Family Caregivers and Case Managers Working Together to Coordinate Care

By Carol Levine

As case managers are well aware, “patient and family engagement” has become one of the most popular terms in the new health care lexicon. What the phrase actually means, however, is not so clear. As Humpty Dumpty explained in Through the Looking Glass, “When I use a word, it means just what I choose it to mean—neither more nor less.” From their different perspectives, proponents claim that patient and family engagement will prevent hospital readmissions, improve satisfaction survey scores, or gain market share. A physician may see engagement as a way to ensure adherence to a medication regimen. An administrator may see it as a way to prevent medical errors. A policy maker may see it as a way to control costs. All good things, but heavy burdens to place on sick patients and their families! For their part, case managers know how hard it is to make this catch phrase a reality.

Most patients and families haven’t heard the term and don’t know what engagement means. They do not typically see themselves as “passive” or “noncompliant,” disparaging terms often applied to people who do not follow every aspect of professionals’ advice. Patients and family caregivers exist on a continuum of engagement, from uninvolved or only marginally involved to very actively involved, some might say, over-involved.

The reasons people are on the lower end of the engagement spectrum are complex. Most people are not indifferent to their health. Some, however, lack the skills, experience, and confidence to navigate a complex health care system. Some learn better with visual, rather than written or oral presentations of information. Others feel that they have no control over what happens to them in hospitals or doctors’ offices. Their history of prior unsatisfactory encounters may limit their ability to become engaged in the current episode. Patients and families bring to the health care system not only medical problems but often social and economic problems that they perceive to demand more immediate attention than yet another doctor visit. All these barriers can and must be addressed for true engagement.

Yet all too often, it is professionals, not patients and families, who are not engaged. Some professionals make quick judgments about patients and families based on external characteristics, previous experience, time constraints, or other factors. Engagement should be a two-way street, but professionals often do not offer timely, consistent, and understandable information to patients and families.

Case Managers’ Critical Role

Often it is up to case managers to clarify, consult, and actually engage—that is, have conversations with—patients and families. Case managers are the mediators between clinicians and patients and families. They can find out what patients and families actually understand, not just what they have been told. This realistic assessment is essential for setting up a care plan that is feasible in the particular circumstances facing the patient and family. It is also the basis for coordinating care once the plan is in place. This article will discuss both aspects of working with family caregivers.

Case managers, perhaps more than many other professionals, know how essential family caregiver involvement is to a successful care plan, although they may not realize how difficult the plan may be to implement in a specific circumstance. Many discussions of care planning assume a patient who is independent, able to “self-manage,” and not cognitively impaired. But the reality is often quite different. Even such an idealized patient may be temporarily unable to function independently after a hospitalization. A recent report identified a “post-hospital syndrome,” similar to post-traumatic stress disorder, which is caused by the trauma of hospitalization itself. Most people who are

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hospitalized or who need ongoing care management have multiple chronic conditions that affect not only their health but also their ability to function at home. Without assistance, usually provided by family members, they will be at further risk of poor outcomes, rehospitalization, and eventual nursing home placement.

The best-laid care plans fall apart when one key partner—the family caregiver—cannot do the job. If family caregivers are not involved in planning, they may not understand what is expected of them. They may have no opportunity to point out barriers to implementing the plan. Here are a few examples:

• A case manager may work hard to set up an appointment for a consultation with a specialist, but the family caregiver has to coordinate all the steps it takes to get the person ready for the visit, arrange transportation, and take time off from work to accompany the patient. Any misstep in this chain of events can mean a missed appointment and a potentially worsening medical condition.

• A case manager has ordered durable medical equipment and it has been delivered. But the family caregiver doesn’t know how to assemble or operate it and puts it away rather than letting the case manager know about the problem. The caregiver is hesitant to reveal this problem, fearing that he or she will be shamed and blamed.

In these, as in the many other examples, the case manager can both anticipate problems and respond to them when they occur. The trust that has been built in the care planning process will be essential in this process.

**Building Patient and Family Caregiver Engagement Into the Care Plan**

While most descriptions of care planning include the patient, the family caregiver is not always explicitly mentioned. Changes are underway, largely driven by the proliferation of transitional care programs that are aimed at reducing hospital readmissions and the resulting financial penalties. In their initial stages, these programs largely did not include family caregivers as essential partners. But as the developers gained experience in working with patients with multiple chronic illnesses and disabilities, they recognized the gap and, in response, integrated new ways of involving family caregivers.

