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. Allex, personal communication, July 29, 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. Allex, 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. Allex, personal communication, September 10, 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

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, Dible, 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, & Petroysan, 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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Changes in Healthcare Financing and Delivery

Increasingly complex cancer care treatment is being delivered in the outpatient setting, and as a result, “Families are now providing the majority of supportive and continuing cancer care” (Given & Given, 1996, p. 93). The impetus for this initially came from a desire by payors and policymakers to cut costs and deliver care more efficiently, but patients also have experienced benefits. Summers and Chisholm (1997) reported that not all patients need or want to be hospitalized. Remaining at home, continuing to work, and maintaining usual sleeping and eating patterns contribute to an enhanced quality of life for patients with cancer. The risk of nosocomial infections also is decreased. The role of the family caregiver, however, has become more complicated and includes patient monitoring, symptom management, proper use of sophisticated equipment such as infusion pumps, patient transport, and patient advocacy. Expenses that formerly were reimbursed or included in inpatient care are now patient responsibilities (Berkman & Sampson, 1993; Moore, 1998). As cancer evolves into a chronic disease, these expenses become long-term burdens that can have a major impact on family finances (Given et al., 2001; Jones, 2000). The variable nature of the disease trajectory also calls for a continual reevaluation of patient and family needs (Bried & Scheffler, 1992; Given et al., 2001; Given & Given; Houts et al., 1988; Jones).

At-Risk Populations

Lower socioeconomic status is associated with lower cancer survival rates. How much of this is related to ethnicity is not clear because some evidence suggests that educational level and type of cancer also are factors in survival. Socioeconomic status is influenced by insurance status and occupation and may affect provider attitudes toward patients with cancer (Greenwald, Borgatta, McCorkle, & Polissar, 1996). Still, African Americans continue to experience higher incidence and mortality rates for many cancers than any other ethnic group, despite some decrease in mortality from all cancers from 1992–1999 (American Cancer Society, 2003a, 2003b).

Certain patient populations are at much greater risk for financial burden; therefore, healthcare providers must identify them as soon as possible and link them with needed services early in the disease process (Given & Given, 1996; Glajchen, 1994; Guidry, Aday, Zhang, & Winn, 1998; Jones, 2000; Summers & Chisholm, 1997). Although the poor are obviously at risk, the working poor and middle classes that do not have significant assets and are dependent on earned income also are vulnerable to loss of income and employment (Berkman & Sampson, 1993; President’s Cancer Panel, 2002; Secombe & Amey, 1995; Underwood, Hoskins, Cummins, Morris, & Williams, 1994). Short and Banthin (1995) calculated the risk of being underinsured using a linear regression involving age, race or ethnicity, gender, income, perceived health status, disability days, and limitation of usual activity. The researchers concluded that, in any given year, nearly one-third of the U.S. population younger than age 65 is not adequately insured. This was attributed to unusually limited insurance policies or standard policies whose cost-sharing provisions represent a large percentage of family income.

In 2002, 16.1% of the U.S. population younger than 65 had no health insurance coverage, 27.8% of families with incomes at or below the poverty level were uninsured, and 27.4% of the “near poor” (i.e., families with incomes of 100% to less than 200% of the poverty threshold) had no health insurance coverage (Cohen, Ni, & Hao, 2002). Patients’ concerns related to lacking health insurance coverage or being underinsured have been documented since the early 1980s. Out-of-pocket expenses; the need for services such as meal preparation, housekeeping, and home health care; and the unavailability of family caregivers because of their need to work have stressed many families with cancer (Houts et al., 1984, 1985, 1988; Houts, Yasko, Kahn, Schelzel, & Marconi, 1986; Mor, Guadagnoli, & Wool, 1987).

Emanuel, Fairclough, Slutman, and Emanuel (2000) found that low income, older age, poor physical function, and incontinence, none of which can be modified easily, were associated with significant care needs and economic burdens. Living in a rural area also is a barrier to care access that may require substantial time, money, and effort to overcome (President’s Cancer Panel, 2002).

Emanuel et al. (2000) noted that being female was independently associated with unmet care needs. Stommel (1992) examined the cost of cancer care to families in relation to living arrangements, labor force participation, and household arrangements. He stated that cancer increasingly is a disease of the aged and women, and because more women have professional careers, a cancer diagnosis may put them at a serious competitive disadvantage. Moore (1997) considered employed women who are single heads of households to be at increased risk of unmet care needs and financial burden. Bried and Scheffler (1992) included “elderly, single, or widowed women; persons living alone; those over 85 years of age; and minorities” (p. 154) in the high-risk category. Given the tendency of women to serve as family caretakers, have lower incomes, and have a longer life span than men, these issues are likely to become significant as the female population ages (Given & Given, 1996).

Defining and Measuring Hidden Costs

Several problems are evident when studying the hidden costs of cancer care (Pearce, Kelly, & Stevens, 2001). For example, comparing different variables is problematic (see Table 1). Most researchers include insurance copayments, deductibles, and out-of-pocket medical expenses, whereas others include nonmedical out-of-pocket expenses incurred as a direct result of the disease such as transportation, food, lodging, child or elder care, housekeeping assistance, wigs, ostomy supplies, prostheses, and assistive devices. Expenses that must be paid immediately and are not reimbursable are particularly onerous.

Transportation consistently is named as a significant source of out-of-pocket expenses and a barrier to care (President’s Cancer Panel, 2002). In fact, Murphy et al. (1993) described a New York City radiology practice that began to give brachytherapy immediately after surgery so that patients could avoid daily trips into the city and high parking costs.

Lost wages are somewhat measurable, but estimating the cost of lost promotions and career advancement possibilities for patients and their caregivers is almost impossible. In addition, the effect of “job lock” that Glajchen (1994) defined as the inability to leave a position for fear of losing insurance coverage is not easily calculated. If the unpaid labor of family caregivers was included in cost estimates, the cost of caring for a patient with cancer at home would approximate that of nursing home care (Stommel, Given, & Given, 1993).

