses			Measures the physical and emotional
emotional health	1986; Kosberg et al., 1990	4	range from "strongly disagree" to "strongly agree"	.91	NA	consequences of providing care with statements like, "I feel that caring for my relative has negatively affected (will negatively affect) my appetite" and "I feel that caring for my elderly relative has caused me (will cause me) to be physically fatigued."
a) 1/a/a	Maahana 0 Cainl		A maint analyse spanning			Management the management of weathing and of
c) Value investment in caregiving	Kosberg & Cairl, 1986; Kosberg et al., 1990	4	4-point scale: responses range from "strongly disagree" to "strongly agree"	.91	NA	Measures the perceived worthiness of providing care with items like, "I feel that meeting the daily needs of my relative is (will be) worth the effort."
		1				
d) Perception of the care recipient as a provocateur	Kosberg & Cairl, 1986; Kosberg et al., 1990	4	4-point scale: responses range from "strongly disagree" to "strongly agree"	.91	NA	Measures the degree that the personality or characteristics of the care recipient may precipitate mistreatment by a caregiver. Items include statements such as, "I feel that my relative is (will be) an overly demanding person to care for," and "I feel that my relative tries (will try) to manipulate me."
-> <b>F</b> i-	Manhann O Cairl		A maint and a very series			Management the appropriate and a first with
e) Economic costs	Kosberg & Cairl, 1986; Kosberg et al., 1990	4	4-point scale: responses range from "strongly disagree" to "strongly agree"	.91	NA	Measures the economic costs of care with statements like, "I feel that as a result of caring for my relative, I and my family must forego (will forego) necessities because of the expense to care for him/her."

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

	RDEN			1 -			
Mea	asure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
3.	Family Strain Scale	Morycz, 1985	14	4-point scale: responses range from "not experienced at all" to "experienced a great deal"	.77	construct	Measures caregivers' subjective burden in terms of emotional/psychological affect, changes in living patterns, and changes in relationships/health. All items are prefaced by the lead-in question: "Does the caregiver experience the following burdens:" "Feels blue," "Has poor sleep", or "Social isolation or decreased time out.
					T	T	
4.	Measurement of Burden: Objective and Subjective	Montgomery et al., 1985a, 1985b	9 obj. 13 subj.	5-point scale: objective responses range from "a lot more better" to "a lot less worse"  subjective responses range from "rarely or never" to "most of the time"	.85 objective .86 subjective	construct	Objective scale measures caregiver's life: amount of privacy; time; personal freedom; amount of money available; amount of energy; amount of vacation activities; recreational activities; relationships with other family members and health.  Subjective scale measures caregiver burden in terms of attitudes and emotional reactions toward caregiving. Includes items such as, "I feel that I don't do as much for my [recipient] as I could or should."
5.	Novel Caregiver Burden	Elmstahl et al., 1996	20	4-point scale: responses include "not at all," "seldom," "sometimes," and "often"	Strain =.87 Isolation =.70 Disappoint- ment=.76 emotional involvement =.70	construct	Measures various dimensions of burden including general strain, isolation, disappointment, and emotional involvement.
6.	Perceived Burden <sup>1</sup>	Pruchno & Resch, 1989	1	5-point scale: responses range from "not at all" to "most of the time"	NAP	NA	Measures how burdened the caregiver feels with a single item: "Overall, how burdened do you feel in caring for your [relative]?"

\_

<sup>&</sup>lt;sup>1</sup> This scale is part of a larger instrument: *Mental Health Effects*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

	RDEN	Course	# of	Mana was na sa	Delieb!!!	Validit	Description
Me	asure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
7.	Perceived Burden Scale	Poulshock & Deimling, 1984; Moss et al., 1987; Strawbridge & Wallhagen, 1991	22	5-point scale: categories included "not a problem or concern," "sometimes," "usually," "often," and "always"	.94	NA	Measures the extent to which caregivers believe that the changes in their lives have occurred because of caregiving problems or concerns. Items include "Now, I worry about him/her all the time" and "Now, I feel tired all the time."
			1				
8.	Role Captivity	Pearlin et al., 1990; Zarit & Whitlatch, 1992; Aneshensel et al., 1995	3	4-point scale: responses range from "not at all" to "very much"	.83	construct	Measures feelings of being "trapped" in the caregiving role. Items ask caregivers how well these statements describe their feelings and thoughts about being a caregiver: "wish you were free to lead a life of your own, feel trapped by your (relative's) illness, [and] wish you could just run away."
			T				
9.	Role Overload	Pearlin et al., 1990; Zarit & Whitlatch, 1992; Aneshensel et al., 1995	3	4-point scale: responses range from "not at all" to "completely"	.78	construct	3 items from the original 4-item scale are used to measure feelings of exhaustion and fatigue related to caregiving responsibilities. Includes the following items: "How much does each statement describe you?: you are exhausted when you go to bed at night, you have more things to do than you can handle, [and] you don't have time just for yourself?"
		T	T				
10.	Screen for Caregiver Burden	Vitaliano et al., 1991	25	5-point scale for subjective burden: from "no occurrence" to "occurrence with severe distress"; objective burden: from "no occurrence/occurrence but no distress" to "severe distress"	.85 = objective burden .88 = subjective burden	construct; and criterion	Measures objective and subjective caregiver burden in terms of the occurrence of care demands and distress associated with them.

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

BU	RDEN						
Mea	asure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
11.	Subjective caregiving burden <sup>2</sup>	Lawton et al., 1989	13	5-point scale: responses range from "strongly agree" to "strongly disagree" or from "never" to "nearly always"	.85	construct	Measures the caregiver's appraisal of stress attributable to both general and specific caregiving experiences. It is designed to capture positive, neutral and negative aspects of caregiving.
12.	Zarit Burden Interview	Zarit et al., 1980	22	5-point scale: responses range from "not at all" to "extremely"	.88 - 91	construct; correlated with a single global rating of burden (r=.71)	Provides a single summary measure of the caregiver's appraisal of the impact caregiving has had on their lives.
13.	Zarit Burden Interview: short version	Zarit et al.,1980;Bédard et al., 2001	12	5-point scale: responses include "never," "rarely," "sometimes," "quite frequently," and "nearly always"	.88	Correlations between the short and full versions:	This abbreviated burden measure includes items such as: "Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?"
14.	Zarit Burden Interview: screening version	Zarit et al., 1980; Bédard et al., 2001	4	5-point scale: responses include "never," "rarely," "sometimes," "quite frequently," and "nearly always"	.78	Correlations between the screening and full versions:0.83-0.93	Designed for use as a screening tool for the assessment of caregiver burden, this scale includes items such as: "Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?"

\_

<sup>&</sup>lt;sup>2</sup> This scale is part of a larger instrument: *Caregiver Appraisal Measure*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

CO	PING						
Me	asure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.	Avoidance Scale	Braithwaite, 1996	5	NA	.70	NA	Measures degree of caregiver's involvement in activities that distract them from their caregiving role.
2.	Coping Inventory	Barusch, 1988	34	5-point scale: responses range from "not at all effective" to "completely effective"	.82 inter-rater	NA	A tool describing problem situations in 6 major areas: care management, personal and psychological response to caregiving, interpersonal with spouse, interpersonal with others, financial, and personal health-related. Using an open-ended format, the caregiver has the chance to describe the coping response used, and then evaluate its effectiveness.
3.	Coping Strategies Inventory	Quayhagen & Quayhagen, 1982; 1988	48	4-point scale: responses range from "very likely" to "not at all likely"	.5779	content	Measures six dimensions of coping: problem-solving; help-seeking; existential growth; minimization of threat through diversional activities; fantasy; and blame.
4.	Inventory of Coping Strategies	Kiyak et al., 1985; Pruchno & Resch, 1989a	16	5-point scale from: "never," "rarely/seldom," "sometimes," "often," to "most of the time"	.6173	construct	Measures coping using 4 subscales: wishfulness, acceptance, intrapsychic, and instrumental. Items include: "wished you could change the way you felt," "accepted the situation," "daydreamed/imagined a better time or place than the one you were in," and "felt inspired to be creative in solving problem."

CO	PING						
Me	asure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
5.	Jalowiec Coping Scale	Jalowiec et al., 1984; Pierce et al., 1989	40	5-point scale with responses ranging from "never" to "almost always"	.86	content construct	Measures differences in burden levels and coping strategies using 8 subscales: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant.
6.	Reinter- pretation and Acceptance	Braithwaite, 2000	12	4-point scale	.87	NA	[not caregiver specific] Measures emotion-focused and cognitive reframing strategies such as: "telling yourself there is no alternative and you just have to see it through," "thinking of good things that have come out of the situation," and "having a cigarette or a drink."
			<u> </u>				
7.	Ways of Coping Checklist	Lazarus & Folkman, 1984; Vitaliano et al., 1985	42	4-point scale: response options include: "not used/not applicable," "used somewhat," "used quite a bit," to "used a great deal"	.7688	Construct	Measures coping with 5 subscales: problem-focused coping, wishful thinking, avoidance, seeks social support, and blames self. Items include statements such as: "Talked to someone about how I was feeling," "Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, and so forth," and "Didn't let it get to me; refused to think about it too much."

GF	RIEF/LOSS	_			_		
Me	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.	Bereavement Consequences	Bass et al., 1991	6	2-point scale: responses are "yes" or "no"	.72	NA	Measures negative consequences of bereavement for the caregiver with the following items: "Because of my relative's death, I have difficulty: eating properly; having enough energy to get things done; having someone around to talk to; controlling my grief; getting good advice or suggestions about how to manage this situation; because my physical of emotional health has changed for the worse."
2.	Family Bereavement Difficulties	Bass & Bowman, 1990; Bass et al., 1991	3	2-point scale: responses are "yes" or "no"	.64	NA	Measures whether care recipient's death has resulted in tension or strain among family members, a lack of family cooperation, and anger among family members with items such as: "Because of my relative's death, I have difficulty with: tension or strain among family members; getting family to cooperate with me."
3.	Grief Scale	Wells & Jorm, 1987; Wells et al., 1990	10	4-point scale: responses include "not at all," "a little," "a lot," and "almost unbearably"	.86	NA	Measures grief experienced by caregivers as distinct from general distress with items such as: "I miss not being able to talk to my relative," "I feel helpless in the face of my relative's illness," "I feel that grief has aged me."
	Loss/ Powerlessness <sup>3</sup>	Farran et al., 1991	19	5-point scale ranging from "strongly agree" to "strongly disagree"	.8889	convergent and discriminant	Measures feelings of loss for family member and for self, as well as feelings of powerlessness associated with caregiving. Includes items like, "I am sad about losing the person I once knew."

<sup>&</sup>lt;sup>3</sup> This scale is part of a larger instrument: *Finding Meaning Through Caregiving Scale.* See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

	RIEF/LOSS easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
	Personal Bereavement Difficulties	Bass & Bowman, 1990; Bass et al., 1991	6	2-point scale: responses are (0)No and (1)Yes	.72	NA	Measures caregiver's difficulty adjusting to bereavement with items like, "Because of my relative's death, I have difficulty: eating properly; having someone around to talk to; controlling my grief."
	JILT Guilt	Mullan, 1992; Aneshensel et al., 1995	5	4-point scale: from "not at all" to "very much"	.6874	NA	Measures feelings of guilt and regret specific to the caregiver's relationship with the care recipient.  Caregivers are asked: "How much do you: feel that you are not doing all that you should for your (relative), feel bad about something you said or did when your (relative) was well, regret that you didn't get a chance to make your peace with your (relative) before (his/her) illness?"
2.		Wells & Jorm, 1987; Wells et al., 1990	9	4-point scale: responses include "not at all," "a little," "a lot," and "almost unbearably"	.79	NA	Measures guilt felt by caregivers specific to that role with items like: "I feel guilty regarding my decision to seek help for my relative," "I keep thinking I should be doing more for my relative," "I feel bad about my lack of patience with my relative," and "I sometimes feel guilty because I can enjoy myself."
	TIMACY Loss of Intimate Exchange	Pearlin et al., 1990; Aneshensel et al., 1995	3	4-point scale: responses range from "completely" to "not at all"	.76	NA	Measures the extent to which caregivers feel they have experienced a loss of closeness and intimacy because of the care recipient's decline with the following items: "To what extent do you feel that you personally have lost the following: How much have you lost: being able to confide in your (relative)," "the person that you used to know," [and] "having someone who really knew you well?"

LIVING ARRANGEM						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
Inconveniences in Living Arrangements	Mindel, C.H., & Wright, R. Jr. 1982	8	5-point scale	.76	NA	Measures the level of potential inconveniences in living arrangements in the caregiving household with respect to food, social life, leisure activities, employment, household chores, expenses, privacy, and child care.
MASTERY 1. Mastery OTHER	Pearlin & Schooler, 1978; Mullan, 1992; Aneshensel, 1995	7	4-point scale: responses range from "strongly disagree" to "strongly agree"	.7579	NA	Measures a generalized sense of personal control or efficacy that individuals feel they have over their lives. Caregivers indicate their level of agreement with statements such as, "There is really no way I can solve some of the problems I have" and "I can do just about anything I really set my mind to do."
1. Appraisal of Caregiving a) Threat	Folkman et al., 1986; Pakenham, 2001	7	7-point scales: responses range from "no harm" to "extremely harmful"	.87	NA	Measures the extent to which caregiver experiences caregiving as a threat or potential harm to important life goals and financial security.
b) Challenge	Folkman et al., 1986; Pakenham, 2001	3	7-point scale: responses range from "nil potential" to "high potential"	.76	NA	Measures the extent to which caregiver perceives the caregiving experience as providing an opportunity for personal growth, a personal challenge, or the strengthening of a relationship.
c) Controllabilty	Folkman et al., 1986; Pakenham, 2001	2	7-point scale	.64	NA	Caregiver rates the extent to which s/he perceives caregiving as a problem that either could be changed or must be accepted.