Recently, the United Hospital Fund (UHF) and Boston University Medical Center (BUMC) collaborated on one such effort. BUMC developed Project RED (Re-Engineered Discharge) in 2007, and it has been adopted by over 500 hospitals nationally. The first addition to the RED Toolkit since its inception is Tool 7, “Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge,” created by UHF and BUMC. (See the box on Resources for links.) While it is aimed primarily at hospital discharges, Project RED has also been successfully used in a skilled nursing facility to reduce hospital readmissions. The principles and key features of Tool 7 can be adapted to any setting in which family caregivers play an important role in follow-up care.

The tool—as well as all UHF work in this area—is based on a broad definition of family caregiver, who can be a member of a biological family, spouse, partner, or friend—anyone who provides or manages care for a person with chronic illness or disabilities. The family caregiver may, but need not, live with the patient. Sometimes there are several family caregivers; they may take turns in providing care, or they may have different roles and responsibilities.

The Project RED tool has five steps to guide practitioners:

**Step 1: Identify the Family Caregiver**

Sometimes on admission clinicians will have identified the person who is going to be responsible for the patient’s follow-up care, and that information will be readily available to the case manager. Often, however, there is no name, or information is incomplete, for example, failing to note the person’s relationship to the patient or contact information. Sometimes vague terms like “next of kin” or “emergency contact” are used. If there is a designated health care proxy, it may be assumed—incorrectly—that that person is also going to be managing the care at home.

Identifying the family caregiver early in the episode of care is critical because everything that follows depends on the information being up-to-date and accurate. Talking about a care plan with a family member who is only visiting from out-of-state and will have no role in the ongoing care is not going to be helpful. Assuming that a daughter, rather than a son, will take over can be a mistake. If a person has been listed as the primary contact, it is important to verify what that person should be contacted about; that person may simply be the family member who is easy to reach and not a decision-maker (such as a power of attorney) or a person who will provide or organize...

**RESOURCES**

- Project RED’s Tool 7, “Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge”
- United Hospital Fund’s Next Step in Care family caregiver assessment guides for providers, “What Do You Need as a Family Caregiver” and an overall guide to caregiver assessment
- “Four Questions About Engaging Family Caregivers”

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care going forward. And if no one has been listed, then the first order of business is to find out who will play that role. If there is no one willing and able to do the job, alternate sources of support have to be investigated.

Many family caregivers do not identify themselves as caregivers; they think of themselves solely as daughters, husbands, partners, or friends. And many patients do not see themselves as needing “help” of any kind. They may fear losing independence or burdening their families. So it is important to use neutral language in opening discussions, for example, asking a patient, “Who arranges your pill box?” rather than “Who helps you take your medicines?” And to a family caregiver who adamantly says that she is not and never will be a caregiver, just ask, “What do you do as a daughter to help your Mom?”

Since communication is essential to these discussions, asking about the person’s language preference is important. If the patient or the family caregiver does not feel comfortable speaking English, then a trained interpreter should be requested. Asking a staff member or another family member, particularly a child, to translate is not a good option because of the possibility of misunderstandings or hesitation about disclosing bad news.

**Step 2: Assess the Family Caregiver’s Needs**

Making the family caregiver part of the team means recognizing that partner’s strengths and limitations. There will certainly have been an assessment of the patient’s needs, but that alone does not tell what the family caregiver can and cannot do and what his or her own needs are. That requires a separate step, best accomplished by a guided self-assessment. This is a technique that combines both a professional assessment and the caregiver’s own assessment so that there is room for discussion, questions, and clarification.

Some professionals are wary of opening a discussion of caregiver needs because they feel that “caregivers don’t know what they need.” Or they may feel that once a need is identified, it will be up to them to make sure it is addressed. These concerns are real, but most caregivers accept limitations once they are explained and are grateful that they are even seen as having needs of their own. They do not generally have professional expertise, but they do know their own lives and what is important to them.

There are many caregiver assessment tools available. Some are short and some take hours. Most focus on long-term stress and burden. The United Hospital Fund’s Next Step in Care website has a guide to caregiver assessment and a three-part tool to assist a caregiver to assess his or her own needs. (See the Resource box.)