The reliability and validity of data collection tools often are not addressed (Pearce et al., 2001). Other limitations include small sample size, convenience sampling, subjects with only one type of cancer or those from a limited geographical area, and reliance on patient report and/or memory. Even studies with larger samples are prone to selection bias or less-than-accurate patient reporting.
<table>
<thead>
<tr>
<th>Study</th>
<th>Research Design and Sample</th>
<th>Financial Variables</th>
<th>Significant Conclusions</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lansky et al., 1979</td>
<td>Questionnaires and data collected over one week at three-month intervals; 70 patient families</td>
<td>Food, lodging, transportation, family care, clothing, miscellaneous disease-related costs, and lost wages</td>
<td>Transportation, food, and miscellaneous items were the largest categories; level of care, performance status, family size, and distance from the treatment center explain 47% of variability of expenses. Half of the families responding to the lost-work survey reported lost income.</td>
<td>Only limited funds are available to assist with nonmedical, out-of-pocket expenses. Families may be faced with long-term financial hardships that even the best social work services and financial counseling cannot overcome.</td>
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<td>Houts et al., 1984</td>
<td>Patient diaries recording out-of-pocket expenditures during treatment and non-treatment weeks; 139 outpatients undergoing chemotherapy</td>
<td>Food, transportation, lodging, family care, clothing, telephone, miscellaneous disease-related costs, and lost wages</td>
<td>Distance from the treatment center is related to higher out-of-pocket expenditures; patient age and marital status are positively related to higher loss of wages. Lower-income patients spend higher proportions of their income on out-of-pocket expenses.</td>
<td>Better data would be helpful in counseling patients about what expenses to expect.</td>
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<td>Houts et al., 1985</td>
<td>Questionnaires; 185 patients</td>
<td>Uninsured medical costs, illness-related out-of-pocket expenses, and lost wages over six months</td>
<td>Total expenses averaged $1,670; distance from treatment center, being young or male, more outpatient visits, and days in hospital correlated with higher out-of-pocket expenses.</td>
<td>Distance from the treatment center, being young or male, more outpatient visits, and days in hospital could be used by healthcare personnel for identifying patients at risk for financial hardships.</td>
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<td>Houts et al., 1986</td>
<td>Telephone interviews with a stratified random sample drawn from the Pennsylvania Cancer Registry; 629 patients with cancer and 397 caregivers</td>
<td>Unmet financial, insurance, employment, transportation, and homecare needs</td>
<td>Financial (14%) and insurance (10%) needs were the second- and third-largest categories of unmet needs; younger patients, advanced disease, low income, and a history of emotional problems were associated with more unmet needs.</td>
<td>Patients and caregivers can help to identify needs; such data can be used to estimate demand for new services. Healthcare personnel need to be alert to needs and aware of available services.</td>
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<td>Mor et al., 1987</td>
<td>Interviews; 217 patients with advanced cancer</td>
<td>Physical, instrumental, and administrative needs</td>
<td>87% noted an increase in monthly expenses, and 72% had to use savings or sell investments to meet needs. Prevalence of reported needs increased with advancing disease, and needs are interrelated.</td>
<td>Patient and caregiver age, female gender, level of education, time since diagnosis, and low income correlate with increased needs and could be used to screen for patients at risk.</td>
</tr>
<tr>
<td>Houts et al., 1988</td>
<td>Telephone interviews with a stratified random sample drawn from the Pennsylvania Death Registry; 433 family members or close friends</td>
<td>Unmet financial, insurance, home healthcare, transportation, and activities of daily living needs</td>
<td>42% reported unmet activities of daily living needs in the dying; younger patients showed greater unmet financial and insurance needs. Lower-income patients spend higher proportions of their income on out-of-pocket expenses.</td>
<td>Patients and caregivers can help to identify needs and influence planning of services; homecare services are needed. Efforts to increase use of existing programs should be made, especially where social service support is minimal.</td>
</tr>
<tr>
<td>Wingate &amp; Lackey, 1989</td>
<td>Descriptive exploratory; 10 patients with cancer, 14 caregivers, 9 nurses</td>
<td>Household management, physical, legal, and financial needs</td>
<td>Physical needs accounted for 24.6% of the total needs studied; patients, caregivers, and nurses perceived different needs.</td>
<td>Initial and ongoing assessment of patient needs with referral to appropriate resources is requisite; better measurement instruments are needed.</td>
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<tr>
<td>Jansen et al., 1993</td>
<td>Longitudinal descriptive, in-person interviews; 100 patients with cancer and 126 family members</td>
<td>Financial problems, loss of work, insufficient funds for medical care, and other expenses</td>
<td>Financial concerns were consistently among the five most-often discussed issues.</td>
<td>Financial problems were consistent over time; no differences were found based on gender or type and stage of cancer.</td>
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### Table 1. Studies Examining the Hidden Costs of Cancer Care, by Year (Continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Research Design and Sample</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Stommel et al., 1993</td>
<td>Telephone interviews or questionnaires; 192 patients</td>
<td>Out-of-pocket expenditures, labor costs of caregiver services and other family members, and lost patient income</td>
<td>Caregivers and family labor costs are substantial; when included in homecare cost calculations, home care is comparable to the cost of nursing home care. Limitations in activities of daily living are the strongest predictors of costs.</td>
<td>Policymakers need to consider whether Americans can continue to rely on family labor to cover the need for home care as cancer evolves into a chronic disease.</td>
</tr>
<tr>
<td>Blendon et al., 1994</td>
<td>In-person and telephone interviews; 1,897 households</td>
<td>Insurance status, medical bills, financial problems, and employment concerns</td>
<td>75% of patients who have problems paying medical bills are insured; Americans of all socioeconomic status are affected.</td>
<td>The need for insurance reform or some type of coverage for catastrophic illness is great.</td>
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<tr>
<td>Given et al., 1994</td>
<td>Longitudinal, descriptive telephone interviews and questionnaires; 49 breast cancer survivors, 13 deceased</td>
<td>Out-of-pocket expenditures and labor costs of primary and nonprimary caregivers (estimated market value)</td>
<td>Survivors reported a mean of $2,983 and decedents $7,290 in out-of-pocket expenses and caregiver labor costs for three months; strongest predictor of total costs is functional status of patient.</td>
<td>Because family caregiver costs are not included in the cost of care, actual costs are underestimated and may approximate nursing home care for some patients.</td>
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<td>Rasell et al., 1994</td>
<td>Microsimulation model using data from the 1987 National Medical Expenditure Survey, Consumer Expenditure Survey, and the Internal Revenue Service’s Individual Tax Model</td>
<td>Out-of-pocket spending, insurance premiums, and federal, state, and local taxes as the ultimate source of all healthcare funding</td>
<td>Out-of-pocket spending rises with use of services; low-income families bear a disproportionate burden. Income-tax–financed health care is the most progressive form of healthcare spending.</td>
<td>Equity in healthcare financing has been neglected and could be improved by making the distribution within each funding source less regressive.</td>
</tr>
<tr>
<td>Seccombe &amp; Arney, 1995</td>
<td>Data from a subset of the 1987 National Medical Expenditure Survey; 7,734 employed adults</td>
<td>Health insurance benefits among the working poor</td>
<td>The working poor are more likely to be uninsured but ineligible for public health insurance; they are disproportionately young, female, single, minority, less educated, rural, and less likely to work full-time or be unionized.</td>
<td>Reliance on employer-sponsored insurance neglects large segments of the population and should be addressed in healthcare reform discussions.</td>
</tr>
<tr>
<td>Short &amp; Banthin, 1995</td>
<td>Data from the 1987 National Medical Expenditure Survey</td>
<td>The uninsured, defined as being at risk of out-of-pocket expenses for more than 10% of family income if faced with a catastrophic illness</td>
<td>18.9% of patients younger than 65 and 61.6% of patients below the poverty level with private insurance are underinsured; these numbers increased from 1977–1987.</td>
<td>Nongroup or members of small insurance plans are at greater risk. Healthcare reformers need to take income into account when formulating insurance plans for low-income families.</td>
</tr>
<tr>
<td>Gera et al., 1996</td>
<td>Questionnaires; 40 target families and 38 comparison families</td>
<td>Illness-related out-of-pocket expenses not covered by insurance</td>
<td>Travel to treatment center (81%), meals during hospitalizations (75.7%), child care for siblings (48.6%), unpaid leave from work (59.5%), special foods (16.2%), and supplies for sick children (21.6%) were listed as out-of-pocket costs by target families; 30% had to borrow money to cover expenses.</td>
<td>The stress of having a child with cancer is increased further by the financial burden imposed by the illness. Having health insurance is not adequate protection from these out-of-pocket expenses.</td>
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<td>Guidry et al., 1998</td>
<td>Questionnaires; 242 African American, 248 Caucasian, 90 Hispanic, and 13 Asian patients with cancer in Texas</td>
<td>Problems with insurance coverage, treatment, travel, housing, parking, and drug costs; insurance copayments and lost wages</td>
<td>Many experienced coverage problems and had to forgo needed treatments; Hispanics experienced more difficulty paying for treatment and higher out-of-pocket costs; African Americans had more lost wages.</td>
<td>Healthcare providers need to be aware of the impact of out-of-pocket expenses on compliance with care, the need for insurance reform, and the need for case management of patients with cancer.</td>
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TABLE 1: STUDIES EXAMINING THE HIDDEN COSTS OF CANCER CARE, BY YEAR (CONTINUED)

