

Table 1. Baseline Battery Measures

Category	Name of Measure/Form	Citation/Source	Items	Time	Comments	α
Demographic information	CG/CR demographic	REACH I, 1995	21	8 min	Provides basic descriptive data on CGs and CRs.	N/A
CR cognition	MMSE	Folstein et al., 1975	11	12 min*	* Note: this time will not count in CG interview length	.829
CR quality of care	Personal Appearance	Various sources	13	2 min	Interviewer observation of CR's personal appearance	
CR physical impairment	ADL/IADL	Katz et al., 1963 Lawton et al., 1969	18	12 min	CG proxy report of CR functioning	.836
CR behavior	Revised Memory and Problem Behavior Checklist (RMBPC)	Teri et al., 1992	31	15 min	CG proxy report of the problems CR is experiencing	.785
Burden	Revised Memory and Problem Behavior Checklist (RMBPC)	Teri et al., 1992	31	see above	CG is asked about the burden of each behavior	.785
	Burden Interview	Zarit et al, 1985	12	5 min	Items ask about role strain and personal strain in the caregiver	
Positive aspects of caregiving	Positive Aspects of Caregiving	REACH I, 1995	11	3 min	Based in part on other measures of positive aspects (e.g., Lawton et al., 1991)	.906
Vigilance demands	Vigilance	REACH I, 1995	4	3 min	Items ask about time spent supervising CR	
Desire to institutionalize	Desire to Institutionalize	Morycz, 1985	6	3 min	Assesses the CG's desire to institutionalize the CR	
CR medications	CR Medications	REACH I, 1995	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken	N/A
CG medications	CG Medications	CHS	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken	N/A
CG depression	CES-D	Radloff, 1977	13	6 min	Contains 12 of the original 20 CES-D items plus a question regarding the cg's improvement in mood in the past six month.	
Sleep quality	CG sleep quality	Pittsburgh Sleep questionnaire	2	1 min	Measures sleep quality	
Self care and health behaviors	CG self care	REACH I, 1995	4	1 min	Measures ability to care for oneself	
Comorbidities	Comorbidity	(Juster, 1993)	13	5 min	Measures comorbidity.	
Illness and work	Illness and work		3	1 min	Ask time lost at work and activities due to illness	
Overall health	Overall health	Various sources	3	1 min	Assesses CG's view of own general health	
Symptoms	CG symptoms	Jenkins, Kreger, & Hurst, 1980	21	5 min	Measures health symptoms.	
CG disability	CG disability	Schulz, Newsom, Mittelmark, et al, 1997.	2	1 min	Level of disability	
Received support	Received support	Krause, 1995; Barrera et al., 1981	3	8 min	ISSB as modified by Krause	
Social interaction	Lubben Social Network Index (SNI)	Lubben, 1988;	4	N/A	Eliminates helping, and living arrangement questions	
Negative interaction	Negative Interaction Subscale	Krause, 1995	4	N/A	Interpersonal conflict	
Satisfaction with support	Satisfaction with Support	Krause, 1995	4	N/A	Tangible, emotional, information support	
CG religiosity/spirituality	Religiosity/Spiritual Coping	Pargament, et al, 1998 REACH I, 1995	9	4 min	Assess CG's religiosity and the degree to which their faith helps them cope with stress	
CG social activities	Social activities	REACH I, 1995	7	4 min	Satisfaction with the amount of time spent engaging in recreational activities	.835
CG quality of care	Quality of Care	Various sources	40	8 min	Evaluates living environment, aspects of abuse, and exemplary caregiving	
CG risk	Risk Appraisal	Various sources	51	10 min	Questions form an indicator of risk for the CG. Evaluates education, safety, caregiving skills, social support, caregiver emotional and physical well-being.	
Service utilization	Formal Care and Services	REACH I	19	14 min	Includes in-home services & medical services; obtains info about CG and CR and data for cost estimates	N/A
Cost	Formal Care and Services	REACH I	19	see above	Follow-up questions of frequency of use, difficulty with paying for services, and desire for services unable to afford	N/A

Total time estimate for full battery = 115 mins.

Table 2. Follow-up Battery Measures

Category	Name of Measure/Form	Citation/Source	Items	Time	Comments	α
Demographic information	Follow-up Sociodemographics	REACH I, 1995	7	5 min	Modified CG/CR sociodemographic form to fit follow-up situation	N/A
CR cognition	MMSE	Folstein et al., 1975	11	12 min*	* Note: this time will not count in CG interview length	.829
CR quality of care	Personal Appearance	Various sources	13	2 min	Interviewer observation of CR's personal appearance	
CR physical impairment	ADL/IADL	Katz et al., 1963 Lawton et al., 1969	18	12 min	CG proxy report of CR functioning	.836
CR behavior	Revised Memory and Problem Behavior Checklist (RMBPC)	Teri et al., 1992	31	15 min	CG proxy report of the problems CR is experiencing	.785
Burden	Revised Memory and Problem Behavior Checklist (RMBPC)	Teri et al., 1992	31	see above	CG is asked about the burden of each behavior	.785
	Burden Interview	Zarit et al, 1985	12	5 min	Items ask about role strain and personal strain in the caregiver	
Positive aspects of caregiving	Positive Aspects of Caregiving	REACH I, 1995	11	3 min	Based in part on other measures of positive aspects (e.g., Lawton et al., 1991)	.906
Vigilance demands	Vigilance	REACH I, 1995	4	3 min	Items ask about time spent supervising CR	
Desire to institutionalize	Desire to Institutionalize	Morycz, 1985	6	3 min	Assesses the CG's desire to institutionalize the CR	
CR medications	CR Medications	REACH I, 1995	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken	N/A
CG medications	CG Medications	CHS	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken	N/A
CG depression	CES-D	Radloff, 1977	13	6 min	Contains 12 of the original 20 CES-D items plus a question regarding the cg's improvement in mood in the past six month.	
Sleep quality	CG sleep quality	Pittsburgh Sleep questionnaire	2	1 min	Measures sleep quality	
Self care	CG self care	REACH I, 1995	2	1 min	Measures ability to care for oneself	
Comorbities	Comorbidity	(Juster, 1993)	12	5 min	Measures comorbidity.	
Symptoms	CG symptoms	Jenkins, Kreger, & Hurst, 1980	21	5 min	Measures health symptoms.	
CG disability	CG disability	Schulz, Newsom, Mittelmark, et al, 1997.	2	1 min	Level of disability	
Received support	Received support	Krause, 1995; Barrera et al., 1981	3	2 min	ISSB as modified by Krause	
Social interaction	Lubben Social Network Index (SNI)	Lubben, 1988;	4	2 min	Eliminates helping, and living arrangement questions	
Negative interaction	Negative Interaction Subscale	Krause, 1995	4	2 min	Interpersonal conflict	
Satisfaction with support	Satisfaction with Support	Krause, 1995	4	2 min	Tangible, emotional, information support	
CG religiosity/spirituality	Transition Religiosity/Spiritual Coping	Pargament et al., 1998 REACH I, 1995	8	4 min	Modified versions of Religiosity Form, dropping item that is unlikely to change over the course of the study.	
CG social activities	Social activities	REACH I, 1995	7	4 min	Satisfaction with the amount of time spent engaging in recreational activities	.835
CG quality of care	Quality of Care	Various sources	40	8 min	Evaluates living environment, aspects of abuse, and exemplary caregiving	
CG risk	Risk Appraisal	Various sources	51	10 min	Questions form an indicator of risk for the CG. Evaluates education, safety, caregiving skills, social support, caregiver emotional and physical well-being.	
Service utilization	Formal Care and Services	REACH I	19	14 min	Includes in-home services & medical services; obtains info about CG and CR and data for cost estimates	N/A
Cost	Formal Care and Services	REACH I	19	see above	Follow-up questions of frequency of use, difficulty with paying for services, and desire for services unable to afford	N/A
Program evaluation	Program Evaluation Form	REACH I	21	10 min	Items relate to satisfaction and social validity of the intervention and perception of the CTIS system.	N/A

Table 3. Bereavement Battery Measures

Category	Name of Measure/Form	Citation/Source	Items	Time estimate	Comments
Demographics	Bereavement Sociodemographics	REACH I	6	4 min	Modified CG/CR sociodemographic form to fit bereavement situation.
Service utilization/cost	Transition Formal Care and Services	REACH I	15	10 min	Modified version of the Formal Care and Services form
Sleep quality	CG sleep quality	Pittsburgh Sleep questionnaire	2	1 min	Measures sleep quality
Self care	CG self care	REACH I, 1995	2	1 min	Measures ability to care for oneself
Comorbidities	Comorbidity	(Juster, 1993)	12	5 min	Measures comorbidity.
Symptoms	CG symptoms	Jenkins, Kreger, & Hurst, 1980	21	5 min	Measures health symptoms.
CG disability	CG disability	Schulz, Newsom, Mittelmark, et al, 1997.	2	1 min	Level of disability
CG depression	CES-D	Radloff, 1977	13	6 min	Contains 12 of the original 20 CES-D items plus a question regarding the cg's improvement in mood in the past six month.
Received support	Received support	Krause, 1995; Barrera et al., 1981	3	2 min	Modified Social Support form to fit bereavement.
Social interaction	Lubben Social Network Index (SNI)	Lubben, 1988;	4	2 min	Modified Social Support form to fit bereavement.
Negative interaction	Negative Interaction Subscale	Krause, 1995	4	2 min	Modified Social Support form to fit bereavement.
Satisfaction with support	Satisfaction with Support	Krause, 1995	4	2 min	Modified Social Support form to fit bereavement.
CG Grief	Bereavement	Various sources	25	8 min	TRIG designed to measure grief-related depression; Circumstances Surrounding Death examines CG preparedness
CG social activities	Social activities	REACH I, 1995	7	4 min	Satisfaction with the amount of time spent engaging in recreational activities
CG Risk	Bereavement Risk Appraisal	Various sources	25	10 min	Modified risk appraisal to fit bereavement situation.
CG medications	CG Medications	CHS	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken
Program evaluation	Program Evaluation Form	REACH I	21	10 min	Items relate to satisfaction and social validity of the intervention and perception of the CTIS system.

