THE STATE
OF THE ART:
CAREGIVER
ASSESSMENT
IN PRACTICE
SETTINGS

LYNN FRISS FEINBERG, MSW

SEPTEMBER 2002

About Family Caregiver Alliance

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

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

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ACKNOWLEDGMENTS

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INTRODUCTION

Virtually all older persons living in noninstitutionalized settings (about 95%) receive at least some assistance from relatives, friends and neighbors. About two out of three older persons living in the community (67%) rely solely on informal help, mainly from wives or adult daughters. [1] Families have been, and continue to be, both the major "coordinators" and the "providers" of everyday long-term care. [2]

The complexities and dynamic nature of caregiving as well as the varied tasks required underscore the critical importance of systematic caregiver assessment as part of long-term care policy and practice.

Today, changes in the health care delivery system, including shorter hospital stays, have led to a shift in the cost and responsibility for the care of loved ones from health care providers to family caregivers. [3, 4] Family caregivers now require a greater capacity to understand health and medical information; seek out and use the patchwork of community resources; and navigate the increasingly complex, fragmented and costly health care and home and community-based service system. [5] Moreover, the critical shortage of paraprofessional workers in home, community-based and nursing home settings is adding to the strain of families and friends who struggle to locate appropriate care for their loved ones. [6]

The complexities and dynamic nature of caregiving as well as the varied tasks required underscore the critical importance of systematic caregiver assessment as part of long-term care policy and practice. [7] Although policymakers and practitioners increasingly recognize the central role that families play in coordinating and providing long-term care services to frail elders and persons with disabilities, little attention has been paid to systematic assessment of the situation and well-being of the family or informal caregiver to determine what assistance the caregiver may need. [8, 9]

This monograph summarizes the history and background of caregiver assessment; considers the reasons for assessing family care; discusses what, whom, when and where to assess; illustrates areas to assess; highlights examples of existing tools; explores commonalities as well as differences in caregiver

assessment instruments; points out areas of caregiver assessment that have been neglected; identifies best practice criteria to consider in designing and implementing assessments; and discusses training issues for practitioners.

HISTORY AND BACKGROUND

Origins of Caregiver Assessment

Caregiver assessment originated in the 1960s in the study of families of persons with cognitive impairments due to mental illness, developmental disabilities or traumatic brain injury. [10, 11] Similarly, sociologists and social workers have studied intergenerational relationships, family structure and family care of older persons since the early 1960s. [12, 13, 14] Not until the 1980s did gerontologists begin to study the actual care that family members provide to older persons and the impact of caregiving, however. [15] Most of this early work addressed family caregivers of persons with dementing illnesses, such as Alzheimer's disease. [16, 17, 18, 19]

Caregiver assessment has also been studied in specific programs—for example, in hospice. As early as 1985, researchers suggested that systematic attention to caregiver needs and plans for family caregiver assistance should be a major component in hospice care, regardless of the structure of the hospice program. [20]

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In gerontology, most of the literature on assessment has focused on the older person receiving care, rather than on the family member(s) providing care. In their seminal book on assessment of older persons, first published in 1981, Kane and Kane made no mention of specific tools for assessing family caregivers. [21] Their sequel, in contrast, includes a chapter on assessment of family caregivers, with a review of existing caregiver measures. [22]

Moving Beyond the Concept of Burden

Most of the early research on family caregiving focused on the notion of caregiver "burden," generally with respect to caregivers of persons with dementia. Grad and Sainsbury [23] were the first to mention the concept in the research literature when they described the burden felt by family members who cared for mentally ill relatives at home. [24] Caregiver burden is a broad term with many definitions and meanings, encompassing the impact that caregiving has on the caregiver's mental health, physical health, other family relationships, employment and financial problems. [25, 26]

Beginning in the mid-1980s, critical examinations led to a refinement of the concept of burden. George and Gwyther,[27] for example, noted that burden measures could not be used to compare caregivers with noncaregivers because they were designed to capture specific caregiving experiences. These authors noted that measures of burden could not be administered to noncaregiving populations to assess whether family caregivers are worse off than other groups in similar life situations.[28] The term "burden" is less commonly used in practice today because family caregivers in general have negative associations with the term and because the word may not be culturally appropriate with a diverse caregiving population.

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In the late 1980s and early 1990s, the research community shifted focus to the long-term nature and consequences of caregiving by conducting intervention studies and going beyond the single dimension of "burden" to emphasize multiple dimensions of caregiver impact. [29, 30, 31, 32] Stress process models of caregiving emerged, grounded in the sociological literature on stress. [33, 34, 35] In virtually all of these studies, the focus was on caregivers of persons with dementia.

