

Assessing Family Caregivers: A Guide for Health Care Providers

As a health care professional, you assess patients all the time. But you generally do not assess a patient's family caregiver, except to identify that person as a "resource" or "informal support" when developing a discharge plan. In this traditional view, the family caregiver, who is not a client or a beneficiary and not an official part of the health care team, is typically outside the realm of professional responsibility.

Like so much of health care today, that view is changing. Increasingly professionals "hand off" very sick or disabled patients to family caregivers after a hospital stay, a short-term nursing home stay, or an episode of home care services. In these transitions, especially when the patient is elderly or chronically ill, the patients' continued health and well-being depends on a family caregiver. That person must be willing and able to handle the patient's complex health, financial, legal, and social needs. Sometimes these tasks are temporary, while the patient recovers; in the case of elderly or seriously ill patients, the job can continue for months or years.

Caregiver assessment is a tool to help identify strengths and limitations and to develop a realistic plan for the next stage of care. The goal is twofold: (1) to ensure that the patient's health and well-being are maintained and enhanced; and (2) to ensure that the caregiver's capacities and needs are considered and addressed in a care plan.

This guide is an introduction to caregiver assessment in hospitals, nursing homes, and home health agencies. Although these settings are different, the guide gives some basic information and suggestions. These are the questions we address:

- Who is a family caregiver?
- What is caregiver assessment and why is it important?
- Who should do it, when, and how?
- What should it cover?
- How should the assessment be used?

Who is a family caregiver?

Family caregivers include relatives, partners, friends, or neighbors who provide essential assistance to an adult or child with chronic illness or disability, or to a frail or cognitively impaired older person. Some of the ways in which the family may respond are emotional support, surrogate decision making, financial contributions, care management, and hands-on care. Family caregivers may provide or manage all or some of the care, either part-time or full-time, and may or may not live with the care recipient.

This definition, like many others in the field, is very broad, recognizing the complexity of modern relationships and family life. But it is not open-ended. Not every patient needs or has a family caregiver, and not every family member is a caregiver. And the person who is really a family caregiver may not self-identify in that role. “I’m not her caregiver; I’m her daughter” is a common attitude, reflecting the primacy of the parental relationship, and perhaps a reluctance to acknowledge that the ill family member needs a caregiver.

As a first step in caregiver assessment, it is essential to determine which patients have extensive needs for care at home and who provides and/or manages that care. It may not be the daughter or son who talks to the doctors and nurses and asks a lot of questions; rather, it may be the spouse or granddaughter who sits quietly by the patient’s bedside. In a crisis all kinds of relatives turn up; they may or may not be closely involved in the patient’s day-to-day care. Even when there is a designated family member who receives medical updates and communicates to the rest of the family, that person may not provide the hands-on care.

One way to identify the main family caregiver is to ask the patient, if he or she can respond, “Who helps you at home?” or “Whom do you rely on most for help at home?” If the patient cannot respond, then ask the family member who seems to be most involved if he or she lives with the patient and provides care at home. Instead of asking, “Are you a caregiver?” it is better to ask, “What do you do at home for your family member? Do you do this all the time? Is there anyone who helps you?”

What is caregiver assessment?

Caregiver assessment is

A systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver’s own health and well-being.¹

¹ (National Center on Caregiving at Family Caregiver Alliance, “Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers, June 2006).

This definition has several important features: (1) assessment is a systematic process, not a quick judgment; (2) the caregiver, not the patient, is the focus; and (3) the process recognizes the caregiver's needs and vulnerabilities as well as strengths.

Caregiver assessments are important sources of information for providers and for caregivers themselves. Transitions from one care setting to another are risky. There is substantial evidence that patient safety can be compromised by miscommunication and failures to adequately prepare the personnel at the new setting to meet patients' needs. When the receiving "provider" is an untrained and fearful family member, the risks are multiplied. A caregiver assessment can identify areas for training and follow-up, as well as areas in which the family caregiver is experienced.

For family caregivers, an assessment is a chance to talk about their own lives for perhaps the first time in any encounter with the patient's health care team. They can express concerns about their own abilities to provide certain kinds of care, and the realities of their own situations. In health care settings, assessments will necessarily be brief but they can raise questions that the family caregiver can discuss further with others and can suggest types of resources that may be available and helpful. Some professionals are reluctant to ask questions about the kinds of help that a caregiver may need, because they cannot fill those gaps. But most caregivers are grateful for any suggestions and for the attention being paid to them.

