

The Role of Family Caregivers for People with Chronic Illness

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A chronic disease (e.g., diabetes, cardiovascular disease, stroke, hypertension, dementia, some cancers, rheumatological diseases, human immunodeficiency virus) can occur and cycle in flare ups throughout the lifetime. Chronic illnesses, with their effect on the patient's symptoms, mood, and need for emotional and physical support, exert a burden on family members.¹⁻⁴ Additionally, families influence a patient's psychological adjustment and management of the illness, adoption of behaviors that influence recovery, functioning and adherence to treatments.⁵

The authors, a family physician and a clinical social worker, have been counseling patients and families in a variety of health care and educational settings for 30 years. We have led psycho-educational and medical groups involving patients (and their caregivers) with cancer, chronic pain, diabetes, cognitive impairment and childhood congenital and genetic illnesses. We have seen how the involvement of families and caregivers improves the quality of life for the patient, eases caregivers' burden, encourages adherence to treatments and increases patients' ability to cope with the illness. The clinician's attention to the caregiver can potentially improve family relationships and, therefore, decrease anxiety in the patient and his/her caregiver.

Family caregivers function as advocates and provide physical, emotional and financial support, frequently without any training, often without recognition or support, and rarely with financial reimbursement. Many people living with chronic illness could not live independently without family caregivers. Gail Sheehy, in *Passages in Caregiving: Turning Chaos Into Confidence*, described a want ad for a family caregiver in her wry yet poignantly accurate style:

"HELP WANTED: Untrained family member or friend to act as advocate, researcher, care manager, emotional support for a parent or spouse, sibling

or friend, who has been diagnosed with a serious illness or chronic disability. Duties: Make medical decisions, negotiate with insurance companies or Medicare; pay bills; legal work; personal care and entertainment in hospital and rehab. Aftercare at home: Substitute for skilled nurse if injections, IV's, oxygen, wound care or tube feedings as required. Long-term care: Medication management, showering, toileting, lifting, transporting, etc. Hours: On demand. Salary and benefits: 0"

Without positive reinforcement from physicians and emotional support, these essential people might not be able to function as caregivers.

An 85-year old, married woman, who had been seen by her primary care physician for 5 years, suffers from chronic pain, fibromyalgia, anorexia and weight loss, multiple chemical sensitivity syndrome, chronic gastric problems with severe gastroesophageal reflux disease, irritable bowel and fatigue. She reports feeling helpless and emotionally overwhelmed. She and her husband do not have children or living siblings, but she reports she has a positive, long-term marriage and relies heavily on her husband for support. Her provider has diligently responded to her concerns and treated her illness appropriately. However, the physician had never met this patient's husband and had no understanding about his actual care-taking responsibilities and the impact of his wife's chronic illness on their relationship. The physician encouraged his patient to bring her husband to her next appointment. During that visit, conducted with the couple, the physician learned more about their devotedness and heard his confusion regarding her various illnesses and his consequent feelings of anxiety and helplessness. An in-depth discussion and medical educational session provided crucial information and tremendous relief for the patient's

husband. Additionally, he expressed some of his own difficulty coping with his wife's condition and she in turn shared her appreciation for his consistent support. The husband continues to attend his wife's medical appointments and participate fully in her care. While the patient's physical condition has not improved, their ability to share the experience and express their love for each other inspires both to continue their battle together.

