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# The Hidden Costs of Cancer Care: An Overview With Implications and Referral Resources for Oncology Nurses

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In 1971, President Nixon signed the National Cancer Act, which expanded the mission of the National Cancer Institute (NCI) and released major resources for a national cancer program. The budget was to be submitted directly to the president, bypassing traditional approval pathways. Some of the act's goals were to (a) expand the physical plant at the National Institutes of Health, as well as cancer research facilities across the country; (b) award research contracts and grants; (c) collaborate with other federal, state, or local public agencies and private industry and develop numerous partnerships with private industry; (d) conduct cancer control activities such as antismoking, diet, and lifestyle campaigns; (e) increase early detection of cancer; and (f) establish an international cancer research database to collect, catalog, store, and disseminate results of cancer research undertaken in any country (NCI, n.d.).

This increased attention and funding, along with a desire on the part of numerous disciplines to specialize in oncology, led to the formation of dedicated oncology teams around the country and the founding of several seminal organizations such as the Oncology Nursing Society (ONS) and the Association of Oncology Social Work (M. Alex, personal communication, September 10, 2003). As a result, by the mid-1970s, earlier diagnoses, more effective treatments, and improved survival rates were being reported for patients with cancer (M. Alex, personal communication, July 29, 2003).

Since the 1970s, remarkable advances have been made in the early diagnosis, treatment, and survival rates of patients with cancer. This has coincided with rapid changes in the healthcare industry. As cancer has been transformed into a chronic disease that generally is treated in the outpatient setting, the financial burden on patients with cancer and their families has grown. Insurance premiums, deductibles, copayments, transportation, lost income, and miscellaneous out-of-pocket expenses are just some of the hidden, nonreimbursable costs that significantly affect the financial stability of families over time. In addition, certain populations are at greater risk of financial burden, which may affect compliance with treatment as well as patient outcomes. This article presents an overview of these hidden costs, with implications and referral resources for oncology nurses. Healthcare providers have a responsibility to assess their patients for financial need and assist them in accessing resources.

**Key Words:** economics, health resources, resource allocation

Although this was cause for celebration, researchers began to examine the personal financial burden of a cancer diagnosis on patients with cancer and their families. In an early study, Lansky et al. (1979) found it to be a "major source of distress, second only to the disease itself. Of the financial concerns, nonmedical costs appear to be the most troublesome" (p. 403). Jansen, Halliburton, Dibble, and Dodd (1993) reported that, in their study, financial concerns were consistently among the five most often discussed issues and posited that finances may be a universal problem for families experiencing cancer.

Since the 1980s, many changes have occurred in the delivery of cancer care in the United States (Summers & Chisholm, 1997). Much of the public policy debate has focused on the uninsured and how to best fund and allocate finite healthcare resources (Anderson, Reinhardt, Hussey, & Petrosyan, 2003; Gorey, 1999; Rasell, Bernstein, & Tang, 1994; Seccombe & Amey, 1995). However, the mere possession of health insurance does not protect patients with cancer from the devastating financial consequences of their disease (Berkman & Sampson, 1993; Blendon et al., 1994; Given & Given, 1996; Gross et al., 1999; Jones, 2000; President's Cancer Panel, 2002; Short & Banthin, 1995). Oncology nurses may become aware of these problems over the course of a patient's treatment. However, given the time constraints and lack of available resources, particularly

in freestanding ambulatory settings, nurses often feel ill equipped to assist these patients. Ideally, all patients with cancer would be assigned an oncology caseworker to help them navigate the system, but if this is not done, healthcare providers must assess patients to determine their financial burden and inform them about any and all available resources (Given & Given; Given, Given, & Kozachik, 2001; Glajchen, 1994; Jones).

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