<table>
<thead>
<tr>
<th>STUDY</th>
<th>RESEARCH DESIGN AND SAMPLE</th>
<th>FINANCIAL VARIABLES</th>
<th>SIGNIFICANT CONCLUSIONS</th>
<th>IMPLICATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moore, 1998</td>
<td>Cross-sectional survey; 20 patients with cancer</td>
<td>Transportation, meals, lodging, clothing, telephone, medications, insurance premiums, child or elder care, home assistance, lost wages, and quality-of-life costs</td>
<td>Out-of-pocket expenses may be more costly than previously recognized; magnitude is affected by treatment protocol, functional status, and socioeconomic status.</td>
<td>Nurses need to recognize and anticipate the hidden costs of care for patients with cancer, make referrals, and address quality-of-life issues to avoid treatment delays.</td>
</tr>
<tr>
<td>Gross et al., 1999</td>
<td>Medicare Benefits Simulation Model using 1993 Medicare Current Beneficiary Survey data; 12,000 Medicare beneficiaries; estimates of 1997 spending</td>
<td>Medicare deductibles and coinsurance, premiums for Medicare Part B, private insurance, and Medicare health maintenance organizations, non-covered services, and balance billing by physicians</td>
<td>60% of beneficiaries below the poverty level did not receive medical assistance and spent about half of their income on these healthcare expenses. Those at 100%–125% of the poverty level spent 30% of their income on these expenses.</td>
<td>Medicare reform discussions that propose shifting more costs to beneficiaries need to consider the substantial burden this population already bears and examine whether it affects healthcare use.</td>
</tr>
<tr>
<td>Moore, 1999</td>
<td>One-time survey; 30 patients with breast cancer</td>
<td>Transportation, meals, lodging, clothing, telephone, medications, insurance premiums, child or elder care, home assistance, lost wages, and quality-of-life costs</td>
<td>All patients had transportation costs; looser clothing, home assistance, and foods that could be tolerated were other significant expenses. Increased insurance premiums and telephone bills were reported by 80%, and 60% reported loss of income.</td>
<td>Reductions in healthcare service costs will not necessarily conserve costs for patients. Nurses can help families to anticipate treatment expenses and prioritize referrals for those in need.</td>
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<tr>
<td>Emanuel et al., 2000</td>
<td>In-person interviews; 988 terminally ill patients and 893 caregivers</td>
<td>Transportation, nursing care, homemaking, and personal care needs; out-of-pocket expenses more than 10% of household income</td>
<td>16.3% had high care needs for transportation, nursing care, homemaking, and personal care; their caregivers had higher rates of depression. Significant disparities were related to gender, ethnicity, age, and income.</td>
<td>Additional services are likely to be useful only if they impose no additional costs. Unskilled care that is not usually covered may address many care needs. Attentive listening by physicians reduces caregiver depression.</td>
</tr>
<tr>
<td>Calhoun et al., 2001</td>
<td>Pilot study, questionnaires; 83 patients with ovarian cancer</td>
<td>Direct medical and indirect patient and caregiver costs related to chemotherapy-induced toxicities</td>
<td>Patient and caregiver work loss, payment for caregivers, drugs, and devices were substantial out-of-pocket expenses.</td>
<td>Evaluation of direct and indirect costs is feasible, and more comprehensive studies are needed.</td>
</tr>
<tr>
<td>Hounshell et al., 2001</td>
<td>Questionnaires; 31 patients with leukemia</td>
<td>Changes in health insurance, employment, and lifestyle</td>
<td>20% took a leave of absence from work, 24.1% reported increased insurance premiums, and 63.3% incurred out-of-pocket costs.</td>
<td>Policymakers should be aware that even highly educated, middle-income patients with cancer are vulnerable to insurance coverage denials, loss of income, and out-of-pocket expenses.</td>
</tr>
<tr>
<td>Lloyd et al., 2001</td>
<td>Survey of out-of-pocket expenditures within two years of diagnosis; 51 patients and 27 caregivers</td>
<td>Lost wages; medical, rehabilitative, and nursing home expenses; alternative therapies; prosthetics; food; transportation; and lodging</td>
<td>All patients and caregivers had increased out-of-pocket costs and loss of wages after diagnosis and experienced substantial personal financial costs related to their disease.</td>
<td>Having private insurance did not adequately protect patients from the financial demands of cancer care.</td>
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</table>
Those using government-generated statistics (Gross et al., 1999; Rasell et al., 1994; Secombe & Amey, 1995; Short & Banthin, 1995) often rely on economic models to project need. Unfortunately, these do not always precisely agree with what is being measured (Goldman & Smith, 2001).

What is striking about research since the early 1980s is the uniformity of the conclusions. Without exception, cancer is acknowledged to be a very expensive disease, both to society and the affected individuals and their families. Although some consensus exists that insurance reform, or at least some form of catastrophic coverage, is necessary, how to achieve this remains unresolved.

Impact on Patients and Families

Compliance With Treatment Plan

Many firsthand accounts can be found about patients whose diagnosis was delayed or who were unable to access treatment because of a variety of system, physical, and financial barriers (President’s Cancer Panel, 2002). Strickland and Strickland (1995) found that the inability to pay for care was the second most frequently cited reason for not receiving needed medical services among 281 low-income minority households in Georgia. Moore (1997) documented a relationship between low socioeconomic status and poorer patient outcomes, and Underwood et al. (1994) stated that prohibitive costs caused 72% of their study’s subjects to delay seeking treatment until they were symptomatic. They also noted a disturbing tendency for poor patients to be “discouraged from seeking state-of-the-art care because of the costs” (p. 50). In addition, Matchar, McCrory, and Bennett (1997) determined that out-of-pocket costs for drugs were a significant factor among physicians’ prescribing decisions for hypothetical patients with prostate cancer.