Much of this research utilized scales previously developed in the stress research literature, such as measures of "mastery," or the personal control that individuals feel they are able to have over forces affecting their lives.[36] Meanwhile, other measures were developed to focus on the caregiving situation, such as the concepts of "role overload" (i.e., the experience of being overwhelmed by care-related tasks and responsibilities) and "role captivity" (i.e., the sense of being trapped by caregiving), and to assess how confident and competent family members feel in the caregiving role.[37] In general, this work focused on the negative consequences of providing family care.

Only in recent years have the positive aspects of caregiving received attention. Switzer and colleagues[38] suggest measures to examine the positive aspects of caregiving, including indicators of the extent to which caregiving has made the caregiver feel more useful, feel needed, feel good about him or herself, learn new skills and find more meaning in life. Lawton and colleagues[39] and Kinney and Stephens[40] developed measures to assess caregiver uplifts and fulfillment in the caregiving role. More recently, Picot, Youngblut and Zeller[41] developed a measure to assess the rewards associated with providing care. Little attention has been given to assessing caregiving competence, confidence and mastery in carrying out specific day-to-day tasks associated with caregiving or to determining what help a caregiver might need, however.

Emergence of the Strengths-and-Skills Perspective

In all the helping professions, assessment has largely addressed problems and functional limitations of the person needing care. Since the mid-to-late 1980s, social work and other researchers have increasingly questioned the negative or "problem"-focused aspect of practice rooted in the medical model; they are now emphasizing a strengths-and-skills perspective to examine how people react to stressful life situations and to focus on strengths and capabilities. [42]

Rapp and Chamberlain [43] first developed the strengths model in the early 1980s for people with severe mental illness. They developed this model in response to the failure of diagnostic or functional assessment "to reveal the meaning of that person's struggle and the strengths that lie hidden in that person's story." [44] Tice and Perkins have proposed that "a strengths perspective with older persons and their families requires social workers to actively engage in relationships that position the clients as experts in their life situations." [45] Implementation of the strengths perspective requires mutual participation and decision making among the person with disease or disability, the family or informal caregiver and the practitioner. [46]

Caregiver Needs in Overall Assessment

The focus in caregiver assessment has generally been to incorporate caregivers as part of the care plan for the care recipient, not to include an understanding of the needs of the caregiver as well. [47] If information about the caregiver is sought during the client assessment process, it is generally to clarify the degree to which the caregiver can carry out caregiving tasks or the willingness of the caregiver to provide care, rather than to assess the caregiver and his or her own needs and issues. [48]

In an international review of the literature, a Canadian research team identified and collected both validated and nonvalidated caregiver assessment tools. The researchers did not find any of the validated tools to address a range of caregiver issues or specify caregivers' service needs. [49] The fifty-seven articles and reports found on caregiver assessment referenced sixty-three assessment tools. Of these, thirty-four (54%) were general assessments of the care recipient with a section on caregiver needs and twenty-nine (46%) focused specifically on the needs and situation of the family caregiver. [50, 51] The general assessments with a section on caregivers, usually designed to determine the need for home care or support services, focused on the willingness, ability and capacity of the caregiver to continue

providing care and on how this affected service planning for the care recipient. The perspective in these general assessments was primarily that of the assessor, rather than of the caregiver. In contrast, the caregiver-specific assessment tools reviewed by Fancey and Keefe [52] all had questions for the caregiver on the tasks carried out for the care recipient in everyday care and on issues related to these.

REASONS FOR ASSESSING FAMILY CAREGIVERS

Assessment of family caregivers is important for several reasons. Assessment information is used for different purposes in research, policy and practice. In research and policy arenas, assessment can be used to describe the population being served, review changes over time, identify new directions for service and/or policy development, evaluate the effectiveness of existing programs or a specific service, assure quality of care or examine caregiver outcomes.

In practice settings, caregiver assessment may determine eligibility for caregiver support services and be a basis for a care plan and services to support and strengthen family caregivers. As Fancey and Keefe observed, assessing the caregiver "is a necessary requirement of an assessment tool in order to provide the practitioner with an understanding of the caregiver's everyday experience, to recognize and validate the work performed by the caregiver, and to plan support services accordingly." [53] Particularly with respect to dementia care, family caregiver needs oftentimes differ from the needs of the care recipient. Understanding the role, multiple stressors and particular situation of the family caregiver is essential to any care plan developed for the care recipient. [54, 55] Gwyther, Ballard and Hinman-Smith suggest that "a baseline caregiver assessment can guide, prioritize and target interventions to overcome barriers to appropriate use of informal and formal help." [56]

