Cancer survivors in the United States and their families often encounter tremendous challenges in obtaining and paying for medical care. Multiple research studies have examined these issues in Medicare and Medicaid populations and the underinsured, but very little is known about insurance-related challenges encountered by cancer survivors enrolled in private insurance programs such as managed care. This secondary analysis of data explored the insurance-related and financial challenges reported by women enrolled in a managed care organization during cancer treatment and early follow-up. The researchers reviewed semistructured interviews with 14 women with breast cancer near the time of diagnosis, midway through treatment, and after treatment completion. Most women reported considerable stress related to performance of insurance-related tasks during or immediately after treatment, which resulted in negative emotional and psychological experiences. This article presents recommendations for how oncology nurses can intervene to assess and address these challenges and their effects. Future research should examine best practices related to nursing management of insurance-related and financial challenges during cancer.

At a Glance

- Women with breast cancer who receive health insurance through managed care organizations (MCOs) may experience considerable stress as a result of insurance-related or financial challenges during and after breast cancer treatment.
- Challenges include interacting with MCOs, understanding written information from MCOs, obtaining authorizations for care, paying bills and planning for the costs of care, and obtaining assistance with insurance-related tasks.
- Nurses can address the needs of patients and families who are experiencing insurance-related or financial challenges with thorough assessments, direct interventions, and provision of appropriate referrals.
the proportion of the U.S. population with adequate insurance continues to decline, oncology nurses should remain vigilant for signs of insurance-related and financial distress in the persons they care for in every setting and stage of survivorship.

Nonprofit organizations, professional associations, patient advocacy groups, and cancer care centers are providing an increasingly diverse array of services designed to help survivors and their families to successfully navigate the healthcare system and to maintain or improve their quality of life, including quality of life related to insurance, financial, and legal concerns. Such services can include the availability of patient navigators, oncology social workers, financial advisors, insurance experts, legal advocates, and family counselors. However, although patients and families have many avenues through which they can access services, they may not always be aware of their existence, when and how to apply for them, or how to use them effectively (Rozmovits & Ziebland, 2004).

Oncology nurses are leaders in providing holistic care to patients and their families through every cancer stage, from diagnosis to survivorship. Nurses manage the delivery of comprehensive care by partnering with interdisciplinary care teams as well as the people they care for (Carroll-Johnson, 2009). Financial strain and insurance-related frustrations often contribute to families’ burden during a time when many already are experiencing severe stress. The burden can be detrimental to mental and emotional health, family functioning, relationship dynamics, and quality of life (Higginson, 2001).

Insurance-related and financial worries can occur at any time during the cancer trajectory, and patients often do not discuss them with health professionals (Chapple, Ziebland, McPherson, & Summerton, 2004). Even when patients do approach nurses with such issues, many nurses do not feel prepared or comfortable assessing and addressing these types of problems. When oncology nurses intervene on matters related to cancer survivors’ insurance or finances, they often bring the issues to the attention of oncology social workers or other members of the interdisciplinary team. Although the entry of oncology social workers and other interdisciplinary team members into the treatment plan adds an invaluable service, the ratio of patients to oncology social workers may make it difficult for the social workers to identify, assess, and manage all of the problems of patients and families (Institute of Medicine, 2008).

The nature of the nursing role and the amount of time oncology nurses spend with patients and families often put them in a better position to detect and assess insurance-related concerns when compared to most other members of the healthcare team. Furthermore, nurses work on the front lines of oncology care, where delegating responsibility for survivors’ insurance-related concerns to other professionals may not always be possible. This is especially true in areas with limited resources, such as remote clinics and primary care settings.

**Lack of Knowledge About Experiences of Managed Care Enrollees**

Despite the fact that most Americans younger than 65 receive health care via employer-sponsored private insurance, relatively little research has explored the experiences of private insurance enrollees during treatment for a life-threatening illness such as cancer (Ward et al., 2008; Wenzel & Steeves, 2008). Managed care organizations (MCOs) represent the most common form of private health insurance in the United States, with approximately 126.4 million enrollees in 2008 (HealthLeaders-InterStudy, 2008).