Moore (1998) asked, “At what point do out-of-pocket expenditures become so overwhelming that patients begin to disengage from care?” (p. 1620). While acknowledging that their data did not allow them to determine whether poor and near-poor Medicare beneficiaries are delaying or forgoing needed treatment because of an inability to pay, Gross et al. (1999) expressed concern that the low levels of prescription drug and dental care spending by these populations may indicate that such problems are occurring. Guidry et al. (1998) found that many of their study participants had insurance problems leading them to forgo needed treatment, even though most had some form of coverage. Mor et al. (1987) also reported that “the pressure of unmet needs can inhibit a patient’s compliance with a prescribed treatment regimen” (p. 2). Levy (2002) feared that some patients may be unable to comply with treatment because of overwhelming transportation or prescription drug costs.

Patient Outcomes

Berkman and Sampson (1993) stated that “unmet financial needs actually may inhibit the treatment regimen, making cancer more costly in the long run” (p. 2846). According to Given et al. (2001), if caregivers receive readily understandable information tailored to their specific needs, they will become active members of the healthcare team, thereby contributing to higher-quality patient outcomes and reductions in the cost of care for patients with advanced disease. Caregivers must be supported because excessive caregiver burden may have a profound effect on patient outcomes (Given & Given, 1996). Summers and Chisholm (1997) described a combination of territoriality among healthcare providers, lack of knowledge about referral resources, and access limiting cost-containment measures as contributing to gaps in patient care, system inefficiencies, and poor patient satisfaction.

Family Burden

Many investigators consider the psychological toll of financial burden on patients with cancer and their caregivers. Berkman and Sampson (1993) stated that “financial strain has a significant, negative effect on the family’s emotional status” (p. 2848). Given and Given (1996) identified numerous aspects of family life that are affected by a cancer diagnosis such as family roles, domestic routines, patterns of communication, and self-esteem. Restricted social activities and changes in work roles and career opportunities also contribute to family burden, although caregivers may experience feelings of competence and satisfaction as a result of caring for loved ones. Levy (2002) described a scenario in which patients with cancer may sense resentment from other family members for using a disproportionate share of family resources. Conversely, patients with cancer may resent their dependence on caregivers, and caregivers can become overwhelmed by around-the-clock caregiving even when they have understood the requirements of the task (Varricchio, 1994).

Glajchen (1994) considered the emotional burden on patients with cancer and their caregivers arising from unpaid medical bills and how the need to use savings to meet medical expenses may interfere with other life goals. Mor et al. (1987) noted that the loss of income and depletion of assets represent an important deficit that can have a negative effect on the family’s emotional status far beyond the mere reduction in economic security. Chronic anxiety and hopelessness about the future may develop. Houts et al. (1986) and Jansen et al. (1993) described intertwined emotional and financial stressors as impacting family well-being. Levy (2002) noted that families may feel guilt, shame, and embarrassment over financial concerns that may extend to future needs and crises unrelated to cancer. Emanuel et al. (2000) concluded that unskilled homecare services, if they do not impose an additional economic burden, may alleviate some caregiver emotional and psychological stress. They also reported that physicians can play an important role in reducing caregiver depression simply by listening attentively.

Employment

Because many patients with cancer depend on their jobs for insurance coverage as well as income, maintaining employment is a key concern. However, a patient’s productivity may be lower after cancer treatment, and fear of dismissal, demotion, or a reduction in benefits is real, despite the protections afforded by the Americans with Disabilities Act. Although the Family and Medical Leave Act of 1993 guarantees employees 12 weeks of annual unpaid leave for medical emergencies, childbirth, and adoption, many patients with cancer may be hesitant to take as much time off as is needed or unable to tolerate the income loss. Outpatient radiation and chemotherapy often require additional time off work, contributing to employer resentment and the annoyance of coworkers who have to cover for patients with cancer (Glajchen, 1994). The inability of either the person with cancer or caregiver to change jobs for fear of losing insurance coverage and/or employment itself or a hesitancy to pursue salary increases and promotions causes great psychological and emotional stress as well as having a significant impact on the family’s overall financial status (Berkman & Sampson, 1993; Blendon et al., 1994; Glajchen; Guidry et al., 1998; Hounshell et al., 2001; President’s Cancer Panel, 2002).
Barriers to Accessing Resources

Time

Oncology nurses are under increasing pressure to care for more patients, who are more acute, in a shorter amount of time in hospital and ambulatory settings. Ideally, all patients with cancer would have access to case management or social worker services, but this is not always the case, particularly in outpatient settings. Oncology RNs and physicians may be the only regular contacts that patients have with the medical system, and they need to assess patients for financial need and refer them appropriately within these time constraints (Given et al., 2001; Given & Given, 1996; Glajchen, 1994; Guidry et al., 1998; Jansen et al., 1993; Jones, 2000; Moore, 1997; Shifflett, Gansler, & Baker, 2002; Summers & Chisholm, 1997). Physical referral contributes to higher usage rates of cancer support services (Eakin & Strycker, 2001).

Lack of Resource Awareness

Most healthcare providers are aware of the American Cancer Society and its programs, as well as those of NCI, but physician and nurse referrals to other organizations are significantly below those of social workers. However, healthcare providers are eager for more information, especially a comprehensive descriptive listing of local services (Matthews, Baker, & Spillers, 2002). Lack of awareness of available services and lack of knowledge about how to access services are two barriers to receiving assistance among patients (Shelby, Taylor, Kerner, Coleman, & Blum, 2002). Other patient factors that contribute to a knowledge deficit are low literacy or educational limitations, difficulty with or limited access to Internet-based information, language barriers, poor healthcare provider and patient communication, and culturally insensitive information (Davis, Williams, Marin, Parker, & Glass, 2002; President’s Cancer Panel, 2002; Shifflett et al., 2002). This would indicate that increasing healthcare provider awareness is an important intervention in connecting needy patients with available financial resources (Eakin & Strycker, 2001; Matthews et al.).

Uncoordinated Resources

Even when resources are identified, access to organizations that focus on financial need can be difficult. Many types of support groups are available, as well as resources about diseases, but assistance with out-of-pocket expenses for the practical needs of daily living such as transportation and home care is limited (Shelby et al., 2002). Unfortunately, the need far exceeds available resources (M. Allex, personal communication, July 29, 2003). Some organizations limit their awards to specific cancers or residents of a defined geographical area. Patients whose income is above the poverty level often find they are ineligible for direct financial aid. Educated patients with cancer and caregivers with high social skills have a distinct advantage, but even they may find accessing appropriate resources to be a challenge. Those with lower levels of “health literacy” require assistance (Davis et al., 2002; Shifflett et al., 2002). Patients need information tailored to their specific needs so as not to be overwhelmed by an excess of irrelevant information (Given et al., 2001; Given & Given, 1996; Shifflett et al.).