The process of assessment can be therapeutic in helping the family feel better understood by practitioners and each other [57] and can help caregivers feel recognized, valued, acknowledged and more able to continue in their role. [58] Anecdotal reports from California's Caregiver Resource Centers (CRCs)—a statewide program that has been uniformly conducting caregiver assessments since 1988—suggest that the vast majority of family members who care for loved ones with cognitive impairments appreciate the assessment process and view it as an opportunity to express their own needs and have their situation taken seriously. The information collected during the assessment and reassessment process not only helps families

The process of assessment can be therapeutic in helping the family feel better understood...and can help caregivers feel recognized, valued, acknowledged and more able to continue in their role.

with decision making, but also acknowledges their strengths and the effectiveness of their care.[59] Caregiver assessment helps practitioners to "provide a more systematic, comprehensive and objective service and apply best practice across all levels of staff."[60] An assessment tool "legitimizes the rights of caregivers to be heard"[61] and also legitimizes the needs of family caregivers themselves as distinct but related to the needs of the care recipient.

WHAT AND WHOM TO ASSESS

Caregiver assessment is complex. Assessment (and reassessment) should be outcome-driven, based on the interventions provided to assist family and informal caregivers. In home and community-based settings, a key to a good caregiver assessment is first to identify the goals of the caregiver support program to determine what the intervention can reasonably be expected to accomplish and then to choose measures of the desired outcomes. According to Bass, "Characteristics most likely to function as outcomes are those that can change from initial to follow-up reassessments."[62] If an agency is helping an adult daughter improve her behavior management skills in caring for her father who has Alzheimer's disease, for example, the assessment should include measures of behavior management rather than other measures that have little impact on the desired outcome (e.g., social isolation, life satisfaction). Similarly, if the goal or outcome of a caregiver support program is to enhance a wife's knowledge of the caregiving role and of the nature and course of her husband's particular disease or disorder, it would be unnecessary to assess the wife's physical health status because the program would have little impact on her physical health.[63]

In practice, assessment should "help inform, guide or contribute to making professional judgements about the appropriate course of action for an individual."[64] Caregiving is best understood, however, from a family systems, rather than from an individual, perspective involving multiple family members and friends as well as the care recipient.[65, 66] In family caregiving, therefore, the question is not only what to assess but whom. Just the "primary caregiver" who provides the major share of caregiving? The family member who lives with the care recipient? The adult child, neighbor or friend who called the agency for help? Other family members? In both research and practice, few caregiver assessment tools assess multiple family caregivers or take a family systems perspective whereby the care recipient, family caregiver and other family members and friends are considered the "client system."

An assessment tool...also legitimizes the needs of family caregivers themselves as distinct but related to the needs of the care recipient.

WHEN AND WHERE TO ASSESS

Most caregiver assessments are carried out when a care recipient first enters the service delivery system or when the family caregiver contacts an agency for information and assistance. Family caregivers may be more "open to an assessment of their own needs, as opposed to those of the care recipient, once an immediate crisis has passed, or some support has been put in place."[67] Typically, caregiver assessment takes place at the same time as the assessment of the care recipient. In this situation, consideration should be given to how best to allow both the care recipient and the caregiver to have access to time alone with the assessor when warranted.

Reassessment of caregiver needs is vitally important in service delivery to identify changes in the caregiver's situation, to identify functional ability of the care recipient and to adjust the plan of care as necessary.

The timing of caregiver assessment varies a great deal depending on the situation and resources of the family and on the resources of the assessing agency. The assessment of a wife bringing her husband home from the hospital after he has suffered a stroke will be different from the assessment of a husband who has cared for his wife with Alzheimer's disease at home for five years. At California's CRCs, a telephone intake is done on all caregivers who contact a CRC for help. "Intake" is considered a preliminary screening method for collecting basic demographic information about both the family caregiver and the care recipient. An initial in-person assessment is generally conducted within three weeks following the first telephone call for caregivers identified as needing help beyond basic information and assistance.

Reassessment of caregiver needs is vitally important in service delivery to identify changes in the caregiver's situation, to identify functional ability of the care recipient and to adjust the plan of care as necessary. An initial assessment of a wife whose husband has just been diagnosed with Parkinson's disease will be very different from a reassessment of the situation a year later, for example. California's CRCs carry out telephone reassessments six months after the initial in-person assessment and again one year after the baseline assessment if the case remains open.

Ideally, a caregiver assessment is conducted in the home or in another setting where the caregiver is able to speak openly and candidly about the caregiving situation. Consideration should be given to the day and time of day of the assessment process. For working caregivers, an in-person assessment may be better conducted on a weekend or in the evening or at the caregiver's place of work to ensure a private interview away from the care recipient. Although there is no conventional wisdom about the

degree of privacy needed to interview the family member about the care of a relative, [68] it is generally good practice to conduct an in-home caregiver assessment privately so that the family member feels free to share his or her issues and concerns. In reality, however, particularly when a family member is caring for a loved one with dementia, a private interview is sometimes difficult to arrange.