The National Library of Medicine defined managed care as “a system of providing health care . . . that is designed to control costs through managed programs in which the physician accepts constraints on the amount charged for medical care and the patient is limited in the choice of a physician.” MCOs include health maintenance organizations (HMOs), preferred provider organizations (PPOs), and point of service (POS) plans (see Table 1).

To recognize and address the insurance-related concerns of cancer survivors enrolled in managed care and their families, additional research is needed to elucidate the specific nature of the problems and their effects throughout the survivorship trajectory. The purpose of this study was to use a secondary analysis of data to explore the insurance-related and financial challenges reported by women enrolled in an MCO during and after treatment for breast cancer. The analysis of data focused on providing specific directions for nurses regarding cancer-related financial and psychosocial issues identified by participants in a qualitative study of managed care enrollees. This article

<table>
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<th>TYPE</th>
<th>DESCRIPTION</th>
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| Health maintenance organization (HMO) | • Members must use participating or approved providers for all health services.  
• Designated health services are covered for a fixed, prepaid premium.  
• Health services must be approved through an HMO utilization program.  
• HMOs are considered the most restrictive form of managed care, because they may limit procedures, providers, and benefits. |
| Point of service (POS) plan | • Members may receive health services from participating (in-network) or nonparticipating (out-of-network) providers.  
• Members can choose from HMO, preferred provider organization (PPO), or fee-for-service delivery systems at the time of accessing services, rather than at enrollment.  
• Costs of receiving care in network generally are lower than out of network.  
• Use of out-of-network providers may incur additional out-of-pocket costs. |
| PPO | • Members can receive health services from participating (in-network) or nonparticipating (out-of-network) providers.  
• In-network providers offer care at a discount.  
• Use of out-of-network providers may incur additional fees, copays, or deductibles.  
• Many PPO plans are POS plans. |
presents the results of the analysis, as well as specific examples of insurance-related and financial problems encountered by women during and after treatment. The authors also provide recommendations for nursing assessment, intervention, and referral, in addition to a list of resources for patients, families, and clinicians.

Methods

The design of the primary phenomenologic study was guided by a method described by Cohen, Kahn, and Steeves (2000) and involved semistructured interviews with MCO enrollees diagnosed with breast cancer requiring treatment. The method relies on the belief that people make meaning from their lives through a process of narrative construction. Cohen et al. (2000) explained specific details of the method and related sampling and data collection procedures.

Approval was obtained from the university’s institutional review board and research ethics committee. All women provided written informed consent and selected pseudonyms for use in interviews and reports to ensure confidentiality.

Sample and Setting

A purposive sample of 14 women in treatment or scheduled to receive treatment for breast cancer were recruited through two teaching hospitals and two community cancer centers in the southern United States.

Participants met the following criteria: 18 years of age or older, capable of comprehending written and spoken English, and enrolled in an MCO for at least one year. Literacy was included as a criterion to ensure that patients understood written materials obtained from MCOs, because availability of MCO information has been cited as positively influencing enrollees (Isaacs, 1996).

Data Collection

Initial interviews were conducted at the time each woman entered the study; 3 interviews were conducted at diagnosis or pretreatment, 6 were conducted during treatment, and 13 were conducted in the follow-up period, for a total of 22 interviews with 14 participants. Based on treatment modality and duration, all participant interviews took place over a period ranging from six weeks (surgery) to one year (chemotherapy and radiation).

A researcher asked cancer care providers at each study location to provide study information to eligible patients and to refer them if they expressed interest. Interviews, lasting 45-120 minutes, were recorded on audiotape and transcribed verbatim. In a setting of their choice, participants responded to open-ended questions and probes regarding their overall breast cancer experiences in managed care. Researchers collected information about participants’ sociodemographics, cancer diagnoses, treatments, and type of MCO at the first interview and recorded the data using SPSS® version 10. Each participant was interviewed one to three times, depending on the time of their entry to the study. A single, experienced interviewer conducted all interviews.