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

OTHER	OATIVE ETTEOTO OF					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2.Impact of Caregiving⁴	Lawton et al., 1989	9	5-point scale: responses range from "strongly agree" to "strongly disagree" or from "never" to "nearly always"	.70	construct	Measures the caregiver's perception of the impact of caregiving on his/her social life, family relationships, time management, and physical and emotional space.
3.Loss of self	Skaff & Pearlin, 1992	2	4-point scale: responses range from "not at all" to "completely"	.76	NA	Measures the caregivers sense of a loss of self with the following items: "How much have you lost a) a sense of who you are and b) an important part of yourself?"
PAIN 1.The Pain Responses Self Statements- Spouse Version (PRSS-SO)	Flor et al., 1993	18	NA	.7881	convergent	Measures the cognitive reaction of significant others when their partners are in pain. Respondents are asked to rate how often they have had a particular thought. For example, "S/he needs some pain medication".
2.The Pain Self- Efficacy Questionnaire- Spouse Version (PSEQ-SO)	Bandura, 1977; Nicholas, 1989	10	7-point rating scale ranging from "not at all confident" to "completely confident"	.77	convergent	Measures the degree to which significant others perceive their partners can engage in activities despite pain. Items include statements like, "S/he can do most of the household chores despite the pain."
		1		1		
3.West Haven-Yale Multidimensional Pain Inventory- Spouse Version (MPI-SO)	Flor et al., 1987	50	7-point scale ranging from "no change" to "extreme change" or "not at all worried" to "extremely worried"	.7893	convergent	Section I measures the significant other's perceptions of the degree to which pain is impacting upon theirs and their partner's life. Section II measures significant others' reports of their own responses when their partner is in pain.

-

<sup>&</sup>lt;sup>4</sup> This scale is part of a larger instrument: the *Caregiver Appraisal Measure*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

<b>QUALITY OF LIFE</b>						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Bakas Caregiving Outcomes Scale	Bakas & Champion, 1999	10	7-point scale: responses range from "changed for the worst" to "changed for the best"	.77	criterion	Measures life changes that result from caregiving as experienced by the caregiver with regard to: emotional wellbeing, ability to cope with stress, selfesteem, relationship with friends and with family, physical health, time for social and family activities, future outlook, and relationship with care recipient.
	1 =	I		T	T	
2. Caregiver Well- Being Scale: a)Basic needs	Tebb, 1995	23	7-point scale ranging from 0 to 6	.91	construct, criterion	Based on Maslow's (1968) hierarchy of needs, this scale measures the extent to which the caregivers' basic human needs are met in 3 areas: love; physical needs; and self-esteem.
b)Activities of Living	Tebb, 1995	22	7-point scale ranging from 0 to 6	.81	construct, criterion	Non-basic needs required for a healthy life, such as exercise, skill development, relaxation, personal growth, and social support are measured in 3 areas: time for self, home, and family.
3. Health-related Quality of Life (HRQOL) (as measured by the SF-36)	Ware et al., 1993; Hughes et al., 1999	36	2-point, 3-point, 5-point, and 6-point scales with multiple response options including: "not at all" to "extremely"; "much better now" to "much worse now"; "definitely true" to "definitely false"; Each scale is scored from 0 (worst) to 100 (best)	0.63-0.94	content construct	Measures each of 8 health concepts: physical functioning; role limitations due to physical health problems; bodily pain; general health; vitality; social functioning; role limitations due to emotional problems; and mental health.

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

<b>QUALITY OF LIFE</b>						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
4. Life Satisfaction Scale <sup>5</sup>	Schofield et al., 1997	6	5-point scale: from "very dissatisfied" to "very satisfied"	0.77-0.79	construct	Measures the degree of life satisfaction in 6 areas: finances; health; independence; caregiver respect and recognition; personal, emotional life; and life as a whole.
5. Quality of Life in Alzheimer's Disease Scale (QOL-AD)	Logsdon et al., 1999	13	4-point scale: responses range from "poor" to "excellent"	.87	NA	Measures both the care recipient's and caregiver's rating of the care recipient's quality of life in regard to items such as: Physical health, energy, mood, memory, family, self as a whole, ability to do things for fun, and life as a whole.
6. Quality of Life Inventory (QOLI)	Frisch, 1992; Frisch et al., 1992	16	3-point scale: responses include "not at all important," Important," [and] "very important"  7-point scale: responses range from "very dissatisfied" to "very satisfied"	.7789	convergent discriminant	[not caregiver-specific] Measures positive mental health or overall life satisfaction by assessing satisfaction and dissatisfaction in 16 areas of life such as love, work, and health. The respondent first rates how important each of these areas is to their overall happiness and satisfaction, then rates how satisfied they are in the area.
7. Oalaadada faratlaa	History et al. 4007		Otana 4. Onan andad			Front and a section of the T
7. Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW)	Hickey et al., 1997	15	Stage 1: Open-ended responses; 5 most important areas of life are identified Stage 2: Responses range from 0 (worst possible) to 100 (best possible) Stage 3: Using a pie chart, each of 5 identified areas is quantified by its relative weight	Cronbach: NA; Test-retest reliability	criterion face	[not caregiver-specific] An open measure of quality of life. The respondent identifies 5 areas as those most important in their life, rates each of these 5 areas using a visual analogue scale, and then assigns each area a relative weight.

-

<sup>&</sup>lt;sup>5</sup> This scale is part of a larger instrument: *Aspects of the Caregiving Role*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

RELATIONSHIP ISSU	JES					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Caregiving Burden Scale	Gerritsen & van der Ende, 1994	13	5-point scale: responses range from "disagree very much" to "agree very much"	.84	construct	Comprises two subscales: one measures the quality of the caregiver-care recipient relationship, the other measures the consequences of caregiving with items like, "I never feel free from the care of my spouse" and "I feel pleased about my interactions with my spouse."
2. Closeness of	Whitlatch et al.,	<u> </u>	4-point scale: responses		1	Measures the caregiver's perception of
the Relationship	2001	6	range from "strongly agree" to "strongly disagree"	.90	NA	the "closeness of the relationship" between the caregiver and care recipient with items like, "My relative always understood what I value in life," "My relative always made me feel like a special person," and "My relative was often critical of me."
3. Dyadic Adjustment Scale (DAS)	Spanier, 1977; Bagarozzi, 1985	32	6-point scale: ranging from "always disagree" to "always agree" 5-point scale: ranging from "all the time" to "never"  Other items are rated on a 0-2 or 0-4 scale.	NA	NA	[not caregiver-specific] Measure of marital adjustment; it can also be used by unmarried partners and by homosexual couples. Subjects rate the extent to which they and their partner agree or disagree on a range of issues. Also assesses the frequency with which the pair engage in specific interactions, such as quarreling or confiding in each other.
	I =	1		ı		
4. Family Conflict Scales	Pearlin et al., 1990; Semple, 1992	12	4-point scale: responses range from "no disagreement" to "quite a bit of disagreement"	.8086	NA	Measures conflict around the family's definition of the illness and strategies for care, attitudes and actions toward the patient, and actions and attitudes toward the caregiver.

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

RELATIONSHIP IS:	SUES					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
5. Family Environment <sup>6</sup>	Schofield et al., 1997	6	3-point scale: "less," "the same," or "more"	Closeness: .6873 Conflict: .7075	construct	Measures extent to which caregivers experience more, the same, or less conflict and closeness in the family environment since the onset of caring.
6. Family Hardiness Index	McCubbin et al., 1987	20	4-point scale: responses include "false," "mostly false," "mostly true," and "true"	.82	construct concurrent	[not caregiver-specific] Measures family hardiness specific to the internal strengths and durability of the family unit when confronted with stressors. It is comprised of 4 subscales: Co-oriented Commitment, Confidence, Challenge, and Control. The scale includes items such as: "In our family: "We work together to solve problems," "We do not feel we can survive if another problem hits us" and "Trouble results from mistakes we make."
7. Quality of the caregiver – care recipient relationship	Lawrence et al., 1998	4	4-point scale: responses range from: "not at all close/well/similar" to "very close/well/similar"	.85	NA	Measures current relationship quality such as general closeness, communication, similarity of views about life, and degree of getting along. Items include: "Taking everything into consideration, how close do you feel in the relationship between you and name of care recipient?" and "In general, how similar are your views about life to those of name of care recipient?"

\_

<sup>&</sup>lt;sup>6</sup>This scale is part of a larger instrument: *Aspects of the Caregiving Role*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

RE	<b>ELATIONSHIP ISS</b>	SUES					
Me	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
8.	Deprivation	Pearlin et al., 1990	6	4-point scale: responses range from "completely" to "not at all"	.6777	NA	Measures the extent to which the caregiver feels separated from parts of their lives that had previously been supported by or shared with the care recipient. Items include, "How much have you lost "the person that you used to know"; "a chance to do some of the things you planned", and "contact with other people?"
	ELIGIOSITY	Toylor & Chatters		6 point goals: from "daily"	_		Magauras caragivara' activo religious
1.	Religiosity	Taylor & Chatters, 1986	15	6-point scale: from "daily" to "never" 5-point scale: from "daily" to "almost never" 4-point scale: from "very religious" to "not at all religious" 4-point scale: from "very much" to "none at all"	.7890	NA	Measures caregivers' active religious participation, personal religious beliefs, and satisfaction with support from their religious community with items such as: "How often do you attend religious services or activities", "Would you describe yourself as [very religious] to [not religious at all]" and "How much comfort do you find in religion in times of suffering and distress?"
2	Spiritual	Hays et al., 2001	I	5-point scale: responses			[not caregiver-specific]
۷.	History Scale in Four Dimensions (SHS-4)	1 lay 3 Gt al., 200 I	23	range from "strongly agree" to "strongly disagree"	.5795	construct and convergent	Measures lifetime religious and spiritual experience and its value in explaining late-life health. Items include statements such as, "Overall, my religious life has taught me to have a positive attitude," "For most of my life, my social life has revolved around the (church)/(synagogue)", "When I was a child, my parents left my religion up to me" and "At times, my religious life has caused me stress."

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

RE	LIGIOSITY						
	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
	Meaning <sup>7</sup>	Farran et al., 1991	5	5-point scale ranging from "strongly agree" to "strongly disagree"	.9195	convergent and discriminant	This scale focuses on a higher power or religious/spiritual structure in which the caregiver finds meaning. Includes items such as, "I believe in the power of prayer; without it I couldn't do this."
	WARDS / GAINS	0   11   1   1000					
1.	Care Work Satisfaction Scale	Orbell et al., 1993	6	7-point scale: responses range from: "strongly agree" to strongly disagree"	.92	NA	Measures caregiver satisfaction as an expression of the caregiver's enhanced self-worth.
						1	
2.	Personal Gain	Pearlin et al., 1990; Skaff & Pearlin, 1992	4	4-point scale: responses range from: "not at all" to "very much"	.6881	NA	Measures the degree of personal growth a person has experienced in the caregiver role with the following items: "How much have you: 'become more aware of your inner strengths', 'become more self-confident', 'grown as a person' and 'learned to do things you didn't do before'?"
		1				1	
3.	Picot Caregiver Rewards Scale	Picot et al., 1997a; 1997b	24	5-point scale: responses range from: "not at all" to "a great deal"	.86	construct	Measures the positive feelings and outcomes of caregiving. Respondents rate the extent to which each are experienced.
		T 1 1 1001		Te	I	T	T. A
4.	Provisional Meaning <sup>8</sup>	Farran et al., 1991	19	5-point scale ranging from "strongly agree" to "strongly disagree"	.8892	convergent and discriminant	Measures positive aspects and ways that caregivers find meaning through the caregiving experience.  The Provisional Meaning scale focuses on how persons find day-to-day meaning through caregiving with items like, "Caring for my relative gives my life a purpose and a sense of meaning."

\_

 <sup>&</sup>lt;sup>7</sup>This scale is part of a larger instrument: Finding Meaning Through Caregiving Scale. See also Multidimensional Measures at the end of this inventory.
 <sup>8</sup>This scale is part of a larger instrument: Finding Meaning Through Caregiving Scale. See also Multidimensional Measures at the end of this inventory.
 Key: NA = Not available NAP=Not applicable September 2002

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

<b>REWARDS / GAINS</b>	GATIVE EFFECTS OF					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
5. Role Stress and Rewards Questionnaire	Stephens, Franks, & Townsend, 1994	12	4-point scale ranging from, "did not happen" to "very rewarding"	.87	NA	Measures positive experiences and rewards in the caregiver role such as affection, appreciation, improved relationship, improved care recipient health. Also evaluates rewards specific to being a wife and mother.
6. Uplifts	Pruchno et al., 1990	8	3-point scale: responses include "most of the time," "some of the time," [and] "not at all" 3-point scale: responses include "feel closer," "neither closer nor more distant," and "more distant"	.82	NA	Measures positive component of caregiving by asking respondent how often during the past month the care recipient: "provided companionship," "gave embraces," "was enjoyable to be with," "seemed appreciative or grateful for your help," and "appeared cheerful."
SATISFACTION  1. The AIDS Caregiver Scale	Ferrari et al., 1993	14	7-point scale ranging from: 1 (low) to 7 (high)	.8086	NA	Measures both personal satisfaction and stress associated with caring for a person with AIDS. Items include statements such as, "Helping people with HIV disease is worthwhile to me personally" and "Working with someone or people with HIV has exhausted me."
2. Caregiving Satisfaction <sup>9</sup>	Lawton et al., 1989	5	5-point frequency scale: responses range from "never" to "nearly always" or "strongly agree" to "strongly disagree"	.6776	construct	Measures caregiving satisfaction by indicating level of agreement with statements such as, "you really enjoy being with the [impaired person]", and "you take care of [impaired person] more because you want to than out of a sense of duty."

