

Caregiver Well-Being - Toolkit – Brown University
List of Instruments Referenced in the Toolkit

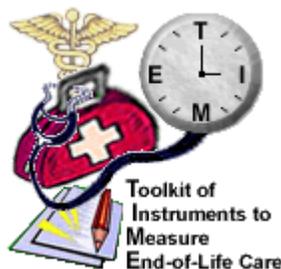
General Instruments:

1. Appraisal of Caregiving Scale, ACS (Oberst et al. 1989; Carey et al. 1991)- a 72-item self-report measure
2. Burden Interview, BI (Zarit SH 1980; Zarit JM 1982) -a 29-item interviewer-administered questionnaire
3. Care Work Impact Appraisals (Orbell et al. 1993)- a 31-item questionnaire
4. Caregiver Burden and Generic Well-Being (Stull et al. 1994)- a structured, telephone interview
5. Caregiver Burden Scale, CB (Elmstahl et al. 1996)- a 22-item questionnaire
6. Caregiver Load Scale, CLS (Oberst et al. 1989)- a 10-item self-report scale
7. Caregiver Perceived Burden Scale, CPB (Strawbridge & Wallhagen 1991)- a 22-item scale
8. Caregiver Reaction Assessment, CRA (Given et al. 1992)- a 24-item instrument
9. Caregiver Self-Efficacy (Zeiss et al. 1999)- a 14-item interview-format
10. Caregiver Social Impact Scale (Poulshock & Deimling 1984)- a 19-item scale
11. Caregiver Strain Index, CSI (Robinson 1983)- a 13-item screening tool
12. Caregiving Appraisal Scale, CAS (Lawton et al. 1989)- a 21-item instrument
13. Caregiving Appraisal Scale, Modified (Hughes and Caliandro 1996)- a 28-item version
14. Caregiving Indices (Bass & Bowman 1990)- an 8-item scale
15. Cost of Care Index, CCI (Kosberg & Cairl 1986)- a 20-item scale
16. Derogatis Stress Profile, DSP (Derogatis 1987)- a 77-item self-report instrument
17. Family Assessment Device, FAD (Epstein, Baldwin & Bishop 1983)- a 60-item self-report measure
18. Family Caregiving Consequences Inventory, FCCI (Shyu et al. 1999)- a 21-item index
19. Family Caregiving Inventory (Archbold et al. 1992)- an inventory
20. Family Caregiving Scale (Schofield et al. 1997)
21. Family Environment Scale, FES (Moos 1990/1974)- a 90-item instrument
22. Family Hardiness Index, FHI (McCubbin et al. 1987)- a 20-item instrument
23. Family Impact Interview (Covinsky 1994)- a 10-item interviewer administered
24. Guilt Scale (Wells & Jorm 1987)- a 3-item scale
25. Impact-on-Family Scale (Stein & Riessman 1980)- a 24-item scale
26. Multidimensional Caregiver Strain Index, MCSI (Stull 1996)- an 18-item tool
27. Objective and Subjective Burden Scales (Montgomery et al. 1985)- a 9-item objective burden scale (OBS) and a 13-item subjective burden scale (SBS)
28. Parent Caregiver Strain Questionnaire, PCSQ (England & Roberts 1996)- a 40-item self-administered
29. Patient-Caregiver Functional Unit Scale, PCFUS (Fredman & Daly)- an interview-administered questionnaire
30. Perceived Caregiver Burden Scale, PCB (Stommel et al. 1990)- a 31-item scale
31. Perceived Caregiver Burden Scale, Revised, PCB-13 (Gupta R 1999)- a 13-item
32. Perceived Social Support for Caregiving, PSSC, and Social Conflict, SC, scales(Goodman 1991)- includes a 9-item (PSSC) scale and a 3-item (SC) scale
33. Perceived Stress Scale, PSS (Cohen et al. 1983)- a 14-item, self-reported unidimensional instrument
34. Picot Caregiver Rewards Scale, PCRS (Picot et al. 1997)- a 16-item
35. Ways of Coping Checklist (Folkman & Lazarus 1980)- a 64-item index

Caregiver Well-Being - Toolkit – Brown University
List of Instruments Referenced in the Toolkit
Page 2 of 2

Disease-specific instruments:

1. AIDS Caregiver Scale (Ferrari et al. 1993)- a 14-item self-administered scale
2. Bakas Caregiving Outcomes Scale, BCOS (Bakas & Champion 1999)- a 10-item (stroke)
3. Caregiver Activity Survey, CAS (Davis et al. 1997)- a self-administered tool (Alzheimer's disease)
4. Caregiver Burden Inventory, CBI (Novak & Guest 1989)- a 24- item scale (cognitively impaired older adults)
5. Caregivers' Stress Scales (Pearlin et al. 1990)- a series of 15 scales (Alzheimer's disease)
6. Care-giving Burden Scale (Gerritsen & van der Ende 1994)- a 13-item scale (Alzheimer's Disease, dementia, or other psychological conditions)
7. Caregiving Hassles Scale (Kinney & Stephens 1989a)- a 42-item instrument (dementia)
8. Caregiving Hassles and Uplifts Scale (Kinney & Stephens 1989b)- a 110-item scale (dementia)
9. Caregiving Self-Efficacy Scale, CSS (Denney 1994)- a 58-item scale (Alzheimer's disease)
10. Finding Meaning Through Caregiving, FMTC (Farran et al. 1999)- a 43-item questionnaire (dementia)
11. Frustration Scale (Motenko 1989)- a 9-item scale (dementia)
12. Memory and Behavior Problems Checklist, MBPC (Zarit JM 1982, Zarit SH et al.1985)- a 30-item interviewer-administered questionnaire (Alzheimer's disease)
13. Memory and Behavior Problems Checklist, Revised, RMBPC (Teri et al. 1992)- a24-item self-administered questionnaire (adapted from #12)
14. Neuropsychiatric Inventory Caregiver Distress Scale, NPI-D (Kaufers et al. 1998) (Alzheimer's disease)
15. Relatives Stress Scale, RSS (Greene et al. 1982)- a 15-item interviewer-administered (dementia)
16. Screen for Caregiver Burden, SCB (Vitaliano et al. 1991)- 25-item scale (Alzheimer's disease)
17. Sense of Competence Questionnaire, SCQ (Vernooij-Dassen et al. 1996)- a 27-item instrument (dementia)
18. Short Sense of Competence Questionnaire, SSCQ (Vernooij-Dassen et al.1999)- a 7-item version of #17
19. Subjective Burden Scale, SBS (Matsuda 1999)- a 14-item self-administered scale (Japanese dementia caregivers)



TIME: TOOLKIT OF INSTRUMENTS TO MEASURE END-OF-LIFE CARE



CAREGIVER WELL BEING

Literature Review

Searches of the Medline, Cancerlit, and PsycInfo databases were conducted to identify measurement instruments pertaining to caregiver well-being. Key search words were family burden, caregiver burden, and cost of care in combination with (palliative care, terminal care, terminally ill) and in combination with (assessment, audit, outcome, measurement, interview, questionnaire, survey, scale). In addition, we reviewed selected references from the methods sections of identified articles and searched for relevant books through an online catalogue.

Potential instruments

Based on the review of the literature, 35 general instruments and 19 disease-specific instruments were found and summarized. Most [disease-specific instruments](#) are for caregivers of people with Alzheimer's Disease or dementia, but there are tools designed for caregivers of stroke survivors and AIDS patients as well.

- **General instruments**

Appraisal of Caregiving Scale, ACS (Oberst et al. 1989; Carey et al. 1991)- a 72-item self-report measure designed to assess the caregiver's perception of the intensity of caregiving in five dimensions (harm/loss, threat, challenge, benefit, and benign). Content of items focuses on areas of potential stress for caregivers- caregiving tasks, relationships and interpersonal support, lifestyle, emotional and physical health, personal impact. Items are scored on a 5-point scale (ranging from "very untrue" to "very true"), with a higher dimension score indicating greater intensity in that dimension.

Burden Interview, BI (Zarit SH 1980; Zarit JM 1982)- a 29-item interviewer-administered questionnaire designed to assess the degree of burden felt by caregivers of older people with senile dementia. Items were selected based on clinical experience with caregivers and fall into five categories (health, psychological well-being, finances, social life, relationship with impaired person). A 20-item version has undergone psychometric testing (Zarit JM 1982); a 22-item version also has been developed (Zarit et al. 1985). The instrument also has undergone psychometric testing in Hebrew, Spanish, and Japanese.

Care Work Impact Appraisals (Orbell et al. 1993)- a 31-item questionnaire measuring both positive and negative aspects of caregiving for an elderly person. The instrument consists of 4 scales (care work strain, care work satisfaction, relationship dissatisfaction, and care lifestyle satisfaction). Items are scored on a 7-point scale, ranging from "strongly agree" to "strongly disagree".

Caregiver Burden and Generic Well-Being (Stull et al. 1994)- a structured, telephone interview that measures care receiver need, caregiver well-being, caregiver burden, and outcomes of caregiving for elderly people living in the community. The domains for burden (physical strain, social constraints, financial strain) are parallel to those for generic well-being (physical health, social activities, income). Items are scored on 5-point scales, ranging from "never" to "all of the time".

Caregiver Burden Scale, CB (Elmstahl et al. 1996)- a 22-item questionnaire to measure the subjective burden of caregivers in five domains (general strain, isolation, disappointment, emotional involvement, and environment). Respondents rate the frequency with which items apply to them on a 4-point scale, ranging from "not at all" to "often".