Table 4. Placement Battery Measures

Category	Name of Measure/Form	Citation/Source	Items	Time estimate	Comments
Demographics	Placement Sociodemographics	REACH I	9	8 min	Modified CG/CR sociodemographic form to fit placement situation.
CR behavior	Transition Revised Memory and Behavior Problem Checklist (RMBPC)	Teri, 1992	3	5 min	Assesses perceived change in CR's cognition, behavior and mood
CG burden	Transition Burden Interview	Zarit, 1985	11	5 min	Measure of caregiver burden through questions which address role strain and personal strain of CG
Service utilization/cost	Transition Formal Care and Services	REACH I	15	10 min	Modified version of the Formal Care and Services form
Sleep quality	CG sleep quality	Pittsburgh Sleep questionnaire	2	1 min	Measures sleep quality
Self care	CG self care	REACH I, 1995	2	1 min	Measures ability to care for oneself
Comorbidities	Comorbidity	(Juster, 1993)	12	5 min	Measures comorbidity.
Symptoms	CG symptoms	Jenkins, Kreger, & Hurst, 1980	21	5 min	Measures health symptoms.
CG disability	CG disability	Schulz, Newsom, Mittelmark, et al, 1997.	2	1 min	Level of disability
CG depression	CES-D	Radloff, 1977	13	6 min	Contains 12 of the original 20 CES-D items plus a question regarding the cg's improvement in mood in the past six month.
Received support	Received support	Krause, 1995; Barrera et al., 1981	3	2 min	Modified Social Support form to fit placement.
Social interaction	Lubben Social Network Index (SNI)	Lubben, 1988;	4	2 min	Modified Social Support form to fit placement.
Negative interaction	Negative Interaction Subscale	Krause, 1995	4	2 min	Modified Social Support form to fit placement.
Satisfaction with support	Satisfaction with Support	Krause, 1995	4	2 min	Modified Social Support form to fit placement.
CG religiosity	Transition Religiosity/Spiritual Coping	Pargament et al., 1998 REACH I, 1995	8	4 min	Modified versions of Religiosity Form, dropping item that is unlikely to change over the course of the study.
CG social activities	Social activities	REACH I, 1995	7	4 min	Satisfaction with the amount of time spent engaging in recreational activities
CR placement	Placement	REACH I	16	8 min	Measures extent of help provided by CG, perceived problems with facility, cost of institutionalization
CG risk	Placement Risk Appraisal	Various sources	27	10 min	Modified risk appraisal to fit placement.
CG medications	CG Medications	CHS	2	N/A	Prescription and non-prescription meds from brown bag are listed/coded at sites; length depends on number of meds taken
Program evaluation	Program Evaluation Form	REACH I	21	10 min	Items relate to satisfaction and social validity of the intervention and perception of the CTIS system.

Table 5. Discontinued Battery Measures

Category	Name of Measure/Form	Citation/Source	Items	Time estimate	Comments
CR behavior	Transition Revised Memory and Behavior Problem Checklist (RMBPC)	Teri, 1992	3	5 min	Assesses perceived change in CR's cognition, behavior and mood
CG burden	Transition Burden Interview	Zarit, 1985	11	5 min	Measure of caregiver burden through questions which address role strain and personal strain of CG
CG depression	CES-D	Radloff, 1977	13	6 min	Contains 12 of the original 20 CES-D items plus a question regarding the cg's improvement in mood in the past six month.
Received support	Received support	Krause, 1995; Barrera et al., 1981	3	2 min	Modified Social Support form to fit discontinued battery.
Social interaction	Lubben Social Network Index (SNI)	Lubben, 1988;	4	2 min	Modified Social Support form to fit discontinued battery.
Negative interaction	Negative Interaction Subscale	Krause, 1995	4	2 min	Modified Social Support form to fit discontinued battery.
Satisfaction with support	Satisfaction with Support	Krause, 1995	4	2 min	Modified Social Support form to fit discontinued battery.
CG preventative health risk	Preventative Health	Various sources	13	5 min	Modified risk appraisal –only CG preventative health items.

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**REACH II MEASURES
DESCRIPTIONS AND ALGORITHMS**

Part I: The baseline assessment

Mini-Mental State Examination (MM)

Name of Measure: Mini-Mental State Examination.

Primary Reference: Folstein, Folstein, & McHugh (1975).

Type of Measure: Established.

Domain of Measurement: Care Recipient Cognitive Functioning.

Purpose: To assess the level of cognitive functioning in the care recipient. Performance on the MMSE is an exclusion criteria – those who score zero and are bed bound will not be enrolled in the study.

Time Frame: N.A.

Estimated Completion Time: 12 minutes.

Description of Measures: The MMSE – developed by Marshal Folstein (1975) – gives a brief assessment of a person’s orientation to time and place, recall ability, short-term memory, and arithmetic ability. It may be used as a screening test for cognitive loss or as a brief bedside cognitive assessment. It cannot be used to diagnose dementia. A cutpoint commonly used to indicate cognitive impairment are 23/24. The MMSE may be biased with regard to educational level, so cutpoints of 20/21 for those with 8-9 years of schooling, 22/23 for those with 10-12 years of schooling, and 23/24 for those with more than 12 years of schooling have been proposed.

Scaling: Varies across questions.

of items: 11 for the MMSE, plus 3 additional questions for data collector to complete.

Recode Statements: No items are recoded.

Missing values: Scores should *not* be prorated. Missing values, due to don’t know or refused responses, should be given zero points for given sub-scale.

Source of Algorithm: Folstein, Folstein, & McHugh (1975).

Algorithm: One total score ranging from 0-30 should be created for the MMSE. The total score is the sum of the subscores for the following items: 1, 2, 3, 4 **OR** 5 (whichever score is greater) 6, 7, 8, 9, 10, 11, 12. Note that this algorithm is slightly different than Folstein’s original paper in that the highest of serial sevens and world backwards is taken. The original instructions say to use serial sevens first and if the respondent is unable or unwilling to answer, then use world backwards. The impetus for the original instructions being to use serial sevens first is that the

test would be applicable to those who are illiterate (and would therefore be unable to spell “world”). However, many studies have shown that respondents fair better with world backwards rather than serial sevens. Thus, the REACH II study will slightly deviate from the original instructions and use the highest of the two tests. Scores for the MMSE range from 0 – 30, with higher scores being suggestive of better cognitive well-being.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Personal Appearance (PA)

Name of Measure: Personal Appearance

Primary Reference: Fulmer & O'Malley, 1987; Hirst & Miller, 1986; McClannahan, McGee, MacDuff & Krantz, 1990.

Type of Measure: Modified.

Domain of Measurement: Quality of Care

Purpose: This measure allows the interviewer to observe possible abuse.

Time Frame: Present.

Estimated Completion Time: 2 minutes.

Description of Measures: This measure contains 13 observational items where the interviewer records what he/she sees. These items ask about specific aspects of the care recipient's clothing and hygiene.

Scaling: Varies across questions.

of Items: 13

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: N.A.

Caregiver/Care Recipient Sociodemographics (SO)

Name of Measure: Caregiver/Care Recipient Sociodemographic Information

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Modified. Ethnicity questions changed to reflect the 2000 U.S. Census guidelines.

Domain of Measurement: Caregiver and Care Recipient Demographics

Purpose: Provides basic descriptive data on care recipients in this sample.

Time Frame: N. A.

Estimated Completion Time: 8 minutes.

Description of Measures:

This form contains 3 literacy items to help determine how to present the remaining materials in the interview and later in the intervention. 6 items (marital status, education, ethnicity, race, country of origin, and number of years in the U.S.) are asked for both the caregiver and care recipient. The race/ethnicity item, based on what the respondent identifies self as (and care recipient as), is based on the 2000 U.S. Census. Additional questions asked only of the caregiver include the caregiver's perception of the care recipient's physical health (ranging from 1 or poor, through 5 or excellent); employment-related questions including status, whether caregiver reduced hours or stopped working due to care recipient; financial-related questions including income (responses are in categories), and ability to pay for the basics; and housing-related questions, including type of dwelling, number of persons in home, years living with care recipient, and whether caregiver started living with care recipient in order to provide care. Lastly, the forms asks for the Medicare and Social Security Number for both the caregiver and care recipient.

Scaling: Varies across questions.

of Items: 21.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: N.A.

ADL/IADL (AD)

Name of Measure: Activities of Daily Living, Instrumental Activities of Daily Living

Primary Reference: Katz Activities of Daily Living / Lawton Instrumental Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969)

Type of Measure: Established.

Domain of Measurement: CR physical impairment. Assesses care recipient's ability to perform tasks of day-to-day importance (Activities of Daily Living: ADLs) and live independently in the community (Instrumental Activities of Daily Living: IADLs) as well as if CG assistance is required in performing such tasks and the amount of bother felt by the CG in assisting. Perceived change in functional abilities of the CR are also addressed.

Purpose: Provides basic descriptive data for characterizing the level of functioning/physical impairment and overall status of the care recipient. May correlate with measures of CG depression, mental health/well being, and others. Original versions of these measures have been widely used, and their measurement properties have been established (for reviews, see Guralnik & Simonsick, 1993; Spector, 1990).

Time Frame: Past week.

Estimated Completion Time: 12 minutes.

Description of Measures: The IADL section consists of eight items (#1-8), based on the list of activities originally used by Lawton and Brody (1969). A yes/no response is used to indicate whether the CR requires help with a given activity over the past week. The caregiver is then asked if he/she provides help with the activity (yes/no response). If the caregiver does provide help with the activity, the caregiver is then asked how much helping with the activity bothers or upsets him/her. A last question (#9) asks if the caregiver has seen any functional improvement overall in the past six months. If improvement, question about whether improvement was minimal (1) or substantial (2), and about the areas of improvement. If no improvement, question about whether there was no change (1), minimal decline (2), or substantial decline (3).

The ADL section consists of seven items (#10-16). These items are based on the list of activities originally used by Katz, Ford, Moskowitz, Jackson, & Jaffe (1963), but "dressing" is asked separately for lower and upper body. Note that these items should be combined into one category – whether assistance is needed in dressing – in calculating the total ADL score. A yes/no response is used to indicate whether the CR requires help with a given activity over the past week. The caregiver is then asked if he/she provides help with the activity (yes/no response). If the caregiver does provide help with the activity, the caregiver is then asked how much helping with the activity bothers or upsets him/her. Another question asks if the caregiver has seen any functional improvement overall in the past six months (#17). . If improvement, question about whether improvement was minimal (1) or substantial (2), and about the areas of improvement. If no improvement, question about whether there was no change (1), minimal decline (2), or substantial decline (3). A final question (#18) asks how many days in the past week other family members or friends have provided help.

Scaling: Varies across questions.

of Items: 18.

Recode Statements: No items need to be recoded.

Missing values: No published instructions on how to handle missing responses. All “unknown” or “refused” responses should be treated as missing.

Source of Algorithm: Katz et al., 1963 (ADL) and Lawton & Brody, 1969 (IADL).

Algorithm:

IADL score: Sum the scores on the 8 IADL items (#1-8) to form a scale ranging from 0 – 8 with higher scores indicating greater functional impairment.

Help with IADL score: Sum the scores for the dependent questions for the 8 IADL items to form a scale ranging from 0 – 8 with higher scores indicating increased levels of helping with IADLs. Note that a zero should be assigned for IADLs which a care recipient does not have impairment with.

ADL score: After combining the dressing questions (#13-14) into one category (i.e., whether assistance is needed in dressing), the ADL score is calculated by summing scores across the 6 ADL items to form a scale ranging from 0 – 6 with higher scores indicating greater functional impairment.

Help with ADL score: Sum the scores for the dependent questions for the 6 ADL items to form a scale ranging from 0 – 6 with higher score indicating increased levels of helping with ADLs. Note that a zero should be assigned for IADLs which a care recipient does not have impairment with. Also note that the dressing questions should be combined into one category (i.e., whether the caregiver helps in dressing the care recipient).