The results of the caregiver assessment should be documented and shared with other members of the care team. The assessment may contain information that will be helpful for ongoing care and planning, and in communications with care partners in other facilities. If case management is ongoing, the assessment should be repeated at regular intervals.

**Step 3: Integrate the Family Caregiver’s Needs Into the Care Plan**

Using the patient and family caregiver assessments as basic starting points, some options for a care plan can be developed. Sometimes what is totally clear to a clinician—for example, this patient is going to need rehab in a skilled nursing facility (SNF)—is not so obvious to or desired by patients and families. And sometimes there is no clearly preferable option; either a SNF rehab program or home care with physical therapy would be clinically acceptable.

Patients and family caregivers frequently complain that they are not consulted on these post-hospital discharges; a nurse simply says, “Your mother is going to a nursing home tomorrow. You’re lucky because there is a bed available. By the way, the nursing home is 50 miles away.” If a case manager is brought into the discussion early on, these options can be discussed with the patient and family so that if a decision has to be made quickly, there will have been basic information about preferences such as location, which is a major concern for patients and families and often a factor in the success of the transition.

Home care might be an option for many patients, but either they don’t know about it or reject it out of hand, saying, “I don’t want strangers in my house!” On the other hand, some patients and family caregivers have unrealistic expectations of the type and level of home care services they might receive. A neighbor may have an aide every day for 8 hours, paid for by Medicaid; a Medicare patient will be eligible for only a few hours of aide services two to three times a week for a few weeks, and then only if he or she needs what is termed skilled nursing care.
It is hard for patients and families to understand how different public programs work. It’s the case manager’s often unpleasant job to apprise them of the realities of the health care system.

**Step 4: Share Family Caregiver Information With the Next Setting of Care**

The wealth of information collected by a case manager should be shared with the providers who will be following the patient on an ongoing basis. That may mean coordinating with other care managers, for example, at a health plan or medical practice. Building good relationships with these providers will also lead to sharing of their information so that everyone has a better idea of what is working out well, what needs to be changed, and what needs may be foreseeable. Sharing information with providers who are directly involved in the health care of a patient is permitted under HIPAA.

**Step 5: Provide Telephone Reinforcement of the Care Plan**

Patient and family caregivers value having a person they feel understands their situation, someone they can trust. Following up with regular phone calls is not just a job requirement, it is a way of reinforcing trust. Patients and family caregivers get many phone calls from hospital or SNF staff who just ask, “How are you doing?,” but do nothing to address any problems that may arise. Patients and family caregivers may resent these calls and even ignore them, even though they have important questions and concerns. Because of the trusting relationship that has been developed, the case manager’s calls should be welcome opportunities for discussion.

At times it may be necessary and advisable to call the patient and family caregiver separately. Each may have things to say that they would prefer not to share with the other. The case manager has to sort out these differences, and find appropriate resolutions.

**Care Coordination: The Family Caregiver’s Role**

A large part of case management is care coordination. Case managers have professional training to take on this demanding role. They bring specific skills and resources to the job. The role of family caregivers in care coordination, however, is less well recognized. The Agency for Healthcare Quality and Research (AHRQ) surveyed the literature on care coordination and found more than 40 definitions that depended on the setting, provider, goal of the program, and other factors.\(^4\) Only a few of these definitions, mostly those related to pediatrics, explicitly recognized the role of the family in coordinating care, even though this is a major activity for family caregivers. In a national survey, only 3% of family members reported having a care coordinator from a public or private insurance program, or a private case manager.\(^5\)

Because care coordination is such an important part of family caregiving, UHF created, with the assistance of an advisory group of professionals, two Next Step in care guides: one for professionals and the second for family caregivers. (See Resource box for links.)

The care manager can assist patients and family caregivers by:

- Building rapport
- Explaining how the system works
- Explaining the boundaries of scope and length of involvement (since most professional care coordination is time-limited)
- Ensuring that the patient, family caregiver, and health care providers (including other professional care coordinators) are working from the same understanding of the patient’s needs and the plan of care
- Preparing the patient and family caregiver to take on additional care coordination duties when the care manager’s services end

Remember that this is often a time of reorganization for the family; roles may shift and new stressors may arise that take a toll on the family system. While the case manager’s job is to coordinate services, a family member’s job is to coordinate life. A skilled and compassionate case manager can make that job easier, and by doing so, serve the patient’s needs as well.

**References**


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