Caregiver Load Scale, CLS (Oberst et al. 1989)- a 10-item self-report scale measuring caregiver demand, i.e. the time and energy required for caregiving tasks. Caregiving tasks include medical/nursing treatments, personal care, assistance with mobility, emotional support, monitoring and reporting, providing transportation, managing illness-related finances, and managing behavior problems. Items are scored on a 5-point scale (ranging from "little or no" time and energy to "a great deal" of time and energy). Higher scores indicate more demand.

Caregiver Perceived Burden Scale, CPB (Strawbridge & Wallhagen 1991)- a 22-item scale that measures the extent to which caregiver's perceive the changes resulting from caregiving as problematic. The scale includes items relating to activity changes, emotional factors, and physical changes. The intensity of concern for each item is rated on a 5-point scale, ranging from "not a problem or concern" to "always" (a problem or concern).

Caregiver Reaction Assessment, CRA (Given et al. 1992)- a 24-item instrument designed to measure the reactions of family members to caring for elderly relatives with a variety of illnesses. The instrument consists of five dimensions (caregiver's esteem, lack of family support, impact on finances, impact on schedule, impact on health). Items are rated on a 5-point scale (from "strongly agree" to "strongly disagree"). (See Review of Selected Instruments below for a more detailed discussion.)

Caregiver Self-Efficacy (Zeiss et al. 1999)- a 14-item interview-format measure of caregiver's self-efficacy (i.e., judgments regarding one's ability to perform effectively in specific situations). The measure is comprised of two sub-scales: Caregiver Self-Care Self-Efficacy and Caregiver Problem-Solving Self-Efficacy. Respondents rate their level of confidence for each item on a scale from 0 to 100.

Caregiver Social Impact Scale (Poulshock & Deimling 1984)- a 19-item scale designed to measure the extent to which specific aspects of family life were altered as a result of caregiving for a frail elderly family member. The instrument

contains two relatively independent dimensions: negative changes in elder-caregiver/caregiver-family relationships and restrictions in caregiver's activities.

Caregiver Strain Index, CSI (Robinson 1983)- a 13-item screening tool to identify strain among caregivers for recently hospitalized hip surgery and heart patients aged 65 and over. Items are scored dichotomously as applying or not. See below (Review of Potential Instruments) for a more detailed explanation of the instrument.

Caregiving Appraisal Scale, CAS (Lawton et al. 1989)- a 21-item instrument designed to measure the positive, neutral, and negative appraisals that caregivers attach to caregiving. The measure consists of three dimensions—subjective caregiving burden, perceived impact of caregiving, and caregiving satisfaction. Items are scored on 5-point scales regarding the extent to which a statement is true (from "never" to "nearly always") or the extent to which the caregiver agrees with a statement (from "strongly agree" to "strongly disagree").

Caregiving Appraisal Scale, Modified (Hughes and Caliendo 1996)- a 28-item version of Lawton's Caregiving Appraisal Scale that includes the original scale's three dimensions plus a fourth dimension—mastery (i.e., competence in caregiving). This modified version is tailored for caregivers of children with HIV/AIDS. As with the original CAS, response categories are on a 5-point scale. Research also has been done to modify the original CAS for use among caregivers of home-based ventilator-assisted persons (Sevick 1997).

Caregiving Indices (Bass & Bowman 1990)- an 8-item scale measuring the caregiver's perceptions of negative consequences of caregiving for a chronically ill or disabled elderly person. The instrument includes three indicators of caregiving consequences: appraisal of the difficulty of caregiving, negative consequences of caregiving for the caregiver, and negative consequences of caregiving for the family. Items are scored either on a 4-point scale (ranging from "strongly disagree" to "strongly agree") or as a dichotomous yes/no response.

Cost of Care Index, CCI (Kosberg & Cairl 1986)- a 20-item scale developed as a case management tool for identifying potential and existing adverse consequences for caregivers of impaired elderly people. The measure contains five dimensions: personal and social restrictions, physical and emotional health, economic costs, value investment in caregiving, and the perception of the care recipient as provocateur. Items are scored on a 4-point scale (strongly agree, agree, disagree, strongly disagree).

Derogatis Stress Profile, DSP (Derogatis 1987)- a 77-item self-report instrument designed as a general measure of stress. The global measure is comprised of three domains (environmental events, personality mediators, and emotional responses), which in turn are made up of 11 dimensions (domestic, vocational, health, time pressure, driven behavior, attitude posture, role definition, relaxation potential, anxiety, depression, hostility). The instrument has been used with many populations, including caregivers of children with HIV/AIDS and mothers of children with cancer.

Family Assessment Device, FAD (Epstein, Baldwin & Bishop 1983)- a 60-item self-report measure designed to measure family functioning. The instrument consists of 7 subscales, six of which reflect the dimensions of the McMaster model of family functioning (problem solving, communication, roles, affective

responsiveness, affective involvement, behavior control) and a seventh addressing general functioning. Although developed for the general population, the measure has been used with families of ill children.