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Vigilance (VG)

Name of Measure: Vigilance

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research. Mahoney, D.M.F., Jones, R., Coon, D. W., Mendelsohn, A., Gitlin, L., & Ory, M. (2003). The Caregiver Vigilance Scale: Application and validation in the Resources for Enhance Alzheimer's Caregiver Health (REACH) project. *American Journal of Alzheimer's Disease and Other Dementias*, 18, 39-45.

Type of Measure: Established for REACH I

Domain of Measurement: Vigilance demand of caregiving.

Purpose: The measure specifically addresses issues of supervision as opposed to active management of problem behaviors or assistance with daily activities. Vigilance may also an important predictor of anxiety, depression and physical health. In addition, these items will be valuable in assessing the costs of caregiving.

Time Frame: N. A.

Estimated Completion Time: 3 minutes.

Description of Measures: Form consists of four items, probing the amount of time that the caregiver is required to spend with the care recipient in order to supervise him or her. The first item asks if the care recipient can be left alone in the event of a family emergency (response options: "yes", "no", "refused", "unknown"). A follow-up item assesses how long the recipient can be left alone. The second item asks if the recipient can be left alone in a room, and a follow-up item assesses how long the recipient can be left alone in a room. The third item asks for the number of hours the caregiver feels he/she must "be there" to care for the care recipient, and the last item asks the caregiver for an estimate of the number of hours he/she is actually doing something to provide care for the care recipient.

Scaling: Varies across questions.

of Items: 4.

Recode Statements: Items 1 and 1.1 should be combined by assigning zero hours to those who answered "no" to question 1. Items 2 and 2.1 should be combined by assigning zero hours to those who answered "no" to question 2. These two scores should then be subtracted from 24 hours (thus, they can be interpreted as the number of hours the caregiver must be at home and in the room with the care recipient, respectively. By subtracting these 2 items from 24 hours, all 4 vigilance items are in the same direction (i.e., higher scores indicate increased vigilance).

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Mahoney, 2003

Algorithm: Each item can be treated separately (i.e., four individual vigilance scores). As noted above, higher scores indicate increased vigilance. To create a combined algorithm, see Mahoney, 2003

Prorating: N.A.

Revised Memory and Behavior Checklist (MB)

Name of Measure: Revised Memory and Behavior Problem checklist (RMBPC)

Primary Reference: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.

Type of Measure: Established.

Domains of Measurement: Caregiver burden, extent of Caregiver concern with problem behaviors.

Purpose: The RMBPC functions as a primary measure of the burden of caregiving. The measure will provide a detailed assessment of the problems the recipient is experiencing as well as the caregiver's subjective assessment of the burden caused by the behavior or symptom. The RMBPC "was designed to be useful for clinical and research settings by a) focusing on observable, conceptually relevant, potentially modifiable behaviors; b) yielding an overall score with subscale scores for patient behaviors and caregiver reactions; and c) using objective criteria within a self-administered framework, to enable clinicians and researchers to pinpoint areas of disturbance and target intervention goals for patients and caregivers in a cost-effective manner." (Teri, et al., 1992, p. 623).

Time Frame: Past week.

Estimated Completion Time: 15 minutes

Description of Measures: This measure includes 24 items from the original instrument (Teri et al., 1992). This questionnaire consists of a list of potential problem behaviors that the care recipient might have exhibited over the past week. Problem behaviors are of three possible types (sub-scales): depressive, disruptive, and memory-related. The response options range from 0 (not in the past week) through 3 (daily or more often), indicating the frequency of the behaviors being exhibited by the care recipient.

Each item is accompanied by two follow-up items, which are contingent upon a "yes" response for the problem behavior. The follow-up items read as follows: "How bothered or upset by this?" and "How confident do you feel about handling this problem?" Response options range from 0 (not at all) to 4 (extremely).

In addition to the 24 items from the original instrument, 7 other items (distributed across 9 questions) have been added, as described here:

1. The first question asks whether the care recipient has shown any memory or behavior problems in the past week.
2. After the memory-related questions, the caregiver is asked whether the care recipient has shown any improvement in these memory-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement.
3. After the behavior-related questions, the caregiver is asked whether the care recipient has shown any improvement in these disruption-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement.
4. After the mood-related questions, the caregiver is asked whether the care recipient has shown any improvement in these depression-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement.
5. An open-ended item has been added toward the end of the form, which asks whether the care recipient has had any problems that were not covered by the preceding list. This item

provides space for one additional problem behavior. If there is another problem behavior, the caregiver is asked how often this problem occurred in the past week, how bothered or upset they were by the behavior, and how confident they feel in handling the problem. This question is then repeated twice more, when applicable (i.e., when the care recipient exhibits more problem behaviors).

6. Two “alert” items complete the form. These items ask whether the Principal Investigator has been notified about care recipients who have threatened to hurt themselves and about care recipients who have been commenting about their own deaths or the death of others.

Scaling: Varies across questions.

of Items: 31.

Recode Statements: Caregiver bother sub-items should be coded “0” where appropriate (as described below). Similarly, confidence sub-items should be coded “0” where appropriate.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.

Algorithm: There are four main scales and three sub-scales to be created for the RMBPC. The three main scales are Behavior Frequency (BF), Caregiver Bother (CB), and Caregiver Confidence scale (CC).

Behavior Frequency (BF):

Total BF is formed by summing the stem items for questions 2-8 and 10-18, 20-27. The BF scores for the three sub-scales are formed by summing the stem items for questions 14, 16, 20-26 (Depression); 10-13, 15, 17, 18, 27 (Disruption); 2-8 (Memory-Related Problems). Possible total BF scores range from 0 – 72. Scores for the three sub-scales range from 0-27, 0-24, and 0-21 for the depression sub-scale, disruption sub-scale, and memory sub-scale, respectively. Higher scores indicate a greater number of behaviors exhibited by the care recipient.

Caregiver Bother (CB):

The CB scale is calculated using two methodologies: (1) average conditional score (average CB for only those behaviors exhibited by the care recipient) and (2) total unconditional (total CB for all behaviors – for those behaviors not exhibited by the care recipient, a zero is assigned to the corresponding bother item). Both types of CB scores are calculated overall and for each of the three sub-scales. Higher scores indicate a greater level of bother on the part of the care recipient.

Calculation of Average CB Conditional Score:

Note: Bother items for which the behavior was not exhibited are ignored in calculating the conditional scores.

To calculate the average CB conditional score, using items 2-8, 10-18, and 20-27:

- a. If more than 25% of the behaviors are missing OR more than 25% of the bother scores for exhibited behaviors are missing, assign a missing value to the conditional bother score.
- b. If no more than 25% of the behaviors are missing AND no more than 25% of the bother scores for exhibited behaviors are missing:
 - i. Count the number of non-missing bothers.

- ii. Divide the sum of the responses for the bother questions by the number of non-missing bothers.

This algorithm is to be applied to the overall score as well as the individual sub-scales.

If care recipient exhibits no behaviors either overall or within a sub-scale, then the appropriate conditional bother score(s) should be set to "Not Applicable".

CB conditional scores, overall and for the 3 sub-scales, range from 0-4.

Calculation of Total CB Unconditional Score:

Note: Scores for bother items should be coded as zero for questions in which the care recipient does not exhibit the behavior (stem questions).

For the overall CB unconditional score, sum bother items for questions 2-8, 10-18, and 20-27 (only bother sub-items (e.g., question 2.1; not stem questions and not confidence sub-items). For Depression, sum bother items 14, 16, and 20-26. For Disruption, sum bother items 10-13, 15, 17, 18, and 27. For Memory, sum bother items 2-8.

The total CB unconditional score ranges from 0-96. CB unconditional scores for depression-, disruption-, and memory-related items range from 0-36, 0-32, and 0-28, respectively.

Caregiver Confidence (CC):

Similar to the CB, the CC scale is calculated using two methodologies: (1) average conditional score (average CC for only those behaviors exhibited by the care recipient) and (2) total unconditional (total CC for all behaviors – for those behaviors not exhibited by the care recipient, a zero is assigned to the corresponding confidence item). Both types of CC scores are calculated overall and for each of the three sub-scales. Higher scores indicate a greater level of confidence on the part of the care recipient.

Calculation of Average CC Conditional Score:

Note: Confidence items for which the behavior was not exhibited are ignored in calculating the conditional scores.

To calculate the average CC conditional score using items #2-8,10-18, and 20-27:

- c. If more than 25% of the behaviors are missing OR more than 25% of the confidence scores for exhibited behaviors are missing, assign a missing value to the conditional confidence score.
- d. If no more than 25% of the behaviors are missing AND no more than 25% of the confidence scores for exhibited behaviors are missing:
 - i. Count the number of non-missing confidence questions.
 - ii. Divide the sum of the responses for the confidence questions by the number of non-missing confidence questions.

This algorithm is to be applied to the overall score as well as the individual sub-scales.

If care recipient exhibits no behaviors either overall or within a sub-scale, then the appropriate conditional confidence score(s) should be set to "Not Applicable".

CC conditional scores, overall and for the 3 sub-scales, range from 0-4.

Calculation of Total CC Unconditional Score:

Note: Scores for confidence items should be coded as zero for questions in which the care recipient does not exhibit the behavior (stem questions).

For the total CC unconditional score, sum confidence items for questions 2-8,10-18, and 20-27 (only confidence sub-items (e.g., question 2.1; not stem questions and not bother sub-items). For Depression, sum confidence items 14, 16, and 20-26. For Disruption, sum confidence items 10-13, 15, 17, 18, & 27. For Memory, sum confidence items 2-8.

The total CC unconditional score ranges from 0-96. CC unconditional scores for depression-, disruption-, and memory-related items range from 0-36, 0-32, and 0-28, respectively.

Items #9, 19, and 28 may be examined individually to yield three types of information:

- A. whether or not there was any change
 - (no change = “no” to question #9.0 **AND** “no change” to question #9.2
“no” to question #19.0 **AND** “no change” to question #19.2
“no” to question #28.0 **AND** “no change” to question #28.2)
- B. the magnitude of improvement (questions #9.1; 19.1; 28.1- minimal, substantial)
- C. the magnitude of decline (questions #9.2; 19.2; 28.2- minimal, substantial)

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Burden Interview (BI)

Name of Measure: Burden Inventory

Primary Reference: Zarit, Orr, Zarit (1985); modified by Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001).

Type of Measure: Established.

Domain of Measurement: Caregiver burden.

Purpose: This instrument provides a measure of caregiver burden through questions which address role strain and personal strain in the caregiver.

Time Frame: N.A.

Estimated Completion Time: 5 minutes.

Description of Measure: This instrument contains 12 questions from the original Zarit Burden Interview (ZBI) which included 22 questions. Bedard et al. who created this shortened version of the ZBI found two primary factors: one factor containing 9 questions (items #1-#9) regarding the emotional and physical strain on the caregiver, and the second factor containing 3 questions (whether caregiver is uncertain about what to do for care recipient, whether caregiver thinks he/she should be doing more, and whether caregiver thinks he/she could be doing a better job; items #10-#12).

Scaling: Response options are on a 5-point scale ranging from 0 (Never) through 4 (Nearly always).

of items: 12.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001).