AREAS TO ASSESS

Table 1 summarizes the potential domains generally identified as important components in a multidimensional assessment of family caregivers. Although not all domains and elements are appropriate to all caregivers, these provide a framework for adopting a common approach to assessment of family needs.

Table 1.
DOMAINS FOR CAREGIVER ASSESSMENT

Potential Domains	Examples of What is Assessed
Caregiving Context	Basic demographic characteristics about both the caregiver (CG) and the care recipient (CR)—e.g., age, gender, ethnicity, relationship to each other, living arrangement of CR, employment status of CG.
Knowledge	Understanding, diagnosis, course of disease/disorder, care options; information needed to help with specific caregiving tasks (e.g., information on medication management); use of the Internet.
Functional Level of Care Recipient	CR's ability to carry out *activities of daily living* (ADLs) (e.g., bathing, dressing) or *instrumental activities of daily living* (IADLs) (e.g., using the telephone); frequency of CG's help with ADL or IADL tasks; functional limitations and impact on CG (e.g., how tiring, difficult or upsetting it is to bathe CR). Frequency of occurrence of *memory and behavior problems* (e.g., repeating the same question over and over, waking CG at night); CG reaction (e.g., degree of upset) to specific problem behaviors.
Care Tasks & Skills	Total "amount of care" (e.g., hours per week) CG spends in caregiving tasks and supervision. Task assistance provided by CG can include finding information, doing personal care, supervising and cuing, administering medications, using medical equipment, giving injections, providing emotional support, navigating medical care and social services, hiring and managing in-home help and making decisions about care options and living arrangements. Specific caregiving skills can include communication strategies, behavior management, ability to fill out forms, decision-making ability, ability to coordinate care and ability to supervise workers in the home.

Table 1. (continued)

DOMAINS FOR CAREGIVER ASSESSMENT

Potential Domains	Examples of What is Assessed
Health	*Physical health:* generic measures of health status to compare to the general population (e.g., overall health status, doctor visits or hospital days in past year, health care payment mechanisms); identification of specific health problems of the CG (e.g., arthritis, hypertension); measures to tap the specific effect of caregiving on health (e.g., how much health problems stand in the way of providing care); questions about alcohol and drug use. *Mental health:* generic measures of depression to compare to the general population; measures of anxiety, anger, overall psychological well-being, suicide ideation.
Social Support	*Informal (family & friends) and formal (home & community-based services) support*: amount available, provided and received by CG; CG's subjective perception of the adequacy of support; satisfaction with service use.
Financial, Legal & Employment Information	Income level, out-of-pocket costs of caregiving (including lost wages from quitting a job to give care), financial and employment strain; knowledge and use of advance directives, conservatorships/ guardianships, other legal planning tools.
Coping Strategies	Problem- and emotion-focused strategies; religion/spirituality, exercise, hobbies.
Confidence & Competence in Caregiving Role	Perception of competence in providing care; degree of self-confidence in the ability to do what needs to get done; CG mastery of specific tasks.
Values & Preferences	In *everyday life* (e.g., accepting restrictions in order to be safe, having personal privacy, being part of family celebrations, maintaining dignity) as well as relating to *end of life* (e.g., establishing do-not-resuscitate orders, having money to leave to family) from the perspective of both CR and CG.
Positive Aspects of Caregiving	The extent to which caregiving has made positive contributions to CG's life and has been rewarding (e.g., feeling more useful, feeling needed, learning skills, finding more meaning in life).
Strengths	Existing or potential strengths, resources or capabilities (e.g., how CG has coped with challenges in the past, what CG wants and needs, what is presently going well for CG).

EXAMPLES OF CAREGIVER ASSESSMENT TOOLS

This section highlights selected tools used in the United States, illustrating various approaches and methods to assessing family care, and explores several promising directions.

State-Funded Caregiver Support Programs in the United States

Prior to the enactment of the National Family Caregiver Support Program (NFCSP) under the Older Americans Act Amendments of 2000, some states established state-funded caregiver support programs with various approaches to assessing the needs of family caregivers. While the majority of state programs apply some form of assessment to determine eligibility or develop the care plan for the care recipient, most publicly funded programs in the United States currently do not uniformly or systematically assess the needs and situation of the family caregiver. In a study of thirty-three caregiver support programs in fifteen states, few programs looked systematically at the caregiver's own service needs, even though the majority of programs surveyed identified both the family caregiver and the person with disease or disability as "clients." [69]

Although the United States has no national policy on caregiver assessment, a few state-funded caregiver support programs have developed uniform caregiver assessment tools, using various approaches and procedures. California's caregiver support program, for example, utilizes a distinct assessment focusing on the needs and situation of the family caregiver. In contrast, Pennsylvania incorporates caregiver information as part of the state's comprehensive assessment instrument used by all publicly funded long-term care programs to assess consumers in the state. Some states that provide a specific service statewide (e.g., respite) also conduct a caregiver assessment. New Jersey is one of these.