Family Caregiving Consequences Inventory, FCCI (Shyu et al. 1999)- a 21-item index developed to provide home care nurses with a clinical assessment tool for measuring the outcomes of family caregiving. Home care nurses rate a family's caregiving outcomes on three scales (the frail elder outcome scale, the caregiver outcome scale, and the family outcome scale) using a scoring range from 1 (least positive outcome) to 3 (most positive outcome). The index was developed and tested in Taiwan.

Family Caregiving Inventory (Archbold et al. 1992)- an inventory designed to assess mutuality and preparedness of caregivers for frail older people. The overall inventory contains a Mutuality Scale, a Preparedness for Caregiving Scale, and nine scales measuring caregiver role strain. The Mutuality Scale is a 15-item, self-administered questionnaire that measures the extent to which a caregiver/receiver relationship is characterized by love and affection, shared pleasurable activities, shared values, and reciprocity. The Preparedness for Caregiving Scale contains 5 items that may be self-administered or interview-administered and that measure the caregiver's perception of his/her preparedness for the caregiving role.

Family Caregiving Scale (Schofield et al. 1997)- developed to assess the experience of caregiving for persons with a variety of disabilities and at a variety of ages. Instrument addresses eight empirically-derived domains (the caring role, family environment, emotional well-being, health, feelings of social support and overload, assistance with ADLs, severity of disability, and behavior problems).

Family Environment Scale, FES (Moos 1990/1974)- a 90-item instrument designed to measure family environment as it is perceived by family members. The instrument consists of 10 subscales (including cohesion, expressiveness, conflict, organization, control, independence, and relationships). The scale has been used with a wide variety of families, including family caregivers of patients with progressive serious illnesses (see Kissane et al. 1998).

Family Hardiness Index, FHI (McCubbin et al. 1987)- a 20-item instrument developed to adapt hardiness on an individual level to the family unit. The instrument contains four subscales (co-oriented commitment, confidence, challenge, and control). Items are scored on a 4-point scale (from "false" to "true") plus a "not applicable" option. The FHI has been used with caregivers of patients receiving chemotherapy (see Carey et al. 1991).

Family Impact Interview (Covinsky 1994)- a 10-item interviewer-administered questionnaire designed to measure the financial impact and caregiving burden of a patient's illness on family members. The interview was used as part of the SUPPORT study of seriously-ill hospitalized adults and their families. Responses to seven items are dichotomous (yes/no); responses to two items are recorded verbatim; and the response to one item is on a 4-point scale.

Guilt Scale (Wells & Jorm 1987)- a 3-item scale designed to measure guilt felt as a result of the caregiving role. Although designed for use among caregivers of dementia patients, the items are not disease-specific. Items are rated on a 4-point scale, with higher scores indicating more guilt.

Impact-on-Family Scale (Stein & Riessman 1980)- a 24-item scale measuring the impact of childhood chronic illness on family life. The scale yields a total score and four subscores regarding the family's financial situation, social interaction within and outside the home, personal strain on primary caregiver, and potential sense of mastery gained from coping with the stress.

Multidimensional Caregiver Strain Index, MCSI (Stull 1996)- an 18-item tool measuring 6 dimensions of subjective response to stressors. Dimensions include physical strain, social constraints, financial strain, time constraints, interpersonal strain, and elder demanding/manipulative. Respondents are asked about the frequency with which items apply, ranging from "never" to "all of the time".

Objective and Subjective Burden Scales (Montgomery et al. 1985)- a 9-item objective burden scale (OBS) and a 13-item subjective burden scale (SBS). The OBS measures the extent to which caregiving activities have impacted aspects of the caregiver's life; items are rated on a 5-point scale (from "a lot more" to "a lot less"). The SBS measures the frequency with which caregiver's experience certain attitudes or feelings; items are rated on a 5-point scale (from "rarely or never" to "most of the time").

Parent Caregiver Strain Questionnaire, PCSQ (England & Roberts 1996)- a 40-item self-administered questionnaire regarding the reactions of adult children caregivers to circumstances involved in parent care. The instrument measures five domains (psychosocial exhaustion, physical exhaustion, instrumental exhaustion, emotional arousal, and goal discrepancy distress). Exhaustion items are rated on a 5-point scale (from "not at all drained" to "very drained"); emotional arousal is scored by rating key descriptive words; goal discrepancy distress is rated on a 10-rung Cantril-type ladder.

Patient-Caregiver Functional Unit Scale, PCFUS (Fredman & Daly)- an interview-administered questionnaire assessing the stability of the patient-caregiver dyad for 14 ADLs and IADLs. Caregiver respondents indicate the patient's functional ability, whether the caregiver assists with the task, and whether the caregiver has emotional and/or physical difficulty assisting in a task.

Perceived Caregiver Burden Scale, PCB (Stommel et al. 1990)- a 31-item scale measuring the impacts of and/or reactions to the experience of caregiving. The instrument contains five dimensions of caregiver burden: impact on finances, feelings of abandonment, impact on work schedule, impact on health of caregiver, sense of entrapment. Items are scored on a 5-point Likert scale, ranging from "strongly disagree" to "strongly agree".