Algorithm: To calculate the overall Burden Inventory score, sum the responses across questions 1 through 6 and 8 through 12 (i.e., all questions except for #7). Question #7 is not included in the total score because it is not applicable to caregivers of care recipients who are institutionalized. The factor scores should be calculated in the same manner as the overall score, i.e., summing the response across the 8 questions (#1-6, 8, 9) and 3 questions (#10-12) comprising factor 1 and factor 2. A higher overall score and higher factor scores indicate greater levels of caregiver burden. Overall score ranges from 0-44; factor 1 scores range from 0-32; and factor 2 scores range from 0-12.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Formal Care and Services (FC)

Name of Measure: Formal Care and Services.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: New. Same as REACH I, but REACH I did not ask about who used the service (care giver or care recipient).

Domain of Measurement: Types and amount of community-based services utilized, cost of caregiving.

Purpose: A wide variety of social and medical services are available to recipients of home care. Obtaining some measure of their utilization is crucial, since these services may have a profound impact on health outcomes. Additionally, these data may be used to estimate the costs associated with home care (e.g., Harrow, Tennstedt, & McKinlay, 1995). Taking repeated measurements of service usage is essential, since participants may enter or leave these programs at will during the course of the study. Finally, some of the proposed interventions may provide participants with information on and/or encouragement to utilize certain existing services. In these cases, utilization frequency might be considered an outcome.

Time Frame: Past month.

Estimated Completion Time: 14 minutes.

Description of Measure: Form consists of 12 items assessing whether a service was used during the past month, 0=no, 1=yes. Each item is accompanied by a follow-up item, answered only if the service was used, asking who used the service (caregiver or care recipient), and the number of times the service was used (or how often and how long was the service used for a question about whether the care recipient was in a nursing home) during the past month. Two questions help to clarify if the home maker and home health aide is the same person. Up to 2 additional services, specified by the caregiver, may be reported for both the caregiver and the care recipient. Two questions ask about difficulty paying for services and desire for services unable to afford. A final item assesses whether the care recipient is in any study or takes any drugs for Alzheimer's Disease.

Scaling: Varies across items.

of Items: 23

Recode Statements: Recode as necessary. For some analyses, it may be necessary to combine trigger and dependent questions by assigning those who do not use a given service as having used the service zero times.

Missing Values: All "unknown" (-3) or "refused" (-4) should be coded as missing.

Source of Algorithm: N/A.

Algorithm: Treat as individual items. Depending upon the research question and analytic strategy, investigators may wish to combine items (e.g., total # of services used).

Positive Aspects of Caregiving (PC)

Name of Measure: Positive Aspects of Caregiving.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research. Tarlow, B., Belle, S., Wisniewski, S., Ory, M., Gallagher-Thompson, D., & Rubert, M. (in press). Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving Research on Aging. (Journal of Research on Aging)

Related Reference:

Roff L.L., Burgio L.D., Gitlin L.N., Nichols L., Chaplin W., Hardin J.M. (in press). Positive Aspects of Alzheimer's Caregiving: The Role of Race. Journal of Gerontology: Psychological Sciences.

Type of Measure: Established.

Domain of Measurement: Caregiver burden.

Purpose: One of the ways in which caregivers may cope with the stress and negative affect associated with caregiving is by emphasizing the positive aspects of providing such care. This form, which probes agreement with statements such as "Providing help to (CR) has made me feel more useful," provides a means of measuring these compensatory mechanisms.

This topic has received considerable attention in recent years as a counterpoint to the negative aspects of caregiving emphasized in the majority of the literature (e.g., Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). Indeed, it may be that positive aspects of caregiving counteract the many stresses associated with caregiving to maintain the quality of life of individuals. Conceptually, this measure provides important outcome information that is not captured anywhere else in the core battery.

Time Frame: N.A.

Estimated Completion Time: 3 minutes.

Description of Measure: The scale contains 11 items, phrased as statements about the caregiver's mental/affective state in relation to the caregiving experience. This form differs from the Caregiver Health Effects Study (Schulz, Newsom, Burton, Hirsch, Jackson, & Mittlemark, 1997) for in three ways (1) response options have been changed from the yes/no format used on the original in order to increase variability of responses and improve reliability; (2) questions have been rephrased as statements to accommodate the agree/disagree response option; and (3) overall instructions have been modified to avoid negative reactions from caregivers.

Scaling: Response options are on a 5-point agree/disagree scale.

of items: 11.

Recode Statements: N.A.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Tarlow et al., (Journal of Research on Aging, in press)

Algorithm: Psychometric analyses from REACH I revealed that the variables for “enabled me to learn a new skill” and “given more meaning to my life” should be dropped before computing a summary score. Then, the responses for the 9 remaining items (#1-6, 9-11) should be summed. Scores range from 0-36, with higher scores indicating more positive feelings toward caregiving.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Desire to Institutionalize (DI)

Name of Measure: Desire to Institutionalize.

Primary Reference: Morycz, 1985.

Type of Measure: Established.

Domain of Measurement: Desire to institutionalize care recipient.

Purpose: To assess the caregiver's desire to institutionalize the care recipient.

Time Frame: Past six months, with the exception of the last question which ask about the future six months.

Estimated Completion Time: 3 minutes.

Description of Measure: The scale contains 5 items asking the caregiver about their plans, thoughts, and discussions with others, regarding institutionalizing the care recipient. A final question asks the caregiver whether he/she is likely to institutionalize the care recipient in the next 6 months.

Scaling: Yes/no responses.

of items: 6.

Recode Statements: N.A.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Morycz, 1985.

Algorithm: The total score is calculated by summing the responses across all questions. Scores range from 0 – 6 with higher scores indicating a greater desire to institutionalize the care recipient.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Caregiver Health and Health Behaviors (CH)

Name of Measure: Caregiver Health and Health Behaviors

Primary Reference: SF-36; REACH I; CHES; Pittsburgh Sleep Questionnaire; Schulz & Beach 1999; Schulz, Newsom, Mittlmark, et al., 1997; Jenkins, Kreger, & Hurst, 1980.

Type of Measure: Modified Hybrid

Domain of Measurement: Physical health, preventative health behaviors, symptoms

Purpose: The measure is designed to assess perceived health, preventative health behaviors, comorbidity, and symptoms. Caregiver health symptoms and preventative health behaviors are considered key outcome measures. Comorbidity is not expected to be substantially influenced by caregiving or interventions but will be used as general descriptors of overall caregiver health. Previous research has suggested that health behaviors are affected by caregiving burden and stress, and these behaviors may be important mediators of other health outcomes (Burton, Newsom, Schulz, Hirsch, & German, 1996; Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson, 1997). Stress-related symptoms may also be important mediators of health outcomes.

Time Frame: Varies.

Estimated Completion Time: 10 minutes.

Description of Measure: This form consists of 48 items. Four domains of self-reported health are assessed: general and perceived health, comorbidities, preventative health behaviors, and stress-related symptoms. Items from each domain are based on health questionnaires used elsewhere.

The first eight items probe general health, sleep, smoking, drinking, rest, and doctor visits. The next fifteen items (#9-23) assess comorbidity, and are taken from AHEAD (Juster, 1993). These items ask the caregiver whether he/she currently has or has been told by a doctor that he/she has any of several chronic health problems, ranging from arthritis to stroke. Response options are yes/no. The next 21 items (#24-44) asks the caregiver if they have experienced any of several symptoms in the past month, and if so, how many total days in the past month, did they experience that symptom. Three additional questions (#45-47) ask how illness has impacted on daily activities and work in the past month. Items #24-47 are based on a scale developed by Jenkins, Kreger, & Hurst, 1980. One last question (#48) asks if the caregiver has seen any improvement in their physical health overall in the past six months.

Scaling: Items 1-2 are measured on a 5 point scale ranging from 0 to 4. Items 3-4 are measured on a 4 point scale, ranging from 0 to 3. Items 5-44 are based on a 0/1 (no/yes) scale. Items 45-47 are measured in days. Item 48 asks about whether health has improved in the past 6 months, with a 0/1 (no/yes) response; if yes, asks about improvement (1 = minimal/2 = substantial); if no, asks about decline (1=no change, 2 = minimal decline, 3 = substantial decline).

of items: 48

Recode Statements: Recode items as described below under Algorithms.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithms: SF-36; REACH I; CHES; Pittsburgh Sleep Questionnaire; Schulz & Beach 1999; Schulz, Newsom, Mittlemark, et al,1997; Jenkins, Kreger, & Hurst, 1980.

Algorithm: Several summary scores can be calculated. These are:

1. *Sleep Quality:* Reverse code the responses for item #4, trouble staying awake (i.e., 0=3, 1=2, 2=1, 3=0). Then add the reverse-coded responses from item #4 to the responses from item #3. Sleep Quality scores range from 0 – 6, with higher scores indicating better sleep quality. No prorating should be performed for this score.
2. *Self-Care:* Sum the responses for items #7 and #8. Total scores range from 0 – 2, with higher scores indicating decreased levels of caring for oneself. No prorating should be performed for this score.
3. *Comorbidities:* Sum the response for items #9 – #20. Total scores range from 0 – 12, with higher scores indicating a greater number of comorbidities.
4. *Caregiver Disability:* Sum the responses for items #22 and #23. Total scores range from 0 – 2, with higher scores indicating greater disability. No prorating should be performed for this score.
5. *Symptoms:* Total number of symptoms can be calculated by summing the responses for items #24-#44. Symptom scores range from 0 – 21, with higher scores indicating more symptoms.
6. *Days Ill:* Items #45-47. Treat as individual items.

The remaining item (question #21) is treated separately.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Center for Epidemiologic Studies – Depression Scale, CES-D (SD)

Name of Measure: CES-D.

Primary Reference: Radloff, 1977.

Type of Measure: Established.

Domain of Measurement: Depression, depressive symptoms.

Purpose: Depression is a key outcome measure. The CES-D was chosen as the measure of depression because it is brief, can be administered by interviewers with little special training, and is widely used in medical, epidemiological, and psychological studies. Previous research using confirmatory factor analysis has indicated that four depression-related factors are represented in the measure: negative affect, positive affect, somatic symptoms, and interpersonal judgment (Hertzog, Van Alstine, Usala, & Hultsch, 1990)

Time Frame: Past week.

Estimated Completion Time: 6 minutes.

Description of Measure: This form contains 12 of the original 20 items on the CES-D instrument as initially described by Radloff (1977). The first 10 of these 12 items are based on a reduced version of the CES-D through methodology. Additionally, two other questions not including in the 10-item list (“People were unfriendly”, “I felt that people disliked me”) which have been found to yield a distinct factor in the complete 20 item version of the scale, were asked. Finally, one question which was not part of the original CES-D was added to the end of this form regarding the caregiver’s improvement in mood or emotional well-being in the past six months.

Scaling: Items are measured on 4-point scales, ranging from 0 (Rarely or none of the time) through 3 (Most or almost all of the time). The lone exception is the last question on the form (caregiver’s improvement in mood or emotional well-being in the past six months). This question is measured on a 5-point scale, ranging from 0 (A lot worse) through 4 (A lot better).

of items: 13.