In *California's Caregiver Resource Center System*, established by law in 1984 and administered by the California Department of Mental Health, the family or informal caregiver of an adult with cognitive impairment is considered the client of the program, and information is collected from the client's (i.e., caregiver's) perspective. The initial assessment tool, developed in consultation with Steven Zarit, PhD, was implemented statewide in 1988 and has been revised twice. The current version has 103 items [70] chosen for uniform identification and recording of problem areas to help determine the most appropriate type and mix of services to meet caregiver needs. [71]

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The CRCs collect information on all first-time family callers at intake to describe their general characteristics and delineate their major needs. Additional assessment (and reassessment) data are collected on the subset of family caregivers in need of direct services. The assessment includes demographic data on the care recipient (e.g., marital status) and the caregiver (e.g., marital status, educational level, employment status); legal/financial/health insurance information (e.g., powers of attorney, income level, health care payment mechanism); functional level of the care recipient (i.e., ADLs, IADLs) and resulting demands on the caregiver (i.e., degree of upset); adaptation of the Revised Memory and Behavior Problems Checklist; [72] driving status of the care recipient; the caregiver's perception of his or her role and mastery; [73] physical health status of the caregiver; the caregiver's current help situation, including both informal and formal help; adequacy of social support; the Center for Epidemiological Studies-Depression Scale (CES-D); open-ended questions to elicit the caregiver's view of the situation; and a summary section/care plan. In 2000–01, more than thirty-four hundred California caregivers completed an in-person, in-home assessment, averaging 1.5 hours each.

The Pennsylvania Family Caregiver Support Program (FCSP), established by law in 1990 and administered by the Pennsylvania Department of Aging, is designed to assist family caregivers of functionally dependent older persons or cognitively impaired adults. Caregiver assessment was added to the Pennsylvania Department of Aging's Comprehensive Options Assessment Instrument for the "consumer" (i.e., care recipient) around 1996. The comprehensive assessment typically occurs in the home, with a full reassessment every two years or more frequently if necessary. The family caregiver components of Pennsylvania's assessment tool include measures of informal supports and caregiver stress. The informal supports section is used to "describe the help provided and the suitability of informal helpers to perform or continue to perform the tasks in caring for the consumer." [74] After identifying any informal supports for the care recipient, the assessor evaluates the ability of the primary caregiver to continue in a caregiving role by asking the care recipient or other resources to identify any limitations or constraints on the primary caregiver (e.g., poor health, employment status, lack of reliability, lack of knowledge and skills). In addition, the primary caregiver is asked fifteen questions regarding, for example, current employment status, hours spent providing care each day and emotional concerns or difficulties. Within the assessment tool is an optional caregiver stress interview that includes a modified version of the Zarit

Burden Interview (twenty-two items with responses on a 5-point scale from "never" to "nearly always") to indicate the caregiver's emotional state and to assist in developing a plan of care for the caregiver.

The *New Jersey Statewide Respite Care Program,* enacted in 1988 and administered by the Department of Health and Senior Services, provides respite care services for family and informal caregivers of the elderly and functionally impaired persons (age 18 and older). A uniform assessment of the care recipient and caregiver occurs at the time of application to the program, with a reassessment every six months. The assessment is always conducted in person, usually in the home. The care recipient and caregiver assessments are typically done at the same time. [75] The current version of the caregiver assessment tool, in use since 1990, includes questions about demographics (e.g., ethnicity, employment status); health status and social supports; reasons for requesting respite; types of care tasks performed (e.g., ADLs, IADLs, changing dressing/bandages, medication management, assistance with exercise); and need for in-home instruction. [76] An in-home caregiver education form may also be completed to document the need for skills training. After the caregiver interview, the assessor rates the caregiver's degree of social participation, positive coping behavior and mood based on observations during the interview. These ratings are used to develop the care plan.