Perceived Caregiver Burden Scale, Revised, PCB-13 (Gupta R 1999)- a 13-item measure derived from a factor analysis of the Perceived Caregiver Burden Scale when administered to first-generation Indian/Pakistani caregivers in the U.S. The instrument contains three dimensions of burden: impact of finances, impact on work schedule, sense of entrapment. Items are scored on a 4-point response scale.

Perceived Social Support for Caregiving, PSSC, and Social Conflict, SC, scales (Goodman 1991)- includes a 9-item (PSSC) scale and a 3-item (SC) scale to measure the impact of self-help and support groups for caregivers.

Perceived Stress Scale, PSS (Cohen et al. 1983)- a 14-item, self-reported unidimensional instrument developed to measure a perceived stress in response to situation's in a person's life. Respondents report the prevalence of an item within the last month on a 5-point scale, ranging from never to very often. A 4-item version is available for telephone interviews, and a 10-item version has been psychometrically tested (see Cole 1999). Although developed for a general population, the tool has been used with caregivers of people with dementia/Alzheimer's and spinal cord injuries.

Picot Caregiver Rewards Scale, PCRS (Picot et al. 1997)- a 16-item, unidimensional scale measuring the positive consequences of caregiving. Respondents rate the degree to which items describe positive consequences of their caregiving on a 5-point Likert scale (ranging from "not at all" to "a great deal").

Ways of Coping Checklist (Folkman & Lazarus 1980)- a 64-item index of problem-focused and emotion-focused coping strategies in response to a particular event or stressor. Respondents indicate utilization of each strategy in a dichotomous "yes/no" format. A Revised Ways of Coping Checklist contains 42 items within 5 domains: problem-focused, seeks social support, blamed self, wishful thinking, avoidance (Vitaliano et al. 1985). Although developed for the general population, the instrument has been used with caregivers of Alzheimer's and dementia patients.

- ***Disease-specific instruments***

AIDS Caregiver Scale (Ferrari et al. 1993)- a 14-item self-administered scale measuring two domains of emotional experiences (satisfaction and stress) of health care workers and volunteers providing social support to people with AIDS. Respondents rate the pertinence of each item on a 7-point scale, ranging from "low" to "high".

Bakas Caregiving Outcomes Scale, BCOS (Bakas & Champion 1999)- a 10-item unidimensional scale developed to measure life changes as a result of caregiving for stroke survivors. The instrument has been both self- and interviewer-administered. Items are scored on a 7-point response scale, ranging from "changed for the worst" to "changed for the best".

Caregiver Activity Survey, CAS (Davis et al. 1997)- a self-administered tool measuring time spent caregiving for a person with Alzheimer's disease. The instrument includes 6 areas of caregiving activities (communicating with the person, using transportation, dressing, eating, looking after one's appearance, and supervising the person). CAS also includes 4 demographic questions and uses a 24-hour time frame.

Caregiver Burden Inventory, CBI (Novak & Guest 1989)- a 24-item scale designed to assess the experience of caregivers of cognitively impaired older people. The multidimensional instrument assesses five domains of burden (time-dependence, developmental, physical, social, and emotional). Items are scored on a 4-point scale, ranging from "not at all descriptive" to "very descriptive".

Caregivers' Stress Scales (Pearlin et al. 1990)- a series of 15 scales based on a conceptual model of Alzheimer's caregivers' stress. Scale topics include primary stressors (cognitive status, problematic behavior, overload, relational

deprivation), secondary role strains (family conflict, job-caregiving conflict, economic strains), secondary intrapsychic strains (role captivity, loss of self, caregiving competence, personal gain) and mediators (management of situation, management of meaning, management of distress, expressive support). Response categories range from 3-point to 5-point scales.

Care-giving Burden Scale (Gerritsen & van der Ende 1994)- a 13-item scale that evaluates distress related directly to caregiving for elderly patients with Alzheimer's Disease, dementia, or other psychological conditions. The instrument contains two dimensions: relationship (a negative evaluation of the caregiver/receiver relationship) and personal consequences (a subjective measure of impact of caregiving). Response categories are on a 5-point scale (from "disagree very much" to "agree very much") and are re-coded to dichotomous scores.

Caregiving Hassles Scale (Kinney & Stephens 1989a)- a 42-item instrument measuring daily stressors for caregivers of people with dementia. The questionnaire includes five subscales: hassles with ADLs, with IADLs, with care-recipient's cognitive status, with care-recipient's behavior, and with caregiver's support network. Items are reported as having occurred in the past week or not; if the item did occur, then respondents rate its extent on a 4-point scale (ranging from "not at all" a hassle to "a great deal" of a hassle).