Recode Statements: * Items # 5 (“I felt hopeful about the future”) and 8 (“I was happy”) should be reverse coded (i.e., 0 = 3, 1 = 2, 2 = 1, 3 = 0), so that all questions are in the same direction.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: Radloff, 1977.

Algorithm: The total score is calculated by summing the responses across items 1 – 10 only (after reverse coding items 5 and 8, as described above). Possible scores range from 0 – 30, with higher scores indicating a greater frequency or amount of depressive symptoms.

Two additional items (#11, #12) can be summed to form a separate scale. Possible scores range from 0 – 6.

Item #13 is treated separately.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Social Support (SS)

Name of Measure: Social Support.

Primary Reference: Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990).

Type of Measure: Modified from a hybrid form – hybrid was used in REACH I.

Domain of Measurement: Social networks (family, friends, confidants), received support (emotional, tangible, informational), satisfaction with support, and negative interactions.

Purpose: Social support as an important predictor of both health and psychological outcomes (e.g., Berkman, 1995; George, 1989). Support has been found to be particularly important in buffering the effects of stressful life events such as health problems, bereavement, and natural disasters (Cohen & Wills, 1985). Based on their demonstrated importance in the literature, four broad categories of social support constructs were considered: social networks, perceived support, perceived adequacy or satisfaction with support, and negative interactions. Social networks typically assess variables such as the size, interconnectedness, and frequency of contacts with network members. Perceived support can involve the self-reports of support received or perceptions of the availability of support.

Time Frame: Most questions refer to the past month.

Estimated Completion Time: 8 minutes.

Description of Measure: The form is a modification of a hybrid form used in REACH I. Questions are asked in 4 major domain areas: 1) Received support, 2) Satisfaction with support, 3) Social network, and 4) Negative interactions. Further details are provided below.

Scaling: Varies.

of total items: 16.

Recode Statements: Items comprising the negative interaction domain should be reverse coded (e.g., 0=3) when calculating a total social support score, as described below.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: Multiple.

Algorithm: See below for methods for computing summary scores for each of the 4 specific domains.

DOMAIN 1

Name of Measure: Received Support, from the Inventory of Socially Supportive Behaviors.

Primary Reference: Barrera, Sandler, & Ramsey, 1981, modified by Krause (Krause, 1995; Krause & Markides, 1990).

Description of Measure: Original was modified for the present study to consist of 3 items, with 1 each for tangible, emotional, and informational subscales. Response is on a 4-point rating of frequency (“never” to “very often”).

Scale Creation: An overall measure of received support can be formed by summing items 6, 8, and 10. Items for tangible support (#6), emotional support (#8), and informational support (#10) can be formed by averaging the items in parentheses. Total scores range from 0 – 9, with higher scores indicating increased levels of the amount of support received. Prorating is not appropriate for this factor.

DOMAIN 2

Name of Measure: Satisfaction with Support.

Primary Reference: Krause, 1995; Krause & Markides, 1990.

Description of Measure: Scale consists of 3 items (one each concerning the overall satisfaction with tangible, emotional, and informational support received). The original measure used a yes/no response format, but in order to increase sensitivity, these items were changed to a 4-point scale, “not at all satisfied” to “very satisfied.”

Scale Creation: An overall measure of satisfaction with received support can be formed by summing items 7, 9, and 11. Scores range from 0 – 9, with higher scores indicating increased satisfaction with the amount of support received. Prorating is not appropriate for this factor.

DOMAIN 3

Name of Measure: Social Network.

Primary Reference: Lubben, 1998 (Lubben Social Network Index).

Description of Measure: Scale is adapted from Berkman & Syme (1979) for older adults, and consists of 2 items (10 in original scale). Unlike REACH I, questions are not asked separately for family, friends, and confidants. Another change is that two items from the original scale were dropped: one item which assesses whether the respondent lives alone or with others (caregivers must live with care recipients to be included in the present study); and a second item which assesses whether the respondent helps others or is helped by others (this information is obtained elsewhere in the interview). Items are on a 6-point scale, with categories for the number of network members (none, one, two, three or four, five to eight, nine or more).

Scale Creation: An overall measure of satisfaction with received support can be formed by summing items 2 and 3. Scores range from 0 – 10, with higher scores indicating larger social networks. Prorating is not appropriate for this factor.

DOMAIN 4

Name of Measure: Negative Interactions.

Primary Reference: Krause, 1995.

Description of Measure: Consists of 4 items on a 4-point frequency rating (“never” to “very often”) over the past month.

Scale Creation: An overall measure of negative interactions can be formed by summing items 12, 13, 14, and 15. Scores range from 0 – 12, with higher scores indicating higher degrees of negative interactions. Prorate if only 1 missing. To prorate, divide score on 3 non-missing items by 3 and then multiply by 4.

OVERALL TOTAL SOCIAL SUPPORT SCORE is calculated by summing 10 questions (#s: 6–15). The last four questions (12-15) should be reverse coded (e.g., 3 = 0) so that all questions are in the same direction (higher scores are positive). Total Social Support scores range from 0 – 40. Higher scores suggest increased levels of social support.

Prorating: For individuals with missing values for not more than 2 questions, divide the score on the non-missing items by the number of non-missing items and multiply by 10 (total number of items on the scale).

Religiosity/Spiritual Coping (RG)

Name of Measure: Short Form of the Brief RCOPE and general religion/religiosity questions.

Primary Reference: Pargament, Smith, Koenig, & Perez 1998; REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Established, with additional items.

Domain of Measurement: Negative and positive factors of coping; religious preference; formal and informal prayer exhibited by caregiver.

Purpose: To assess caregiver's religiosity and the degree to which their faith helps them to cope with stressful situations.

Time Frame: N.A.

Estimated Completion Time: 4 minutes.

Description of Measure: The RCOPE scale was designed to assess the positive and negative aspects of religious/spiritual coping. The RCOPE taps into 17 religious/spiritual coping methods including: benevolent religious appraisals, spiritual discontent, and religious helping. In 1998, Pargament, Smith, Koenig and Perez developed a shortened version of the RCOPE (Brief RCOPE). The Brief RCOPE consists of 21 items, divided into two primary factors: positive factor which represents benevolent religious involvement in the quest for significance (12 items) and a negative factor which represents religious struggle in coping (9 items). Pargament et al. also present an adapted form of the Brief RCOPE which consists of 6 items. The 3 items with the highest load values for the positive factors and the 3 items with the highest load values for the negative factors make up the 6 item adapted (short form) Brief RCOPE. It is this Short Form of the Brief RCOPE which is used in the present study. One additional item concerns the caregiver's religious preference. Fifteen options include major religions of the world and their largest sects, as well as "none" and "other" categories. Two final questions ask the frequency of attendance at religious services and how often the care recipient prays or meditates

Scaling: Brief RCOPE responses are measured on a 4-point scale, ranging from 0 ("A great deal") through 3 ("Not at all"). Frequency of formal and informal prayer response options are on a 6-point scale, ranging from 0 ("never") to 5 ("nearly every day").

of items: 9.

Recode Statements: The positive factor items (questions 1 – 3) should be reverse coded (e.g., 0=3) when calculating the total religious/spiritual coping score.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Pargament, Smith, Koenig, & Perez, 1998.

Algorithm: After reverse coding the positive factor items (#1-3), the total religious/spiritual coping score is computed by summing the values for all 6 items. The total score ranges from 0-18, with higher scores indicating higher levels religiosity/spiritual coping. The positive factor score is calculated by summing the values for the first 3 items (#1-3), recoded. Positive factor scores range from 0-9, with higher scores indicating higher levels of religiosity/spiritual coping. The negative factor score is calculated by summing the values for items #4-6. Thus, the negative factor score ranges from 0-9, with higher scores indicating higher levels of religiosity/spiritual coping.

The remaining items (questions #7, 8, & 9) are treated separately.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Social Activities (SA)

Name of Measure: Social or Leisure Activities.

Primary Reference: Modified from REACH I. The measure now asks about “how often” in addition to about “amount of time” Stevens, A. B., Coon, D.W., Wisniewski, S., Vance, D., Arguelles, S., Belle, S. H. Mendelsohn, A.B., Ory, M. G., Haley, W. E. (in press). Measurement of Leisure Time Satisfaction in Family Caregivers, *Aging and Mental Health*.

Type of Measure: Modified.

Domain of Measurement: Satisfaction with social/leisure activities.

Purpose: One of the primary impacts of caregiving is on the individual’s ability to engage in desirable social activities, and that ability to engage in desired activities serves as an important mediator of depressive symptomatology in the elderly (Williamson & Schulz, 1992). Moreover, it is conceptually distinct from other outcome measures included in that it focuses on the absence of positive states as opposed to the presence of negative states. There is a growing literature showing that these two dimensions are not different sides of the same coin. This measure is also useful in helping us understand the reasons for reductions in support and/or social integration. That is, reductions in the opportunity for social activities may in turn be related to reduced social networks and social support.

Time Frame: Past month.

Estimated Completion Time: 4 minutes.

Description of Measure: The form consists of 7 questions asking the caregiver how often have they been able to participate in various social/leisure activities (e.g., quiet time, attending church/religious services). For each of the 7 activities, the caregiver is asked how satisfied they are with the amount of time they are able to spend on said activity.

Scaling: All items are measured on a 3-point scale, with 0 = “Not at all”, 1 = “A little”, and 2 = “A lot”.

of items: 7.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: REACH I, unpublished data.

Algorithm: Two summary scores can be calculated:

1. *Social/Leisure Activities Time:* This measure is based upon the trigger (i.e., root) questions for items #1 – #7. The response to these items should be summed to form a scale ranging from 0 – 14. Higher scores suggest greater amounts of time for social/leisure activities.

2. *Satisfaction with Social/Leisure Activities Time*: This measure is based upon the dependent questions (i.e., 1.1, 2.1, 3.1, 4.1, 5.1, 6.1, 7.1). Sum the responses to these items to form a scale ranging from 0 – 14, with higher scores suggesting increased satisfaction with the time spent doing social/leisure activities.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Quality of Care (QC)

Name of Measure: Quality of Care.

Primary References:

Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002; Williamson, G. et al., 1996; Straus, 1979; Steinmetz, 1988; Hinrichsen, G. A., Niederehe, G. 1994.

Type of Measure: Modified Hybrid

Domain of Measurement: Quality of care provided by caregiver

Purpose: This measure evaluates the living environment as well as aspects of abuse and exemplary caregiving to indicate the quality of care given by the caregiver.

Time Frame: Past month.

Estimated Completion Time: 8 minutes.

Description of Measure: Form consists of questions in specific domains: living environment, frustrations in caregiving, exemplary caregiving.

Scaling: Varies across items.

of Items: 40

Recode Statements: Recode items as described in algorithm section.

Missing Values: All “not applicable” (-2), “unknown” (-3), or “refused” (-4) should be coded as missing.

Source of Algorithm: Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002; Williamson, G. et al., 1996; Straus, 1979; Steinmetz, 1988; Hinrichsen, G. A., Niederehe, G. 1994.

