

Family Caregivers of Elderly Patients With Cancer: Understanding and Minimizing the Burden of Care

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With the number of older persons with cancer growing, and with the shift from inpatient to outpatient treatment, the importance of informal caregivers continues to increase. Caregivers provide essential and unpaid support for patients that healthcare systems cannot provide, and they should be recognized as a valuable resource. Most informal caregivers of patients with cancer are family members, who may not be prepared for, or have the resources and energy to meet, the needs of the patient [1]. Caregiving can be highly rewarding, but it can also be burdensome and pose a risk for depression, anxiety, and sleep disruption [2–4]. The benefits of caregiving can be maximized and the drawbacks minimized by proper intervention and guidance from healthcare professionals. This article reviews the stressors of cancer caregiving and their potentially negative effects and discusses interventions that can help caregivers cope with their responsibilities.

Role of Caregivers and Challenges of Caregiving

The diverse needs of elderly patients with cancer reflect the diversity of the experience with cancer in later life. Older patients with cancer differ greatly in physiologic age, frailty, and cognitive ability, and they may be treated for palliation, cure, or remission [5]. The degree of physical impairment due to the disease and its treatment differs considerably, so that the demands of caregiving range from minimal assistance with activities of daily living to the complete care of highly debilitated patients. Caregiving can also involve administering

Abstract Family caregivers play an essential role, usually unpaid, in caring for patients with cancer. Most older patients with cancer are cared for by a family member, who may not be prepared for the challenges. The needs of older patients are diverse and may include assistance with medication, transportation for treatment, activities of daily living, and emotional support. The activities that caregivers find most stressful include helping patients with their self-care, managing their treatment and symptoms, and dealing with the suffering of a family member. Families may be affected by other stressors, such as changes in roles and employment and disruptions in schedules (eg, frequent clinic visits). Caregivers respond to these stressors differently; older spouses may be particularly vulnerable because of their own frailty. There can also be negative effects on caregivers' psychological, social, or physical health functioning. Social and economic deficits due to caregiving may include lifestyle disruption, less socializing, and greater out-of-pocket and lost productivity costs. Studies have shown, however, that caring for an older person with cancer also has rewards, such as satisfaction and a greater sense of self-worth. The negative aspects of caregiving can be lessened by psychological support and assistance in problem solving from healthcare professionals. Caregivers should also be provided with options to reduce the stress of frequent clinic visits, such as using long-acting growth factors or telephone triage. Educating caregivers on pertinent aspects of cancer management and the community resources available to them can be done through individual contact with health professionals or through more-formal educational programs.

medications, managing side effects, and providing nutrition. Caregivers may also have to accompany patients on frequent clinic visits for treatment, as well as for the management of adverse events [6, 7]. Patients may require care for a short time or a long time, and in many cases caregiving ends with the death of a loved one, which is followed by the stress of bereavement [1]. Caregivers may have to take part in stressful end-of-life decisions, such as whether to use a hospice or other palliative care programs and even whether to terminate life support [8], while remaining a source of emotional support to the patient. The role of a caregiver may extend to reporting the patient's physical symp-

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toms, especially if the patient has dementia, depression, or hearing impairment, and training may be required for accurately assessing symptoms [9].

The stressors that are particularly burdensome to caregivers include managing physical care, managing symptoms and treatments [10], giving emotional support [11], dealing with fear and uncertainty about the disease, and watching the patient suffer [12]. Helping patients with personal tasks, such as washing and eating, appears to be more stressful to caregivers than helping with non-personal tasks, such as grocery shopping [13]. Caring for patients with comorbidities and cognitive impairments such as delirium [14] may be particularly challenging.

The secondary stressors of caregiving include disruptions in the caregiver's schedule, which may affect the caregiver's employment [10, 15, 16]. Home care may be more cost-effective and convenient than inpatient care, but limited finances and a lack of transportation to treatment sites pose problems for many caregivers [15]. Establishing a primary support person may change the distribution of responsibility within a family, prompting family members to adapt their roles to maintain daily household functioning [17]. A perceived lack of support from other family members can be a major source of distress for primary caregivers [15].

People respond differently to the stress of caregiving: Some find the experience burdensome and may suffer depression or poor health, and others report minimal negative effects and may even find benefits in it [18]. In general, having greater social support and personality traits such as optimism and problem-focused coping are related to more-positive reactions to the stresses of caregiving [16, 19]. Spousal caregivers of older patients may be particularly vulnerable to the negative effects of caregiving, such as fatigue and sleep disruption, because of their own old age, poor health, and willingness to suffer to care for their partner [20–22]. There is evidence that women caregivers report greater strains of caregiving [10] and more depression [3] than men.

Consequences of Cancer Caregiving

Most research on the consequences of providing informal care has focused largely on intensive caregiving for elderly patients with Alzheimer's disease and other forms of dementia. Not all stressors in this type of care overlap with the stressors in cancer care, so generalizations are of limited benefit [18].