\_

<sup>&</sup>lt;sup>9</sup> This scale is part of a larger instrument: *Caregiver Appraisal Measure*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

#### I. POSITIVE AND NEGATIVE EFFECTS OF CAREGIVING

SA	TISFACTION						
Me	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
3.	Caregiving Satisfaction Scale	Strawbridge, 1991	15	4-point scale: responses range from "strongly disagree" to "strongly agree"	.90	NA	Measures long-term satisfactions and rewards of caregiving.
4.	Carer Satisfaction	Pound et al., 1993	9	4-point scale range from "strongly disagree" to "strongly agree"	Carer Hospsat= .87 Carer Homesat= .79	construct	Measures caregiver satisfaction with services for stroke patients. One section is focused on in-patient services and includes items like, "The hospital recognizes the difficulties and problems of caring or someone who has had a stroke"; the other section is directed at services after discharge and includes items such as, "I was given all the information I needed about the allowances and services I might need when my relative/friend came out of hospital."
5	Caring Role	Schofield et al.,	T	5-point scale: "strongly			Measures positive responses to the care
<b>5</b> .	Satisfaction <sup>10</sup>	1997	6- items; 5- items; 4-items	agree" to "strongly disagree"	Satisfaction: .6571; Resent- Ment: .6975; Anger: .6871	construct	recipient and to the caring role; negative effects on the caregiver's life, time, opportunities and social relationships; and negative emotional responses to the care recipient through anger, embarrassment and guilt. Some of the items for this scale were drawn from the Caring for Relatives Questionnaire (Greene et al., 1982) and the Caregiver Appraisal Questionnaire (Lawton et al., 1989).

1/

<sup>&</sup>lt;sup>10</sup>This scale is part of a larger instrument: *Aspects of the Caregiving Role*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

	LF-EFFICACY/CO	MPETENCY					
	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.	Caregiving Competence	Pearlin et al., 1990; Skaff & Pearlin, 1992	4	4-point scale: responses include: "not at all," "just a little," "somewhat," and "very much" and "not at all," "just a little, "fairly," and "very"	.74	NA	Measures the caregivers' evaluation of the adequacy of their own performance in the job of caregiver with items such as, "How much do you believe that you've learned how to deal with a very difficult situation?" and "How much do you feel that all in all, you're a good caregiver?"
2.	Caregiving Effectiveness	Noelker & Townsend, 1987	3	4-point scale: responses range from "not satisfied at all" to "very satisfied"; "not successful at all" to "very successful"	.64	NA	Measures perceptions of caregiving effectiveness with the following items: "How satisfied are you with the present arrangement for caring for your [relative]," "How successful do you think you've been in achieving your goals in caring for you [relative]," [and] "How satisfied are you with the way in which decisions concerning your [relative] are made?"
3.	Revised Scale for Caregiving Self-Efficacy	Zeiss, et al., 1999; Steffen et al., 2002	51	For each item, a rating of between 0% – 100% is assigned.	.7485	construct	Caregiver self-efficacy is measured in terms of self-care and obtaining respite; responding to disruptive patient behaviors; and controlling upsetting thoughts activated by caregiving activities. Caregivers rate the level of confidence they have in performing each activity.
4.	Satisfaction With One's Own Performance as a Caregiver <sup>11</sup>	Scholte op Reimer et al., 1997	12	4-point scale: Responses range from "disagree very much" to "agree very much"	.89	NA	Includes items such as, "I'm capable to care for my [relationship]" and "I feel useful in my interactions with my [relationship]."

<sup>&</sup>lt;sup>11</sup> This scale is part of a larger instrument: Sense of Competence Questionnaire. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

ST	TRAIN/STRESS - G	ENERAL					
Me	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.	Caregiver Distress Activities	Pearlin et al., 1990	8	4-point scale: responses range from "very often" to "never"	NA	NA	Measures the caregiver's effort to decrease the symptoms of stress that result from caregiving with the following items: "Here are things that some people do when they are under stress from caregiving. How often do you do them?" "Spend time alone," Eat," "Smoke," "Get some exercise," "Watch TV," "Read," "Take some medication to calm yourself," [and] "Drink some alcohol?"
		T =		T		_	
2.	Caregiver Strain Index	Robinson, B., 1983	13	2-point scale: responses are (0)No and (1)Yes	.86	construct	Measures caregiver strain with items such as: "It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)", "There have been other demands on my time (e.g., from other family members)", and "It is upsetting to find [name of care recipient] has changed so much from his/her formal self (e.g., he/she is a different person than he/she used to be)."
2	Caregiver	Deimling & Bass,	T	NA	I	I	Measures caregiver's perception that,
J.	Stress Effects a. Negative changes in elder, caregiver and family relationships	1986a	8	IVA	.88	NA	because of caregiving, specific aspects of family life were negatively affected.
			<u> </u>				
b.	. Restrictions in caregivers' activities	Deimling & Bass, 1986a	5	NA	.80	NA	Measures the restrictions in caregivers activities resulting from caregiving, such as visiting less often with family or friends, and taking part in fewer social and recreational activities.

ST	RAIN/STRESS - G	ENERAL					
Me	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
4.	Measures of Strain a. Appraised difficulty of caregiving	Bass & Bowman, 1990; Bass et al., 1991	3	4-point scale: responses range from "strongly disagree" to "strongly agree"	.67	NA	Measures the degree to which caregiving is perceived as threatening to the family's well-being with items like, "Caring for my impaired relative is the most difficult problem I have ever faced" and "It is easy to feel overwhelmed in a situation like this."
						I	
	b. Negative consequences of caregiving	Bass & Bowman, 1990; Bass et al., 1991	3	2-point scale: responses are (0)No and (1)Yes	.66	NA	Measures individual consequences of caregiving with the following items:  "Because of my relative's impairments and care, I have difficulty with: too many demands being made of me; getting enough rest; my physical or emotional health changing for the worse."
	c. Perceptions	Bass & Bowman,	T	2-point scale: responses		Ι	Measures family consequences of
	of negative consequences of caregiving on the family	1990; Bass et al., 1991	2	are (0)No and (1)Yes	.96	NA	caregiving with the following items:  "Because of my relative's impairments and care, I have difficulty with: tension and strain among family members; getting family members to cooperate in caring for my relative."
5.	Perceived Stress Scale	Cohen et al., 1983	14	5-point scale: responses range from "never" to "very often"	.8486	concurrent and predictive	[not caregiver-specific] Measures the degree to which situations in one's life are appraised as stressful with items such as: "In the last month, how often have you been able to control irritations in your life?," "how often have you found that you could not cope with all the things that you had to do?" and "how often have you been able to control the way you spend your time?"

ST	RAIN/STRESS - F	AMILY					
	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.	Family Conflict	Pearlin et al., 1990; Aneshensel et al., 1993	12	4-point scale: responses range from "no disagreement" to "quite a bit of disagreement"	.8090	NA	Measures disagreement concerning treatment of the care recipient and caregiver with items such as: "How much disagreement have you had with any one in your family because they "Don't spend enough time with (care recipient)," "Lack patience with (care recipient)," "Don't give you enough help," or "Give you unwanted advice?"
	Family Relationship Strain	Bass et al., 1988; Feinberg et al., 2000	5	4-point scale: responses range from "strongly agree" to "strongly disagree"	.65	NA	Measures strain within the family unit as perceived by both the caregiver and the care recipient. Questions include "feeling closer to my other family members," "relying more on other family members for support," and "relationship with other family members has become strained."
	RAIN/STRESS - R Dyadic Relationship Strain	Bass et al., 1994b; Bass et al., 1999; Feinberg et al., 2000	9	4-point scale: responses range from "strongly agree" to "strongly disagree"	.8693	NA	Measures the quality of the relationship between caregiver and care recipient with 3 positive items and 6 negative items. Caregivers are asked whether they feel appreciated for caregiving and get pleasure out of helping, as well as whether they feel manipulated by care recipients and feel angry or resentful towards them.
2.	History of Conflict between the Caregiver and Care Receiver	Parker, 1978; Braithwaite, 2000	8	4-point scale: responses range from "not at all like him/her" to "very like him/her"	.84	NA	Measures the degree of conflict that existed between the care recipient and caregiver prior to the need for care.

	RAIN/STRESS - R asure	Source	# of	Item responses	Reliability	Validity	Description
IVIC	aguit	Cource	items	Rem responses	(Cronbach's alpha)	validity	Description
1.	Role Stress and Rewards Questionnaire	Stephens, Franks, & Townsend, 1994	12	4-point scale: responses range from "did not happen" to "very rewarding"	.87	NA	Measures experience of caregiver role- related stress by asking if stressor event occurred within the last 2 months and, if so, how distressing it had been. Items included: "Care recipient asked repetitive questions," "Care recipient was agitated," [and] "[I] did not receive help with caregiving from family or friends."
1.	Social Isolation	Deimling & Bass, 1986b; Bass et al., 1996	5	3-point scale: responses include: "more often," "the same," or "less often"	.85	NA	Measures whether caregiving increased, decreased, or had no effect on caregivers' participation in various social activities, including religious activities, visiting with family and friends, participating in organizations or groups, volunteering, and attending entertainment activities.
	RAIN/STRESS - W Job - Caregiving Conflict	Pearlin et al., 1990; Aneshensel et al., 1993; Aneshensel et al., 1995	5	4-point scale: responses range from "strongly agree" to "strongly disagree"	.75	NA	Measures degree to which caregiving is impacting current work situation with items like: "In the last two months or so: You have had less energy for your work," "You worry about your (care recipient) while you're at work," and "Phone calls about or from your (care recipient) interrupt you at work."

#### **II. CARE TASKS AND SKILLS**

<b>ACTIVITIES AND TA</b>	SKS					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.Caregiving Tasks Scale	Archbold & Stewart, 1988	36	3-point scale	NAP	NA	Measures 36 types of assistance that are potentially provided by caregivers to the care recipient. Many of the items deal with activities of daily living as well as aspects of decision making and supervision. [subscale of larger instrument: The Family Caregiving Inventory. See also multidimensional measures]
2.Impact on Disrupted Schedule <sup>12</sup>	Given et al., 1992	5	5-point scale: responses range from "strongly agree" to "strongly disagree"	.81	construct	Measures the extent to which caregiving interrupts usual daily activities, causes the elimination of some activities, and interferes with relaxation time. It also assesses the degree to which activities center on caregiving. Items include statements like, "I visit family and friends less since I have been caring for my partner."
		•		•		
3.Impact on Social Activities <sup>13</sup> (a.k.a. Social Participation)	Cantor, 1983; George & Gwyther, 1986	7	Number of visits and phone contacts with family/ friends; frequency of club and church attendance; time spent engaged in hobbies or relaxing; satisfaction with social activities	.79	NA	Includes both objective and subjective indicators of the caregiver's level of social activity and participation. Each objective measure is accompanied by a subjective assessment of the caregiver's satisfaction with the frequency and quality of the activity.
4.Stetz Inventory, Part I	Stetz, 1986; Wallhagen, 1988	15	6-point scale: "never," "rarely," "several times a month," "every week," "several times a week," and "daily"	.85	NA	Measures the extent of caregiver tasks including questions about caregiving activities, such as "I help [care recipient] with eating his/her food" and "I do shopping, appointments, or run errands for [care recipient]."

<sup>&</sup>lt;sup>12</sup>This scale is part of a larger instrument: *Caregiver Reaction Assessment*. See also Multidimensional Measures at the end of this inventory. <sup>13</sup>This scale is part of a larger instrument: *Caregiver Well-Being*. See also Multidimensional Measures at the end of this inventory.

#### II. CARE TASKS AND SKILLS

ΔC	CTIVITIES AND TA	SKS					
	easure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
5.	Task Management Strategy Index	Gitlin et al., 2002	19	5-point scale: responses range from "never" to "always"	.7481	construct	Measures caregiver's use of specific strategies to cope with physical dependency and agitation in individuals with ADRD. Items assess the caregiver's use of visual and tactile cueing, simplifying routines, communication techniques, and removing or rearranging objects and items with questions such as: "How often do you" give short instructions," "use pictures or labels to identify objects in rooms," and "use clothing that is easy to put on or take off?"
	Time Constraints Scale	Braithwaite, 2000	5	NA	.79	NA	Measures degree of involvement with questions about whether or not the caregiver had missed out on holidays, had spent less time with family, and had little time to themselves.
CA	ARE RECIPIENT F	UNCTIONAL LEVEL A	ND ITS IN	MPACT ON CAREGIVER			
1.	Behavior and Mood Disturbance (BMD) Scale and Relatives' Stress (RS) Scale	Greene et al., 1982	BMD= 34 RS= 15	5-point scale: Responses range from "never" to "always" and from "not at all" to "considerably"	BMD=.84 RS=.85	construct	Two rating scales which measure the degree of behavior and mood disturbance demonstrated by the care recipient with items such as, "wanders outside the house and gets lost," and the amount of stress and upset experienced by the relative as a result of having to care for them with items like, "How much has your household routine been upset?"
2.	Caregiving Hassles and Uplifts Scale	Kinney & Stephens, 1989	110	4-point scale	.7190	NA	Caregivers appraise caregiving events occurring in the past week of caregiving as a hassle, an uplift, or both or neither. 4 subscales assess caregiving events with respect to: care recipients limitations in ADL; care recipients cognitive status; care recipients' behavior, and practical aspects of caregiving.

#### II. CARE TASKS AND SKILLS

Measure	UNCTIONAL LEVEL A Source	# of	Item responses	Reliability	Validity	Description
incasure	Jource	items	item responses	(Cronbach's alpha)	Validity	Description
3. Caregiving Task Difficulty	Shyu, 2000	6	Responses range from "not difficult at all" to "very difficult"	.73	content and construct	Measures the degree of difficulty in performing caregiving tasks pertaining to: unpredictability of the care recipient's condition; lack of cooperation of the care recipient; uncontrollable external factors; heavy physical labor; and the length of time providing care.
4. Care Recipient	Golden, Teresi, &	T	4-point scale: responses		<u> </u>	Measures the frequency with which care
Impairment a) Cognitive impairment	Gurland, 1984; Deimling & Bass, 1986b; Bass et al., 1999	6	include: "none of the time," "some of the time," "often," [and] "most or all of the time"	.86	NA	recipients repeat things, hear or see things that are not there, talk to themselves, forget names, forget words, and get confused.
		1				
b) Physical disability	Nagi, 1976; Bass et al., 1999	7	4-point scale: responses include: "none of the time," "some of the time," "often," [and] "most or all of the time"	.88	NA	Measures the amount of difficulty care recipients have with standing, lifting, going up or down stairs, walking, bending, using hands or fingers, and reaching with arms.
					1	
c) Problem behaviors	Noelker & Wallace, 1985; Deimling & Bass, 1986b; Bass et al., 1999	6	4-point scale: responses include: "none of the time," "some of the time," "often," [and] "most or all of the time"	.85	NA	Measures the frequency with which care recipients interfere or offer unwanted advice, yell or swear, act restless or agitated, act fearful without reason, complain or criticize things, and display inappropriate sexual behavior.
<u> </u>	1					
5. Family Burden Interview	Morycz, 1985	15	4-point scale: responses range from "not serious at all" to "very serious"	.87	NA	Measures both the existence and the severity of particular problems or stresses for caregivers. The caregiver rates care recipient functional deficits and behavior according to the severity of the problem.