Algorithm: Three separate summary scores should be calculated:

1. *Living Environment* – First, recode the items in section B (#6-14), Hazards in Environment (i.e., 0=1 and 1=0). Then, sum the recoded responses for section B. This value should then be added to the total for responses in section A, Positive Aspects of Environment (#1-5). The total score for the Living Environment ranges from 0 – 14, with higher scores indicating superior environment conditions.

2. *Frustrations of Caregiving* – Sum responses for the 8 items included in the Frustrations of Caregiving section (#15-22). Total scores range from 0 – 24, with higher scores indicating increased frustration.

3. *Exemplary Caregiving* – Sum responses for the 18 items included in the Exemplary Caregiving section (#23-40). Total scores range from 0 – 54, with higher scores indicating increased exemplary caregiving.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Risk Appraisal (RA)

Name of Measure: Risk Appraisal.

Primary Reference: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Type of Measure: Hybrid.

Domain of Measurement: Caregiver Risk.

Purpose: This measure compiles questions across five areas: education, safety, caregiver skills, social support, and caregiver emotional and physical well being. These questions form an indicator of risk for caregivers.

Time Frame: Varies.

Estimated Completion Time: 10 minutes.

Description of Measure: This measure contains 4 questions regarding the general education of the caregiver in memory loss, dementia and Alzheimer's disease as well as advanced planning legal issues. The safety section contains 10 items addressing issues such as home safety, wondering, CR driving, CR smoking etc. The caregiver skills section contains 8 questions which deal with the ability to manage the CR's behaviors. The social support section is made up of 7 questions which probe the type and amount of social support the caregiver receives. Lastly, the caregiver emotional and physical well being section contains 22 questions that ask about the caregiver's preventative health behaviors and emotional health.

Two alert items complete the form. The first asks whether the respondent has answered "yes" to question 7 (Can CR get to dangerous object). This is followed by a nested item that asks if the dangerous object is a gun. The second alert item asks whether the respondent has answered (1) Sometimes or (2) Often to Question 14 (Does (CR) drive?)

Scaling: Questions are either "Yes" or "No" or on 3-point scales: "Never" (0), "Sometimes" (1), and "Often" (2).

of items: 51.

Recode Statements: Questions #38 and #39 should be combined when calculating the Self Care score. A point should be given if the caregiver has had both a mammogram and a pap smear in the past two years. Questions #26, #27 and #29 should be reverse coded (e.g., 0=2) when calculating the Social Support Score. Questions #41 should be reverse coded (0=1) when calculating the Self-Care score.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Algorithm: Scores should be calculated for the following factors:

Education: Sum the responses for the 4 items (#1-4) in the education section. Scores range from 0-4, with higher scores indicating increased levels of preparedness in dealing with Alzheimer’s disease and end-of-life care.

Safety: Sum the responses for the 10 items (#5-14) in the safety section. Items 5-8 are 0/1 (yes/no) and items 9-14 range from 0 (never) to 2 (often). Scores range from 0-16, with higher scores indicating decreased safety levels.

Caregiving Skills: Sum the responses for the 8 items (15-22) in the caregiving skills section. Scores range from 0 – 16, with higher scores suggesting decreased levels of caregiving skills.

Social Support: Sum the responses for items #23-25, 28 and recoded items #26, 27, 29 in the social support section. Scores range from 0 – 13, with higher scores suggesting increased social support. Item 23 is 0/1 (no/yes). The rest of the items range from 0 (never) to 2 (often).

Self Care: The Self-Care score is calculated FOR WOMEN: by summing the scores for items #30-39, #41, #50, - 51 (use combined #38-39 as described in *Recode Statements*, and recoded #41) and FOR MEN: by summing the scores for items #30-37 & #40-41, #50-51 (using recoded #41). Note that this Self Care score is different than the outcome measure as the outcome measure additionally includes two questions from the Caregiver Health and Health Behaviors form, questions #7 (have you found time to see the doctor?) and #8 (have you been able to slow down and get rest when sick?) from the CH form. Scores range from 0 – 14 with higher scores indicating increase self-care.

Emotional and Physical Well-Being: The emotional and physical well-being score is calculated by summing items #42-49. Scores range from 0-16. Two sub-scores can also be created. The emotional well-being subscale is created by summing items #42-45. The physical well-being sub-score is created by summing items #46-49.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Caregiver/Care Recipient Medications Forms (GM, RM)

Name of Measures: Caregiver Medications, Care Recipient Medications.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: New.

Domains of Measurement: All medications, prescription or non-prescription, currently being taken by study participants.

Purpose: To assess the types and quantity of medications taken by the caregiver and care recipient, particularly drugs for anxiety, depression, stress, and cognitive-enhancing medications for the care recipient.

Time Frame: N.A.

Description of Measures: The procedure follows the commonly used "brown bag" method of assessment. (An example of a similar procedure can be found in Psaty, Lee, Savage, Ratan, German, & Lyles, 1992). Study participants will be telephoned in advance of the initial interview and asked to gather all medications. During the interview, the caregiver will be asked to produce the medications, at which time the interviewer will write down the names of all of them. Interviewer training should include explicit instructions not to offer any advice on medications to interviewees. All prescription and non-prescription medications will be recorded and later assigned a numerical code. The data collector is instructed to indicate for every medication used whether it is being taken for anxiety, depression, or stress. On a related note, there is a final question in which the caregiver is asked whether he/she (form GM) or the care recipient (form RM) takes any drugs for anxiety, depression, or stress.

Scaling: Yes/no and lists of medications used.

of items: 2

Recode Statements: N.A.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: N.A.

Algorithm: N.A.

Original Psychometric Data : N.A.

Additional References : N.A.

Follow-up Sociodemographics (FS)

Name of Measure: Caregiver/Care Recipient Sociodemographic Information

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Modified. Ethnicity questions changed to reflect the 2000 U.S. Census guidelines.

Domain of Measurement: Caregiver and Care Recipient Demographics

Purpose: Provides basic descriptive data on care recipients in this sample.

Time Frame: N. A.

Estimated Completion Time: 5 minutes.

Description of Measures:

This form contains an item (marital status,) which is asked for both the caregiver and care recipient. Additional questions asked only of the caregiver include the caregiver's perception of the care recipient's physical health (ranging from 1 or poor, through 5 or excellent); employment-related questions including status, whether caregiver reduced hours or stopped working due to care recipient; financial-related questions including income (responses are in categories), and ability to pay for the basics; and housing-related questions, including type of dwelling, number of persons in home, years living with care recipient, and whether caregiver started living with care recipient in order to provide care.

Scaling: Varies across questions.

of Items: 7.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: N.A.

Transition Religiosity/Spiritual Coping (TR)

Name of Measure: Short Form of the Brief RCOPE and general religion/religiosity questions.

Primary Reference: Pargament, Smith, Koenig, & Perez 1998; REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Established, with additional items.

Domain of Measurement: Negative and positive factors of coping; religious preference; formal and informal prayer exhibited by caregiver.

Purpose: To assess caregiver's religiosity and the degree to which their faith helps them to cope with stressful situations.

Time Frame: N.A.

Estimated Completion Time: 4 minutes.

Description of Measure: The RCOPE scale was designed to assess the positive and negative aspects of religious/spiritual coping. The RCOPE taps into 17 religious/spiritual coping methods including: benevolent religious appraisals, spiritual discontent, and religious helping. In 1998, Pargament, Smith, Koenig and Perez developed a shortened version of the RCOPE (Brief RCOPE). The Brief RCOPE consists of 21 items, divided into two primary factors: positive factor which represents benevolent religious involvement in the quest for significance (12 items) and a negative factor which represents religious struggle in coping (9 items). Pargament et al. also present an adapted form of the Brief RCOPE which consists of 6 items. The 3 items with the highest load values for the positive factors and the 3 items with the highest load values for the negative factors make up the 6 item adapted (short form) Brief RCOPE. It is this Short Form of the Brief RCOPE which is used in the present study. Two final questions ask the frequency of attendance at religious services and how often the care recipient prays or meditates. This scale differs from the baseline measure due to the removal of the one question that asks for the religious preference of the respondent.

Scaling: Brief RCOPE responses are measured on a 4-point scale, ranging from 0 ("A great deal") through 3 ("Not at all"). Frequency of formal and informal prayer response options are on a 6-point scale, ranging from 0 ("never") to 5 ("nearly every day").

of items: 8.

Recode Statements: The positive factor items (questions 1 – 3) should be reverse coded (e.g., 0=3) when calculating the total religious/spiritual coping score.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Pargament, Smith, Koenig, & Perez, 1998.

Algorithm: After reverse coding the positive factor items (#1-3), the total religious/spiritual coping score is computed by summing the values for all 6 items. The total score ranges from 0-18, with higher scores indicating higher levels religiosity/spiritual coping. The positive factor score is calculated by summing the values for the first 3 items (#1-3), recoded. Positive factor scores range from 0-9, with higher scores indicating higher levels of religiosity/spiritual coping. The negative factor score is calculated by summing the values for items #4-6. Thus, the negative factor score ranges from 0-9, with higher scores indicating higher levels of religiosity/spiritual coping.

The remaining items (questions 7 & 8) are treated separately.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Bereavement Sociodemographics (BS)

Name of Measure: Caregiver/Care Recipient Sociodemographic Information

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Modified. Ethnicity questions changed to reflect the 2000 U.S. Census guidelines.

Domain of Measurement: Caregiver and Care Recipient Demographics

Purpose: Provides basic descriptive data on care recipients in this sample.

Time Frame: N. A.

Estimated Completion Time: 4 minutes.

Description of Measures:

This form contains questions asked only of the caregiver include the caregiver's marital status; employment-related questions including status, whether caregiver reduced hours or stopped working due to care recipient; financial-related questions including income (responses are in categories), and ability to pay for the basics; and housing-related questions, including type of dwelling, and number of persons in home.

Scaling: Varies across questions.

of Items: 6.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: N.A.

Transition Formal Care and Services (TF)

Name of Measure: Transition Formal Care and Services.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: New. Same as REACH I but REACH I did not ask about who used the service (caregiver or care recipient).

Domain of Measurement: Types and amount of community-based services utilized, cost of caregiving.

Purpose: A wide variety of social and medical services are available to recipients of home care. Obtaining some measure of their utilization is crucial, since these services may have a profound impact on health outcomes. Additionally, these data may be used to estimate the costs associated with home care (e.g., Harrow, Tennstedt, & McKinlay, 1995). Taking repeated measurements of service usage is essential, since participants may enter or leave these programs at will during the course of the study. Finally, some of the proposed interventions may provide participants with information on and/or encouragement to utilize certain existing services. In these cases, utilization frequency might be considered an outcome.

Time Frame: Past month.

Estimated Completion Time: 10 minutes.

Description of Measure: Form consists of 12 items assessing whether a service was used during the past month, 0=no, 1=yes. Each item is accompanied by a follow-up item, asking the number of times the service was used during the past month. A question helps to clarify if the home maker and home health aide is the same person. Up to 2 additional services, specified by the caregiver, may be reported. Two questions ask about difficulty paying for services and desire for services unable to afford.