Nursing Implications

Although oncology nurses may feel overwhelmed by the prospect of taking on another patient care responsibility, ignoring the financial distress that patients experience may affect their ability to follow through with the plan of care. This is not to imply that becoming a personal social worker or case manager to each patient is realistic. However, oncology nurses can inform themselves of available resources and empower patients to access those resources. To review a list of financial aid resources, including brief descriptions and contact information, access this article in the CJON area of the ONS Web site (www.ons.org).

The first step is to assess patients with cancer for financial need. This should be done as part of the initial assessment (Glajchen, 1994; Jones, 2000; Summers & Chisholm, 1997) and should not be particularly time consuming. Indeed, sensitivity is called for when inquiring about personal financial information. In some cases, a need clearly exists and help should be offered discreetly in a setting that respects patient privacy. In other cases, nurses can make a general statement to patients along the lines of “Many patients encounter unanticipated expenses while undergoing cancer treatment. If this becomes an issue for you, let us know. We have information about organizations that provide assistance.”

Numerous national organizations offer varying types of assistance. The American Cancer Society, Cancer Care, and Eldercare Locator, among others, have searchable databases of local listings, both governmental and private. Cancer Care has specially trained oncology social workers who can assist patients in determining their specific needs and obtaining and completing forms from the appropriate organizations for patients and caregivers who are unable to do so themselves. Other organizations provide assistance with lodging, transportation, meals, prescription drugs, home heating, and remodeling expenses. Most have toll-free telephone numbers, along with Internet access.

In oncology offices that have Internet access and adequate terminals, patients can use their infusion time to research aid possibilities. If patients do not have Internet access at home, local libraries often have free computer access. The American Cancer Society will connect non-English-speaking patients with cancer with interpreters, and Cancer Care has Spanish-speaking social workers. Most government sites offer information in several languages.

Because many freestanding oncology practices do not have on-site social workers, oncology nurses could compile a listing of experienced social workers who are willing to work with patients on a private pay basis. This would be especially useful for patients whose needs exceed the services offered by the American Cancer Society or Cancer Care. Hospital-based social workers and the Association of Oncology Social Work may be able to refer patients. Some private insurance companies reimburse for palliative care services that allow patients to continue active treatment while accessing services that traditionally were limited to hospice patients (Schaipro, Byock, Parker, & Twohig, 2003). This provides patients with another path to social services.

ONS chapters should consider compiling a list of local community resources (e.g., church groups, fraternal and volunteer organizations). Assistance with transportation is usually local and not always found in national databases. Pharmaceutical representatives can provide information about patient assistance programs and may be willing to facilitate paperwork (Viale & Misk, 2001). They often have samples of nonchemotherapy drugs that are helpful in managing side effects.

Finally, and perhaps most importantly, oncology nurses need to advocate for their patients. They should be aware of major healthcare issues that affect insurance coverage and patient care. Insurance companies, the American Medical Association, and large pharmaceutical firms all maintain powerful lobbying presences in Washington, DC; oncology nurses must do the same. The ONS Legislative Action Center Web...
References


Continuing education credit for this and other CJON articles is available in the Publications area of www.ons.org.

For more information on this topic, visit the following Web sites.

American Cancer Society: Costs of Cancer
www.cancer.org/docroot/MIT/content/MIT_3_2x_Costs_of_Cancer.asp

Cancer Information Network
www.thecancer.info/financial_aid.htm

National Cancer Institute: Costs of Cancer Care
http://progressreport.cancer.gov

Links can be found at www.ons.org.

Rapid Recap

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

• Since the 1970s, improvements in the early detection of cancer and more effective treatments have led to increased survival rates.

• At the same time, healthcare financing and delivery have undergone dramatic changes.

• Patients with cancer and their families increasingly find that hidden costs are associated with cancer treatment and are not completely covered by insurance.

• Low-income patients, minorities, the elderly, women, and patients with advanced disease are at greater risk of being underinsured and experiencing devastating financial consequences secondary to a cancer diagnosis.

• Healthcare providers have a responsibility to assess patients for financial need and help connect them with sources of aid.

• The financial aid resources list, available exclusively on the ONS Web site (www.ons.org), describes national organizations that offer varying types of assistance. Healthcare providers can give this list to patients or use it as a guide in compiling their own lists of local resources.

Interested in more information on this topic?

Visit the CJON area of www.ons.org and access this article to review a detailed guide of financial aid resources, including descriptions and contact information.
Financial Aid Resources for Patients With Cancer

GENERAL INFORMATION

American Cancer Society
800-227-2345, phone; www.cancer.org, Web site
Some printed patient information is available in Spanish. Non-English speakers can call the main number and talk with an interpreter. Limited direct financial assistance is offered at local offices. Call to locate a nearby branch. In addition, the society provides a national, searchable database of local programs and services and other local assistance and referral resources (visit www.cancer.org/asp/search/crd/crd_global.asp). Enter the patient’s zip code to access selected resources and contact information.

American Red Cross
www.redcross.org/more/commsserv/mapintro.html, Web site
Many wide-ranging programs are offered, including home-delivered meals, food pantries, transportation to medical appointments, homeless shelters, transitional housing, caregiver education and support groups, and fuel assistance. Use this link to find local chapters and services.

Cancer Care
800-813-4673 or 212-712-8080, phone; www.cancercare.org, Web site
Patients can call the main number, fill out an online application, or visit a branch office (mainly in the New York metropolitan area) and speak with an oncology social worker. Some direct financial assistance is available. Some patient information is offered in Spanish. A national, searchable database of local programs, services, assistance, and referral resources can be accessed at www.cancercare.org/HelpingHandsGuide/DatabaseSearch.cfm. Enter the patient’s zip code or region for selected resources and contact information. A free copy of The Helping Hands Guide is also available.

Candlelighters Childhood Cancer Foundation
P.O. Box 498, Kensington, MD 20895-0498; 800-366-2223 or 301-962-3520, phone; 301-962-3521, fax; info@candlelighters.org, e-mail; www.candlelighters.org, Web site
This foundation provides for emergency funds, summer camps, and transportation for families of children with cancer.

Catholic Charities USA
1731 King St., Alexandria, VA 22314; 703-549-1390, phone; 703-549-1656, fax; www.catholiccharitiesinfo.org, Web site
Catholic Charities USA is a national network of agencies, institutions, and individuals that seeks to reduce poverty, support families, and empower communities. Use its Web site to find affiliated local agencies.

United Jewish Communities: The Federations of North America
www.ujc.org/ir_home.html, Web site
Use this link to find local Jewish federations that offer a variety of services. Contact individual agencies for specific information.

Salvation Army National Headquarters
615 Slaters Ln., P.O. Box 269, Alexandria, VA 22313; www.salvationarmyusa.org, Web site
This organization’s national telephone hotline has been shut down indefinitely. The Web site describes services offered and has links to regional divisions. The regional Web sites have a search function to find local organizations, which generally are listed in local telephone directories.