Promising Directions

The American Medical Association (AMA) recently developed and tested a brief, practical Caregiver Self-Assessment Questionnaire to encourage physicians and health practitioners to recognize and support family caregivers. Its eighteen short questions appear in a brochure format. It is designed so that caregivers can complete the questions in health care settings, including the physician's office, while waiting for the care recipient to be seen. [77] Beginning with the simple phrase "How are you?," the tool has sixteen yes/no questions (e.g., "had trouble keeping my mind on what I was doing," "felt I couldn't leave my relative alone") and two global scales designed to measure emotional and physical distress. It was tested on a national sample of caregivers (n=150) and found to be valid and reliable (alpha = .78). [78] While data on usage are not available, anecdotal information suggests that physicians who use the tool in practice generally do so in their waiting rooms, and several residency programs have incorporated the tool as part of geriatric or home care training. [79]

Work is underway to field test, in mid-2002, a dementia caregiver risk appraisal form containing forty-eight items for use in the National Institute on Aging's REACH II initiative, a multisite intervention study for enhancing Alzheimer's caregiver health. The appraisal form has five domains: education (four items), safety (nine items), caregiver skills (eight items), social support (seven items) and caregiver self-management of emotional and physical health (twenty items). [80] The tool is being tested for use in a research study, but investigators hope the caregiver instrument will be useful in both research and practice settings. [81]

COMMONALITIES AND DIFFERENCES IN CAREGIVER ASSESSMENT TOOLS

Consensus does not yet exist on a common set of measures or methods for caregiver assessments.

Consensus does not yet exist on a common set of measures or methods for caregiver assessments. Nevertheless, some commonalities exist on type and use of caregiver assessment tools:

- Caregiver assessment tools generally reflect a recognition that caregiving is complex, with multiple components, and typically use a combination of caregiver-specific (e.g., burden) and generic (e.g., health status) measures.

- Most tools assess the type and frequency of help the caregiver provides to the care recipient in carrying out ADLs and IADLs; areas of other responsibilities (e.g., employment) or personal health that may be barriers to care; caregiver burden; and emotional reactions to giving care.

- Caregiver assessments typically collect basic demographic information about both the care recipient and the caregiver (e.g., ethnicity, living arrangement) to aid in understanding the caregiving context and describing the characteristics of the population served.

- Most caregiver assessments are conducted in-person, usually in the home.

Fancey and Keefe [82] identified six common elements found in caregiver assessment tools: (1) type and frequency of current care provision, (2) caregiver's ability to continue with care, (3) additional responsibilities or stressors affecting care provision, (4) informal support, (5) formal services required and (6) caregiver's overall health status.

Existing caregiver assessment tools show important differences, too. To date, there has been little focus on standardization either in the development or use of a caregiver assessment tool or in the measurement and interpretation of the outcomes of assessment. In some states, each local program uses a different tool to meet its agency requirements.

In practice, caregiver assessments generally take one of two approaches. Typically, they are part of overall home and community-based care assessments of the care recipient, with a brief section addressing the type and frequency of help provided to the care recipient and the willingness of the family member to continue in the caring role. These tools focus on the needs primarily of the care recipient, not of the caregiver.[83, 84] Less common are distinct caregiver screening tools or more comprehensive assessment instruments that primarily or exclusively address the caregiver's needs and situation, including an understanding of the social support available to the family caregiver.

In some states, each local program uses a different tool to meet its agency requirements.

Existing caregiver assessment tools differ from program to program in purpose, target population (e.g., age- or disease-specific), design, method of administration, application (i.e., depending on the resources, knowledge and skills of the assessor), analysis and use of data collected. How a question is asked or measured in a particular area (e.g., ADLs/IADLs, burden) varies substantially, as does the degree to which the assessment process actually addresses issues from the caregiver's perspective. Types of instruments vary from brief screening tools with single-item questions (e.g., "Overall, how burdened do you feel in caring for your relative?") to domain-specific instruments that ask multiple questions about a particular aspect of caregiving.

Some (but not all) tools assess the caregiver's information needs about specific caregiving tasks (e.g., medication management or use of the Internet). Several tools address financial and legal information (e.g., out-of-pocket costs of caregiving and financial strain; emergency preparedness and alternative contacts if the caregiver becomes ill; knowledge and use of advance directives, conservatorships/guardianships and other legal planning tools). Still others include questions about housing and the home environment.

Many measures used in caregiver assessments were developed for research studies, with small, primarily white, middle-class samples, but are now being used in various forms and formats by a range of practitioners to assess caregiver needs.[85] Little

information is available about the extent to which existing measures or assessment tools have been translated from English into other languages for administration to an increasingly diverse caregiving population.

NEGLECTED AREAS OF CAREGIVER ASSESSMENT

Assessments still neglect five important areas of caregiving:

1. actual tasks performed by family caregivers beyond personal care functions (i.e., ADLs and IADLs)