Scaling: Varies across items.

of Items: 17

Recode Statements: Recode as necessary. For some analyses, it may be necessary to combine trigger and dependent questions by assigning those who do not use a given service as having used the service zero times.

Missing Values: All "unknown" (-3) or "refused" (-4) should be coded as missing.

Source of Algorithm: N/A.

Algorithm: Treat as individual items. Depending upon the research question and analytic strategy, investigators may wish to combine items (e.g., total # of services used).

Transition Social Support (TS)

Name of Measure: Transition Social Support.

Primary Reference: Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990).

Type of Measure: Modified from a hybrid form – hybrid was used in REACH I.

Domain of Measurement: Social networks (family, friends, confidants), received support (emotional, tangible, informational), satisfaction with support, and negative interactions.

Purpose: Social support as an important predictor of both health and psychological outcomes (e.g., Berkman, 1995; George, 1989). Support has been found to be particularly important in buffering the effects of stressful life events such as health problems, bereavement, and natural disasters (Cohen & Wills, 1985). Based on their demonstrated importance in the literature, four broad categories of social support constructs were considered: social networks, perceived support, perceived adequacy or satisfaction with support, and negative interactions. Social networks typically assess variables such as the size, interconnectedness, and frequency of contacts with network members. Perceived support can involve the self-reports of support received or perceptions of the availability of support.

Time Frame: Most questions refer to the past month.

Estimated Completion Time: 8 minutes.

Description of Measure: The form is a modification of a hybrid form used in REACH I. Questions are asked in 4 major domain areas: 1) Received support, 2) Satisfaction with support, 3) Social network, and 4) Negative interactions. Further details are provided below.

Scaling: Varies.

of total items: 16.

Recode Statements: Items comprising the negative interaction domain should be reverse coded (e.g., 0=3) when calculating a total social support score, as described below.

Missing values: All missing responses are either “unknown” or “refused”.

Source of Algorithm: Multiple.

Algorithm: See below for methods for computing summary scores for each of the 4 specific domains.

DOMAIN 1

Name of Measure: Received Support, from the Inventory of Socially Supportive Behaviors.

Primary Reference: Barrera, Sandler, & Ramsey, 1981, modified by Krause (Krause, 1995; Krause & Markides, 1990).

Description of Measure: Original was modified for the present study to consist of 4 items (#5, 6, 8, 10), with separate items for tangible, emotional, and informational subscales. Response is on a 4-point rating of frequency (“never” to “very often”).

Scale Creation: An overall measure of received support can be formed by summing items #5, 6, 8, and 10. Total scores range from 0 – 13, with higher scores indicating increased levels of the amount of support received.

DOMAIN 2

Name of Measure: Satisfaction with Support.

Primary Reference: Krause, 1995; Krause & Markides, 1990.

Description of Measure: Scale consists of 4 items (# 1, 7, 9, 11) (separate items for the overall satisfaction with tangible, emotional, and informational support received). The original measure used a yes/no response format, but in order to increase sensitivity, these items were changed to a 4-point scale, “not at all satisfied” to “very satisfied.”

Scale Creation: An overall measure of satisfaction with received support can be formed by summing items #1, 7, 9, and 11. Scores range from 0 – 12, with higher scores indicating increased satisfaction with the amount of support received. Item #1 can be used as a single general indicator of satisfaction with support.

DOMAIN 3

Name of Measure: Social Network.

Primary Reference: Lubben, 1998 (Lubben Social Network Index).

Description of Measure: Scale is adapted from Berkman & Syme (1979) for older adults, and consists of 3 items (10 in original scale). Unlike REACH I, questions are not asked separately for family, friends, and confidants. Another change is that two items from the original scale were dropped: one item which assesses whether the respondent lives alone or with others (caregivers must live with care recipients to be included in the present study); and a second item which assesses whether the respondent helps others or is helped by others (this information is obtained elsewhere in the interview). Items are on a 6-point scale, with categories for the number of network members (none, one, two, three or four, five to eight, nine or more).

Scale Creation: An overall measure of social network can be formed by summing items 2, 3, and 4. Scores range from 0 – 15, with higher scores indicating larger social networks. Prorating is not appropriate for this factor.

DOMAIN 4

Name of Measure: Negative Interactions.

Primary Reference: Krause, 1995.

Description of Measure: Consists of 4 items (#12-15) on a 4-point frequency rating (“never” to “very often”) over the past month.

Scale Creation: An overall measure of negative interactions can be formed by summing items 12, 13, 14, and 15. Scores range from 0 – 12, with higher scores indicating higher degrees of negative interactions. Prorate if only 1 missing. To prorate, divide score on 3 non-missing items by 3 and then multiply by 4.

OVERALL TOTAL SOCIAL SUPPORT SCORE is calculated by summing 15 questions (#s: 1–15). The last four questions (12-15) should be reverse coded (e.g., 3 = 0) so that all questions are in the same direction (higher scores are positive). Total Social Support scores range from 0 – 53. Higher scores suggest increased levels of social support.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Bereavement (BF)

Name of Measure: Bereavement Form, composed of the 13-item Present Feelings subtest from the Texas Inventory of Grief - Revised (TRIG, Faschingbauer, 1981), Circumstances Surrounding Death Questionnaire (O'Bryant, 1990-91; Nieboer & Ormel, 1994); three items on service use.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Modified from a hybrid form – hybrid was used in REACH I.

Domain of Measurement: grief, circumstances surrounding death, service use.

Purpose: The TRIG was chosen because it is the shorter of the two leading self-report inventories assessing the grief response. The Circumstances Surrounding Death questionnaire items were chosen because certain factors, such as forewarning of death, have been found to influence the adjustment of the bereaved individual. Since the ADRD caregiving situation inherently allows for an extended period of forewarning, and presently allows for little or no hope for the recovery of the (CR), the experience can be likened to a long and stressful period of waiting. Thus, the death of the (CR) may come as a relief to some caregivers, perhaps depending upon the intensity of the stress they have experienced. These items provide a categorization of level of care provided and associated stress, extent to which death was a relief for both (CG) and (CR), and extent of preparedness for the death. Finally, the Service Use items were included for study of the relation of the utilization of various types of community-based psychological and social services to symptoms of grief.

Time Frame: present, time of death to present.

Estimated Completion Time: 8 minutes.

Description of Measures: *Texas Inventory of Grief - Revised:* The "Present Feelings" subtest from Faschingbauers (1981) inventory comprise the first 13 items (questions #1-13) in the form. These items are first-person statements regarding the thoughts and behaviors of the respondent, who is asked to choose a response from a five-point (1-5) true/false scale (possible responses are "completely false", "mostly false", "true and false", "mostly true", and "completely true"). These items deal with various aspects of grief-related depression, such as acceptance of loss, crying behavior, and intrusive thoughts.

Circumstances Surrounding Death: The next nine items were adapted from Nieboer & Ormel's (1994) questionnaire, and from O'Bryant (1991). The first item (#14) simply asks where the (CR) died; response options are "home", "hospital", "nursing home", and "other". The next four items (#15-18) assess the extent to which the (CG) perceives (CR)'s death as a relief, either to him/herself or to the (CR). Two items (#19, #20) then assess the extent to which the (CG) was prepared for the death. The above six items utilize a 3-point response set (1-3): "not at all", "somewhat", and "very much". Then, two items (#21, #22) assess the amount of physical and mental discomfort experienced by the (CR) before he/she died. These items have a 4-point response scale (1-4), from "never" to "all the time".

Service Use: The final three items (#23-25) in the form assess the types of services in use and/or desired by the bereaved (CG). These items were developed for REACH.

Scaling: Varies across questions.

of Items: 25

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: Sum the responses from the first 13 items (#1-13). Scores range from 13 to 65, a higher score indicating greater grief-related depression. Faschingbauers (1981). Remaining items (#14-25) are typically examined individually.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Bereavement Risk Appraisal (BA)

Name of Measure: Bereavement Risk Appraisal.

Primary Reference: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Type of Measure: Hybrid.

Domain of Measurement: Caregiver Risk.

Purpose: This measure compiles questions across five areas: education, safety, caregiving skills, social support, and caregiver emotional and physical well being. These questions form an indicator of risk for caregivers.

Time Frame: Varies.

Estimated Completion Time: 10 minutes.

Description of Measure: The safety section contains 1 item (#1), which addresses fire extinguisher and smoke detectors. The social support section is made up of 4 questions (#2-5) which probe the type and amount of social support the caregiver receives. Lastly, the caregiver emotional and physical well being section contains 20 questions that ask about the caregiver's self-care/preventative health behaviors as well as physical and emotional health.

Scaling: Questions are either "Yes" or "No" or on 3-point scales: "Never" (0), "Sometimes" (1), and "Often" (2).

of items: 25

Recode Statements: Questions 14 and 15 should be combined when calculating the Self Care score. A point should be given if the caregiver has had both a mammogram and a pap smear in the past two years (#14 & 15). Question #5 should be reverse coded (0=2) when calculating the Social Support Score. Questions #17, 24-25 should be reverse coded when calculating the Self-Care score (0=1 for #17; 0=2 for #24 and 25).

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Algorithm: Scores should be calculated for the following factors:

Safety: Item (#1) should be treated separately.

Social Support: Sum the responses for items #2-5 and recoded item #5 in the social support section. Scores range from 0 – 8, with higher scores suggesting increased social support. Items range from 0 (never) to 2 (often).

Self Care: The Self-Care score is calculated by FOR WOMEN: summing the scores for items #6-15, #17, #24, and #25 (use combined #14-15 as described in *Recode Statements* and reverse codes for #17, 24-25) and FOR MEN: summing the scores for items #6-13, #16-17, #24-25 (using reverse codes for #17, 24-25). Note that this Self Care score is different than the outcome measure as the outcome measure additionally includes two questions from the Caregiver Health and Health Behaviors form, questions #7 (have you found time to see the doctor?) and #8 (have you been able to slow down and get rest when sick?) from the CH form. Scores range from 0 – 14 with higher scores indicating increase self-care.

Emotional and Physical Well-Being: The emotional and physical well-being score is calculated by summing items #18-23. Scores range from 0-12. Two sub-scores can also be created. The emotional well-being subscale is created by summing items #18-19. The physical well-being sub-score is created by summing items #20-23.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Placement Sociodemographics (PS)

Name of Measure: Caregiver/Care Recipient Sociodemographic Information

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: Modified. Ethnicity questions changed to reflect the 2000 U.S. Census guidelines.

Domain of Measurement: Caregiver and Care Recipient Demographics

Purpose: Provides basic descriptive data on care recipients in this sample.

Time Frame: N. A.

Estimated Completion Time: 8 minutes.

Description of Measures:

This form contains an item (marital status) which is asked for both the caregiver and care recipient. Additional questions asked only of the caregiver include the caregiver's perception of the care recipient's physical health (ranging from 1 or poor, through 5 or excellent); employment-related questions including status, whether caregiver reduced hours or stopped working due to care recipient; financial-related questions including income (responses are in categories), and ability to pay for the basics; and housing-related questions, including type of dwelling, number of persons in home and whether caregiver started living with care recipient in order to provide care.