Volunteers of America
703-341-5000, phone; 703-341-7000, fax; info@voa.org, e-mail; www.volunteersofamerica.org/ext_locations.cfm, Web site
This group offers outreach programs that deal with today’s most pressing social needs. Programs are created, managed, and delivered locally through a network of community-based offices. Use this link to find local programs.

Blood and Marrow Transplant Information Network
The Web site lists numerous organizations that provide direct financial aid or fund-raising assistance for patients facing a bone marrow, blood stem cell, or umbilical cord blood transplant. If a health insurance plan has refused to pay for all or part of treatment, the network can make referrals to not-for-profit organizations and attorneys who may be able to help. All of the attorneys on the referral list have successfully persuaded insurers to pay for transplant-related expenses, usually without resorting to litigation.

Leukemia and Lymphoma Society
The Leukemia and Lymphoma Society provides the public, health professionals, and patients and their families living with blood cancers with accurate, current, disease-related information. Information specialists are social workers, nurses, and health educators. They are available Monday through Friday, 9 am–6 pm EST. The Web site has information on employment and insurance issues in English, Spanish, French, Portuguese, and Chinese. The society provides supplementary financial assistance to patients in significant need. Types of services covered by the Patient Financial Aid program include (a) specific approved drugs related to the treatment or control of leukemia, Hodgkin and non-Hodgkin lymphoma, and multiple myeloma; (b) processing, typing, screening, and cross-matching of blood components for transfusions and infusion of marrow, cord blood, or stem cells; (c) transportation to and from a doctor’s office, hospital, treatment center, or family support group; and (d) x-ray therapy, initial induction x-ray therapy, or other procedures according to the specific approval of the national Patient Services Committee. Reimbursement requests, up to a maximum of $500 per year, are processed through local chapters, and payments are issued directly to patients.

DISEASE-SPECIFIC ORGANIZATIONS

Eldercare Locator
800-677-1116, phone; www.eldercare.gov, Web site
The Eldercare Locator is a national toll-free public service of the U.S. Administration on Aging that helps people locate aging services in every community throughout the United States. The primary goal of the service is to promote awareness of and improve access to state, area agency, and local community aging programs and services.

Resource Directory for Older People
The Resource Directory for Older People offers a downloadable document that is intended to serve a wide audience, including older people and their families, health and legal professionals, and social service providers. The directory lists organizations’ contact information alphabetically and by type of service offered.

United Way of America
http://national.unitedway.org/myuw, Web site
Most donation, funding, and assistance issues are handled at the local level, and questions relating to these issues are best addressed to a local United Way office. Use this link to find a local United Way and click on the “How to Get Help” button on the local office’s home page.

(Continued on next page)
Financial Aid Resources for Patients With Cancer (Continued)

DRUG REIMBURSEMENT RESOURCES

BenefitsCheckUp
www.benefitscheckup.org, Web site
This is an Internet-only service that helps to find programs for people aged 55 and older that may pay for some of the costs of prescription drugs, health care, utilities, and other essential items or services. Fill out a simple questionnaire to locate programs.

Medicine Program
P.O. Box 515, Doniphan, MO 63935-0515; 573-996-7300, phone; www.themedicineprogram.com/info.html, Web site
For a nominal fee, this volunteer organization assists patients in obtaining and completing forms for various patient assistance programs. Individuals with family incomes ranging from below the national poverty level up to $60,000 annually can qualify for free medicine. Various programs sponsor determine which medications are provided and which individuals are accepted into the programs.

Needy Meds
P.O. Box 83716, Philadelphia, PA 19147; 215-625-9609, phone; www.needymeds.com, Web site
A comprehensive listing of patient assistance drug programs including 1,030 covered drugs is offered with links to specific companies.

Pharmaceutical Research and Manufacturers of America
1100 15th St. NW, Washington, DC 20005; 202-835-3400, phone; 202-835-3414, fax; www.phrma.org, Web site
Search for patient assistance programs by drug manufacturer on this organization’s Web site.

RXAssist
877-844-8442, phone; www.rxassist.org/default.cfm, Web site
This is a national program sponsored by the Robert Wood Johnson Foundation and has a searchable database of patient assistance programs and a downloadable information packet for patients.

State Pharmaceutical Assistance Programs
State Pharmaceutical Assistance Programs offer financial assistance to the seriously ill to help them pay for their medications. Patients can apply directly for these programs. However, amounts and eligibility are different for each program. Also, please note that patients are only eligible for programs that are offered in their state of residence.

HOUSING AND UTILITIES

Energy and Telephone Assistance in the States: Public Programs That Help Low-Income Households
http://research.aarp.org/consume/d17577_energy.html, Web site
Access the downloadable PDF document on this Web page. Across the United States, programs mandated, funded, or approved by federal or state governments to help low-income households initiate and maintain home energy and telephone service vary significantly with regard to the type and amount of assistance, level of government support, rate of participation, and requirements for eligibility. Most of this extensive document describes the programs, but pages 293–323 list various state, utility, and charitable patient assistance programs with their Internet addresses.

Habitat for Humanity
Partner Service Center, 121 Habitat St., Americus, GA 31709-3498; 229-924-6935, ext. 2551 or 2552, phone; publicinfo@hfhi.org, e-mail; www.habitat.org/local, Web site
Through volunteer labor and donations of money and materials, Habitat for Humanity builds and rehabilitates simple, decent houses with the help of the homeowner (partner) families. Habitat houses are sold to partner families at no profit and are financed with affordable, no-interest loans. Habitat is not a giveaway program. In addition to a down payment and monthly mortgage payments, homeowners invest hours of their own labor into building their home and the houses of others. Families in need of decent shelter apply to local Habitat affiliates. The affiliate’s family selection committee chooses homeowners based on their level of need, willingness to become partners in the program, and ability to repay the no-interest loan.

Low-Income Home Energy Assistance Program Clearinghouse’s National Energy Assistance Referral
866-674-6327, phone; energyassistance@ncat.org, e-mail; www.ncat.org/lieap/referral.htm, Web site
This is a free service for people who want information about where to apply for the Low-Income Home Energy Assistance Program, which may pay a portion of the energy bills of eligible, low-income people. It requesting information via e-mail, please include the patient’s city, county, and state. To locate regional coordinators, visit www.acf.hhs.gov/programs/lieap/states.htm.

National Resource Center on Supportive Housing and Home Modification
University of Southern California Andrus Gerontology Center, 3715 McClintock Ave., Los Angeles, CA 90089; 213-740-1364, phone; 213-740-7069, fax; www.homemods.org, Web site
The National Directory of Home Modification Resources on the Web site’s home page is a very comprehensive list of links to local organizations that provide direct assistance.

NeighborWorks: Neighborhood Reinvestment Corporation
This is a national network of more than 220 community-based organizations creating healthy communities through the work of residents, business people, government officials, and other partners. Organizations are listed with contact information.