2. skills necessary to provide care

3. quality of care provided

4. values and preferences of the care recipient and the caregiver

5. positive aspects of caregiving

Actual Tasks, Caregiving Skills, Quality of Care

Family caregiving tasks vary in their intensity, scope and duration. These tasks include, but are not limited to, seeking out information about a disease/disorder on the Internet or calling disease-specific organizations; providing personal care (e.g., bathing, feeding); carrying out medical tasks (e.g., administering medications, giving injections); using medical equipment; providing emotional support; accessing, coordinating and utilizing health care and social services; hiring and managing in-home help; making decisions about care options and living arrangements; and keeping other family members and friends informed about the care recipient's condition and the caregiver's needs. Tools to measure the range of tasks and specific caregiving skills (e.g., communication strategies, behavior management, ability to fill out forms, comfort in making decisions, ability to coordinate care, ability to supervise workers in the home) are underdeveloped and rarely used.[86, 87] Similarly, the quality of care provided, mastery of specific tasks and need for caregiver training and education to increase skills and self-confidence are rarely addressed. Families need better training about the management of long-term care as well as training in how to be an effective caregiver without burning out.[88]

Values and Preferences

Most instruments that probe values and preferences have been developed for research purposes, typically focusing on end-of-life rather than on everyday care issues (e.g., accept restrictions in order to be safe, have personal privacy, maintain dignity, be part of family celebrations). The assessment of values and care preferences and resulting discussions about decision making are, practically speaking, difficult and challenging for families to undertake. [89] Nevertheless, caregiving requires an understanding not only of personal values and preferences, but also of what the care recipient values in life. Little attention has been paid to assessing the care recipient's values and preferences regarding care issues [90] or to understanding the congruence between the values and preferences of the care recipient and the needs and practices of the caregiver. [91] Recent research suggests that family caregivers of persons with cognitive impairment generally underestimate how important certain values and preferences are to the care recipient. [92, 93]

Positive Aspects of Caregiving

Last, relatively little attention has been paid to the positive aspects of caregiving (e.g., feeling more useful, feeling needed, feeling good about self, finding more meaning in life) or to the caregiver's existing or potential strengths, resources or capabilities. A strengths assessment may include, for example, questions about how a family caregiver has coped with challenges in the past; what the caregiver wants and needs; potential personal and environmental strengths, skills and resources; and what is going well for the caregiver at the present time. [94, 95] Including a strengths-and-skills inventory as part of a comprehensive caregiver assessment process, as well as incorporating both the caregiver's and the care recipient's values and preferences for daily care, would likely enhance the family's decision-making skills and improve caregiver well-being. [96, 97]

BEST PRACTICE CRITERIA FOR CAREGIVER ASSESSMENT

What criteria should be considered in designing and implementing a caregiver assessment tool? The selection of measures to assess caregivers depends on the goal or purpose to be achieved. Whenever possible, measures that are valid and reliable are a better choice than measures with poor or no reported psychometrics. Other factors to consider include the

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caregiving population to be assessed (e.g., all caregivers of older persons or just those of the dementia population), ease of administration, privacy issues (i.e., the interview of a caregiver separate from the care recipient), scoring, cost of administration, time constraints of the staff (i.e., assessor) as well as the family caregiver and translation of the tool into other languages for non–English-speaking populations. Another issue to consider is how the information will be used: For clinical purposes and care planning only? For quality assurance? For outcomes analysis? For policy development?

According to Bass, it is important to control the length and complexity of caregiver assessment in practice settings.[98] He suggests that when adapting a measure developed for research purposes "that uses four response categories from 'strongly agree' to 'strongly disagree,'" it may be sufficient to use only two response categories of "agree" and "disagree."[99] Moreover, a uniform client tracking system should be established to eliminate the collection of duplicate information obtained at other points in the service delivery process.[100] Using this process, for example, intake staff who gather a variety of information about the caregiving context (e.g., age, gender) could transfer the data electronically into the assessment.[101]

Table 2 highlights twenty best practice criteria to consider in developing and implementing an assessment system for practitioners who work with family caregivers. Not all these criteria will be appropriate for all caregiver assessments. Rather, they are intended to serve as a framework for assessment development and implementation in practice settings.

Table 2.

BEST PRACTICE CRITERIA FOR DESIGNING AND IMPLEMENTING CAREGIVER ASSESSMENT TOOLS

1. *Design*: Use standardized measures that have been tested or used over a reasonable amount of time and found to be effective in assessing family caregivers.

2. *Design*: Balance scientific rigor with practical constraints. Assessments must be reliable (i.e., the measure yields consistent answers with repeated applications) and valid (i.e., the measure reflects what it intends to measure). Assessors themselves should be involved in the design of the tool.

3. *Design*: Develop tools that are comprehensive in scope (e.g., addressing multiple domains), are sensitive to change over time in caregiver status (i.e., can be used for reassessment) and demonstrate a multidimensional assessment of the caregiver situation.

4. *Design*: Incorporate multiple sources of information (e.g., questionnaires, interviews, observation by the assessor), including subjective self-ratings of the caregiver's situation by the family caregiver.

5. *Design*: Ensure that tools are relevant to ethnically diverse caregivers, culturally sensitive and translated into other languages for non–English-speaking caregiving populations.