Scaling: Varies across questions.

of Items: 9.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm: N.A.

Formatted: English (U.S.)

Transition Revised Memory and Behavior Checklist Form (TM)

Name of Measure: Transition Revised Memory and Behavior Problem checklist (RMBPC)

Primary Reference: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.

Type of Measure: New.

Domains of Measurement: Perceived change in care recipient's cognition, behavior and mood.

Purpose: The RMBPC functions as a primary measure of the burden of caregiving. The measure will provide a detailed assessment of the problems the recipient is experiencing as well as the caregiver's subjective assessment of the burden caused by the behavior or symptom. The RMBPC "was designed to be useful for clinical and research settings by a) focusing on observable, conceptually relevant, potentially modifiable behaviors; b) yielding an overall score with subscale scores for patient behaviors and caregiver reactions; and c) using objective criteria within a self-administered framework, to enable clinicians and researchers to pinpoint areas of disturbance and target intervention goals for patients and caregivers in a cost-effective manner." (Teri, et al., 1992, p. 623).

Formatted: English (U.S.)

Time Frame: Past week.

Estimated Completion Time: 5 minutes

Description of Measures: Problem behaviors are of three possible types (sub-scales): depressive, disruptive, and memory-related. 1. The memory-related questions, the caregiver is asked whether the care recipient has shown any improvement in these memory-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement. 2. The behavior-related questions, the caregiver is asked whether the care recipient has shown any improvement in these disruption-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement. 3. The mood-related questions, the caregiver is asked whether the care recipient has shown any improvement in these depression-related areas in the past six months. If the care recipient has shown improvement, the caregiver is asked to state the areas of improvement.

Scaling: Varies across questions.

of Items: 3.

Recode Statements: Caregiver bother sub-items should be coded "0" where appropriate (as described below). Similarly, confidence sub-items should be coded "0" where appropriate.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.

Algorithm: Items (#1,2,3) may be examined individually to yield three types of information:

- A. whether or not there was any change
 - (no change = "no" to question #1.0 **AND** "no change" to question #1.2
"no" to question #2.0 **AND** "no change" to question #2.2
"no" to question #3.0 **AND** "no change" to question #3.2)
- B. the magnitude of improvement (questions #1.1; 2.1; 3.1- minimal, substantial)
- C. the magnitude of decline (questions #1.2; 2.2; 3.2- minimal, substantial)

Transition Burden Interview (TB)

Name of Measure: Transition Burden Inventory

Primary Reference: Zarit, Orr, Zarit (1985); modified by Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001).

Type of Measure: Established.

Domain of Measurement: Caregiver burden.

Purpose: This instrument provides a measure of caregiver burden through questions which address role strain and personal strain in the caregiver.

Time Frame: N.A.

Estimated Completion Time: 5 minutes.

Description of Measure: This instrument contains 11 questions from the original Zarit Burden Interview (ZBI) which included 22 questions. Bedard et al. who created this shortened version of the ZBI found two primary factors: one factor containing 9 questions (items #1-#9) regarding the emotional and physical strain on the caregiver (8 items included in this measure- one question, "amount of privacy" has been removed), and the second factor containing 3 questions (whether caregiver is uncertain about what to do for care recipient, whether caregiver thinks he/she should be doing more, and whether caregiver thinks he/she could be doing a better job; items #10-#12).

Scaling: Response options are on a 5-point scale ranging from 0 (Never) through 4 (Nearly always).

of items: 11.

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Bedard, Molloy, Squire, Dubois, Lever, & O'Donnell (2001).

Algorithm: To calculate the overall Burden Inventory score, sum the responses across questions 1 through 11 (question 7 from the baseline burden inventory has been removed because it is not applicable to caregivers of care recipients who are institutionalized). The factor scores should be calculated in the same manner as the overall score, i.e., summing the response across the 8 questions (#1-8) and 3 questions (#9-11) comprising factor 1 and factor 2. A higher overall score and higher factor scores indicate greater levels of caregiver burden. Overall score ranges from 0-44; factor 1 scores range from 0-32; and factor 2 scores range from 0-12.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Placement (PL)

Name of Measure: This form is composed of ADL questions and three additional ADL items developed for REACH I, a revised version of the Facility Problems Questionnaire (Skaff, Pearlin, & Mullan, 1996), and some items pertaining to cost.

Primary Reference: REACH I: Resources for Enhancing Alzheimer's Caregiver Health. (1995 - 2001). National Institute on Aging and National Institute of Nursing Research.

Type of Measure: new

Domain of Measurement: Extent of help provided by (CG), perceived problems with facility, cost of institutionalization

Purpose: Skaff, et al. (1996) found that the amount of participation that (CG)s had in the care provided at the nursing home was positively related to the (CG)s' sense of mastery, which is in turn related to positive health outcomes. Zarit & Whitlatch (1992) suggested that problems encountered with care facility staff and conditions might constitute a continued source of stress to (CG)'s. Finally, the cost items are consistent with an overall goal of the REACH II project to estimate, on a broad basis, the costs associated with ADRD caregiving to individuals, insurers, and to society as a whole.

Time Frame: date of institutionalization to present

Estimated Completion Time: 8 minutes.

Description of Measures: ADL items (#1-7) are asked. Three new ADL items(#8-10) were written in order to deal specifically with placed (CR)s. These items ask whether (CG) provides assistance in addition to what is offered by the care facility, if (CG) met with staff to discuss special care, did (CG) do things for (CR) such as managing finances or running errands;and if so, how much time is spent doing each of these. The ADL items are followed by an adapted version of the Facility Problems Questionnaire (Skaff, et al., 1996). The next three items (#11-13) assess satisfaction with quality of care, social, and physical environment, respectively. The next item (#14) consists of a list of potential problems with the facility, and the (CG) is asked for the frequency with which they occur, on a 4-point scale (0-3), from "never" to "very often". One item (#15) assesses the frequency of (CG)'s visits to (CR). Finally, two items (#16-17) assess the cost of institutionalization.

Scaling: Varies across questions.

of Items: 17

Recode Statements: No items need to be recoded.

Missing values: All missing responses are either "unknown" or "refused".

Algorithm:

ADL score: After combining the dressing questions (#4-5) into one category (i.e., whether assistance is needed in dressing), the ADL score is calculated by summing scores across the 6

ADL items to form a scale ranging from 0 – 6 with higher scores indicating greater functional impairment.

Items #8-10 may be examined as individual items.

Facility Satisfaction Scale: Items #11-13 should be summed to form a scale ranging from 3-12, a higher score indicating greater satisfaction.

Items # 14-17 may be examined as individual items.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Placement Risk Appraisal (RP)

Name of Measure: Placement Risk Appraisal.

Primary Reference: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Type of Measure: Hybrid.

Domain of Measurement: Caregiver Risk.

Purpose: This measure compiles questions across five areas: education, safety, social support, and caregiver emotional and physical well being. These questions form an indicator of risk for caregivers.

Time Frame: Varies.

Estimated Completion Time: 10 minutes.

Description of Measure: This measure contains 2 questions regarding advanced planning legal issues. The safety section contains 1 item addressing smoke detectors and fire extinguishers in the home. The social support section is made up of 4 questions which probe the type and amount of social support the caregiver receives. Lastly, the caregiver emotional and physical well being section contains 20 questions that ask about the caregiver's self-care/preventative health behaviors as well as physical and emotional health.

Scaling: Questions are either "Yes" or "No" or on 3-point scales: "Never" (0), "Sometimes" (1), and "Often" (2).

of items: 27.

Recode Statements: Questions #16 and #17 should be combined when calculating the Self Care score. A point should be given if the caregiver has had both a mammogram and a pap smear in the past two years. Question 7 should be reverse coded (0=2) when calculating the Social Support Score. Questions #19, 26-27 should be reverse coded when calculating the Self-Care score (0=1 for #19; 0=2 for #26 and 27).

Missing values: All missing responses are either "unknown" or "refused".

Source of Algorithm: Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992.; Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsey, 1981); Lubben Social Network Index (LSNI: Lubben, 1988); Satisfaction with Support, and Negative Interactions (Krause, 1995; Krause & Markides, 1990); Schulz & Beach 1999; Schulz, Newman, Mittlemark, et al.; Jenkins, Kreger, & Hurst, 1980; Gitlin, L. N., Schinfeld, S., Winter, L., Corcoran, M., & Hauck, W. 2002

Algorithm: Scores should be calculated for the following factors:

Education: Items (#1, 2) should be summed.

Safety: Item (#3) should be treated separately.

Social Support: Sum the responses for items #4-7 and recoded item #7 in the social support section. Scores range from 0 – 8, with higher scores suggesting increased social support. Items range from 0 (never) to 2 (often).

Self Care: The Self-Care score is calculated by FOR WOMEN: summing the scores for items #8-17, # 19, #26, and #27 (use combined #14-15 as described in *Recode Statements* and reverse codes for #19, 26-27) and FOR MEN: summing the scores for items #8-15, #18-19, #26-27 (using reverse codes for #19, 26-27). Note that this Self Care score is different than the outcome measure as the outcome measure additionally includes two questions from the Caregiver Health and Health Behaviors form, questions #7 (have you found time to see the doctor?) and #8 (have you been able to slow down and get rest when sick?) from the CH form. Scores range from 0 – 14 with higher scores indicating increase self-care.

Emotional and Physical Well-Being: The emotional and physical well-being score is calculated by summing items #20-25. Scores range from 0-12. Two sub-scores can also be created. The emotional well-being subscale is created by summing items #20-21. The physical well-being sub-score is created by summing items #22-25.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

Preventative Health (PH)

Name of Measure: Preventative Health

Primary Reference: Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., Jackson, S., & Burton, L. (2001).

Type of Measure: new

Domain of Measurement: Caregiver preventive health.

Purpose: These questions ask about the caregiver's preventative health behavior and form an indicator of risk for caregivers.

Time Frame: Varies

Estimated Completion Time: 3 minutes.

Description of Measures: This measure contains 13 questions that ask about the caregiver's preventative health behaviors which correspond with the self-care section of the risk appraisal measure.

Scaling: Varies across questions.

of Items: 13

Recode Statements: Questions #11 and #12 should be combined when calculating the Self Care score. A point should be given if the caregiver has had both a mammogram and a pap smear in the past two years.

Missing values: Questions are either "Yes" or "No".

Algorithm: Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., Jackson, S., & Burton, L. (2001). *Self Care:* The Self-Care score is calculated by FOR WOMEN: summing the scores for items #1-12 (use combined #11-12 as described in *Recode Statements*) and FOR MEN: summing the scores for items #1-10, #13. Note that this Self Care score is different than the outcome measure as the outcome measure additionally includes two questions from the Caregiver Health and Health Behaviors form, questions #7 (have you found time to see the doctor?) and #8 (have you been able to slow down and get rest when sick?) from the CH form. Scores range from 0 – 12 with higher scores indicating increase self-care.

Prorating: For individuals with missing values for not more than 25% of questions used in a score, use the average for non-missing items with the same response range.

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