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Editorial

The Full Burden of Cancer

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Each year, >1.4 million people are diagnosed with cancer in the U.S. [1]. To match this staggering statistic, substantial resources are devoted to research the causes, treatments, and outcomes of cancer. The budget for the National Cancer Institute was $5.1 billion in fiscal year 2010 [2]; other federal government agencies, states, the pharmaceutical industry, and private foundations provide substantial support for cancer research as well. As a result of these efforts, we now have a much better understanding of the causes of cancer than we did when the war on cancer was first declared almost 40 years ago. More importantly, researchers have identified new treatments that have led directly to improvements in outcomes.

It is understandable that the vast majority of cancer-directed research focuses on the disease and the patients who suffer from it. Yet the number of families, friends, and loved ones impacted by a cancer diagnosis certainly exceeds the number of people actually diagnosed with cancer. Unfortunately, we know relatively little about the consequences of a cancer diagnosis for family, friends, and loved ones. These individuals play a critical role as informal caregivers. Whereas informal caregivers are an essential part of a cancer patient's care and have the potential to substantially impact a patient's quality of life, they also experience psychological and emotional distress, disruption of their daily routine of work and family life, and financial hardship as they dedicate substantial amounts of time to the care of another person.

In this issue of ***The Oncologist***, Van Houtven and colleagues [3] strive to advance our understanding of the economic impact a cancer diagnosis has on the informal caregiver. They surveyed caregivers of patients diagnosed with lung and colorectal cancer who participated in the Cancer Care Outcomes Research and Surveillance (CanCORS) consortium study [4]. Caregivers reported the number of hours spent providing care in a typical week, their hourly wage, and their direct expenditures on cancer care. Using this information and knowing the number of weeks that had elapsed from the cancer diagnosis to the survey date, the authors estimated that the total economic burden experienced by informal caregivers was $14,060 per year per cancer diagnosis.

The caregiver survey was conducted according to a prescribed schedule—either 6–12 months or 12–24 months after the patient's cancer diagnosis. To determine whether the economic burden of informal care varied by phase of illness, caregivers were stratified into three groups based on when the survey occurred relative to the patient's diagnosis and, if appropriate, death. Caregivers surveyed ≤1 year from diagnosis but not within 6 months of death reflected care provided during the initial phase of illness. Caregivers surveyed within 6 months of death reflected care during the

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terminal phase of illness. All others reflected care during the continuing phase of illness.

When comparing informal care provided during the initial and continuing phases of illness, there are more similarities than differences. The type of cancer was relatively evenly split between lung and colorectal, the stage distribution reflected that seen for the full sample, and the numbers of caregiving hours per week were similar (15.3 hours versus 15.0 hours). The most prominent difference was the amount of time from diagnosis to survey—29.9 weeks for the initial phase group versus 71.5 weeks for the continuing phase group. As a result, the total economic burden was 2.8 times greater for the continuing than for the initial phase group ($19,701 versus $7,028). However, the economic burden per week of care provided was relatively similar for the two groups ($276 per week versus $235 per week; 1.2 times greater for the continuing phase group).

Informal care provided to patients in the terminal phase of their illness stood out. These patients were older, more likely to be male, more likely to have lung cancer, and more likely to have stage IV disease. The average time from diagnosis to survey was 37 weeks (the assumed duration of informal caregiving). Informal caregivers devoted 24.5 hours per week to caregiving activities—many more than the 15 hours per week dedicated to caregiving during the initial or continuing phases of illness. The total economic burden of informal care during the terminal phase of illness, $14,234, was greater than the burden during the initial phase but less than the burden during the continuing phase. After adjusting for the duration of care provided, the economic burden during the terminal phase was $385 per week (1.4 times that of the continuing care group and 1.6 times that of the initial care group). Not surprisingly, individuals who provided care during the terminal phase of an illness were more likely to report symptoms of depression.

In addition to the economic burden associated with informal caregiving activities, this analysis provides important information regarding the characteristics of caregivers and the care they provide. Approximately two thirds of caregivers were spouses, 76% were female, 42% were >65 years of age, and half were employed. Regardless of the type of cancer or phase of illness, caregivers provide a substantial amount of support—16 hours per week on average. To find time to provide this assistance, employed caregivers used a mix of sick time, vacation time, and unpaid leave. A relatively small percentage of informal caregivers (13%) paid others to help them provide care; these paid caregivers assisted with independent activities of daily living, activities of daily living, or other skilled/hospice services.

The findings from the study by Van Houtven and colleagues reinforce those reported elsewhere—that cancer can have substantial psychological and financial impacts on family and caregivers. A survey of 310 caregivers of cancer patients from Korea found that 67% had responses on a survey that indicated a diagnosis of depression [5]. In 2006, the *USA Today*, the Kaiser Family Foundation, and the Harvard School of Public Health surveyed a representative sample of 930 adults from households across the U.S. in which a family member had been diagnosed with or treated for cancer in the past 5 years [6]. Ten percent of those approached for the survey reported living in just such a household. Nearly half of all respondents (and 68% of the uninsured) reported that the costs of cancer care were a burden; 36% were unable to do their job as well as before, 25% used up most or all of their savings, 11% were unable to pay for basic necessities (e.g., food, heat, or housing), 11% sought the aid of charity or public assistance, and 3% declared bankruptcy.

CanCORS patients who reported that they did not need or had not received informal care at the time of the survey were excluded from this analysis. Consequently, the estimates of economic burden reported by Van Houtven and colleagues only reflect the experiences of households where informal caregiving occurred. That having been said, only 13% of individuals who were nominated as caregivers by patients with newly diagnosed cancer enrolled in the CanCORS study were excluded for this reason. Moreover, it is likely that these results underestimate the true economic burden associated with informal caregiving. Only one caregiver was surveyed for each cancer patient; in many households, it is probably not uncommon for multiple family members to pitch in if help is needed. Most importantly, dollar figures do not tell the full story. Caregivers who have relatively low wages report relatively small values when estimating the loss of income associated with missed work, but for economically disadvantaged populations even small reductions in income can lead to substantial hardship.

Being diagnosed with cancer is a traumatic event, and negotiating the complexities and complications of cancer treatment can be especially daunting. When faced with these challenges, most family members likely view the caregiving role as a responsibility, not a choice. Because informal caregiving is a vital part of cancer patient management and providing this care incurs substantial burden for the caregiver, it is important to consider what can be done to minimize this burden. The Family and Medical Leave Act of 1993 requires that employers grant eligible employees up to 12 weeks of unpaid leave during any 12-month period for the care of an immediate family member with a serious health condition. In some states, Medicaid will directly pay a person needing home care, and that person can use the money to pay a family member to provide the care. Many cancer centers have introduced patient navigator programs. Navigators help guide cancer patients who lack substantial family support through the health care system and allow such patients to receive the best possible care [7–9]. These are all steps in the right direction, but they only scratch the surface. New policies, enhanced support programs, and additional resources are needed to help alleviate the burdens of cancer—those that are obvious as well as those that are frequently overlooked.

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