6. *Measures*: Use measures designed primarily or exclusively to develop a care plan and provide caregiver support services, rather than measures designed primarily for research projects.

7. *Measures*: Use measures that are applicable to caregivers who care for persons with a wide variety of impairments (i.e., across various disabilities).

8. *Measures*: Consider questions that address the positive aspects of caregiving.

9. *Measures*: Incorporate a values assessment to understand the values and preferences of the caregiver and the values and preferences of the care recipient, including the care recipient's perspective or reaction to family care.

Table 2. (continued)

**BEST PRACTICE CRITERIA FOR DESIGNING AND IMPLEMENTING
CAREGIVER ASSESSMENT TOOLS**

10. *Format*: Develop a practical, user-friendly format that is easy to administer. The order of sections and of questions within sections should be consistent with the flow of a conversation and interview, and space should be allowed for the assessor to record observations and notes. [102]

11. *Format*: Provide clear skip patterns for questions that don't need to be asked of all caregivers, as well as "branching" to explore areas for caregivers with certain characteristics (e.g., employed caregivers). [103, 104]

12. *Administration*: Standardize the assessment tool across agencies and programs (i.e., use a common assessment tool for programs that provide caregiver support).

13. *Administration*: Make assessments available at the many intervals experienced by the family: at onset or initial diagnosis of the care recipient's condition, at crisis points in the care recipient's or caregiver's situation, at placement outside the home, even at and following the death of the care recipient. [105]

14. *Administration*: Respect the caregiver's own needs, situation and privacy and seek to interview the caregiver separately from the care recipient.

15. *Administration*: Identify how the caregiver prefers to learn new information: from written fact sheets, audiotapes, video-tapes, the Internet, educational classes, support groups (e.g., Does the caregiver like group interaction or prefer one-to-one interaction?).

16. *Administration*: Link the intake, assessment, care plan and reassessment through computer applications so that the information collected is used to guide service delivery. [106]

17. *Training*: Ensure that staff (i.e., assessors) are committed to the importance of assessing family caregivers and trained in the use of the particular caregiver assessment tool.

18. *Training*: Incorporate staff training on cultural diversity and cultural sensitivity, including training on how the assessor's values, beliefs and attitudes may impede the ability of caregivers to respond to assessment questions and on how cultural, linguistic and other modes of expression vary among ethnic and racial groups of caregivers. [107]

19. *Use of Data*: Analyze assessment data and provide results on a regular basis to staff collecting the information. [108]

20. *Use of Data*: Use results of the assessment (and reassessment) to improve services that meet the needs of family caregivers.

TRAINING ISSUES

Developing a standardized, comprehensive caregiver assessment tool for use in practice settings is daunting in and of itself. For a caregiver assessment to be successful, staff at all levels of an organization must appreciate the importance of the assessment. The reality of and need for support from upper management is vital. If a uniform tool is adopted, implementing a systematic process will likely be even more challenging. As Kane observes, "It is easier for a program to settle on an assessment tool than to find a way to use it consistently over time and across assessors." [109] A caregiver assessment tool will only be as good as the training provided to assessors in the purpose and use of the tool.

A caregiver assessment tool will only be as good as the training provided to assessors in the purpose and use of the tool.

In practice, considerably more time is spent in developing an assessment tool and in identifying measures to use in an instrument than is spent on consistent and uniform training in use of the tool. Geron and Chassler suggest that "to perform assessments effectively requires specialized skills and competence, including the following: interviewing skills; the ability to establish and maintain empathic relationships; experience in conducting social and health assessments; knowledge of human behavior, family and caregiver dynamics, aging and disability; and awareness of community resources and services." [110] In conducting assessments, it is important for assessors to know not only how to fill out forms and calculate scores, but how to ask questions and probe for clarification. Assessors must also understand how the assessment process guides and informs their work with family caregivers.

SUMMARY

A consistent theme of this monograph is the lack of attention paid to systematic assessment of the needs and situation of the family or informal caregiver and ways in which such a caregiver assessment could guide daily care practices. Although the research community has examined family caregiving for decades, the notion of caregiver assessment is just beginning to take hold in policy and practice arenas. To date, caregiver assessment functions primarily as a supplement to the care plan of the care recipient, rather than as a tool to understand the needs of the family as well. Few of the published articles that address caregiver assessment in service delivery focus on what help a family caregiver might need.

Because support for family caregivers is an emerging area of debate in long-term care, there is no consensus on a consistent approach to assessing family care or on what should be included in a comprehensive caregiver assessment tool. The complexities of caregiving and the varied tasks performed, however, make the case for implementing caregiver assessment as part of long-term care policy and practice.

...the notion of caregiver assessment is just beginning to take hold in policy and practice arenas.

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