#### II. CARE TASKS AND SKILLS

<b>CARE RECIPIENT FU</b>	UNCTIONAL LEVEL A	ND ITS IN	MPACT ON CAREGIVER			
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
6. Frequency of Behavior Problems Scale	Niederehe & Fruge, 1984	28	5-point frequency responses from "never" to "every day"	.87	NA	Summarizes the level of behavior problems presented by the impaired family member, including cognitive symptoms such as forgetfulness, misplacing, or losing objects; behavioral symptoms such as wandering or hoarding; aggressive behaviors such as destroying property; and psychiatric symptoms such as hallucinations or delusions.
7. Negative Perception of Care Situation	Noelker & Townsend, 1987	7	4-point scale: responses range from "strongly agree" to "strongly disagree"	.77	NA	Measures the extent to which respondent defines the caregiving situation in a negative manner with items such as: "I think of this situation as a problem that will only become more serious with time," I'm troubled by not having many choices available about ways to meet my [relative]'s care needs," [and] "I never know what to expect from day to day in this situation."
		_				
8. Perceived Burden Measure	Macera et al., 1993	15	2-point scale: "yes" or "no"  Possible scores range from 0-15	.87	construct	Measures the number of care recipient needs – e.g., transportation, bathing, and administering medication; the amount of support provided by the caregiver; and whether or not providing assistance adds to the caregiver's stress level.
9. Physical Labor Scale	Morycz, 1985	11	One point is counted for every deficit that exists  Possible scores range from 0 to 11	.76	NAP	Measures whether care recipient needs physical assistance in eating, bathing, dressing, toileting ability, medications, shopping, or cleaning. Combined with vigilance/disruptiveness scale score (see below), creates an objective stress scale.

#### **II. CARE TASKS AND SKILLS**

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
10. Revised Memory and Behavior Problems Checklist	Teri et al., 1992; Zarit & Zarit, 1983	24	5-point frequency scale: responses range from "never occurs" to "occurs daily or more often" 5-point reaction scale: responses range from "not at all" to extremely	.6790	concurrent and discriminant	Using two scales, measures the frequency of problematic behaviors in persons with dementia and the caregiver reactions to these behaviors.
44 0-4-54	Oakalta an Daiman	1	I descript and a Description	T		Leader there it was a little of the state of
11. Satisfaction with [relative] as a Recipient of Care <sup>14</sup>	Scholte op Reimer et al., 1997	7	4-point scale: Responses range from "disagree very much" to "agree very much"	.84	NA	Includes items like, "I feel that my [relative] behaves the way he/she does to annoy me" and "I feel that my [relative] makes requests which I perceive to be over and above what he/she needs."
12. Social Interaction Measure	Bass et al., 1994b	5	4-point scale: responses include: "almost never," "sometimes," "frequently," [and] "almost always"	.74	NA	Measures positive aspects of care recipient behavior. Items ask about the degree to which the care recipient is cooperative, friendly, and enjoyable to be with.
13. Vigilance/ Disruptiveness Scale	Morycz, 1985	13	One point for every functional or behavioral symptom that exists. Possible scores range from 0-13.	.74	NA	Measures whether care recipient needs reminding or watching for various tasks or symptoms. Combined with Physical Labor Scale (see above) score, creates an objective stress scale.
KNOWLEDGE						
1. Alzheimer's Disease Knowledge Test	Dieckmann, L. 1988	20	5-point scale: responses include the correct response, 3 distractors, and "I don't know"	.7192	content construct	Using a multiple choice format, this test measures the overall level of knowledge of Alzheimer's disease demonstrated by caregivers, professionals, and other persons involved in providing care.

.

This scale is part of a larger instrument: Sense of Competence Questionnaire. See also Multidimensional Measures at the end of this inventory.

Key: NA = Not available NAP=Not applicable September 2002

## II. CARE TASKS AND SKILLS

KNOWLEDGE						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Caregiver Competence	Kosberg & Cairl, 1991	21	2-point scale: yes or no 4-point scale: from "no provision" to "extensive provision"	NA	NA	Measures level of caregiver competence. First, caregivers are asked questions such as: "Have you read any books or pamphlets on [name of disease] or caregiving the past year," "Do you consult a physician or nurse when an unexplained change occurs in [care recipient's] health or behavior," "Do you make sure [care recipient] is not disturbed by high levels of sensory stimulation," [and] "Do you make sure [care recipient] can take a shower or bath regularly?" A 3-person clinical team then reviews the caregivers close-ended and open-ended responses and assigns a rating of competence for each of 5 conceptual categories, as well as an overall rating of competence on a 10-point scale.
3. Knowledge of the Care Recipient <sup>15</sup>	Shyu, 2000	10	Responses range from "very poor" to "very well"	.91	content and construct	Measures the degree of understanding the caregiver has for the care recipient's physical condition, and how this understanding might influence his/her caregiving actions. Items assess, for example, caregiver's knowledge of whether or not care recipient has pressure sores or joint contractions.

\_

This scale is part of a larger instrument: *Family Caregiving Factors Inventory*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

GENERAL						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. General Health Survey Questionnaire, Short Form 36 (SF-36)	Ware et al., 1993; Ware et al., 1996	36	2-point, 3-point, 5-point, and 6-point scales with multiple response options including: "not at all" to "extremely"; "much better now" to "much worse now"; "definitely true" to "definitely false" Each scale is scored from 0 (worst) to 100 (best)	.6794	construct content	[not caregiver-specific] Measures each of 8 domains of health: physical functioning; role limitations due to physical health problems; bodily pain; general health; vitality; social functioning; role limitations due to emotional problems; and mental health.
2. General Health Survey Questionnaire, Short Form 12 (SF-12)	Ware et al., 1993; 1996	12	2-point, 3-point, 5-point, and 6-point scales with multiple response options (see General Health Survey Questionnaire, Short Form 36 [SF-36], above).	.6391	construct content	[not caregiver-specific] This scale is comprised of a subset of items from SF-36 that measure the same 8 domains of health. Items assess the degree to which the respondent feels: "limited because of physical health," [they've] "accomplished less because of emotional problems," Other items address how often they "felt calm and peaceful," "had a lot of energy," or "felt downhearted and low" in the last 4 weeks.
1. Brief Symptom Inventory	Derogatis & Melisaratos, 1983	53	5-point scale: responses range from "not at all" to "extremely"	.8487	construct and criterion	[not caregiver-specific] Measures symptoms of depression, anxiety, and hostility. Brief form of the SCL-90-R (see below).
2. Brief Symptom Inventory - 18	Derogatis & Savitz, 1999	18	5-point scale: responses range from "not at all" to "extremely"	NA	NA	[not caregiver-specific] Measures psychological distress and psychiatric disorders in medical and general community populations.

## III. CAREGIVER HEALTH

MENTAL HEALTH -	GENERAL					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
3. Consequences of Caring <sup>16</sup>	Pruchno & Resch, 1989	17	5-point scale: responses range from "not at all" to "most of the time"	.89	NA	Measures how often the caregiver has experienced a variety of feelings such as: loneliness; guilt; nervousness; irritability; helplessness; trapped; and overwhelmed.
4. 0	D	ı	I so a sint and a sint and a	1	I	Frank and a state of the T
4. Symptom Checklist SCL-90-R (Hopkins Symptom Checklist)	Derogatis, 1974; Derogatis & Melisaratos, 1983	90	5-point scale: responses range from "not at all" to "extremely"	.7790	construct, criterion and convergent	[not caregiver-specific] Measures psychological symptoms and distress in terms of 9 primary symptom dimensions: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism.
MENTAL HEALTH -						
1. Positive and Negative Affect Scales (PANAS)	Bradburn, 1969; Watson et el., 1988	20	5-point scale: responses range from "very slightly or not at all" to "extremely"	PA scale: .8285 NA scale: .8386	construct	[not caregiver-specific] Measures psychological well-being by asking respondent to rate to what extent they experience different feelings and emotions including, for example, "guilty," "inspired," "attentive," "strong," and "irritable." Ratings may be obtained with different temporal instructions: Time frames include, for example: Moment (you feel this way right now, at the present moment); Week (you have felt this way during the past week); General (you generally feel this way, that is, how you feel on the average).

-

This scale is part of a larger instrument: *Mental Health Effects*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

#### III. CAREGIVER HEALTH

MENTAL HEALTH -						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Vulnerability Scale	Weisman & Worden, 1977; Oberst, M. et al., 1988	13	A score is derived from observer ratings	.8493	NA	[not caregiver specific] The scores of 4 subscales - dysphoria, alienation, annihilation, and denial - are determined by an observer rating of an individual's affective behavior.
MENTAL HEALTH –  1. Resentment and Anger <sup>17</sup>		6- items; 5- items; 4-items	5-point scale: "strongly agree" to "strongly disagree"	Satisfaction: .6571; Resent- Ment: .6975; Anger: .6871	construct	Measures positive responses to the care recipient and to the caring role; negative effects on the caregiver's life, time, opportunities and social relationships; and negative emotional responses to the care recipient through anger, embarrassment and guilt. Some of the items for this scale were drawn from the Caring for Relatives Questionnaire (Greene et al., 1982) and the Caregiver Appraisal Questionnaire (Lawton et al., 1989).
2. Tension	Zarit & Whitlatch, 1992	5	4-point scale: "5 or more days," "3-4 days," "1-2 days," and "no days"	.82	NA	Measures tension and frustration the caregiver feels in dealing with the care recipient.
MENTAL HEALTH –  1. Filial Anxiety Scale	ANXIETY Cicirelli, V.G. 1988	13	5-point scale: responses range from "strongly agree" to "strongly disagree"	.7788	construct	Measures 2 types of anxiety experienced by the adult child caregiver: anxiety over one's ability to take on a caregiving role and anxiety over the aging parent's welfare. Items include: "I worry that I'll break down if I have to give my parent a great deal of care," "I don't know what I'll do if my parent asks for help," [and] "I always feel a nagging sense of concern about my parent."

\_

<sup>&</sup>lt;sup>17</sup>This scale is part of a larger instrument: *Aspects of the Caregiving Role*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Neuropsychiatric Inventory Caregiver Distress Scale	Kaufer et al., 1998	10	6-point scale: from "not at all distressing" to "extremely distressing"	test-re-test: r = .92	criterion	Measures subjective caregiver distress as impacted by the personality changes, depression, psychosis and agitation often associated with persons with Alzheimer's disease. Caregivers first rate the frequency and severity of each symptom and then rate the level of emotional or psychological distress experienced.
3. State-Trait Anxiety Inventory (STAI, Form Y)	Spielberger, 1980	40	4-point scale: responses range from "almost never" to "almost always" 4-point scale: responses range from "not at all" to "very much so"	.92	construct concurrent content discriminant	[not caregiver-specific] A general measure of anxiety assessing both state (situational) and trait (dispositional) anxiety. Measures the presence or absence of state anxiety with items like: "I am tense; I am worried" and "I feel calm; I feel secure." Trait anxiety items include: "I worry too much over something that really doesn't matter" and "I am content; I am a steady person."
MENTAL HEALTH –  1. Beck's    Depression    Inventory (BDI)	DEPRESSION Beck et al., 1961; 1979	21	4-point scale: scores range from 0 (absence of depression) to 3 (maximal depression severity)	.5893	concurrent	[not caregiver-specific] Measures depression by asking the respondent to choose the response that best fits him/her "over the past week, including today", for example: from (0) "I do not feel sad" to (3) "I am so sad or unhappy I can not stand it."

MENTAL HEALTH - I	DEPRESSION					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Center for Epidemiological Studies – Depression Scale (CES-D)	Radloff, L., 1977	20	4-point scale: responses range from 0 (rarely or none of the time / less than 1 day) to 3 (most or all of the time / 5-7 days)	.90	construct	[not caregiver-specific] A general measure of depression frequently used in caregiver studies. Respondents are asked how often they have felt a particular way in the past one week, e.g., "How often have you become bothered by things that don't usually bother you?," "felt that everything you did was an effort?," or "felt hopeful about the future?"
						•
3. Geriatric Depression Scale	Brink et al., 1982; Yesavage et al., 1983	30	2-point scale: "yes" or "no"	.94	discriminant concurrent	[not caregiver-specific] Measures depression in older adults in terms of loss, cognitive complaints, somatic complaints, and self-image with items like: "Are you in good spirits most of the time," "Do you feel pretty worthless the way you are now," "Do you have trouble concentrating," [and] "Is it easy for you to make decisions?"
4. Zoor or Oalf Data d	7 W 4005	I	0			Front and a single state of the T
4. Zung Self-Rated Depression Scale	Zung, W., 1965	20	2-point scale: "yes" or "no"	.8387	NA	[not caregiver-specific] A measure of depressive symptomatology applicable to the general population which assesses how often the respondent has experienced 20 symptoms of depression.
MENTAL HEALTH -	SELF-ESTEEM	·				
1. Self-esteem Scale	Rosenberg, 1962; Bakas & Champion, 1999	10	5-point scale: responses range from "strongly agree" to "strongly disagree"	.84	convergent discriminant	[not caregiver specific] Measures belief s in one's worth, competence, and capacity for success.

