WHAT KNOWLEDGE AND SKILLS DO CAREGIVERS NEED?

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PATIENTS WITH CHRONIC ILLNESSES and multiple comorbid conditions have intricate treatment protocols that require caregiver involvement, further complicating this already-difficult care. Because better treatments have extended the life spans of most patients with chronic illnesses, caregiver involvement often is required for several years (Given et al., 2001). Many family caregivers report they don't have the necessary skills and knowledge to provide sustained care for a person with a chronic illness, so they lack confidence and feel unprepared. Caregivers say they receive little guidance from providers, that they don't know how to assume the caregiver role, that they aren't familiar with the type and amount of care needed, and that they don't know how to access and utilize resources (Given & Given, 1999-2002). Their feelings of uncertainty contribute to their distress (Northouse et al., 2000).

Most research about caregivers explores the emotional health of those who care for people with dementia. The research documents that caring for a family member with dementia affects the emotional and physical health of the caregiver (Beach et. al., 2000; Cameron et al., 2002; Gitlin et al., 2005; Pinquart & Sörensen, 2003; Vitaliano et al., 2003). Little information is available about the knowledge and skills that family caregivers need to provide care (Farran et al., 2004) or how their knowledge and skills affect care.

Most studies don't organize or classify interventions according to caregivers' tasks or the knowledge and skills they require, but this information is vital for planning and implementing interventions that will help them. The concepts of mastery, preparedness, and competence have been considered as necessary components for effective decision making and problem solving by family caregivers (Archbold et al., 1995; Silver et al., 2004), but the formal care system has paid little attention to these components.

Recently investigators have suggested that family caregivers require both knowledge and skill to provide care and to reduce their own distress (Farran et al., 2004; Gallagher-Thompson & Coon, 2007; Schumacher et al.,

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2000). Schumacher and colleagues describe *family caregiving skill* as the "ability to engage effectively and smoothly" in nine care processes requiring psychomotor, cognitive, and psychological skills (Schumacher). *Skill* was defined as "goal-directed, well-organized behavior that is acquired through practice and performed with an economy of effort." Farran and colleagues defined a *caregiver skill* as "something that caregivers do" using "goal-directed behaviors based on knowledge, experience, or personality style" (Farran et al., 2007).

The basic knowledge that caregivers use to make decisions and solve problems provides the foundation for developing and improving skills. In turn, this enables caregivers to receive guidance, counseling, and direction from health clinicians and to rehearse what they learn so they can take appropriate action with their family members. Over time, caregivers can develop their skills.

The requisite caregiver skills described by Schumacher and colleagues include monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system (Schumacher et al., 2000). Skills such as monitoring and interpreting require complex reasoning.

Nurses and social workers should assess the care situation and help family caregivers develop the skills they need. Caregivers who have these skills report lower levels of burden, stress, and distress (Archbold et al., 1995; Scherbring, 2002; Silver et al., 2004), which may enable them to provide care that improves outcomes.

Care Demands

The demands of providing care depend on factors such as the patient's personality; the type or stage of illness; and the caregivers' physical, cognitive, social, organizational, and psychological knowledge and skills. Professionals must assess care demands while evaluating the caregiver's availability, capacity, knowledge, skills, competing family roles, and resources. The predictability and routine nature of the care as well as its duration (weeks or months) and quantity (daily hours of care) must be considered when implementing therapeutic plans of care with the family (Bakas et al., 2004; Langa et al., 2002a).

Caregivers need to perform complex medical tasks, supervise patients, make decisions, solve problems, provide emotional support and comfort, and coordinate care. Using these skills, caregivers administer medications, plan and provide meals, handle medical equipment, and provide direct care such as wound care and lifting and turning. Caregivers also provide custodial care, transportation, and advocacy. Some tasks are merely time-consuming; others are difficult. Family caregivers also typically manage the household. To improve function and safety for the patient, caregivers may need to modify the environment and acquire equipment and assistive devices.

Caregivers also need to learn to monitor patients for new signs and symptoms, adverse events, and positive responses to treatment. Caregiving is more complex and the family's distress more acute if the patient has impaired cognition or neuropsychological symptoms

(Pinquart & Sörensen, 2003; Sherwood et al., 2004).

Changes in the severity of symptoms or the appearance of new symptoms as the disease progresses can heighten the caregiver's perception of loss of control. This may cause distress and uncertainty because worsening or increasing symptoms can affect physical function and increase the demand for care (Given et al., 2006; Kurtz et al., 2005). As symptoms change, caregivers should communicate directly with health care providers.

