

The Costs of Cancer

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National Cancer Survivors Day traditionally is held in June, and we have much to celebrate. People are diagnosed with cancer earlier and are living longer than ever before. However, many costs are related with that progress. As oncology nurses, we are very aware of the physical and emotional costs of cancer—we see it every day—but we don't see some of the other costs that our patients and their families pay. We don't see them at home reviewing their medical bills. We don't see them return to work and try to resume their responsibilities. Two recent reports give us a glimpse into what that looks like.

Most people have health insurance as a benefit of employment, but most of us likely don't really know what would be covered if we were diagnosed with cancer. You are probably under the assumption that your insurance would cover all of your cancer care costs. A recent report from the Kaiser Family Foundation and the American Cancer Society explored some of those assumptions (Schwartz, Claxton, Martin, & Schmidt, 2009). The report identified five ways in which cancer creates financial burden for families.

- High cost-sharing, capitations on benefits, and lifetime maximum benefits leave patients vulnerable to high out-of-pocket healthcare costs.
- People who depend on employer-provided health insurance may not be protected from catastrophically high healthcare costs if they become too ill to work.
- Patients and survivors often are unable to find adequate and affordable coverage in the individual market.
- Although high-risk pools are designed to help patients and others who are uninsurable, these plans are not available

to all patients and some premiums are too high to afford.

- Waiting periods, strict restrictions on eligibility, or delayed application for public programs can leave patients who are too ill to work without an affordable insurance option.

Some of the “invisible” out-of-pocket expenses routinely incurred include copayments, medications, transportation costs, new or additional family and living expenses, and lost wages. Until recently, many insurance companies would not pay for experimental therapies, including clinical trials sponsored by the National Institutes of Health. As a result, half of all personal bankruptcies in 2005 were related to medical expenses (Himmelsstein, Warren, Thorne, & Woolhandler, 2005). Regardless of insurance status, medical debt is a significant and common problem (Seifert & Rukavina, 2006). Yet how many of us work in settings that routinely screen for these issues? Do we ask our patients and their families how they are managing financially? Do we make referrals to available resources? Do we even know what resources are available within our practice settings, locally and nationally? The Lance Armstrong Foundation (www.laf.org), the Patient Advocate Foundation (www.patientadvocate.org), and CancerCare (www.cancercare.org)

all provide information and services addressing some of these issues.

Because most private insurance is linked to employment, who regularly assesses for work status and issues related to work in cancer care settings?

We need to better understand how financial burdens and employment concerns converge to create additional problems for cancer survivors as they reclaim their lives.

In a meta-analysis and meta-regression, cancer survivorship was associated with higher unemployment when compared to healthy, age-matched controls (de Boer, Taskila, Ojajarvi, van Dijk, & Verbeek, 2009). Although the report suggested that fewer cancer survivors are employed, the reasons for unemployment are unknown. Is it because of fatigue or other long-term issues? Is subtle (or not so subtle) discrimination occurring in the workplace based on the survivor's diagnosis?

Pediatric oncology nurses assess for school issues and activate programs for school-aged children with cancer. Why don't we have similar programs for adults who are working during treatment or returning to work after treatment? Have you asked your patients if they are having any work-related problems or want someone to speak to their employer? Are you familiar with the provisions of the

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newly revised Americans With Disabilities Act and how that might be helpful (U.S. Equal Employment Opportunity Commission, n.d.)? Perhaps we need to better understand how these issues—insurance and working—converge to create additional problems for cancer survivors as they reclaim their lives but find themselves with new financial burdens and employment concerns.

While we celebrate National Cancer Survivors Day this month, let us remember all the costs of having cancer. Identifying those costs raises many health policy issues that are longer-term problems (e.g., system of employment-based health insurance, adequacy of insurance coverage for cancer care), but we can intervene for those in our care now to reduce this burden. Think about what you can do to identify those who are having financial or work issues related to their cancer. Find out more about what resources are available and then

make the referral. You will do much for relieving some of the cancer burden they face.

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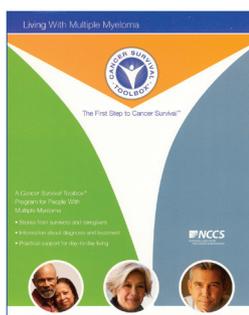
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NCCN Releases a Free Multiple Myeloma Program



The National Coalition for Cancer Survivorship's Cancer Survival Toolbox® Program for People With Multiple Myeloma is a free, self-learning audio program designed to help people develop skills to better meet and understand the challenges of

multiple myeloma. The program contains a set of basic skills to help navigate a diagnosis and special topics on key issues faced by people with cancer.

Access the program in English and Spanish online at www.canceradvocacy.org/toolbox. Chinese transcripts are available. Or, order a free CD version of the program by filling out an online form or calling 877-NCCS-YES.

Join in to support Nutrition Day in the U.S., an annual benchmarking of nutritional status among hospitalized patients

Up to 55% of hospitalized patients are undernourished or at risk. Many have found that it is a variable associated with poor healing, higher complication rates, as well as higher rates of morbidity and mortality and ultimately higher costs to health care.

nutritionDay in the U.S., supported by the American Society for Parenteral & Enteral Nutrition and part of a global initiative, addresses improved patient safety and quality of care by raising awareness and increasing knowledge about disease-related malnutrition. To participate in data collection on **November 5, 2009**, contact:

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