Data Analysis

The researchers searched the transcripts for participants’ experiences of financial or insurance-related problems or concerns near the time of cancer diagnosis, during treatment, or during early follow-up. Preliminary coding of the primary data followed multiple readings of interview transcripts with resulting categorization and a search for possible themes. The researchers used a multistep analysis plan detailed by Cohen et al. (2000) to: (a) identify the smallest units of meaningful dialogue, usually referred to as strips (Agar, 1979); (b) group the strips into categories based on observed similarities; (c) group the categories into larger meaningful units or themes based on observed similarities in the categories; and (d) specify the relationship(s) between the themes in such a way as to take into account the complete participant context (historical, cultural, socioeconomic, etc.) (Kocklemans, 1965). During the primary study, participants clarified ambiguous interview information at the time of the interview or during subsequent interviews or follow-up. Member checks with participants at the time of the final interview or follow-up ensured trustworthiness and authenticity (Lincoln & Guba, 1985). The primary study’s principal investigator was involved in the secondary analysis and had the opportunity to review all findings. Two nurse researchers experienced in the care of managed care enrollees with cancer and a nurse attorney experienced in guiding numerous patients and families through financial, insurance-related, and legal difficulties during serious illness participated in the review of the findings.

Results

The 14 women who participated in the primary study were predominantly white, were middle-aged (X age = 52.9 years), were not currently married, lived in an urban or suburban setting, were of middle to high socioeconomic status, and were employed either full- or part-time. Almost all participants expressed a religious affiliation (mostly Protestant), all had a high school education, and half reported some college education. Four women had a family history of breast or ovarian cancer, and two reported first-degree relatives who had had breast cancer.

Most of the insurance-related and financial challenges reported by participants during treatment and early follow-up centered around five tasks, which are represented by the following categories: (a) interacting with MCOs, (b) understanding written information from MCOs, (c) obtaining authorizations, (d) paying bills and planning for the costs of care, and (e) obtaining assistance with MCO-related tasks. As illustrated in Table 2, negative reactions to the challenges ranged from mild frustration to severe distress.

Interacting With Managed Care Organizations

Participants often became frustrated, aggravated, or angry when interacting with MCOs. They described lengthy periods of time “on hold” with automated answering services and difficulties finding someone who would take responsibility for answering their questions, even after waiting for long periods of time and being transferred among multiple departments.
Table 2. Responses to Insurance-Related Challenges During or After Treatment