MENTAL HEALTH -	SELF-ESTEEM					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Impact on Self-esteem <sup>18</sup>	Given et al., 1992	7	5-point scale: responses range from "strongly agree" to "strongly disagree"	.90	construct	Measures the extent to which caregiving imparts individual self-esteem. Items assess whether respondent views caregiving as a privilege; as enjoyable; as rewarding; or whether it causes resentment.
MENTAL HEALTH -						
1. Caregiver Well- Being Scale a) Low affect scale	Zarit & Whitlatch, 1992	7	4-point scale: responses range from "not at all" to "very much"	.86	NA	Measures feelings of sadness and loss of interest or energy in usual activities experienced by the caregiver during the past 7 days.
	_					
b) Cognitive depression	Zarit & Whitlatch, 1992	6	4-point scale: responses range from "not at all" to "very much"	.78	NA	Measures how often the caregiver has experienced - during the past 7 days - cognitive dimensions of depression, including feelings of hopelessness, worthlessness, and blaming one's self.
\ <b>A</b>	I = 11 0 14 11 1 1	<u> </u>		<u> </u>	T.	
c) Anxiety	Zarit & Whitlatch, 1992	4	4-point scale: responses range from "not at all" to "very much"	.80	NA	Measures how often the caregiver has experienced - during the past 7 days - common symptoms of anxiety: feeling nervous, tense, afraid, or worrying about everything.
		1				
d) Anger	Zarit & Whitlatch, 1992	4	4-point scale: responses range from "not at all" to "very much"	.81	NA	Measures how often caregivers have felt irritated or angry during the past 7 days.

<sup>&</sup>lt;sup>18</sup>This scale is part of a larger instrument: *Caregiver Reaction Assessment*. See also Multidimensional Measures at the end of this inventory.

#### III. CAREGIVER HEALTH

PHYSICAL HEALTH						
Caregiver     Subjective     Physical Health	Whitlatch et al., 1999	4	Four 3-point scales: responses included: "better," "about the same," [and] "worse"; "not at all," "a little," [and] "a great deal"; "excellent/good," "fair," [and] "poor"	.82	NA	Measures caregiver's perception of their physical health status with the following items: "Is your health now better, about the same, or worse than it was five years ago," "How much do your health troubles stand in the way of your doing the things that you want to do," "How much do your health troubles stand in the way of your assuming a greater role in caregiving," [and] "How would you rate your overall health at the present time?"
	W 4000		Each and in a search from			
2. General Health Perceptions Scale	Ware, 1993	5	Each scale is scored from 0 (worst) to 100 (best)	.85	construct content	[not caregiver-specific] Provides a measure of self-reported physical health.
		,		1		
3. Health Problems <sup>19</sup>	Given et al., 1992	4	5-point scale: responses range from "strongly agree" to "strongly disagree"	.80	construct	Measures the caregiver's physical capability and energy to provide care. It further assesses the caregiver's health in relation to the caregiving role. For example: "I am healthy enough to care for my partner."
		T		T		
4. Perceived Health Index	Deimling & Bass, 1986a	4	5-point scale: responses range from "almost never" to "almost always"	NA	NA	Measures both caregiver's and care recipient's perceptions of self-health status with items that assess worry, exhaustion, aches, and pains.
		1		1	1	
5. Physical Health Deterioration	Deimling & Bass, 1986b; Bass et al., 1988; Bass et al., 1996	5	4-point scale: responses range from "strongly agree" to "strongly disagree"	.89	NA	Measures caregivers' perceptions about whether caregiving causes them to be sick more often, have more aches and pains, feel physically worse, be more nervous, and have less energy.

\_

This scale is part of a larger instrument: *Caregiver Reaction Assessment*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

## IV. FINANCIAL IMPACT OF CAREGIVING

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Economic Strain	Aneshensel et al., 1993	1	2-point scale: (1) not enough or just enough to make ends meet or (0) some money left over	NA	NA	Measures degree of financial strain with the following item: "In general how do your family finances work out at the end of the month?"
	T			T		
2. Economic Strains	Pearlin et al., 1990; Aneshensel et al., 1995	3	5-point scale: from "much less now" to "much more now" 3-point scale: "not enough to make ends meet," "just enough to make ends meet," and "some money left over"	NA	NA	Caregiver's assessment of current household expenses and standard of living as compared to before he/she began to give care. Includes the following items: "Compared to that time, how would you: describe your total household income from all sources;" "describe your monthly expenses" and "In general how do your family finances work out at the end of the month?"
O Financial luna at	Tadkaras 0	I	F a sint a salar managana	T	T	Management the Constraint and of information
3. Financial Impact Scale	Todtman & Gustafson, 1991	20	5-point scale; responses range from "strongly agree" to "strongly disagree"	.91	concurrent	Measures the financial impact of informal long-term caregiving with items such as: "I feel that my family argues more about money now than we did before I was responsible for caregiving," "My caregiving responsibilities have been so stressful that I have had to pay to go to the doctor for my own medical attention" and "I feel resentful because I have had to cut down on my own expenses because of caregiving costs."

## IV. FINANCIAL IMPACT OF CAREGIVING

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
4. Financial Problems <sup>20</sup>	Given et al., 1992	3	5-point scale: responses range from "strongly agree" to "strongly disagree"	.83	construct	Measures caregiver financial strain, in regard to adequacy, the difficulty, and the strain of the financial situation on the caregiver and the family. Items include statements like, "Caring for my partner puts a financial strain on me."
5. Financial Resources <sup>21</sup>	George & Gwyther, 1986	2	Single-item measure of household income; measure of perceived economic status	Subjective assessment: .85	NA	Assessment of the caregiver's financial resources includes both an objective and a subjective measure.

This scale is part of a larger instrument: Caregiver Reaction Assessment. See also Multidimensional Measures at the end of this inventory.
 This scale is part of a larger instrument: Caregiver Well-Being. See also Multidimensional Measures at the end of this inventory.
 Key: NA = Not available NAP=Not applicable September 2002

#### V. CAREGIVER SOCIAL SUPPORT

General						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
Assistance with Caregiving	Braithwaite, 1996	2	2-point scale: yes or no	NAP	NA	Measures assistance with caregiving with the following items: "Have you asked for help and received it?" and "Have you been offered help and accepted it?"
		T				
2. Helping Network Composition	Bass et al., 1991; Bass et al., 1999	16	3-point scale: responses include: "not helpful at all," "somewhat helpful," and "very helpful"	NA	NA	Caregiver reports the presence and helpfulness of 4 types of informal helpers and 4 types of formal helpers. Caregivers are asked who helps care recipients with 6 categories of tasks. Caregiver identifies one helper who is the "overall most helpful", and then ranks the degree of helpfulness of the remaining identified helpers.
0 N ()	D		1 4 2 4 1			NA
3. Negative Service Attitudes and Experiences	Bass et al., 1994a	6	4-point scale: responses range from, "strongly agree" to "strongly disagree"	.6667	NA	Measures negative attitudes toward formal services in 2 areas: the inadequacy of services; and the respondent's perceptions that someone in the family has avoided using services because they are in denial about the relative's illness.
4. Service Use: Formal and Informal	Feinberg et al., 2000;Whitlatch, 2002	6	2-point scale: yes or no;  3-point scale: "family/friend," "volunteer," or "paid helper";  3-point scale: "yes, definitely," "perhaps would use," and "no, definitely not"	NAP	NA	Measures 13 different kinds of help that the caregiver and/or care recipient may have received during the past 3 months, who provided the service, and whether or not the caregiver was satisfied with the quality of services received. Also addressed is whether the caregiver could use more help, if he/she is aware of the availability of paid professionals, and if caregiver would consider using this type of paid help.

## V. CAREGIVER SOCIAL SUPPORT

Formal						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Negative Service Experiences	Bass et al., 1994a	11	4-point scale: responses range from, "strongly agree" to "strongly disagree"	.6684	NA	Measures the reasons that services were not used; difficulties finding services; and inconveniences encountered when attempting to use services.
Informal  1. Perceived Emotional Support Scale	Pearlin et al., 1990; Aneshensel et al., 1995	8	4-point scale: responses range from "strongly disagree" to "strongly agree"	.87	NA	Measures level of perceived expressive support. Caregivers are asked the degree to which they agree or disagree with statements pertaining to the availability of friends and family who are caring, understanding, and familiar or trustworthy.
2. Perceived Social Support for Caregiving	Goodman, 1991	9	5-point scale: responses range from "not at all" to "extremely"	.84	NA	Measures aspects of self-help support, information exchange, and social support. Items include: "I can talk over my feelings about caregiving with others who have similar values," "Others I know have given me useful advice about how to plan for the future," "Others I know have helped me realize my problems are not unique," [and] "Others have helped me gain insight into my behavior and feelings as a caregiver."
3. Social Change Index <sup>22</sup>	Pruchno & Resch, 1989	13	5-point scale: responses range from "not at all" to "most of the time"	.78	NA	Measures level of participation in social activities such as: volunteer or community work, recreation, and other leisure activities.

-

This scale is part of a larger instrument: *Mental Health Effects*. See also Multidimensional Measures at the end of this inventory. Key: NA = Not available NAP=Not applicable September 2002

#### **V. CAREGIVER SOCIAL SUPPORT**

Informal						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
4. Social Conflict	Goodman, 1991	3	5-point scale: responses range from "never" to "nearly always"	.72	NA	Measures negative aspects of supportive relationships with the following items: "The stresses of caregiving have caused quarrels with people I love," "I've been in conflict with others I know about how to manage the problems of <i>[name of disease]</i> ," "People don't approve of some things I've done to care for my relative with <i>[name of disease]</i> ."
5. Social	George & Gwyther,		Number of visits and			Includes both objective and subjective
Participation <sup>23</sup>	1986	7	phone contacts with family/ friends; frequency of club and church attendance; time spent engaged in hobbies or relaxing; satisfaction with social activities	.79	NA	indicators of the caregiver's level of social activity and participation. Each objective measure is accompanied by a subjective assessment of the caregiver's satisfaction with the frequency and quality of the activity.
24		1				
6. Social Support <sup>24</sup>	Schofield et al., 1997	7	5-point scale: "strongly disagree" to "strongly agree"	(Of total sum score): .6670	construct	This scale was modified from the Provision of Social Relations Scale (Turner et al., 1983). Social support is characterized by factors of family support; friends' support; and the degree to which caregiver is esteemed by family and friends.
		_				
7. Social Support Measure	Krause, Markides, & Kyriakos, 1990	44	4-point scale: responses range from "never" to "very often" 3-point scale: includes "more often," "satisfied," and "less often"	.6783	NA	[not caregiver-specific] Measures the amount of informational, tangible, and emotional support given and received, the perceived need for support, and degree of satisfaction with support.

 <sup>&</sup>lt;sup>23</sup>This scale is part of a larger instrument: Caregiver Well-Being. See also Multidimensional Measures at the end of this inventory
 <sup>24</sup>This scale is part of a larger instrument: Aspects of the Caregiving Role. See also Multidimensional Measures at the end of this inventory.
 Key: NA = Not available NAP=Not applicable September 2002

## V. CAREGIVER SOCIAL SUPPORT

Informal						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
8. Socioemotional Support	Pearlin et al., 1990; Aneshensel et al., 1995	8	4-point scale: responses range from "strongly agree" to "strongly disagree"	.8187	NA	Measures degree of help and support the caregiver receives from friends and relatives with items such as: "The people close to you let you know that they care about you," "You have someone who you feel you can trust", and "You have at least one friend or relative you can really confide in."

Attitudes about fami	ly/caregiving respons	sibility				
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Visual Analogue Scale	Wolfson et al., 1993	3	Visual analogue scale: ratings are marked along a visual continuum	NA	NA	Using a visual analogue scale, caregivers rate the perceived amount of support they believe they "should" and "could" provide to care recipients. They are asked to mark a "slash" on the line to indicate level of assistance with the following items:  No financial Enough financial assistanceassistance to at all cover all expenses  No emotional As much emotional support support at all as needed  No physical As much physical assistance assistance at all as needed
2. Willingness to	Abell, N., 2001		5-point scale:			Measures the experiences of informal
Care Scale		30	responses range from "completely unwilling" to "completely willing"	.92	content factorial	caregivers for persons living with AIDS and their attitudes towards providing emotional, instrumental, and nursing support. The respondent first indicates the tasks they feel able to do for the care recipient and then rate their willingness to engage in activities such as: "hold hands with someone who is afraid," "wash someone's dishes," "negotiate someone's health care options with a physician," and "change dressings on someone's sores."

Measure	Source	# of items	Item responses	Reliability	Validity	Description
		01.1000	Попровод	(Cronbach's alpha)		
1. Care-related Strain	Whitlatch et al., 2001	7	4-point scale: responses range from "strongly agree" to "strongly disagree"	.90	NA	Measures the stress a caregiver feels as a result of having a relative in a nursing home with items such as: "I don't have enough time for myself," "I feel that my social life is limited" and "I have trouble managing all the demands on my life."
O. Dooling to	Momine 1005:		O maint apple			Magazina the decire to institutionaline by
2. Desire to Institutionalize	Morycz, 1985; Pearlin, 1990; Pruchno et al., 1990	6	2-point scale: yes or no	.7182	NA	Measures the desire to institutionalize by asking: "Has caregiver: ever considered a nursing or boarding home," "ever felt care recipient would be better off in a nursing or boarding home," "ever discussed institutionalization with family or others[or] with the care recipient," "be likely to move care recipient," or "take steps toward placement?"
			<u>.</u>			
3. Factors Influencing Placement Decision	Aneshensel, 1995; Feinberg & Whitlatch, 1995	19	4-point scale: responses range from "strongly disagree" to "strongly agree"	NA	NA	Measures the reasons a caregiver decides to move their relative to a care facility, such as caregiver's exhaustion or physical and mental health, or care recipient's behavior.
	1000		1 4		T	The state of the s
4. Family Conflict	Semple, 1992; Gaugler et al., 1999	8	4-point scale: responses range from "no disagreement" to "quite a bit"	.90	NA	Measures conflict among caregivers who institutionalize their relatives. Caregivers are asked how much disagreement they experience with other family members over particular care issues.