Rebuilding Together
1536 16th St., Washington, DC 20036-1042; 800-473-4229 or 202-483-9083, phone; www.rebuildingtogether.org/find_program_near_you/index.shtml, Web site
Rebuilding Together’s mission is to preserve and revitalize houses and communities, ensuring that low-income homeowners live in warmth, safety, and independence. Homeowners must be low-income, be elderly or disabled, or have children and be unable to perform revitalization work themselves. The site selection process takes place locally. All repairs are free.

(Continued on next page)
Financial Aid Resources for Patients With Cancer (Continued)

**LEGAL AND INSURANCE**

**Cancer Legal Resource Center**
Western Law Center for Disability Rights, Barbara Ulman Scherwin, Esq., Director, 919 S. Albany St., Los Angeles, CA 90015-1211; 213-736-1455, phone; 213-736-6310, phone for hearing impaired; 213-736-1428, fax; Barbara.Scherwin@lls.edu, e-mail; http://wlcdr.everybody.org/special-programs/cancer.html, Web site
The Cancer Legal Resource Center answers callers’ questions and provides access to a volunteer panel of attorneys and other professionals. It also offers seminars, educational outreach programs, workshops, and other activities to educate the public about cancer-related legal topics. Services are available in English and Spanish.

**Center for Medicare Advocacy, Inc.**
Judith Stein, Executive Director, P.O. Box 350, Willimantic, CT 06226; 860-456-7790, phone; 860-456-2614, fax; www.medicareadvocacy.org, Web site
The center represents thousands of individuals in appeals of Medicare denials and healthcare access problems. It also provides consultants and trainers for groups that are interested in learning about healthcare rights, Medicare coverage, and appeals and developing advocacy projects.

**Dignity Resources**
P.O. Box 1437, Los Altos, CA 94023; 877-563-2100, phone; 425-871-8484, fax; info@dignityresources.com, e-mail; www.dignityresources.com, Web site
Dignity Resources was created to help people understand the assets and financial options available during a serious or life-threatening illness and assist them in making the most informed choices possible given their particular situation, assets, and needs.

**Insure Kids Now**
877-543-7669, phone; www.insurekidsnow.gov, Web site
Every state in the nation has a health insurance program for infants, children, and teens. Insurance is available to children in working families, including families that have members of uncertain immigration status. States have different eligibility rules, but most accept uninsured children who are being treated away from home and their family members. All services are free of charge.

**American Cancer Society Hope Lodges**
800-227-2345, phone; www.cancer.org/docroot/SHR/content/SHR_2_1_x_Hope__Lodge.asp?sitearea=SHR, Web site
This site offers a searchable database of the society’s Hope Lodges facilities around the country that provide housing for patients with cancer who are being treated away from home and their family members. All services are free of charge.

**National Association of Hospital Hospitality Houses**
P.O. Box 18087, Asheville, NC 28814; 800-542-9730 or 828-253-1188, phone; 828-253-8082, fax; helpinghomes@nahhh.org, e-mail; www.nahhh.org, Web site
This organization offers referrals to free or low-cost lodging near medical facilities.

**Ronald McDonald House Charities**
Web site users can search by state for free or low-cost lodging at Ronald McDonald houses near medical facilities.

**MEDICAL CARE**

**Healthy Hearing**
5282 Medical Dr., Ste. 150, San Antonio, TX 78229; 800-567-1692, phone; 210-615-6832, fax; www.healthyhearing.com/healthyhearing/newroot/relatedlinks/index.asp, Web site
Healthy Hearing offers a link to a free, online hearing test on its Web site home page. Also on its site are Financial Aid, Hearing Device Funding, and Community Clinics links, which list sources for free or low-cost medical care and hearing aids.

**Hill Burton Free Care Program**
800-638-0742 or 800-492-0359 for Maryland residents, phone; http://ask.hrsa.gov/pc, Web site
This program’s Web site provides free or reduced medical care to patients who qualify at designated facilities that receive federal funds.

**Lighthouse International**
800-829-0500, phone; www.lighthouse.org/resources_financial.htm, Web site
Lighthouse International’s Web site features links to various organizations that provide free or low-cost eye care and corrective lenses.

(Continued on next page)
### Financial Aid Resources for Patients With Cancer (Continued)

#### NUTRITION

**Elderly Nutrition Program**

The Elderly Nutrition Program provides for congregate and home-delivered meals. These meals and other nutrition services are offered in a variety of settings, such as senior centers, schools, and individual homes. The organization’s services are targeted to older people with the greatest economic or social need, and special attention is given to low-income minorities. This Web site lists suggestions for finding local programs.

**God’s Love We Deliver**
166 Avenue of the Americas, New York, NY 10013; 800-747-2023 or 212-294-8102, phone; 212-294-8101, fax; info@glwd.org, e-mail; www.godslovewedeliver.org/about_home.html, Web site

God’s Love We Deliver provides nutritious, freshly prepared meals to people living with HIV, AIDS, or other serious illnesses who cannot shop or cook for themselves in New York, NY, and Hudson County, NJ.

#### PROSTHESES AND ASSISTIVE DEVICES

**Ambucs**
3315 N. Main St., High Point, NC 27265; 336-869-2166, phone; 336-887-8451, fax; www.ambucs.com/Aamttryke.htm, Web site

Ambucs provides disabled children with a tricycle that can be driven by hand or foot to help improve coordination and motor skills. The organization also provides educational grants for physical and occupational therapists.

**American Amputee Foundation, Inc.**
P.O. Box 250218, Hillcrest Station, Little Rock, AR 72225; 501-666-2523, phone; 501-666-8367, fax

The American Amputee Foundation, Inc., helps with insurance claims, justification letters to payors, testimony and life care planning, direct financial aid for prosthetic devices and home modifications, technical assistance in developing self-help programs, hospital visitations, counseling services, and telephone inquiries and referrals. The organization also has self-supporting chapters in various states that provide multiple forms of peer support. To locate a local chapter, contact the national office.

**Amputee Coalition of America**

The Amputee Coalition of America advocates for the rights of people with limb loss. This includes access to and delivery of information, quality care, appropriate devices, reimbursement, and the services required to lead empowered lives. The National Limb Loss Information Center refers amputees to sources for rehabilitative and prosthetic services and appropriate state and federal agencies.

**Limbs for Life Foundation**
5929 N. May, Ste. 511, Oklahoma City, OK 73112; 888-235-5462 or 405-843-5174, phone; 405-843-5123, fax; www.limbsforlife.org/faq.htm, Web site

The mission of the Limbs for Life Foundation is to benefit amputees by promoting advanced research and provide comfortable and fully functional prosthetic care for individuals who cannot otherwise afford it. Each qualified applicant will be provided with partial or complete funding for a prosthetic that is fitted by a highly qualified prosthetist. Requests for assistance must be made in writing.

**National Amputation Foundation**
Al Pennacchia, President, 40 Church St., Malverne, NY 11565; 516-887-3600, phone; 516-887-3667, fax; amps76@aol.com, e-mail; www.nationalamputation.org, Web site

The National Amputation Foundation offers donated durable medical equipment to any person in need.