<table>
<thead>
<tr>
<th>INSURANCE-RELATED TASK</th>
<th>PERCEIVED CHALLENGES</th>
<th>PARTICIPANTS’ RESPONSES</th>
<th>NURSING ASSESSMENT</th>
<th>NURSING INTERVENTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interacting with managed care organizations (MCOs)</td>
<td>• Long periods of time waiting on the phone to reach MCOs</td>
<td>• Perception of MCOs as inhumane and uncaring</td>
<td>• Patient and family insurance-related needs</td>
<td>• Provide humane, rapid, and responsive care.</td>
</tr>
<tr>
<td></td>
<td>• Difficulty finding “knowledgeable or helpful MCO personnel,” even after waiting or transferring among multiple departments</td>
<td>• Frustration, aggravation, and anger</td>
<td></td>
<td>• Provide assistance and appropriate referrals.</td>
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<td></td>
<td></td>
<td>• Feeling unable to obtain needed information</td>
<td></td>
<td>• Ensure that patients are aware of their rights to prompt and clear information from health insurance plans.</td>
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<td></td>
<td></td>
<td>• Perception of penalties for not completing tasks on time</td>
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<td></td>
<td></td>
<td>• Belief that they do not have the skills or resources necessary to keep up with MCO-related tasks</td>
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<tr>
<td>Understanding written information from MCOs</td>
<td>• Written communications ambiguous and in non-cancer-specific “lawyer lingo”</td>
<td>• Perception of system fragmentation</td>
<td>• —</td>
<td>• Provide lists and explanations of medical terms.</td>
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<td></td>
<td></td>
<td>• Increased frustration</td>
<td></td>
<td>• Work with social workers or financial counselors to develop or provide educational materials.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Refer to social workers or legal advocates as necessary.</td>
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<tr>
<td>Obtaining authorization</td>
<td>• Lengthy waiting periods for some referrals, specialists, diagnostics, and treatments</td>
<td>• Perception of delays in treatment</td>
<td>• —</td>
<td>• Give clear explanations of any delays in treatment (when known) and what is happening.</td>
</tr>
<tr>
<td></td>
<td>• Lack of transparency in the approval process</td>
<td>• Denials leading to questioning of MCO rules and perception of a system “without heart or logic”</td>
<td></td>
<td>• Understand the rules that govern insurance plans (e.g., mandated payment for second opinion).</td>
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<td></td>
<td>• Exclusion of medications from MCO formularies</td>
<td>• Increased anxiety, stress, frustration, and anger</td>
<td></td>
<td>• Make timely documentation and expedite communications with insurance companies (e.g., provider justification of nonformulary drugs).</td>
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<td></td>
<td></td>
<td>• Decreased ability to make educated treatment choices</td>
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</tr>
<tr>
<td>Paying bills and planning for the cost of care</td>
<td>• Lack of clear explanations of billing and financial costs from treatment teams</td>
<td>• Inability to determine out-of-pocket costs or to plan for the future</td>
<td>• Financial goals and concerns; assisting families to strategize in the face of uncertainty</td>
<td>• Recognize that prioritizing care does not mean ignoring financial and insurance worries.</td>
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<td></td>
<td>• Higher specialty co-payments charged for cancer providers</td>
<td>• Sense of overall vulnerability</td>
<td></td>
<td>• Review the American Cancer Society (2008) document on costs of cancer care.</td>
</tr>
<tr>
<td></td>
<td>• Higher copayments on medications required to treat cancer or manage side effects</td>
<td>• Fear of becoming a financial “burden” on family or others</td>
<td></td>
<td>• Maintain open communication with patients and talk openly about out-of-pocket costs so that problematic areas can be addressed.</td>
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<tr>
<td></td>
<td>• Lack of transparency</td>
<td>• Fear of being unable to “leave something behind” for children</td>
<td></td>
<td>• Advocate for lower-cost but high-quality alternatives (e.g., generic drugs, elimination of unnecessary prescriptions).</td>
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<td></td>
<td>• Delays in processing and billing</td>
<td>• Increased scrutiny of all bills and additional time spent monitoring bills</td>
<td></td>
<td>• Provide appropriate referrals to oncology social workers, financial counselors, etc.</td>
</tr>
<tr>
<td></td>
<td>• Billing errors</td>
<td>• Painful reminder of cancer</td>
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<td></td>
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<tr>
<td>Obtaining assistance with MCO-related tasks</td>
<td>• Desire to negotiate role of “being sick” or requiring assistance with MCO-related tasks with independence</td>
<td>• Some waiting to ask for assistance until they are too exasperated or too fatigued</td>
<td>• —</td>
<td>• Validate patient’s desire (if expressed) to maintain independence.</td>
</tr>
<tr>
<td></td>
<td>• Feelings of complete responsibility for performing all MCO-related tasks</td>
<td>• Burnout</td>
<td></td>
<td>• Assist patients and families to understand how some insurance-related tasks can be delegated.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Refer, when appropriate, to low-cost legal services, which can help with proxies or power-of-attorney so patients do not have to manage all tasks independently.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Know how legal advocates can assist and inform patients.</td>
</tr>
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</table>
This led to feelings of futility, as women who had tried to take responsibility for their care were worn down by the incessant string of roadblocks they perceived between themselves and the information they needed. The essence of their frustrations was encapsulated by one respondent.

To have to do all this with, with the people [in charge of referrals and authorizations] and to be told, “I don’t know. They’re supposed to do it;” and then I call and, like, they say, “They don’t do it, you do it.” And to not feel in control is part of it. You give over any control to these people. And yet, you’re responsible. That’s difficult—to be both responsible but not have control is . . . kind of scary. There are many staying awake nights that I worry about, have I done, you know, is everything in place for this? Did I forget to call something?

The absence of responsive, human connections at the MCO level also led to perceptions of MCOs as fundamentally uncaring organizations. Many participants brought up areas where they found MCOs lacking in sensitivity, citing a perceived lack of humanity: “For [the MCO] to just look at the bottom line, these aren’t, these are human lives that we’re talking about. These are human—these are, these are people.” Participants were clear in understanding penalties for not completing MCO-required tasks, such as delayed approvals and higher nonreimbursed costs. One woman explained,

I know when I was going through my biopsies, they’d constantly say, “If you don’t have [the referral] in time, we won’t treat you.” Because I guess that they feel like they won’t be paid. So I was—it made me fanatical about trying to be sure all my ducks were in a row.