Attitudes toward re	eceiving help					
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Community Service Attitudes Inventory	Collins et al., 1991	25	4-point scale: responses range from "strongly agree" to "strongly disagree"	.7484	content and construct	Measures 5 dimensions of attitudes toward community services including: concern for opinions of others; confidence in service system; preference for informal care; belief in caregiver independence; and acceptance of government services. Items include statements such as: "My family would think less of me if I used services for my relative's care" and "I would rather use community services than ask for help from family."
Cultural/religious b			4 maintenales			Management and the second control for silica
1. Cultural Justifications Scale	Dilworth-Anderson, 1995; 1996	10	4-point scale: responses range from "strongly agree" to "strongly disagree"	.8494	NA	Measures cultural reasons why families provide care to the elderly. Items reflect socialization, values, and attitudes of the group with statements such as: "I give care becauseIt is my duty to provide care to elderly dependent family members," "It strengthens the bonds between me and them," "It is what my people have always done," [and] "My family expects me to provide care."
Decision making 1. Decision Control Inventory	Feinberg & Whitlatch, 2002	15	4-point scale: responses range from "not at all involved" to "very involved"	Care recipient: .79 Caregiver: .86	NA	The DCI measures the care recipient's level of involvement in 15 dimensions of daily decision-making (e.g., what to do with money; when to get up, etc.). This measure can be administered to both care recipient and caregiver.

<b>Decision making</b>						
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2. Informed Decision Making	Fortinsky & Hathaway, 1990; Feinberg & Whitlatch, 2001	18	3-point scale: responses include "very helpful," "somewhat helpful," [and] "not at all helpful"	NA	NA	Measures the degree to which the caregiver perceives specific types of information helpful to the decision making process. Includes items such as: "How helpful do you think information on"when to involve your [REL] in care planning," "the availability of public benefits," managing problem behaviors," "incontinence"would be for you in making informed decisions about the care of you [REL]?"
• · · · · · ·	140 11 1 1 1	1		1		
3. Values and Preferences Scale	McCullough et al., 1993; Degenholz et al., 1997; Whitlatch & Tucke, 2000; Feinberg & Whitlatch, 2001; Whitlatch, 2002	37	3-point scale: responses include "very important," "somewhat important," [and] "not at all important"	.6480	NA	Measures both the caregiver's and the care recipient's values and preferences for care with respect to environment, social interactions, autonomy, self-identity, and family caregiver issues. Items include: "How important is it for you tobe safe from crime," "maintain dignity," "have reliable help," "feel safe in the home, even if it restricts activities," and "not live in a nursing home?"

Perception of qualit	y/effectiveness of ca	re				
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Nursing Home Stressors a) Nursing assistants' communication with residents' family	Whitlatch et al., 2001	6	3-point scale: responses include "most of the time," "some of the time," and "hardly ever"	.73	NA	Measures caregivers' perceptions of how well they were treated by the nursing assistants when they visited the nursing home. It includes the following questions: "Do Nursing Assistants" greet you when you visit," "have all the information they need to care for your relative properly" and "act rude or unpleasant?"
b) Nursing assistants' support for families	Whitlatch et al., 2001	5	3-point scale: responses include "most of the time," "some of the time," and "hardly ever"	.76	NA	Measures caregivers' perceptions that Nursing Assistants provided support and reassurance to family caregivers with statements such as: "The Nursing Assistant"reassures me that my family member's behavior is not unusual", "encourages me to talk about my fears and concerns" and "understands that having my family member in a home is stressful for me."
c) Measures of positive and negative interactions	Whitlatch et al., 2001	10	3-point scale: responses include "most of the time," "some of the time," and "hardly ever"	.6580	NA	Measures the positive and negative interactions family caregivers have with their institutionalized relatives, the staff at the facility, other residents, and the families of other residents. Positive items include whether caregivers feel they are able "to confide in relative/staff/families," and whether the care recipient, the staff, and families of other care recipients are "capable of reassuring them when they are upset." Negative items included assess whether relative, staff or families of other residents make the caregiver feel "frustrated," "angry," or "guilty."

Perception of quality	Perception of quality/effectiveness of care								
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description			
2. Quality of Care Scale	Bass et al., 1999	6	4-point scale: responses range from "strongly agree" to "strongly disagree"	.83	NA	Measures caregivers' perceptions of the quality of care with items like, "I was satisfied with the help the care recipient got from others" and "the care recipient could have been cared for better if there were more people helping him or her."			

VII. MULTIDIMENSIO	NAL CAREGIVER ME	EASURES				
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1. Aspects of the Caregiving Role a) Life satisfaction scale	Schofield et al., 1997	6	5-point scale: "very dissatisfied" to "very satisfied"	.7779	construct	Measures the degree of life satisfaction in 6 areas: finances; health; independence; caregiver respect and recognition; personal, emotional life; and life as a whole.
b) Positive and negative affect scale	Watson et al., 1988; Schofield et al., 1997	20	NA	PA scale: .8285 NA scale: .8386	construct	Measures psychological well-being. It can be self-administered or the questionnaire can be asked over the telephone.
c) Health	Schofield et al., 1997	5	3 single-item objective indicators; 1 subjective measure of overall health as: "poor," "fair," "good," or "excellent"	NA	construct	Caregiver health is assessed by rate of major health problems; number of visits to medical practitioners; number of nights in hospital; and self-reports of overall health.
d) Social support	Schofield et al., 1997	7	5-point scale: "strongly disagree" to "strongly agree"	(Of total sum score): .6670	construct	This scale was modified from the Provision of Social Relations Scale (Turner et al., 1983). Social support is characterized by factors of family support; friends' support; and the degree to which caregiver is esteemed by family and friends.
e) Overload	Schofield et al., 1997	3	5-point scale: "strongly disagree" to "strongly agree"	.6973	construct	Caregiver overload is measured using a 3-item scale adapted from a 4-item scale (Pearlin et al., 1990). The scale includes the following statements: "I am exhausted when I go to bed at night;" "I have more things to do than I can handle;" "I don't have time just for myself."

VII. MULTIDIMENSIC	NAL CAREGIVER ME	EASURES				
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
1.Aspects of the Caregiving Role: f) Family environment	Schofield et al., 1997	Two 3- item scales	3-point scale: "less," "the same," or "more"	Closeness: .6873 Conflict: .7075	construct	Measures extent to which caregivers experience more, the same, or less conflict and closeness in the family environment since the onset of caring. The factor loading for the 'closeness' scale includes compassion, love and closeness. The 'conflict' scale includes measures of tension, conflict and resentment.
			I =	T		1.1
g) Caring role: satisfaction, resentment, and anger	Schofield et al., 1997	6-items; 5-items; 4-items	5-point scale: "strongly agree" to "strongly disagree"	Satisfaction: .6571; Resent- ment: .6975; Anger: .6871	construct	Measures positive responses to the care recipient and to the caring role; negative effects on the caregiver's life, time, opportunities and social relationships; and negative emotional responses to the care recipient through anger, embarrassment and guilt. Some of the items for this scale were drawn from the Caring for Relatives Questionnaire (Greene et al., 1982) and the Caregiver Appraisal Questionnaire (Lawton et al., 1989).
2.Caregiver Appraisal Measure a) Subjective Caregiving Burden	Lawton et al., 1989	13	5-point scale: responses range from "strongly agree" to "strongly disagree"	.85	construct	Measures the caregiver's appraisal of stress attributable to both general and specific caregiving experiences. It is designed to capture positive, neutral and negative aspects of caregiving.
		•			•	
b) Impact of Caregiving	Lawton et al., 1989	9	5-point scale: responses range from "never" to "nearly always"	.70	construct	Measures the caregiver's perception of the impact of caregiving on his/her social life, family relationships, time management, and physical and emotional space.

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
2.Caregiver Appraisal Measure: c) Caregiving Satisfaction	Lawton et al., 1989	9	5-point scale: responses range from "never" to "nearly always" or "strongly agree" to "strongly disagree"	.67	construct	Measures caregiving satisfaction by indicating level of agreement with statements such as, "you really enjoy being with the [impaired person]", and "you take care of [impaired person] more because you want to than out of a sense of duty".
d) Caregiving/ Mastery	Lawton et al., 1989	12	5-point scale: responses range from "never" to "nearly always"	NA	NA	Measures a sense of caregiving mastery with items such as "In general, I feel able to handle most problems in the care of [impaired person]" and "I'm pretty good at figuring out what [impaired person] needs."
e) Caregiving Ideology	Lawton et al., 1989	4	5-point scale: responses range from "strongly agree" to "strongly disagree"	NA	NA	Measures caregiving ideology: whether the caregiving experience is shaped by family or religious tradition, the principle o reciprocity, or a concern about modeling a principle for one's own children.
3. Caregiver Reaction Assessment a)Disrupted schedule	Given et al., 1992	5	5-point scale: responses range from "strongly agree" to "strongly disagree"	.81	construct	Measures the extent to which caregiving interrupts usual daily activities, causes the elimination of some activities, and interferes with relaxation time. It also assesses the degree to which activities center on caregiving. Items include statements like, "I visit family and friends less since I have been caring for my partner."
b) Financial problems	Given et al., 1992	3	5-point scale: responses range from "strongly agree" to "strongly disagree"	.83	construct	Measures caregiver financial strain, in regard to adequacy, the difficulty, and the strain of the financial situation on the caregiver and the family. Items include statements like, "Caring for my partner puts a financial strain on me."

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
3. Caregiver Reaction Assessment: c) Lack of family support	Given et al., 1992	5	5-point scale: responses range from "strongly agree" to "strongly disagree"	.62	construct	Measures the caregiver's perception of abandonment and the extent to which family supports and works together with the caregiver. For example: "Since caring for my partner, I feel my family has abandoned me."
			T =		1	
d) Health problems	Given et al., 1992	4	5-point scale: responses range from "strongly agree" to "strongly disagree"	.80	construct	Measures the caregiver's physical capability and energy to provide care. It further assesses the caregiver's health in relation to the caregiving role. For example: "I am healthy enough to care fo my partner."
	10: 11000		<u> </u>			
e) Caregiver esteem	Given et al., 1992	7	5-point scale: responses range from "strongly agree" to "strongly disagree"	.90	construct	Measures the extent to which caregiving imparts individual self-esteem. Items assess whether caregiving is rewarding and enjoyable or whether it causes resentment. Items include statements such as: "I enjoy caring for my partner."
	<u> </u>					
4. Caregiver Well- Being a) Physical health	George & Gwyther, 1986	2	1 single-item measure of number of physicians visits in past 6 months; 1 measure of self-rated health as: poor, fair, good, or excellent	NA	NA	Measures both objective and subjective measures of caregiver physical health.
b) Mental health	George & Gwyther, 1986	4 indi- cators	NA	Psychiatric symptoms: .85; Affect: .89	NA	Caregiver mental health is measured using 4 indicators: a checklist of psychiatric symptoms (Pfeiffer,1979); a measure of affect (Bradburn, 1969); a single-item measure of life satisfaction; and the absence or presence of psychotropic drug use during the past 6 months.

Key: NA = Not available NAP=Not applicable

VII. MULTIDIMENSIO	ONAL CAREGIVER ME	EASURES				
Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
4. Caregiver Well- Being: c) Financial resources	George & Gwyther, 1986	2	Single-item measure of household income; measure of perceived economic status	Subjective assessment: .85	NA	Assessment of the caregiver's financial resources includes both an objective and a subjective measure.
d) Social participation	George & Gwyther, 1986	7	Number of visits and phone contacts with family/ friends; frequency of club and church attendance; time spent engaged in hobbies or relaxing; satisfaction with social activities	.79	NA	Includes both objective and subjective indicators of the caregiver's level of social activity and participation. Each objective measure is accompanied by a subjective assessment of the caregiver's satisfaction with the frequency and quality of the activity.
					1	
5. Family Caregiving Factors Inventory a) Caregiving Resources	Shyu, 2000	17	3-point scale: from 1 (lack of help) to 3 (adequate help)	.79	content and construct	This scale measures the degree of adequacy of the caregiver's resources and supports, i.e., skills, competence and attitudes, the ability to achieve desirable caregiving consequences, and the amount of help received from others in managing caregiving.
b) Caregiver Self- Expectations	Shyu, 2000	9	0 = unrealistic or 1 = realistic	.68	content and construct	Measures whether the caregiver has realistic or unrealistic self-expectations in performing the caregiver role. These may include expectations of caregiving attitude, e.g., being patient and loving; actions and standards, e.g., doing one's best; and beliefs about the needs of the care recipient.

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
5. Family Caregiving Factors Inventory: c) Caregiving Task Difficulty	Shyu, 2000	6	Responses range from "not difficult at all" to "very difficult"	.73	content and construct	Measures the degree of difficulty in performing caregiving tasks especially as it pertains to the unpredictability of the care recipient's condition, the lack of cooperation of the care recipient, uncontrollable external factors, heavy physical labor or long duration of providing care.
d) Knowledge of the Care Recipient	Shyu, 2000	10	Responses range from "very poor" to "very well"	.91	content and construct	Measures the degree of understanding the caregiver has for the care recipient's physical condition, and how this understanding might influence his/her caregiving actions. Items assess, for example, caregiver's knowledge of whether or not care recipient has pressure sores or joint contractions.
6. Finding Meaning Through Caregiving Scale a) Loss/ Powerlessness	Farran et al., 1991	19	5-point scale ranging from "strongly agree" to "strongly disagree"	.8895	convergent and discriminant	The Loss/Powerlessness scale measures feelings of loss for family members and self, and feelings of powerlessness associated with caregiving. Includes item like, "I am sad about losing the person I once knew" and "My situation feels endless."
b) Provisional Meaning	Farran et al., 1991	19	5-point scale ranging from "strongly agree" to "strongly disagree"	.8092	convergent and discriminant	Measures positive aspects and ways that caregivers find day-to-day meaning through the caregiving experience with items like, "Caring for my relative gives my life a purpose and a sense of meaning" and "Caregiving has helped me learn new things about myself."