Demands on caregivers escalate as treatment plans change, the disease progresses, the patient's functional or cognitive capacity deteriorates, or the patient nears the end of life. Nurses and social workers should reassess caregivers' capabilities when such changes occur.

Interventions to Increase Knowledge and Skills

Although research has begun to identify the knowledge and skills caregivers require, researchers have paid little attention to the implementation of interventions by clinicians. Interventions are those helpful strategies recommended and guided by health care clinicians that can ease the task of caregiving and reduce stress. Most interventions provide basic written materials that teach caregivers about the expected course of an illness, treatment plans, short- and long-term adverse events, or strategies for dealing with these effects.

Family caregivers need a working knowledge of the patient's plan of care and they must be able to interact with nurses and social workers.

Health care providers should complete a formal skill assessment of caregivers as part of the plan to determine what training is needed (Farran et al., 2004; Gallagher-Thompson & Coon, 2007). Skills are based on knowledge and can be classified as psychomotor (such as catheter or wound care), cognitive (such as monitoring, decision making, and problem solving), or psychological (such as offering emotional support). One of the most important skills is the ability to communicate effectively with health care providers, yet we can find nothing evaluating its effect on patient outcome.

Assessing caregivers' capacity to provide care and identifying caregivers who need assistance is essential to improving patient care. Few studies look at how caregivers care and what care family caregivers should provide. The care system does not incorporate "family care" into plans of care. Therefore, the contribution of family care to patient outcomes has not been evaluated.

The sufficiency of caregivers' knowledge and skills vary depending on patient acuity, illness type, or both. Weuve and colleagues suggest that practitioners should evaluate care demands, caregiver knowledge and capacity, caregiver skills, family roles, and available resources (Weuve et al., 2000). Assessments should include the number of hours of care required and the expected duration of care. Competing demands such as work, travel, and child care should alert professionals to the risk of overload, strain, or an inability to continue to provide care. Plans of care should be based on a thorough assessment of both recipient need and caregiver capacity. Health professionals and family caregivers should collaborate to ensure optimal care is given.

What the Research Shows

Best practices for enhancing caregivers' knowledge and skill should be examined and tested with interventions focused directly on caregivers. Caregivers need interventions to help manage patient symptoms. Reducing uncertainty about care relieves their stress. If they know to call a physician for a fever of 101.4°F, for example, they can make decisions and worry less. Studies demonstrate that these interventions can help caregivers set priorities, solve problems, and make decisions. As a result, caregivers may have a more positive outlook, have more confidence, and feel better informed. Some studies have also involved family caregivers improving their symptom management skills.

Categories that might be useful for future studies of caregiver interventions include educational, psychoeducational, problem-solving, decision-making, social support, and multimodel interventions (two of which are discussed below). Nurses and social workers should determine how well caregivers access health care support and information. Interventions should examine how well caregivers adjust their skills and knowledge to accommodate changes in the patient's condition and changes in treatment plans (Farran et al., 2007; Grobe et al., 1981; Schumacher et al., 2000). Caregivers should be referred to community and educational programs for additional knowledge, skills, and strategies. Cognitive behavioral management approaches are the most common interventions used with caregivers. They focus on cognitive stimulation, supervision, monitoring, medication administration, communication, memory enhancement, and problem solving. Caregivers need to acquire knowledge for goal-directed behaviors and for priority-setting, decision-making, and problem-solving skills. However, most educational programs are not evidence based. Specific and tailored information, such as books and videos, helps support caregivers and reduce their uncertainty (Farran et al., 2007; Gaugler et al., 2007).

Given and colleagues (Given et al., 2006) implemented a cognitive behavioral intervention to assist caregivers of cancer patients with symptom management (Sherwood et al., 2005; Sikorskii et al., 2007). The tailored intervention addressed specific symptoms and severity levels. Caregivers became involved in symptom management and were able to help patients control their symptoms. When the patient's symptoms responded to the intervention and the number and severity of symptoms were reduced, caregivers were not as negative about each symptom and experienced less distress per symptom. Caregivers used information, direct care strategies, coaching, and emotional support to work with the patients. In turn, patients experienced fewer symptoms that were also less severe, had less interference from symptoms, and showed improved physical function.

Blanchard and colleagues (Blachard et al., 1996) developed an intervention to help spouse caregivers of cancer patients develop problem-solving skills. Those who needed social support felt encouraged to continue providing care and to be open to problem solving when they could no longer provide care. Interventions that use problem definition and formulation, generate alternatives, involve decision making, and implement strategies should increase a caregiver's sense of effectiveness.