Experiences of being penalized by MCOs despite sincere efforts to comply with MCO procedures also led many to question whether they possessed the necessary resources to keep up with MCO-related tasks, especially in light of the other challenges of cancer treatment.

Understanding Written Information

The language used in MCO written communications was seen as difficult to understand, ambiguous, and often not specific to cancer. This resulted in perceptions of system fragmentation and increased levels of frustration, especially when the women felt they were unable to obtain the information they needed to successfully manage their care. Their descriptions of written materials from MCOs included “generically written,” “semihelpful,” and “lawyer lingo.” Some participants described experiences when referencing the materials actually increased their anxiety levels, as they attempted and repeatedly failed to make sense of their own situations in the seemingly foreign language of health care and managed care.

Obtaining Authorizations

Many of the interviews focused on participants’ stressful experiences related to obtaining authorizations for medical care from MCOs. The challenges of authorizations included perceptions of lengthy waiting periods and refusals for authorization for certain treatments, specialists, or diagnostics. Many of the participants had difficulty separating an MCO from their cancer care, believing the financing of such expensive treatment regimens to be nearly as important as the cancer itself. A few women reported feeling angry or otherwise disturbed at their perceptions of MCOs influencing care decisions with little or no understanding of the true nature of their care needs. In one woman’s words, “The insurance company put their nose in things where they have no business.” Another stated,

For the insurance company to second-guess your physicians who know you, who have seen you, is absurd. It, it just really makes me upset and really makes me angry. That someone who doesn’t know your history, who doesn’t know what’s going with you, has not followed you through all of this, can say “yes” or “no.”

The bureaucracy and lack of predictability inherent in many MCO processes (e.g., referrals, authorizations, billing issues) led to extended waiting on the part of participants, which, in turn, became a source of frustration. Cancer-related appointments were believed to be dependent on MCO approval, and bills could not be paid until MCO determination of coverage and payment had been made. Both delays added stress and anxiety on top of worries related to the cancer diagnosis itself. MCO limitations often were unrealized until after treatment completion, hampering women’s ability to make educated treatment choices.

Paying Bills and Planning for the Costs of Care

The challenges of paying bills and planning for future costs while receiving or recovering from cancer treatment were a constant and consistent theme throughout the interviews. Women shared the emotional distress they experienced as a result of the lack of transparency around billing procedures and their inability to predict out-of-pocket expenses. To some, bills represented the antithesis of the support they felt they should be receiving during a time of great vulnerability, as described by two women.

They were nickel and diming me. . . . I can remember even crying one day when I was writing a check. I was like, I’m just tired of writing these checks, I said, every time I turn around it’s for something. You know, and—just very emotional about it. I can remember vividly.

The worst [part of treatment] was, is the bills coming in . . . when they send you these little nasty-grams saying, “Okay,—this hasn’t been paid; we want you to pay it.”

Women spoke about seemingly random changes related to insurance coverage of their treatment plans or prescriptions, which contributed significantly to emotional and financial stress. Some of the stress arose when changes in insurance plans resulted in providers they had been seeing suddenly becoming “specialists” and therefore requiring higher copayments. In the words of one woman, “And now they’re specialists. That means I have to pay a copayment of $50 instead of the $15 I was getting because I was only referred. So all of a sudden they’re now specialists.” Participants also struggled to make sense of rules governing the classifications and costs of their prescriptions.
I didn’t appreciate the fact that, if I had gone up, if [capecitabine] were a drug that could be delivered IV, they’d be paying for most of it, almost all of it. But because it’s a drug, in fact, somebody told me that—it was delivered IV, they used to use a pump for it when it first came out. So the fact that it’s a pill, I have to pay $600 every six weeks, and that part of it bugs me. It doesn’t make sense to me, because they don’t have to hire any employees to deliver it, I don’t take a room upstairs, but because it’s a pill form, I have to pay through the nose for it. That part bothers me.