Key: NA = Not available NAP=Not applicable

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
6. Finding Meaning Through Caregiving Scale c) Ultimate Meaning	Farran et al., 1991	5	5-point scale ranging from "strongly agree" to "strongly disagree"	.9195	convergent and discriminant	This scale focuses on a higher power or a religious/spiritual structure with which the caregiver may identify. Includes items such as, "I believe in the power of prayer; without it I couldn't do this."
7. Mental Health Effects a) Perceived Burden	Pruchno & Resch, 1989	1	5-point scale: responses range from "not at all" to "most of the time"	NAP	NA	Measures how burdened the caregiver feels with a single item: "Overall, how burdened do you feel in caring for your [relative]?"
b) Consequences of caring	Pruchno & Resch, 1989	17	5-point scale: responses range from "not at all" to "most of the time"	.89	NA	Measures how often the caregiver has experienced a variety of feelings such as: loneliness; guilt; nervousness; irritability; helplessness; trapped; and overwhelmed.
c) Social change Index	Pruchno & Resch, 1989	13	5-point scale: responses range from "not at all" to "most of the time"	.78	NA	Measures level of participation in social activities such as: volunteer or community work, recreation, and other leisure activities.

Measure	Source	# of items	Item responses	Reliability (Cronbach's alpha)	Validity	Description
8. Sense of Competence Questionnaire a) Satisfaction Withas a Recipient of Care	Scholte op Reimer et al., 1998	7	4-point scale: responses include "disagree very much," "disagree," "agree," and "agree very much"	.7080	construct	Measures level of caregiving satisfaction with items such as: "I feel embarrassed over my [care recipient's] behavior," [and "My [care recipient] appreciates my constant care more than the care others give him/her."
h) Ostisfastiau	Cabalta an Dairean		A maint apple.		I	NA
b) Satisfaction With One's Own Performance as a Caregiver	Scholte op Reimer et al., 1998	12	4-point scale: responses include "disagree very much," "disagree," "agree," and "agree very much"	.7177	construct	Measures satisfaction with caregiving performance with items such as: "I feel useful in my interactions with my [care recipient]," "I'm capable to care for my [care recipient]," [and] "I feel guilty abou my interactions with my [care recipient]."
c) Consequences of Involvement in Care for the Personal Life of the Caregiver	Scholte op Reimer et al., 1998	8	4-point scale: responses include "disagree very much," "disagree," "agree," and "agree very much"	.6270	construct	Measures the impact caregiving has on the caregiver's personal life with items such as: "I feel that I cannot leave my [care recipient] alone, he/she needs me continuously," [and] "I feel that my socia life has suffered because of my involvement with my [care recipient]."

#### References

## Major References Used To Compile Inventory

- Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career.* San Diego: Academic Press.
- Antonucci, T.C., Sherman, A.M., & Vandewater, E.A. (1997). Measures of social support and caregiver burden. *Generations* Spring: 48-51.
- Bass, D.M. (2001). Content and Implementation of a Caregiver Assessment. *National Family Caregiver Support Program Issue Brief: Administration on Aging.*
- Deimling, G.T. (1994). Caregiver functioning. In M.P. Lawton & J.A. Teresi (Eds.), *Annual review of gerontology and geriatrics: focus on assessment techniques* (pp. 257-280). New York: Springer Publishing Company.
- Gaugler, J.E., Kane, R.A., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R.L. Kane & R.A. Kane (Eds.), *Assessing older persons: measures, meaning and practical applications* (pp. 320-359). New York, NY: Oxford University Press.
- Kinsella, G., Cooper, B., Picton, C., & Murtagh, D. (1998). A review of the measurement of caregiver and family burden in palliative care. *Journal of Palliative Care* 14: 37-45.
- Kramer, B.J. (1997). Gain in the caregiving experience: where are we? What next? *The Gerontologist* 37: 218-232.
- Kramer, B.J., & Vitaliano, P.P. (1994). Coping: a review of the theoretical frameworks and measures used among caregivers of individuals with dementia. *Journal of Gerontological Social Work* 23: 151-174.
- Roach, MJ., & Welch, L.C. (2000). Caregiver well-being. In *TIME: Toolkit of instruments to measure end-of-life care*. Brown University. www.chcr.brown.edu/PCOC/familyburden.htm
- Roach, MJ. (n.d.). *Caregiver and family burden.* Center to Improve Care of the Dying: George Washington University. www.gwu.edu/~cicd/toolkit/caregive.htm
- Stephens, M.A.P., & Kinney, J.M. (1989). Caregiving stress instruments: assessment of content and measurement quality. *Gerontology Review* 2: 41-54.
- Vitaliano, P.P., Young, H.M., & Russo, J. (1991). Burden: a review of measures used among caregivers of individuals with dementia. *The Gerontologist* 31: 67-75.
- Zarit, S., & Teri, L. (1991). Interventions and services for family caregivers. In K.W. Schaie (Ed.), *Annual review of gerontology and geriatrics* (Vol. 11, pp. 287-310). New York: Springer.
- [Please note: In addition to the above-cited references, a thorough review of Ericae.net, PubMed, PsychInfo, Current Contents, and databases of Gerontological Journals was conducted for articles referencing the use, testing and validation of caregiver assessment measures.]

#### **References For Specific Measures**

- Abell, N. (2001). Assessing willingness to care for persons with AIDS: validation of a new Measure. Research on Social Work Practice 11: 118-130.
- Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career.* San Diego: Academic Press.
- Aneshensel, C.S., Pearlin, L.I., & Schuler, R.H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior* 34: 54-70.
- Archbold, P.G., & Stewart, B.J. (1988). *The Effects of Family Caregiver Relief.* Final Report to the National Center for Nursing Research (#R01 NR01140).
- Archbold, P., Stewart, B., Greenlick, M.R., & Horwath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health* 13: 375-384.
- Bakas, T., & Champion, V. (1999). Development and psychometric testing of the Bakas Caregiving Outcomes Scale. *Nursing Research* 48: 250-259.
- Bandura, A. (1977). Social learning theory. Prentice Hall, Englewood Cliffs, NJ.
- Bagarozzi, D.A. (1985). Family measurement techniques: The Family Coping Strategies scale. *American Journal of Family Therapy* 13: 67-71.
- Barusch, A. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist* 28: 677-685.
- Bass, D.M., Bowman, K. (1990). The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death. *The Gerontologist* 30: 35-42.
- Bass, D.M., Bowman, K., & Noelker, L.S. (1991). The influence of caregiving and bereavement support on adjusting to an older relative's death. *The Gerontologist* 31: 32-42.
- Bass, D.M., McCarthy, C., Eckert, S., Bichler, J. (1994a). Differences in service attitudes and experiences among families using three types of support services. *The American Journal of Alzheimer's Care and Related Disorders & Research*, May/June 1994.
- Bass, D.M., McClendon, M.J., Deimling, G.T., & Mukherjee, S. (1994b). The influence of a diagnosed mental impairment on family caregiver strain. *Journal of Gerontology: Social Sciences* 49: S146-S155.
- Bass, D.M., Noelker, L.S., McCarthy, C.A. (1999). The influence of formal and informal helpers on primary caregivers' perceptions of quality of care. *The Journal of Applied Gerontology* 18: 177-200.
- Bass, D.M., Noelker, L.S., & Rechlin, L.R. (1996). The moderating influence of service use on negative caregiving consequences. *Journal of Gerontology: Social Sciences* 51B: S121-S131.

- Bass, D.M., Tausig, M.B., & Noelker, L.S. (1988). Elder impairment, social support and caregiver strain: A framework for understanding support's effects. *The Journal of Applied Social Sciences* 13: 80-115.
- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry* 4: 561-571.
- Beck, A.T., Kovacs, M., & Weissman, A. (1979). Assessment of suicidal intention: The Scale for Suicide Ideation. *Journal of Consulting & Clinical Psychology* 47: 343-352.
- Bédard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *The Gerontologist* 41: 652-657.
- Bradburn, N.M. (1969). The structure of psychological well-being. Chicago: Aldine.
- Braithwaite, V. (2000). Contextual or general stress outcomes: making choices through caregiving appraisals. *The Gerontologist* 40: 706-717.
- Braithwaite, V. (1996). Understanding stress in informal caregiving: Is burden a problem of the individual or of society? *Research on Aging* 18: 139-174.
- Brink, T. L., et al. (1982). Screening tests for geriatric depression. *Clinical Gerontologist* 1: 37-43
- Cantor, M.H. (1983). Strain among caregivers: A study of experience in the U.S. *The Gerontologist* 23: 597-604.
- Caserta, M.S., Lund, D.A., & Wright, S.D.(1996). Exploring the Caregiver Burden Inventory (CBI): further evidence for a multidimensional view of burden. *International Journal of Aging and Human Development* 43: 21-34.
- Cicirelli, V.G. (1988). A measure of filial anxiety regarding anticipated care of elderly parents. *The Gerontologist* 28: 478-482.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior* 24: 385-396.
- Collins, C., Stommel, M., King, S., & Given, C.W. (1991). Assessment of the attitudes of family caregivers toward community services. *The Gerontologist* 31: 756-761.
- Cronbach, L.J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika* 16: 297-334.
- Degenholz, H., Kane, R.A., & Kivnick, H.Q. (1997). Care-related preferences and values of elderly community-based long term care consumers: Can care managers learn what's important to clients? *The Gerontologist* 37: 767-776.
- Deimling, G., & Bass, D. (1986a). *The strengths and resources of families caring for impaired elders*. A report to The Retirement Research Foundation. Cleveland: The Benjamin Rose Institute.
- Deimling, G., & Bass, D. (1986b). Symptoms of mental impairment among elderly adults and their effects on family caregivers. *Journal of Gerontology* 41: 778-784.

- Derogatis, L.R., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. *Psychological Medicine* 13: 595-605.
- Derogatis, L.R., & Savitz, K.L. (1999). The SCL-90-R, Brief Symptom Inventory, and Matching Clinical Rating Scales. In: M.E. Maruish, (Ed.), *The use of psychological testing for treatment planning and outcomes assessment* (2nd ed.). Lawrence Erlbaum Associates, Inc. Mahwah, NJ.
- Derogatis, L.R., Lipman, R.S., Rickels, K., Uhlenhuth, E.H., & Covi, L. (1974). The Hopkins Symptom Checklist (HSCL): Self-report symptom inventory. *Behavioral Science* 19: 1-15.
- Dieckmann, L., Zarit, S.H., Zarit, J.M., & Gatz, M. (1988). The Alzheimer's Disease knowledge test. *The Gerontologist* 28: 402-407.
- Dilworth-Anderson, P, Marshall, S. (1996). Social support in its cultural context. In: Gregory R. Pierce & Barbara R. Sarason (Eds.), *Handbook of social support and the family.* Plenum Press: New York, NY.
- Elmstahl, S., Malmberg, B., & Annerstedt, L. (1996). Caregiver's burden of patients 3 years after stroke assessed by a Novel Caregiver Burden Scale. *Archives of Physical Medicine and Rehabilitation* 77: 177-182.
- Farran, C.J., Miller, B.H., Kaufman, J.E., Donner, E., & Fogg, L. Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's Disease. *Journal of Clinical Psychology* 55: 1107-1125.
- Feinberg, L.F., & Whitlatch, C.J. (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist* 41: 374-382.
- Feinberg, L.F., & Whitlatch, C.J. (2002). Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias* 17: 1-8.
- Feinberg, L.F., & Whitlatch, C.J. (1995). Final Report: A study of pre- and post-placement family caregiving for individuals with Alzheimer's disease and related disorders. San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L.F., & Whitlatch, C.J. (1996). *Final Report: Family caregivers and consumer choice: Options for in-home respite care.* San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L.F., Whitlatch, C.J., & Tucke, S. (2000). *Final Report: Making hard choices: respecting both voices.* San Francisco, CA: Family Caregiver Alliance.
- Ferrari, J.R., McCown, W. & Pantano, J. (1993). Experiencing satisfaction and stress as an AIDS care provider: The AIDS Caregiver Scale. *Evaluation & the Health Professions* 16: 295-310.
- Flor, H., Behle, D. & Birbaumer, N. (1993). Assessment of pain-related cognitions in chronic pain patients. *Journal of Psychosomatic Research* 31: 251–259.
- Flor, H., Turk, D., & Sholtz, B. (1987). Impact of chronic pain on the spouse: marital, emotional and
  - physical consequences. Journal of Psychosomatic Research 31:63-71.
- Folkman, S., & Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior 21: 219-225.

- Fortinsky, R.H., & Hathaway, T.J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's Disease. *The Gerontologist* 30: 604-609.
- Frisch, M.B. (1992). Use of the Quality of Life Inventory in problem assessment and treatment planning
  - for cognitive therapy of depression. In: A. Freeman & F. M. Dattilio (Eds.), *Comprehensive casebook of cognitive therapy*. Plenum Press Plenum Press: New York, NY.
- Frisch, M.B., Cornell, J., Villanueva, M., & Retzlaff, P.J. (1992). Clinical validation of the Quality of Life Inventory: A measure of life satisfaction for use in treatment planning and outcome assessment. *Psychological Assessment* 4: 92-101.
- Gaugler, J.E., Zarit, S.H., & Pearlin, L.I. (1999). Caregiving and institutionization: Perceptions of family conflict and socioemotional support. *International Journal of Aging & Human Development* 49: 1-25.
- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The Gerontologist* 26: 253-259.
- Gerritsen, J.C., & van der Ende, P.C. (1994). The development of a caregiving burden scale. *Age and Ageing* 23: 483-491.
- Gitlin, L.N., Winter, L., Dennis, M.P., Corcoran, M., Schinfeld, S., & Hauck, W.W. (2002). Strategies used by families to simplify tasks for individuals with Alzheimer's Disease and related disorders: psychometric analysis of the Task Management Strategy Index (TMSI). *The Gerontologist* 42: 61-69.
- Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairment. *Research in Nursing and Health* 15: 271-283.
- Golden, R.R., Teresi, J.A., & Gurland, B.J. (1984). Development of indicator scales for the Comprehensive Assessment and Referral Evaluation (CARE) interview schedule. *Journal of Gerontology* 39: 138-146.
- Goodman, C.C. (1991). Perceived social support for caregiving: measuring the benefit of self-help/support group participation. *Journal of Gerontological Social Work* 16: 163-175.
- Greene, J.G., Smith, R., Gardiner, M., & Timbury, C.C. (1982). Measuring behavioral disturbance of elderly demented patients and its effects on relatives: A factor analytic study. *Age and Ageing* 11: 121-126.
- Hays, J.C., Meador, K.G., Branch, P.S., & George, L.K. (2001). The Spiritual History Scale in Four Dimensions (SHS-4): Validity and reliability. *The Gerontologist* 41: 239-249.
- Hickey, A.M., O'Boyle, C.A., McGee, H.M., & McDonald, N. J. (1997). The relationship between post-trauma problem reporting and carer quality of life after severe head injury. *Psychology & Health*. 12: 827-838.
- Hughes, S.L., Giobbie-Hurder, A., Weaver, F.M., Kubal, J.D., & Henderson, W. (1999).
  Relationship between caregiver burden and health-related quality of life. *The Gerontologist* 39: 534-545.
- Jalowiec, A., Murphy, S., & Powers, M. (1984). Psychometric assessment of the Jalowiec coping scale. *Nursing Research* 33: 157-161.

