Who Cares for Family Caregivers of Patients With Cancer?

Barbara A. Given, PhD, RN, FAAN, and Laurel Northouse, PhD, RN, FAAN

November is recognized as National Family Caregivers Month; however, in reality, caregivers are the long-term care providers for individuals with cancer every month of the year (Kim & Spillers, 2010). Caregivers’ responsibilities have increased dramatically in recent years because of the complexity of cancer treatments, the fragmentation of healthcare services, and a decrease in healthcare resources. Family caregivers are expected to navigate through the myriad of complex and confusing systems with little formal guidance and direction. It is no surprise that many caregivers (70%–80%) report that they need more information to provide care, that they feel unprepared for their role, and that they worry that the care given is less than optimal (Kim, Kashy, Spillers, & Evans, 2010).

We, as nurses, spend more time with patients and their family caregivers than other professionals do, and we are well positioned to provide them with support and guidance. However, we often are unaware of the stress that family caregivers experience because most of the care they provide is in the home and invisible to others (Yabroff & Kim, 2009). However, nurses can help caregivers provide high-quality care in the home by preparing them for their caregiving role (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000).

There a number of ways that we can help caregivers of patients with cancer. First, the patient-caregiver dyad (i.e., pair) must be recognized as the unit of care. Research has clearly documented that the responses of patients with cancer and their caregivers are interdependent—each person affects the other (Northouse, Mood, Templin, Mellon, & George, 2000). To provide comprehensive care, nurses should provide information and support to both patients and caregivers.

Second, nurses need to briefly assess caregivers’ needs and capacity to provide care. This assessment could be as straightforward as asking, “What questions do you have?” “What problems are you experiencing?” “What can we do to help you?” “What information do you need?” and “What would you like to know right now?” These assessment questions will help identify caregivers’ needs and also determine the caregivers who are overwhelmed and require additional resources.

Third, nurses can give caregivers basic information and help them to acquire the skills they need to assist patients. Educating caregivers also may improve patients’ adherence to treatments and lower costs related to clinical toxicities and unscheduled office visits. For example, by teaching family members how to monitor pain levels, identify signs of complications or adverse events, manage symptoms, and perform tasks (e.g., dressing changes), nurses can help patients and caregivers and possibly reduce healthcare delivery costs. In addition, nurses should review plans of care with patients and caregivers because they are the ones that have the major responsibility for implementing them. It also is important that nurses document teaching or communication that has occurred with family caregivers.

Fourth, and perhaps most importantly, nurses need to help caregivers understand the importance of taking care of themselves, monitoring their own distress levels, and learning strategies to manage the stress of caregiving. Nurses should refer caregivers to their primary care providers as needed to ensure that caregivers receive routine care, support for healthy lifestyles, appropriate health screening, and management of any chronic health problems they may have, including attention to stress or depression management. Nurses also can help caregivers develop problem-solving skills. Because it has been reported that caregivers spend on average of eight hours per day during active treatment providing care, caregivers need guidance on how to plan time so they can meet other work and family responsibilities (van Ryn et al., 2011; Yabroff & Kim, 2009).

Fifth, even if your cancer center does not have specific programs for caregivers, the Internet can provide assistance and nurses can make referrals to appropriate Web sites. Several key Web-based...
resources for cancer caregivers are listed in Figure 1.

We need to be aware of the information needs and stress experienced by caregivers (Given et al., 2009; Northouse et al., 2000). Acknowledged or not, family caregivers are an extension of the healthcare team in the home. We need to form a strong partnership with caregivers, prepare them for their caregiving role, and help them to maintain their own health as they provide care for patients with cancer (Beesley, Price, Webb, Australian Ovarian Cancer Study Group, & Australian Ovarian Cancer Study-Quality of Life Study Investigators, 2010).

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**References**


**Figure 1. Web Resources for Caregivers of Patients With Cancer**

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<tr>
<th><strong>American Cancer Society</strong></th>
<th><strong>National Cancer Institute</strong></th>
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<tr>
<td>• Information in the support and treatment section focuses on caregiving. Chat rooms and discussion boards also are available.</td>
<td>• A resource called Caring for the Caregiver is offered and includes information on asking for help, dealing with feelings, caring for yourself, and talking with others, as well as a set of other resources.</td>
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<th><strong>American Society of Clinical Oncology</strong></th>
<th><strong>National Alliance for Care Giving</strong></th>
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<td><a href="http://www.asco.org/ASCOv2/MultiMedia/Mobile+Apps">www.asco.org/ASCOv2/MultiMedia/Mobile+Apps</a></td>
<td><a href="http://www.caregiving.org">www.caregiving.org</a></td>
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<td>• Tools for mobile devices are available for caregivers. Topics include questions to ask physicians, medication information, recording symptoms, and podcasts.</td>
<td>• Although not cancer-specific, this site features general information for caregivers.</td>
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<th><strong>Cancer Care</strong></th>
<th><strong>Oncology Nursing Society</strong></th>
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<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
<td><a href="http://www.thecancerjourney.org/caregiver">www.thecancerjourney.org/caregiver</a></td>
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<td>• Support groups, telephone sessions, online sessions, one-hour workshops, podcasts, and publications for caregivers all are available.</td>
<td>• The Cancer Journey site has a section dedicated to caregiver resources.</td>
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**American Cancer Society**
www.cancer.org/Treatment/index

- Information in the support and treatment section focuses on caregiving. Chat rooms and discussion boards also are available.

**American Society of Clinical Oncology**
www.asco.org/ASCOv2/MultiMedia/Mobile+Apps

- Tools for mobile devices are available for caregivers. Topics include questions to ask physicians, medication information, recording symptoms, and podcasts.

**Cancer Care**
www.cancercare.org

- Support groups, telephone sessions, online sessions, one-hour workshops, podcasts, and publications for caregivers all are available.

**Oncology Nursing Society**
www.thecancerjourney.org/caregiver

- The Cancer Journey site has a section dedicated to caregiver resources.