**National Amputee Golf Association**
11 Walnut Hill Rd., Amherst, NH 03031; 800-633-6242, phone; 414-376-1268, fax; info@nagagolf.org, e-mail; www.nagagolf.org, Web site

This is the clearinghouse for amputee golf and golf-related activities. The association also conducts the First Swing program and Learn to Golf Clinics that are open to any disabled individual.

**National Odd Shoe Exchange**
3200 N. Delaware St., Chandler, AZ 85225-1100; 480-892-3484, phone; 480-892-3568, fax; www.angelfire.com/in2/oddshoes, Web site

The National Odd Shoe Exchange is a nonprofit organization that provides footwear and contacts for exchanging footwear to amputees and people with feet of different sizes.

**United Amputee Services Association, Inc.**
P.O. Box 4277, Winter Park, FL 32793-4277; 407-359-8855, fax; www.oandp.com/resources/organizations/uasa/buaaf_guide.htm, Web site

The Barr/United Amputee Assistance Fund was established through grants from the Barr Foundation. The organization’s mission is to provide assistance to amputees who cannot afford prosthetic limbs and to promote quality prosthetic care for all amputees by reimbursing for materials and maintenance costs to prosthetists who provide limbs to amputees with no other source of funding. This program is a cooperative effort between the Amputee Assistance Fund and the amputee’s prosthetist to improve the quality of life of the amputee. The United Amputee Services Association, Inc., also publishes A Survivor’s Guide for the Recent Amputee that offers information about amputation, care of the residual limb, and a variety of other topics.

(Continued on next page)
Financial Aid Resources for Patients With Cancer (Continued)

TRANSPORTATION ASSISTANCE

Air Care Alliance
1515 E. 71st St., Ste. 312, Tulsa, OK 74136; 888-260-9707 or 918-745-0384, phone; 918-745-0879, fax; mail@aircareall.org, e-mail; www.aircareall.org, Web site
Pilot and other nonflying volunteers work to transport needy patients to facilities where they are able to receive medical attention they might otherwise have to do without.

Angel Flight™ America
800-446-1231, phone; www.angelflightamerica.org, Web site
Through its members, Angel Flight provides access for people in need seeking free air transportation to specialized healthcare facilities or distant destinations because of family, community, or national crisis.

Corporate Angel Network, Inc.
Westchester County Airport, One Loop Rd., White Plains, NY 10604-1215; 866-328-1313 or 914-328-1313, phone; 914-328-3938, fax; info@corpangelnetwork.org, e-mail; www.corpangelnetwork.org/about/index.html, Web site
The Corporate Angel Network, Inc., arranges free travel on corporate jets for patients with cancer and bone marrow donors and recipients as long as they travel to or from an approved cancer treatment center, are able to walk up and down the steps to a private plane without assistance, and do not require oxygen, IV, or any other form of life support during flight.

National Patient Travel Helpline
800-296-1217, phone; www.patient-travel.org/default.htm, Web site
The National Patient Travel Helpline provides information about all forms of charitable, long-distance medical air transportation as well as referrals to all appropriate sources of help in the national charitable medical air transportation network. The hotline is staffed from 9 am–5 pm EST Monday through Friday. After-hours help is available within 10 minutes of leaving an after-hours message marked urgent.

National Transit Hotline
800-527-8279, phone
Use this hotline to connect with local transit providers who receive federal money to transport older adults and people with disabilities.

MISCELLANEOUS

Association of Oncology Social Work
211 Locust St., Philadelphia, PA 19107; 215-599-6093, phone; 215-545-8107, fax; info@aosw.org, e-mail; www.aosw.org, Web site
Oncology social workers provide a wide range of services directly to patients with cancer and their families, including counseling, support, education, and resource identification. They connect patients and their families with essential community, state, national, and international resources. This association does not have a directory that is available to the general public, but it may be able to refer to local members.

Experience Works, Inc.
2200 Clarendon Blvd., Ste. 1000, Arlington, VA 22201; 866-397-9757 or 703-522-7272, phone; 703-522-0141, fax; http://experienceworks.org/location.html, Web site
Experience Works, Inc., is a national, nonprofit organization that offers training, employment, and community service opportunities for mature workers. This includes a variety of programs designed to help mature individuals enter the workforce, secure more challenging positions, move into new career areas, or supplement their incomes.

Look Good . . . Feel Better
800-395-5665, phone; www.lookgoodfeelbetter.org/women/program_finder, Web site (program locator); www.cancer.org/docroot/SHR/content/SHR_2_1_x_Look_Good_Feel_Better.asp?sitearea=SHR, Web site (American Cancer Society’s page about Look Good . . . Feel Better)
Look Good . . . Feel Better is a free, nonmedical, brand-neutral, national, public service program founded by the American Cancer Society, Cosmetic, Toiletry, and Fragrance Association; and National Cosmetology Association. Its mission is to help women offset appearance-related changes from any form of cancer or its treatment. Programs are available for English- and Spanish-speaking adult women and adolescent boys and girls. A program for men is in development. Each two-hour, hands-on workshop includes a 12-step skin care and make-up application lesson, demonstration of options for dealing with hair loss, and nail care techniques. Participants also use and take home complimentary cosmetic kits in their appropriate skin tones. Professional advice is available regarding wigs, scarves, and accessories, and some programs offer free wigs.

National Adult Day Services Association, Inc.
722 Grant St., Ste. L, Herndon, VA 20170; 800-558-5301, 866-890-7357, or 703-435-8630, phone; 703-435-8631, fax; info@nadsa.org, e-mail; www.nadsa.org/findacenter.htm, Web site
Adult day services are community-based group programs designed to meet the needs of functionally or cognitively impaired adults through an individual plan of care. These structured, comprehensive programs provide a variety of health, social, and related support services in a protective setting during any part of a day but less than 24-hour care. Adult day centers generally operate programs during normal business hours five days a week. Some programs offer services in the evenings and on weekends.

National Family Caregiver Support Program
www.aao.gov/eldfam/How_To_Find/Agencies/Agencies.asp, Web site
This link lists state and area agencies on aging and is one of the first resources caregivers should contact when help is needed. The National Family Caregiver Support Program calls for all states, working in partnership with local area agencies on aging and faith and community service providers and tribes, to offer five direct services that best meet the range of caregivers’ needs; these services (a) provide information to caregivers about available programs; (b) assist caregivers in gaining access to supportive programs; (c) offer individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles; (d) provide respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and (e) offer supplemental services, on a limited basis, to complement the care provided by caregivers.

National Foundation for Credit Counseling
801 Roeder Rd., Ste. 900, Silver Spring, MD 20910; 800-388-2227 or 301-589-5600, phone; 301-495-5623, fax; www.debtadvice.org/takethefirststep/locator.html, Web site
Members of the National Foundation for Credit Counseling are nonprofit organizations dedicated to providing free or affordable services to consumers who need a financial lifeline to pull them out of debt. Some of the members offer free budget counseling and debt management plan services, and all members who charge fees or request contributions offer these services at affordable costs to consumers.