Psychoeducational interventions provide emotional and educational support to caregivers. Northouse and colleagues found that caregivers were not confident about their ability to manage illnesses and perceived a continuing lack of support (Northhouse et al., 2000). Caregivers were more positive after home visits and phone calls by nurses or social workers.

Both Barg and colleagues and Pasacreta and colleagues implemented psychoeducational programs that addressed symptom management, psychosocial support, and resource identification (Barg et al., 1998; Pasacreta et al., 2000). After the intervention, caregivers became informed and confident about giving care and weren't more burdened when patient care demands increased. Other studies document that problem-solving programs help caregivers feel informed about community resources (Bucher et al., 2001).

The *psychoeducational telephone-based intervention* by Jepson and colleagues focused on monitoring problems, managing symptoms, performing self-care, and coordinating resources and improved the psychosocial well-being of the caregiver after three months (Jepson et al., 1999). The effectiveness of the intervention depended on several factors, including the physical health of the caregiver (Chee et al., 2007; Jepson et al., 1999).

Some psychoeducational and cognitive behavioral interventions for caregivers have focused on symptoms. Managing symptoms in order to comfort the patient often becomes a major family concern. Family caregivers need to be able to monitor, interpret, and manage symptoms and may need booster sessions to learn additional knowledge and skills.

Interventions that increase knowledge and skills are targeted at caregivers who work with patients with dementia more often than at those who deal with other illnesses. Pinquart and Sörenson used metaanalysis to integrate the results of 127 such intervention studies (Pinquart & Sörenson, 2006). They concluded that many interventions had little effect on the emotional health or the abilities and knowledge of the caregiver. Psychoeducational interventions that required active participation and involvement by caregivers had the broadest effects.

Families want information about symptoms, disease progression, treatment, and possible adverse events. Caregivers seek information on skills they need to provide day-to-day care. Often caregivers and families are not given information about available social and emotional support sources or how to utilize community resources (Given et al., 2006; Jansen et al., 2007). Caregivers also may need to know how to deal with difficult situations like anger, depression, rehabilitation, disruptive behaviors, and incontinence (Bakas et al., 2001).

To bring about changes in practice, nurses and social workers need to develop evidence-based professional standards and guidelines to help families care for those with common chronic diseases. These should cover the types of knowledge and skills family caregivers need, the conditions under which information and skills should be evaluated, and who should be responsible for determining caregivers' abilities (Given et al., 2006). Professional organizations or disease specialty groups, such as those for cancer, heart disease, and stroke, can endorse these standards.

Complexity of Family Care

The number of required tasks influences the complexity of caregiving. Many of these tasks cannot be predicted. Houts and colleagues showed that family caregivers need a substantial amount of information and that family members typically feel that health care providers do not fulfill this need (Houts et al., 1991). This lack of information negatively affects patient care as well as the physical, psychological, and social well-being of the caregivers. However, no intervention studies were found that focused on helping families set priorities in a dynamic care situation. Complexity of care may increase when medications are added to a regimen or when incontinence exists (Langa et al., 2002a, 2002b). Competing roles and responsibilities can lead to overload for the caregiver. Some caregivers lack the capacity to carry out necessary care, especially when tasks are difficult and require insights, judgment, and critical thinking abilities that they do not possess (Bakas et al., 2004). Nurses and social workers need to assess the care situation for complexity and help caregivers obtain the resources they need.

While tangible social support is considered beneficial to the family caregiver (Mittelman et al., 2007; Nijboer et al., 2001), we found no studies that showed social support and social assistance improve patient outcomes.

Conclusions

The ability of the family caregiver to provide quality care and contribute to the management of chronic disease is a vital health care resource. Health care providers should be supportive of family caregivers and help them acquire knowledge and skills in order to maximize quality care. Providers need to help family caregivers develop problem-solving, organizational, and communication skills. Some caregivers are able to carry out caregiving tasks better than others because of their knowledge, experience, level of engagement, and skills. In other situations, the complexity of care challenges caregivers.

Translating knowledge and skills into care establishes best practices. Unfortunately, our predominant mode of working with caregivers provides information only. Health professionals need to help family members acquire skills while keeping in mind cultural and ethnic differences.

Research on how interventions affect patient outcomes needs further evaluation. We need to conclude from the evidence that family caregivers are an important national health care resource and that formal interventions for caregivers are needed to achieve optimal clinical outcomes. Program planners, providers, and policymakers must work together to provide the support services needed by family caregivers.

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