- Kaufer, D.I., Cummings, J.L., Christine, D., Bray, T., Castellon, S., Masterman, D., MacMillan, A., Ketchel, P., & DeKosky, S.T. (1997). Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The Neuropsychiatric Inventory Caregiver Distress Scale. *Journal of the American Geriatrics Society* 46: 210-215.
- Kinney, J.M., & Stephens, M.A.P. (1989a). Caregiver hassles scale: assessing the daily hassles of caring for a family member with dementia. *The Gerontologist* 29: 328-332.
- Kinney, J.M., & Stephens, M.A. (1989b). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging* 4: 402-408.
- Kiyak, H., Montgomery, R., Borson, S., & Teri, L. (1985). Coping patterns among patients with Alzheimer's disease and non-demented elderly. Paper presented at the 38<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America, New Orleans, LA.
- Kosberg, J.I., & Cairl, R.E. (1992). Burden and competence in caregivers of Alzheimer's Disease patients: research and practice implications. *Journal of Gerontological Social Work* 18: 85-96.
- Kosberg, J.I., & Cairl, R.E. (1986). The cost of care index: a case management tool for screening informal care providers. *The Gerontologist* 26: 273-278.
- Kosberg, J.I., Cairl, R.E., & Keller, D.M. (1990). Components of burden: interventive implications. *The Gerontologist* 30: 236-242.
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *International Journal of Aging and Human Development* 30: 37-53.
- Lawrence, R.H., Tennstedt, S.L., & Assmann, S.F. (1998). Quality of the caregiver-care recipient relationship: Does it offset negative consequences of caregiving for family caregivers? *Psychology and Aging* 13: 150-158.
- Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences* 44: 61-71.
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer Pub. Co.
- Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiving reports. *Journal of Mental Health and Ageing* 5 (1).
- Macera, C.A., Eaker, E.D., Jannarone, R.J., Davis, D.R., & Stoskopf, C.H. (1993). A measure of perceived burden among caregivers. *Evaluation & the Health Professions* 16: 204-211.
- Maslow, A. (1968). Toward a psychology of being. New York: Van Nostrand.
- McCubbin, M.A., McCubbin, H.I., & Thompson, A.I. (1987). Family Hardiness Index. In: McCubbin, H.I., & Thompson, A.I. (Eds.), *Family Assessment Inventories*. The University of Wisconsin-Madison, pp. 123-130.
- McCullough, L.B., Wilson, N.L., Teasdale, T.T., Kolpakchi, A.L., & Skelly, J.R. (1993). Mapping personal, familial and professional values in long tem care decisions. *The Gerontologist* 33: 324-332.
- Mindel, C.H., & Wright, R. (1982). Differential living arrangements among the elderly and their subjective well-being. *Activities, Adaptation & Aging.* 3: 25-34.

- Montgomery, R.J.V., Gonyea, J.G., & Hooyman, N.R. (1985a). Caregiving and the experience of subjective and objective burden. *Family Relations* 34:19-26.
- Montgomery, R.J.V., Stull, D.E., & Borgatta, E.F. (1985b). Measurement and the analysis of burden. *Research on Aging* 7:137-152.
- Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: possible predictors and model development. *Research on Aging* 7: 329-361.
- Moss, M., Lawton, M.P., Dean, J., Goodman, M., & Schneider, J. (1987). Satisfactions and burdens in caring for impaired elderly persons. *The Gerontologist* 27: 164A.
- Mullan, J.T. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist* 32: 673-683.
- Nagi, S. (1976). An epidemiology of disability among adults in the United States. *Milbank Quarterly* 54: 439-467.
- Nicholas, M. (1989). Self-efficacy and chronic pain. Paper presented at the *Annual Conference* of the British Psychological Society, St. Andrews.
- Niederehe, G., & Fruge, E.D. (1984). Dementia and family dynamics: Clinical research issues. *Journal of Geriatric Psychiatry* 17: 21-56.
- Noelker, L.S., & Townsend, A.L. (1987). Perceived caregiving effectiveness: the impact of parental impairment, community resources, and caregiver characteristics. In T. Brubaker (Ed.), *Aging, Health and Family, Long Term Care*. Newbury Park, CA: Sage Publications.
- Noelker, L.S., & Wallace, R.W. (1985). The organization of family care for impaired elderly. *Journal of Family Issues* 6: 23-44.
- Novak, M., & Guest, C. (1989). Application of a multidimensional Caregiver Burden Inventory. *The Gerontologist* 29: 798-803.
- Oberst, M.T., & Scott, D.W. (1988). Postdischarge distress in surgically treated cancer patients and their spouses. *Research in Nursing and Health* 11: 223-233.
- Oberst, M.T., Thomas, S.E., Gass, K.A., & Ward, S.E. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing* 12: 209-215.
- Orbell, S., Hopkins, N., & Gillies, B. (1993). Measuring the impact of informal caregiving. *Journal of Community and Applied Social Psychology* 3: 149-163.
- Pakenham, K.I. (2001). Application of a stress and coping model to caregiving in Multiple Sclerosis. *Psychology, Health & Medicine* 6: 13-27.
- Parker, G.B. (1978). The bonds of depression. Angus & Robertson, Sydney, Australia.
- 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. *The Gerontologist* 30 (5): 583-594.
- Pearlin, L.I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior* 19: 2-21.

- Picot, S.J., Debanne, S.M., Namazi, K.H., & Wykle, M.L. (1997a). Religiosity and perceived rewards of Black and White caregivers. *The Gerontologist* 37: 89-101.
- Picot, S.J.F., Youngblut, J., & Zeller, R. (1997b). Development and testing of a measure of perceived rewards in adults. *Journal of Nursing Measurement* 5: 33-52.
- Pierce, L., Ader, K., & Peter, P. (1989). Caregiver burden and coping strategies. *The American Journal of Alzheimer's Care and Related Disorders & Research* 4: 36-41.
- Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: issues in the measurement of burden. *Journal of Gerontology* 39: 230-239.
- Pound, P., Gompertz, P., & Ebrahim, S. (1993). Development and results of a questionnaire to measure carer satisfaction after stroke. *Journal of Epidemiology and Community Health* 47: 500-505.
- Pruchno, R.A., & Resch, N.L. (1989a). Aberrant behaviors and Alzheimer's disease: mental health effects of spouse caregivers. *Journal of Gerontology* 44: S177-S182.
- Pruchno, R., & Resch, N. (1989b). Mental health of caregiving spouses: coping as mediator, moderator, or main effect? *Psychology and Aging* 4: 454-463.
- Pruchno, R.A., Michaels, J.E., & Patahnik, S.L. (1990). Predictors of institutionalization among Alzheimer's disease victims with caregiving spouses. *Journal of Gerontology* 45: S259- S266.
- Quayhagen, M.P., & Quayhagen, M. (1988). Alzheimer's stress: coping with the caregiving role. *The Gerontologist* 28: 391-396.
- Quayhagen, M.P., & Quayhagen, M. (1982). Coping with conflict: measurement of age-related patterns. *Research on Aging* 4: 364-377.
- Radloff, L. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1: 385-401.
- Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology* 38: 344-348.
- Rosenberg, M. (1962). The association between self-esteem and anxiety. *Journal of Psychiatric Research*. 1: 135-152.
- Rubin, A., & Babbie, E. (2001). *Research Methods for Social Work (4<sup>th</sup> edition)*. Belmont, CA: Wadsworth/Thomson Learning.
- Schofield, H.L., Murphy, B., Herrman, H.E., Bloch, S., & Singh, B. (1997). Family caregiving: measurement of emotional well-being and various aspects of the caregiving role. *Psychological Medicine* 27: 647-657.
- Scholte op Reimer, W.J.M., De Haan, R.J., Pijnenborg, J.M.A., Limberg, M., & Van den Bos, G.A.M. (1998). Assessment of burden in partners of stroke patients with the Sense of Competence Questionnaire. *Stroke* 29: 373-379.
- Semple, S.J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *The Gerontologist* 32: 648-655.
- Shyu, Y-I.L. (2000). Development and testing of the Family Caregiving Factors Inventory for home health assessment in Taiwan. *Journal of Advanced Nursing* 32: 226-234.

- Skaff, M.M., & Pearlin, L.I. (1992). Caregiving: role engulfment and the loss of self. *The Gerontologist* 32: 656-664.
- Spanier, G.B. (1977). Measuring dyadic adjustment: new scales for assessing the quality of marriage and similar dyads. *Journal of Marriage & the Family* 38: 15-28.
- Spielberger, C.D. (1980). *Manual for the State-trait Anxiety Inventory* CA: Consulting Psychologists Press, Palo Alto.
- Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: reliability and validity studies. *Journal of Gerontology: Psychological Sciences* 57B: P74-P86.
- Stephens, M.A., Franks, M.M., & Townsend, A.L. (1994). Stress and rewards in women's multiple roles: The case of women in the middle. *Psychology and Aging* 9: 45-52.
- Stetz, K. (1986). The experience of spouse caregiving for persons with advanced cancer. Unpublished doctoral dissertation, School of Nursing, University of Washington, Seattle.
- Strawbridge, W.J. (1991). The effects of social factors on adult children caring for older parents (Doctoral dissertation, University of Washington). *Dissertation Abstracts International* 52: 1094.
- Strawbridge, W.J., & Wallhagen, Margaret I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist* 31: 770-777.
- Taylor, R.J., & Chatters, L.M. (1986). Church-based informal support among elderly blacks. *The Gerontologist* 26: 637-642.
- Tebb, S.S. (1995). An aid to empowerment: A caregiver well-being scale. *Health and Social Work* 20: 87-92.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). The revised memory and behavior problems checklist. *Psychology & Aging* 7: 622-631.
- Todtman, K., & Gustafson, A.W. (1991). The financial impact scale: An instrument for assessing informal long-term caregivers. *Journal of Gerontological Social Work* 18: 135-150.
- Vitaliano, P.P., Russo, J., Carr J.E., Maiuro, R.D., & Becker, J. (1985). The ways of coping checklist: revision and psychometric properties. *Multivariate Behavioral Research* 20: 3-26.
- Vitaliano, P.P., Russo, J., Young, H.M., Becker, J., & Maiuro, R.D. (1991). The screen for caregiver burden. *The Gerontologist* 31: 76-83.
- Wallhagen, M.I. (1988). Perceived control and adaptation in elderly caregivers. (Doctoral dissertation, University of Washington) Dissertation Abstracts International. 50: p. 128.
- Ware, Jr., J.E. (1999). SF-36 Health Survey. In M.E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment* (Chapter 40). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.
- Ware, Jr., J.E., Kosinski, M., & Keller, S.D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care* 34: 220-233.

- Ware Jr., J.E., Snow, K.K., Kosinski, M., & Gandek, B. (1993). *The SF-36 Health Survey manual and interpretation guide*. Boston: The Health Institute, New England Medical Center.
- Watson, D., Clark, L.A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personality and Social Psychology* 54: 1063-1070.
- Weisman, A.D., & Worden, J.W. (1977). The existential plight in cancer: significance of the first 100 days. *International Journal of Psychiatry in Medicine* 7: 1-15.
- Wells , Y.D., & Jorm, A.F. (1987). Evaluation of a special nursing home unit for dementia sufferers: A randomized controlled comparison with community care. *Australian & New Zealand Journal of Psychiatry* 21: 524-531.
- Wells , Y.D., Jorm, A.F., Jordan, F., & Lefroy, R. (1990). Effects on caregivers of special day care programmes for dementia sufferers. *Australian & New Zealand Journal of Psychiatry* 24: 82-90.
- Whitlatch, C.J. (2002). Older consumers and decision making: A look at family caregivers and care recipients. Paper presented at Scripps Gerontology Center's *Consumer Voice and Choice Conference*, *Oxford*, *OH*.
- Whitlatch, C.J., Feinberg, L.F., & Stevens, E.J. (1999). Predictors of institutionalization for persons with Alzheimer's disease and the impact on family caregivers. *Journal of Mental Health and Aging* 5: 275-288.
- Whitlatch, C.J., Schur, D., Noelker, L.S., Ejaz, F.K., & Looman, W.J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist* 41: 462-473.
- Whitlatch, C.J., & Tucke, S. (2000). *Autonomy and functioning in African American caregiving families*. AARP Andrus Foundation Final Report. August, 2000.
- Wolfson, C., Handfield-Jones, R., Glass, K.C., McClaran, J., & Keyserlingk, E. (1993). Adult children's perceptions of their responsibility to provide care for dependent elderly parents. *The Gerontologist* 33: 315-323.
- Yesavage, J.A., et al. (1983). Development and validation of a Geriatric Depression Screening Scale: A preliminary report. *Journal of Psychiatric Research* 17: 37-49.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* 20: 649 -655.
- Zarit, S.H., & Whitlatch, C.J. (1992). Institutional placement: phases of the transition. *The Gerontologist* 32: 665-672.
- Zeiss, A., Gallagher-Thompson, D., Lovett, S., Rose, J., & McKibbin, C. (1999). Self-efficacy as a mediator of caregiver coping: Development and testing of an assessment model. *Journal of Clinical Geropsychology* 5: 221-230.
- Zung, W. (1965). A self-rating depression scale. *Archives of General Psychiatry* 12: 63-70.