Participants’ perceptions that they received less reimbursement for lower-level procedures, which appeared to them to be more cost-efficient for providers, also resulted in anger and confusion. Two women reflected on how they felt that their choices to undergo lumpectomies, rather than full mastectomies, ended up costing them significantly more money out of pocket than if they had chosen to have the more invasive procedure, which would have required overnight hospitalization but might have been covered in full by their insurance providers. “If I would have had a mastectomy and I would have had to spend a night in the hospital, they would have paid for everything. But since mine was a lumpectomy and it was done as outpatient, they didn’t pay for it.” Another woman, who became aware of the cost differential after she already had had the procedure, concluded that if she had known how much the lumpectomy ended up costing her she probably would have had a full mastectomy.

Finding out about the high out-of-pocket treatment costs was like somebody deflated my balloon. It was, it was an unpleasant surprise. It was: Should I have just had the mastectomy, and it would have all been paid for because that was an option? Yeah. I still think that . . . but it would have all been paid for. If I would have known, I would have probably had the mastectomy done.

For some participants, the lack of clear information about costs prior to the initiation of treatment was considered a form of provider irresponsibility and neglect, resulting in a decreased level of trust in both the MCO and the healthcare system. Participants who had identified errors in bills they received from their MCOs described how the experience caused them to adopt a state of constant vigilance over all medical bills, expending considerable time scrutinizing every bill received. Finally, participants described how concerns about the financial welfare of their families added to their sense of burden. Some described their frustration with the inability to plan for their families’ futures, as well as fear of being unable to “leave something behind” in their estates for loved ones.

### Difficulty Obtaining Assistance With Insurance-Related Tasks

Despite the numerous insurance-related challenges participants confronted during cancer treatment and the early stages of survivorship, most expressed a sense of bearing sole responsibility for managing the issues. Some women saw tasks related to their insurance providers as impossible to delegate to others. Others described their independence as a result of their attempts to negotiate their autonomy against the role of “being sick.” This approach resulted in some participants experiencing burnout as a result of juggling managed care tasks in addition to the work of cancer treatment and survivorship.

Having cancer is a big job. . . . I’m a pretty strong person, I think. . . . You try not to let it overwhelm your life. It does, no matter how you look at it. And, so, you’re trying to do your best to take care of yourself. To me, there’s been two parts to my cancer: there’s been the physical; there’s been, you know, all the physical issues of it, and the paperwork issues. . . . It shouldn’t be that complicated to get the treatment I need.

Some participants also shared how they had waited to ask for assistance with MCO-related tasks until they were too exasperated or fatigued. Those who were able to obtain assistance with the tasks expressed the tremendous relief they experienced to have a bit of that burden lifted.

Yeah, it just wasn’t something I could have done on my own. . . . The office upstairs [in the cancer center], they’re so good, I think, about dealing with insurance. So it’s kind of like it’s taken off my shoulders. I know they’re going to take care of it. . . . If I didn’t have that support, it would be very, very difficult I think.

### Discussion

During this study, the researchers found that managed care enrollees with breast cancer felt highly vulnerable and sometimes even dehumanized as a result of their interactions with their insurance companies during treatment. Dealing with the insurance-related challenges of breast cancer also left some participants highly stressed, and many felt unable to obtain assistance with the tasks. Nurses may be in the position to offset the negative effects of such interactions by providing humane, rapid, and responsive care and appropriate referrals to resources and other members of the care team. Breast cancer survivors also may need assistance understanding written information from their insurance companies (Cooley et al., 1995). Nurses can help them to understand the medical language included in their information. They also may be able to refer patients to other resources, such as oncology social workers, patient navigators, or patient advocates who can assist them to interpret the information they receive (Morgan, 2009).

Previous studies have acknowledged the financial strains of cancer treatment (Mathews & Park, 2009; Wagner & Lacey, 2004). The American Cancer Society (2008) outlined approaches to reduce costs. A number of other resources are available to clinical staff, including nurses, who seek to facilitate patients’ access to disability benefits, patient assistance programs, and financial reimbursement programs for the costs of cancer drugs. Nurses can partner with other members of the interdisciplinary care team, including financial counselors and oncology social workers, to provide access to such resources (Morgan, 2009; Oncology Nursing Society, 2009; Schwaderer & Itano, 2007; Wilson & Amir, 2008). Nurses also can implement standard approaches to assessment of patients’ financial needs, such as those outlined by Mathews and Park (2009). Table 2 provides a summary of recommendations for nursing assessment and
interventions to reduce insurance-related challenges and their effects on patients.