MENTAL HEALTH

Research shows that most family members of elderly patients with cancer do not have clinically problematic emotional distress [23]. Other studies have found, however, that depression is greater in cancer caregivers than in the general population, particularly in those who care for patients with severe illness or terminal illness [3, 24]. A recent study in female caregivers of adults with advanced-stage cancer, age-related dementia, or AIDS found that the groups were similar in depressive mood but that cancer caregivers had more anxiety and trouble staying asleep [2]. Research suggests that patients' behavioral problems, pain, and mood disturbances are more likely to be related to the depression and burden of their caregivers than to their own physical impairment [4, 25–27].

PHYSICAL HEALTH

Stress may have a negative effect on the function of the immune system, blood pressure, and lipid profiles of caregivers [28–33], and high levels of stress in elderly spousal caregivers may be a risk factor for death [34]. In a study in caregivers of terminally ill patients with lung cancer, spousal caregivers reported lower perceived health than matched non-caregiver controls [3].

SOCIAL AND ECONOMIC COSTS

The caregivers of patients with cancer have reported negative social consequences, including disruptions in their routines, less socializing, and a sense of interpersonal loss [24, 35], consistent with the findings in studies of caregiving in the broader literature. Caregiving takes away time that might otherwise be spent in paid employment. The average amount of caregiving for patients aged 70 years or older with cancer was recently estimated at 10 hours per week, which translates to \$1,200 per patient per year and just more than \$1 billion nationally [36]. Additionally, out-of-pocket expenses for cancer care must be borne by patients, their caregivers, or their families. Accompanying patients on frequent visits to treatment sites may be a significant drain on finances, because transportation and meals away from home can be major non-reimbursable costs [37–39].

SUSTAINED COSTS AFTER BEREAVEMENT

The end of caregiving when the patient dies may bring relief, in particular to those caregivers

who have been highly stressed [40]. Some, however, may be depressed and lonely for years afterward, in particular those with low levels of social support and high levels of repetitive thinking about caregiving [41]. A recent study found that the unrelieved mental distress of patients with cancer during the last 3 months of their lives increased the likelihood of their surviving partner's having long-term psychological morbidity [42].

BENEFITS

Caregiving can have serious negative consequences, but it can also have rewards—greater self-esteem, satisfaction, personal growth, meaning and purpose in one's life, and gratitude for being able to reciprocate care [3, 43, 44]. A study in 34 long-term survivors of testicular cancer and their wives showed that the marital relationships of the majority of them were strengthened by the experience, with greater intimacy, communication, and sensitivity to one another's feelings [45].

Strategies to Minimize the Negative Effects of Caregiving

Healthcare professionals, including nurses, social workers, and psychologists, can have a positive effect on caregivers' well-being by providing emotional support, information, and advice for solving problems. Establishing a rapport with caregivers can make it possible to discuss difficult or stressful topics. Because caregivers may feel unappreciated, they should be encouraged and praised for the valuable services they provide [46].

Research has found that caregivers are frequently unprepared for their role and would like much more guidance and support from healthcare professionals [47]. Important areas for education are preparing for and managing caregiving, the disease, its treatment, its symptoms, and medications [46]. Educational programs in pain management can improve caregivers' knowledge about and attitudes toward this particularly distressing aspect of caregiving [48]. Caregivers may not be aware of the community resources that are available, such as respite care, support groups, and individual counseling, which can help when the immediate family and friends cannot meet the patient's needs [48, 49].

Healthcare professionals can help identify and prioritize caregivers' problems and develop strategies for solving them. Behavioral interventions, such as teaching new coping skills, may be neces-

sary to reduce caregiver distress [46]. Formal educational programs on cancer and caregiving taught by healthcare providers are valued by family caregivers. For example, after a 6-hour Family Caregivers Education Program that taught skills such as communication, symptom management, and resource identification, the participants reported feeling less overwhelmed, more knowledgeable, and better able to cope with caregiving [50].

A number of interventions have been successful in reducing the psychological distress of caregivers of terminally ill patients with cancer. Strategies such as specialized oncology home services [51] and transmural care that focuses on communication and continuity of care [52] have produced sustained benefits for the duration of the studies.

To reduce caregiver stress, physicians should discuss options for home care that minimize the time spent traveling to treatment sites. The number of clinic visits required may be reduced by better management of treatment-related adverse events, for example, by telephone triage or by using long-acting growth factors for supportive care [6, 53–55]. Studies with medications that decrease the frequency of dosing, such as the long-acting form of the antipsychotic drug risperidone (Risperdal), have shown that fewer clinic visits reduces the inconvenience for patients and caregivers, with marked increases in patient adherence to treatment [56, 57].

Primary caregivers must deal with the logistics of caregiving in addition to watching the suffering, and possibly the loss, of a friend or family member [24]. Dividing household management and caregiving tasks among relatives can help in sharing the burden and relieving the primary caregiver of some stress.

Conclusions

Our society needs to recognize informal caregivers as a valuable resource. The innate emotional, physical, and practical resources of caregivers may not always meet the needs of the patient. Studies of the demands of providing care for older patients with cancer are few, but they do indicate that caregiving can have a negative effect on the caregiver's mental and physical health and can entail social and economic costs. Assistance and information from healthcare professionals are the key to improving the ability of caregivers to cope with caring for older patients with cancer.

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