Caregiving Hassles and Uplifts Scale (Kinney & Stephens 1989b)- a 110-item scale that measures the appraisal of caregiving events by caregivers of people with dementia. Areas of caregiving events include care recipients' limitations in ADLs, care recipients' cognitive status, care recipients' behavior, and practical aspects of caregiving. The instrument assesses whether an event happened in the past week of caregiving, the extent to which the event was a hassle for the caregiver, and the extent to which the event was an uplift for the caregiver. The extent to which an event is appraised as a hassle or an uplift is scored on a 4-point scale, ranging from "it wasn't (a hassle/uplift)" to "a great deal (of a hassle/uplift)".

Caregiving Self-Efficacy Scale, CSS (Denney 1994)- a 58-item scale designed to measure perceived self-efficacy among caregivers of people with Alzheimer's.

Finding Meaning Through Caregiving, FMTC (Farran et al. 1999)- a 43-item questionnaire that assesses dementia caregivers' opinions and feelings about their caregiving experiences. The instrument has three sub-scales (loss/powerlessness, provisional meaning, and ultimate meaning). It may be self- or interviewer-administered; items are scored on 5-point scale (from "strongly disagree" to "strongly agree").

Frustration Scale (Motenko 1989)- a 9-item scale adapted from the Emotional Response to Stigmatization Scale to measure frustration among caregivers of husbands with dementia. The scale is intended to assess emotional response toward the care receiver's illness. Items are scored on a 4-point Likert scale.

Memory and Behavior Problems Checklist, MBPC (Zarit JM 1982, Zarit SH et al. 1985)- a 30-item interviewer-administered questionnaire intended to assess both the frequency of problems for a person with Alzheimer's and the reaction of the caregiver to these problems. Caregiver's reactions are rated on a 5-point scale, ranging from "not at all (upsetting)" to "extremely (upsetting)".

Memory and Behavior Problems Checklist, Revised, RMBPC (Teri et al. 1992)- a 24-item self-administered questionnaire adapted from the Memory and Behavior Problems Checklist. The revised version includes 3 sub-scales (memory-related problems, symptoms of depression, and disruptive behaviors) for frequency of problem behaviors and caregiver reactions to these behaviors. Caregiver reactions are scored on a 6-point scale, including a "don't know/not applicable" category. RMBPC provides both an overall score and a score for each sub-scale.

Neuropsychiatric Inventory Caregiver Distress Scale, NPI-D (Kaufert et al. 1998)- measures the emotional or psychological distress of caregivers in relation to 10 neuropsychiatric symptoms of Alzheimer's patients assessed by the Neuropsychiatric Inventory (NPI). Items are scored on a 6-point scale, ranging from "not at all distressing" to "very severely/extremely distressing".

Relatives Stress Scale, RSS (Greene et al. 1982)- a 15-item interviewer-administered questionnaire designed to measure the reaction to caregiving of relative carers of elderly patients with senile dementia living in the community. The scale is comprised of three subscales (personal distress in relation to the elderly relative, life upset as a result of caregiving, and negative feelings toward the elderly relative). Items are rated on two 5-point scales (from "never" to "always" and from "not at all" to "considerably").

Screen for Caregiver Burden, SCB (Vitaliano et al. 1991)- 25-item scale designed to measure objective and subjective burden experienced by spouse caregivers of people with Alzheimer's disease. Prevalence of potentially stressful caregiver events (defined as objective burden) is scored as occurring or not. Distress experienced as a result of these events (defined as subjective burden) is rated on a 5-point scale, ranging from "no occurrence of the experience" to "occurrence with severe distress".

Sense of Competence Questionnaire, SCQ (Vernooij-Dassen et al. 1996)- a 27-item instrument measuring a caregiver's feelings of being capable to care for a person with dementia. The tool contains three domains: satisfaction with the demented person as a recipient of care, satisfaction with one's own performance as a caregiver, and consequences of involvement in care for the personal life of the caregiver.

Short Sense of Competence Questionnaire, SSCQ (Vernooij-Dassen et al. 1999)- a 7-item version of the Sense of Competence Questionnaire developed for the clinical setting. SSCQ maintains a focus on domain-specific interventions. Items are scored on a 5-point scale, ranging from "agree very strongly" to "disagree very strongly".

Subjective Burden Scale, SBS (Matsuda 1999)- a 14-item self-administered scale designed to measure the extent to which Japanese dementia caregivers perceive their caregiving to be stressful. Items are rated on a 5-point scale, ranging from "No (perceived stress)" to "Yes, very much (perceived stress)".

Review of selected instruments

Caregiver Reaction Assessment, CRA (Given et al. 1992)

i. Conceptual and Measurement model (Does the scale represent a single domain or do model scales measure distinct domains? Is the variability of the

scale reported? What is the intended level of measurement i.e. ordinal, interval, ratio, or category?)

CRA is a multidimensional instrument designed to measure a caregiver's reactions to caregiving for elderly family members with a variety of chronic illnesses. The objective in developing the instrument was to further advance research into caregiver burden by refining caregiving measures, comparing measures across different illnesses and care giver/receiver relationships, and applying rigorous psychometric evaluation techniques.