A literature search yielded 139 articles and reviews of caregivers of chronically ill persons, including previous reviews and controlled studies from 1996-2010.⁶ There are very few well-designed randomized controlled quantitative studies documenting the outcomes of interventions for the caregivers.⁷

The effect on family caregivers across most chronic illnesses can be grouped into changes in social, economic, physical and mental status.⁷⁻¹⁰ The burden of care is one of the main consequences for family caregivers with chronic or progressive illness.¹¹⁻¹⁴ This burden may lead the caregiver to postpone his/her own needs.¹⁵ The patient's close family members may experience poor psychological well-being (depression, anxiety), decreased satisfaction in relationships, caregiver burden and poorer physical health.⁷ A recent large retrospective cohort study concluded that male partners of women breast cancer patients had a significant increase in major depression, resulting in psychiatric hospitalization. This study emphasized the importance of screening for depression and providing psychological treatment for the caregivers of breast cancer patients, and may have implications for family caregivers of people with other chronic illnesses.¹⁶ Poor self-esteem, difficulty with intimacy, criticism and over-protective or solicitous behaviors have been linked with consequent changes in the family structure when a family member has a chronic illness. These have been observed in heart disease and stroke.⁵ In patients with cardiovascular disease, hypertension, myocardial infarct-

tion, dementia or stroke, Campbell and Patterson found that the most promising family interventions were psychosocial approaches. In patients with dementia and stroke, caregiver interventions may help the mental health of caregivers and delay nursing home placement.¹⁷ Other reviews have been descriptive not quantitative, focusing on family member outcomes of frail adults and patients with dementia. Quantitative reviews have generally revealed minimal effect on reducing caregiving burden and negative mood.⁵

In a literature review from 1997-2007, Glasdam et al looked at caregivers for adults with strokes, diabetes, cardiovascular disease and cancer; they found 32 controlled studies with 29 of them randomized. In 10 of the 32, the interventions had no effect. In 22 the interventions had some effect on burden reduction, increased knowledge and mastering skills.⁷ In another review, family members felt less burdened, depressed and anxious when the intervention focused on the relationship between the patient and the caregiver.⁵ The vast majority of family interventions combined psychosocial or behavioral approaches. The most common combinations were education with emotional support and emotional support combined with skills training.^{5,7} Overall, more work is necessary to track longitudinal outcomes for family members, including the greater risk for mortality in caregivers.¹⁸ In each illness studied, the impact on the female caregivers was greater than on male caregivers,^{7,10} perhaps because men more readily accepted help from family members and also relied on community resources.^{11,19}

Without the multitude of unpaid family caregivers, many people would live in institutions. How can we as a society provide education and support for these caregivers? We'd like to propose some intervention tools to assist the medical team in assessing the needs of family caregivers.

First, the team should include the patient and her/his support system as active members. Initiating a discussion with the patient regarding the specifics of her/his care out of the office setting and encouraging the patient to include identified family/friend caregivers in future visits can be a first step. It may also be important to assess the patient and caregiver's cultural and spiritual connections and

beliefs, community organizations she/he's involved with, and hobbies. Conducting family meetings, referring to community support groups, web-based education, computerized chat rooms and referral for concrete resources (e.g. financial, medications, respite, etc.) as well as suggesting basic relaxation techniques, visualization, massage, or a referral to psychotherapy should also be considered.

In the many instances where the family physician also treats the caregiver, that physician may already know about the caregiver's support network and coping strategies. But what *should* the physician's role be with the caregiver who is not his/her patient? By asking the caregiver how she/he's doing (coping, managing) the physician demonstrates empathy and acknowledges the role of the caregiver. The physician needs to help the caregiver identify the importance of maintaining her/his own well-being by learning effective self-care techniques, to reduce caregiver burden, stress and burnout.

The shortcomings regarding the evidence-based studies should drive future research for randomized controlled designs, but should not diminish the body of qualitative and observational studies that do address the impact of illness on caregivers. The current studies are inconclusive about what interventions are most effective for caregivers. The most common interventions described combine education with emotional support, emotional support with skills training, and education with emotional support and skills training. Other approaches have been health care planning, structured exercise programs and temporary transfer of patient care to a community care setting, home visits by nurses or social workers, telephone contact, education and teaching, counseling and videotaped information about community resources and coping techniques.⁸ Clearly, however, for as many different diseases, family constellations and situations, there are at least as many options for intervention.

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