Who should do a caregiver assessment, when, and how?

Many different professionals can contribute information that is important in assessing caregivers' needs. Physical therapists, for example, may ask questions about the home environment and the family caregiver's limitations in terms of strength or mobility. Nurses may focus on whether the family caregiver knows how to change dressings or manage medications. Social workers may look at the caregiver's sense of burdens or rewards associated with caregiving, as well as entitlements and community resources.

Depending on the situation, all these emphases are important. However, we recommend that one professional, such as a social worker or nurse, be assigned responsibility for conducting the assessment. More important than the professional status of the assessors are their attitudes and ability to relate to the caregiver in a nonjudgmental and thoughtful way. Assessments should be introduced as – and should be – a way to acknowledge the family caregiver's perspective, not as a test and certainly not as a guilt-inducing technique. The assessor should have good communication skills, including the ability to listen attentively, probe for clarifications, and respect diversity in all its many forms. If the caregiver does not speak English, the assessment should be done by a trained interpreter.

Ideally the assessment should take place early enough in the patient's stay to be useful in the discharge plan. That may be more easily accomplished in a short-term nursing home stay or a home health agency episode of care than in a hospital stay. In those settings assessments might be repeated just before the actual discharge. But even in a hospital, if the assessment is conducted as early as possible after the patient is admitted, it can introduce the process of discharge planning to the family caregiver and establish some baseline information.

The assessment should take place in as private and quiet a place as possible, not at the patient's bedside. It is difficult for family caregivers to talk about themselves under any circumstances (assessors should be aware that the conversation will quickly come back to the patient). But it is practically impossible if the patient is in full view, even if asleep or unable to communicate.

The assessment should be a conversation, not a mechanical exercise. The assessor can note any answers that suggest the need for further exploration and can supplement the assessment answers with direct observations.

What should the assessment cover?

There are a variety of caregiver assessment tools available; most, however, were developed for use in community-based agencies, not in health care settings. Using those assessment tools as a framework, we suggest that these are some basic questions to include:

- The caregiver's background, including age, education, employment, other family responsibilities, living arrangements
- The caregiver's perception of the care recipient's health and functional status
- Length of time the caregiver has been providing care; if is a new event, what the caregiver worries most about in providing care
- Values and preferences about caregiving ("do it all myself,"; "can't deal with needles or incontinence,"; "I can't take Mom to my home because there just isn't room for another person")
- Caregiver's health status, including any limitations relevant to caregiving
- Impact of caregiving on emotional status, finances, other family members
- Knowledge, skills, and abilities to perform necessary caregiving tasks
- Resources used or interested in accessing

Examples of questions that focus on a patient's particular needs are:

- Has anyone shown you how to move your family member from bed to chair so that you don't hurt yourself or her? Can you do it?
- Has anyone explained the medications your family member will have to take at home? Do you understand them? If you have other people in the home, can you show them what to do?
- Because your family member has had a stroke, it will be important to help him swallow food very carefully. Has anyone shown you how to feed him or help him eat?
- You told me that you live in a third-floor walkup, and your family member will be going home in a wheelchair. Has anyone helped you figure out how to manage in that situation?

How should the assessment be used?

In introducing the assessment process to the family caregiver, the assessor should clarify the goals of the assessment and make it clear that all information (unless specified by the caregiver) will be shared with the health care team in order to develop a care plan. Caregivers should understand that a summary of the assessment may be documented in the medical record and perhaps shared with the health care staff of the home care agency or skilled nursing facility. Thus, if there is information that the caregiver does not want shared, this should be made clear to the person conducting the assessment. Family caregivers should be assured that the assessment will not be shared with the patient or other family members.

The assessor should also summarize the conversation, so that the family caregiver feels that his or her concerns have been heard. The assessor can emphasize the positives first, and then list the areas where some questions have been raised, and suggest a process for following up. The family caregiver can also be given a copy of the AMA Caregiver Self-Assessment tool for future use.

Conclusion

Family caregiver assessments are important tools to help obtain critical information about the person who will be responsible for patient care and follow-up after discharge from a hospital, short-term nursing home stay, or episode of home health care services. Although they are being widely used in community-based social service settings, they are a relatively new tool in health care settings. In addition to providing information in a systematic way, assessments recognize the importance of family caregivers as direct care providers and managers, and affords them the opportunity to self-identify as a caregiver and take stock of their strengths, limitations, and needs. To be effective, however, caregiver assessments must be undertaken by professionals with good communication and relationship-building skills.