CRA is a relatively short instrument (24 items) that measures both positive and negative reactions to caregiving. Factor analysis confirms five dimensions:

- Caregiver's esteem assesses the value or worth attributed to caregiving as a result of the experience being rewarding or causing resentment (7 items);
- Lack of family support assesses the caregiver's perception of being left with most of the caregiving responsibility or of family members working together (5 items);
- Impact on finances assesses the adequacy, difficulty, and strain of finances on the caregiver and family (3 items);
- Impact on schedule assesses the extent to which caregiving interrupts or interferes with the caregiver's regular activities (5 items);
- Impact on health assesses the caregiver's capability to provide care and health in relation to caregiving (4 items).

Items are presented as statements and are rated on a 5-point scale, ranging from "strongly agree" to "strongly disagree".

ii. Reliability (Did they address internal consistency? Did they address reproducibility?)

Internal consistency of the CRA was measured by Cronbach's Alpha and found to be good.

| | Dimension | | | | |
|-------------------------|----------------------|-----------------------------|----------------------|--------------------------|------------------|
| | Esteem (positive) | Family Support (lack) | Finances (strain) | Schedule (disruption) | Health (loss) |
| Cronbach's Alpha | .90 | .85 | .81 | .82 | .80 |

Stability over time was assessed by comparing standardized factor loadings across three waves of data collected at baseline, 6 months, and 12 months. Results indicate stability of the CRA sub-scales over time.

iii. Validity (How did they address content related validity? Any information on construct related validity? Any information on criterion validity?)

Content validity is supported by the process of item generation. From a review of existing measures and in-depth interviews with caregivers, recurring dimensions of caregiving reactions were identified. Within these dimensions, 111

items were generated and then subjected to exploratory and confirmatory analyses.

Construct validity is supported by a comparison with caregiver depression (measured by the CES-D) and number of ADL dependencies. Correlations are in the expected directions and of the expected magnitudes (N= 754):

| | Dimension | | | | |
|----------------------|----------------------|-----------------------------|----------------------|--------------------------|------------------|
| | Esteem (positive) | Family Support (lack) | Finances (strain) | Schedule (disruption) | Health (loss) |
| CES-D | -.23 | .39 | .34 | .46 | .57 |
| ADLdependency | -.11 | .20 | .25 | .52 | .29 |

iv. Responsiveness (Any information? Has the scale ever been used as an outcome measure? If so, in what populations?)

Responsiveness to change over time is supported by the highly stable factor structures over three waves of data (see above).

v. Interpretability (What populations has it been applied to? Is the score translated into a clinically relevant event? Does the score predict outcome events?)

CRA has been used with caregivers of elderly family members with physical impairments, and Alzheimer's disease and with caregivers and partners of cancer patients. Comparison of spouse/non-spouse caregivers has also been used to determine factor structures. In terms of scoring, Nijboer and colleagues (1999) calculated mean item scores for each dimension ranging from 1.0-5.0, with higher scores reflecting greater caregiver reaction in that dimension. Information on predicting outcomes is not provided.

vi. Burden (Any information on cost or time to administer? Does the instrument impact on the respondent? How long does a survey take to complete? Response rates? Any problems with missing data?)

Given and colleagues (1992) reported that the response rate over three waves of data collection in a 12-month period was 62.9% (193 at third wave / 307 at first wave). Attrition resulted from patient death, patient institutionalization, caregiver substitution, moving, and refusals. In this longitudinal study, missing data resulted in deletion of 8 cases (2.6%). In addition, Nijboer and colleagues (1999) report no feasibility problems (defined as missing values and completion time) with a sample of caregiving partners of cancer patients; percentage of missing values per item ranged from none to 1.7%, and time to complete a face-to-face interview was less than 10 minutes.

vii. Alternative Forms (What are the modes of administration? Alternatives? If alternatives exist, provide what is known for each of the above categories)

CRA has been administered during face-to-face interviews, but the questionnaire format would allow for a telephone interview or self-administration

as well.

viii. Cultural and Language Adaptations (Any information?)

CRA was developed and tested in the U.S., using the English language. Nijboer and colleagues (1999) also found CRA to be feasible, reliable, and valid with a sample of caregivers in the Netherlands, using the Dutch language.

ix. Conceptual Rationale for Recommendation

CRA is a multidimensional yet relatively short instrument that assesses both negative and positive reactions to caregiving. Since many instruments focus only on negative impacts of caregiving, the CRA allows for a more balanced evaluation of a caregiver's experience by measuring both positive and negative caregiver reactions.

The instrument's five dimensions of caregiver reaction build on previous research in caregiver burden and are empirically confirmed across various chronic illnesses and with spouse/non-spouse caregivers. As a result, CRA makes it possible to compare caregiving reactions across diseases and caregiver/receiver relationship.

The CRA has been tested rigorously for validity and reliability. For the purposes of the toolkit, the ability of an instrument to assess change over time is key. Psychometric evidence showing CRA's stability over time makes the instrument useful for institutions that wish to measure the effectiveness of quality improvement interventions.