Some participants reported extreme difficulties obtaining prompt authorizations from their MCOs, in addition to a sense that they were unable to compel MCOs to respond or to move forward with their treatment. The Patients’ Bill of Rights guarantees patients a right to prompt, clear, and concise information about their healthcare plans (American Cancer Society, 2009). The National Committee for Quality Assurance (NCQA) is the accrediting body for MCOs. According to the NCQA’s industry standards, MCOs have a duty to (a) thoroughly investigate requests for care, (b) promptly respond to requests for care, and (c) provide continuity of care and continuation of care (Glovsky, 2004). Nurses can ensure that patients are aware of their rights to these services from their MCOs, as well as the right to legal recourse if they perceive that their MCOs have failed to uphold the standards.

In addition to finding frustrations related to perceptions of unresponsive MCOs, the study indicated that many women also harbored concerns regarding employer discrimination after treatment and the possibility of losing their insurance coverage in the future because of a change in employment or marriage status. Oncology nurses may not be well equipped to meet the complexity of such medical-legal needs (Fleishman, Retkin, Brandfield, & Braun, 2006; Tames, Tremblay, Wagner, & Lawton, 2002–2005). However, they can become expert in identifying such needs and referring appropriately. Medical-legal partnerships are emerging as an excellent source of referral for patients with cancer. The history of medical-legal partnerships began with the HIV and AIDS crisis of the early 1980s. Early on, legal assistance was recognized as a way to help patients with the avalanche of life crises from the disease and treatment. Hundreds of legal offices were funded nationally to assist the HIV and AIDS community. That highly successful model is being replicated for patients with cancer and other acute and chronic illnesses. Such partnerships are created when a need is identified in a community. Oncology nurses can identify legal services in their geographic areas. Generally, services are funded through the federal Legal Services Commission to assist low-income individuals with their legal needs. Legal services for all 50 states can be located at www.LSC.gov. Once services are identified, nurses can develop relationships and partnerships to provide much-needed referrals to address patients’ medically related legal needs.

The hassles of managing insurance-related challenges in the context of life-threatening illness left some participants feeling burned out and overwhelmed. Prior research has revealed similar findings related to patients’ concerns regarding the economic burdens of cancer treatment and fears related to employment and possible loss of insurance coverage (Mathews, Buehler, & West, 2009; Morgan, 2009). Resources such as the Oncology Nursing Society’s Putting Evidence Into Practice (PEP) publications for assessing and intervening for anxiety and family caregiver strain and burden may be useful (Honea et al., 2008; Mick, 2008; Sheldon, Swanson, Dolce, Marsh, & Summer, 2008).

The Oncology Nursing Society’s position statement on “Quality Cancer Care” highlights the importance of “financial counseling regarding healthcare costs and insurance coverage” (Oncology Nursing Society, 2009). That position was echoed by the American Society of Clinical Oncology, whose 2009 guidance statement on the cost of cancer care supported “the development of resources to help educate patients about the high cost of cancer care to help guide their decision making regarding treatment options” (Meropol et al., 2009, p. 3868). The American Cancer Society (2008) also called for increased attention to the financial and insurance-related needs of patients and families. Nurses who seek to provide high-quality cancer care should be prepared to recognize distress stemming from insurance-related or financial issues and to provide appropriate guidance, resources, and referrals to patients and families seeking assistance with such problems (see Figure 1).

Limitations of this study include the short time of follow-up along the cancer survivorship trajectories of participants in the primary study, as well as the use of a relatively homogeneous sample of participants who were primarily white, well-educated, middle-aged, and of middle to high socioeconomic status. They also had few comorbidities and one type of cancer. Because the researchers used a secondary analysis approach, analyses were limited to data present in transcripts collected during the primary study, and following up on emerging themes of financial or insurance-related challenges with the original participants was not possible.

Future research should investigate the actual costs of cancer care for patients and families with all types of cancer, especially out-of-pocket expenses, as recommended by the American Cancer Society (2008) and the American Society of Clinical Oncology (Meropol et al., 2009). Given the health outcome inequalities associated with certain sociodemographic characteristics and insurance status, more knowledge is needed about the experiences of vulnerable populations related to negotiation and payment for treatment. Finally, the Institute of Medicine (2006, 2008) stressed in two landmark reports an ongoing need for comprehensive evaluation of evidence-based solutions to address survivors’ struggles with insurance and the costs of care. Interventions under evaluation include the use of cancer patient navigators in hospitals and community settings to assist patients in negotiating the challenges of accessing and paying for cancer treatment.

Conclusions

As demonstrated in this study, even patients who possess private insurance are at high risk for tremendous stress when negotiating with their insurance companies. The stress has the potential for negative physical repercussions. Nurses who seek to provide high-quality care as described by the Institute of Medicine (2006, 2008) and the Oncology Nursing Society (2009) cannot ignore the insurance-related and financial needs of their patients. Given current national trends, these issues may worsen in the future. Nurses are in an ideal position to assess for and act on survivors’ insurance-related and financial concerns. The approach to such concerns should be multidisciplinary to ensure that resources available in the care environment are used effectively to maximize benefits for patients and families while minimizing additional burden on nursing staff. As stated in a recent editorial in the Oncology Nursing Forum, “Do not reserve your thinking about . . . any of the myriad resources we
American Cancer Society (www.cancer.org; 800-ACS-2345) offers referrals to patient navigators, social workers, and over-the-phone health insurance information specialists, as well as documents such as “Health Insurance and Financial Assistance for the Cancer Patient,” “In Treatment: Financial Guidance for Cancer Survivors and their Families,” and “Patients’ Bill of Rights.”

Association of Cancer Online Resources (www.acor.org; +1-212-226-5525) is a collection of online resources for patients and families.

Breast Cancer Network of Strength (www.networkofstrength.org; +1-312-986-8338) provides information and support from breast cancer coaches and survivors in multiple languages.

Breastcancer.org (www.breastcancer.org; 800-221-2141) provides information on managing health insurance and finances during treatment.

CancerCare (www.cancercare.org; 800-813-HOPE) provides over-the-phone assistance and referrals from licensed social workers who can help with insurance-related and financial issues, as well as payment assistance programs.


Disability Rights Legal Center (www.disabilityrightslegalcenter.org; 866-999-DRLC) offers legal advocacy resources and over-the-phone support to patients and families needing assistance with health proxies or dealing with employment, consumer rights, insurance, or financial issues related to illness. The center also can refer patients to free legal assistance in their areas.

Kaiser Family Foundation (www.kff.org): “A Consumer Guide to Handling Disputes With Your Employer or Private Health Plan”


LegalHealth (www.legalhealth.org; +1-212-613-5080) provides free legal assistance to patients with chronic illnesses and trains healthcare professionals on legal issues faced by patients (Fleishman et al., 2006).

Legal Services Corporation (www.lsc.gov) is a nonprofit provider of legal aid for families in need.

National Cancer Institute (www.cancer.gov; 800-4-CANCER) provides detailed information on managing health insurance and finances during treatment and survivorship.

National Coalition for Cancer Survivorship (www.canceradvocacy.org; 888-650-9127) provides online and telephone support and information for cancer survivors.

Patient Advocate Foundation (www.patientadvocate.org; 800-532-5274) provides educational materials, over-the-phone case management services, and live online chats to assist with insurance, job retention, and debt crisis.

Patient Assistance (www.patientassistance.com) provides online access to drug-assistance programs for patients with cancer.

Social Security Disability and Medicaid (www.ssa.gov/applyfor/ disability/adult.htm; 800-722-1213)

Susan G. Komen for the Cure® (www.komen.org; 877-GO-KOMEN) provides information and support specifically for women and families experiencing breast cancer.

Figure 1. Resources for Patients and Clinicians

may have for extreme cases only. Those resources need to be available to a broader range of our patients in collaboration with the work we do. This combination of skills and talents will help us ensure that every patient receives ALL the care that he or she needs” (Carroll-Johnson, 2009, p. 377).

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