Caregiver Strain Index (Robinson 1983)

i. Conceptual and Measurement model (Does the scale represent a single domain or do model scales measure distinct domains? Is the variability of the scale reported? What is the intended level of measurement i.e. ordinal, interval, ratio, or category?)

This measure represents the major domains cited in the literature on caregiver burden: Employment, Financial, Physical, Social and Time. Burden is multi-dimensional; therefore, we must measure the different domains. The CSI has at least one item for each domain. There is one overall score, which is obtained by summing the 'yes' responses. The index measures objective burden, but does not measure subjective burden.

Throughout the literature on burden there is debate about the importance of subjective vs. objective measures. On the one hand, subjectivity is important because people interpret their situations differently and to assume care-taking activities are stressful is wrong. However, it is hard to develop interventions on evaluations of subjectivity; whereas, objective measures give more concrete directions for developing programs to help relieve strain. For the purposes of the Toolkit, I [MJR] feel that measuring objective burden is of more significance. The CSI has shown to be significantly related to psychological distress and health of the caregiver; therefore, should be useful in helping hospitals develop interventions to reduce the burden. Also, this index was shown to have significant relationships with caregiver employment and age which indicates that it may be a useful tool in predicting caregivers who are at a higher risk for

burden. This would be helpful for developing programs to target these high-risk caregivers in terms of educational materials and counseling.

Studies have shown that when caregivers have high levels of burden, patients report higher levels of unmet needs. Since, in the last month of life, we would expect care-taking activity to increase, it seems important to measure the level of caretaker burden. By doing this, clinicians can try interventions which could alleviate the burden when it is too high so that the patient is receiving the best care possible. This index would also be useful in evaluating how well the discharge care plan for the patient is working. In other words did the plan have enough service support for the caregiver so that all of the needs of the patient could be met?

ii. Reliability (Did they address internal consistency? Did they address reproducibility?)

The internal consistency of this index was measured by Cronbach's Alpha. The alpha level was high at .86, indicating good internal consistency.

iii. Validity (How did they address content related validity? Any information on construct related validity? Any information on criterion validity?)

The measures were associated with the physical and emotional health of the caregiver which gives the index construct validity. Items for the index were selected from previous interviews about strain with ex-patients and caregiver interviews which gives the index face validity.

iv. Responsiveness (Any information? Has the scale ever been used as an outcome measure? If so, in what populations?)

The index was used as a predictor of psychological and physical distress; although, it also is related to caregivers' subjective perceptions of the caretaker relationship, patient characteristics, age and employment which indicates that it could be used as an outcome measure.

v. Interpretability (What populations has it been applied to? Is the score translated into a clinically relevant event? Does the score predict outcome events?)

This index was used with a population of 85 caregivers of patients who had an acute hospitalization for arteriosclerotic heart disease or an operation of the hip. The caregivers were interviewed 2 months post-discharge.

vi. Burden (Any information on cost or time to administer? Does the instrument impact on the respondent? How long does a survey take to complete? Response rates? Any problems with missing data?)

No information was provided on the amount of time it takes to ask these questions. It does not seem to be very time consuming.

vii. Alternative Forms (What are the modes of administration? Alternatives? If alternatives exist, provide what is known for each of the above categories)

These are meant to be interview questions, although they could probably be written for self-administration.

viii. Cultural and Language Adaptations (Any information?)

This has only been done with US populations. No language adaptation was reported.

ix. Conceptual Rational for Recommendation

Throughout the literature on burden the importance of objective and subjective burden is debated. On the one hand, objective measures are important because they can be used to develop interventions, quality of care and effectiveness of interventions. On other the hand, the meaning one places on a task determines how burdensome the task is. We should not assume that objective burden measures are interpreted as being a burden for everyone.

Since the purpose here is to find instruments which can be used in the last month of life and can help in the assessment of quality of care and identify problem areas with care, I [MJR] think that objective measures of burden are more important to assess at this time, than subjective measures. The CSI I am recommending has been shown to predict the psychological and physical well-being of the caregiver.

I [MJR] must add that if you were to include a tool that could identify high risk caregivers before caregiving actually occurred (i.e. initial acute incidence) I would recommend the Cost of Care Index. It measures the subjective nature of burden and would be useful in identifying problems of burden before caregiving is received and could help in developing a care plan for a patient which would reduce caregiver burden and reduce the chance for unmet needs.

III. Priorities for future research

The area of caregiver burden and well-being research is not lacking in measures, but there are relatively few good measures of objective burden. Most of the measures are especially weak on the objective measures of burden, with economic measures being the least developed. It would be very timely and important to further improve these measures at this time. With length of hospital stays shorter and more care being placed on the shoulders of families, the issue of burden is becoming a major concern. More research needs to be done on the dynamics of burden. What are the psychological, social, economic and health costs of caregiving. We may be reducing health care for the presently ill patient, but are we only creating more health problems for the health care system? What types of programs can be developed to reduce family burden?

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