Putting Together the Pieces of the Puzzle: Identifying Existing Evidence-Based Resources to Support the Cancer Caregiver

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Caring for the caregivers of patients with cancer is an increasingly important part of cancer care. In the past few years, several cancer centers have started caregiver-focused services and programs. However, the number of centers that offer such programs and what they provide is unclear. This article will review the extent to which the 61 National Cancer Institute–designated cancer centers that primarily provide patient care also offer evidence-based support programs for caregivers.

For most of the estimated 1.6 million Americans who will be diagnosed with cancer in 2014, at least one family member or other caregiver will also be affected by the diagnosis (American Cancer Society, 2014). These informal caregivers often provide physical, emotional, financial, and spiritual support to patients, which is a task that sometimes stretches them beyond their capabilities or resources (Given, Given, & Sherwood, 2012). In addition to helping patients and jointly managing the stressors associated with the illness, cancer caregivers often have their own specific issues (Li & Loke, 2013; Mosher, Bakas, & Champion, 2013; Northouse, Williams, Given, & McCorkle, 2012; Stenberg, Ruland, & Miaskowski, 2010).

All of this care can take a toll. Researchers have identified numerous negative physical, psychological, and social outcomes in caregivers (Bevans & Sternberg, 2012; Given et al., 2012; Northouse, Williams, et al., 2012; Stenberg et al., 2010).

A national study of caregivers of people diagnosed with varying illnesses found fatigue, stress, increased pain, depression, headaches, and weight changes to be among the most frequent complaints (Evercare & National Alliance for Caregiving, 2006). More specific to cancer caregivers, a 2010 systematic review of the effects of caregiving cited physical ailments such as pain, problems with sleep, decreased energy, reduced strength, and loss of appetite (Stenberg et al., 2010). The same review elucidated the emotional challenges for caregivers, including anxiety, depression, fear, a sense of hopelessness or helplessness, and uncertainty; caregiver anxiety and depression was sometimes worse for caregivers than for patients (Northouse, Williams, et al., 2012; Stenberg et al., 2010). Caregivers are socially challenged on multiple fronts: missing time at work, losing income or savings, juggling changing roles and responsibilities, coping with schedule interruptions and lost leisure time, and facing isolation (Bevans & Sternberg, 2012; Skalla, Smith, Li, & Gates, 2013; Stenberg et al., 2010). The emotional downsides to caring for patients with cancer are somewhat balanced by positive experiences (e.g., appreciating time together, having a greater sense of connectedness) (Stenberg et al., 2010).

A number of cancer centers have started caregiver-focused services and programs, although the amount and what the centers provide remain unclear. This article reviews the extent to which 61 National Cancer Institute (NCI)-designated cancer centers offer evidence-based support programs focused on patient caregiving, marital and family care, and caregiver self-care (Northouse, Katapodi, Song, Zhang, & Mood, 2010). The authors also make recommendations for leveraging the programs already in place and address other political, financial, and practice obstacles. In this way, healthcare providers can tap into existing resources to reduce the stress placed on cancer caregivers and to help them continue to support patients and care for themselves.

Methods

The authors identified a group of cancer centers that could represent the broader collective of cancer-focused institutions across the country. Sixty-eight institutions have been designated by the NCI as cancer centers (n = 27) and as comprehensive cancer centers (n = 41), and they are characterized by their demonstrated excellence in cutting-edge cancer research, training for future scientists and healthcare providers, state-of-the-art patient care, and public education about cancer prevention and screening.
(NCI, 2012). Seven of the centers only conduct research, so the authors reviewed the websites of the 61 centers that provide direct patient care.

Criteria for Website Evaluation

To guide this evaluation, the authors turned to Northouse et al.’s (2010) meta-analysis of evidence-based interventions for cancer caregivers, in which the content of the caregiver interventions assessed were broadly classified as focused on patient caregiving, marital and family care, and caregiver self-care. In addition, Northouse et al. (2010) classified patient caregiving activities as those that taught hands-on skills, including how to change a dressing, manage an ostomy, or take care of a central line; provided information on cancer; or addressed the physical, emotional, and social side effects that cancer treatment brings. Marital and family care interventions provided caregivers with information or skills to help them manage concerns such as marital conflict, changes in family dynamics and roles, or difficulties in sexual relationships, among other topics (Badr & Krebs, 2013; Northouse et al., 2010; Northouse, Williams, et al., 2012). Finally, caregiver self-care involved helping caregivers develop the means to seek out and maintain a support system, care for their physical and emotional needs, feel more confident in their ability to care for their loved ones, and find resources to lessen the burden of the caregiver function (Northouse et al., 2010; Northouse, Williams, et al., 2012). Using these categories, along with the inclusion parameters, the authors reviewed each of the 61 NCI-designated cancer centers’ websites to identify programs or activities that would qualify as evidence-based interventions for alleviating caregiver stress. The inclusion parameters were programs, services, activities, or topics that were focused on patient caregiving, marital and family care, or caregiver self-care, and were readily accessible to caregivers via video or audio recordings, written material, or in-person sessions.

<table>
<thead>
<tr>
<th>Cancer Center</th>
<th>Category</th>
<th>Name of Resource</th>
<th>Description</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jonsson Comprehensive Cancer Center at the University of California, Los Angeles</td>
<td>Caregiver self-care</td>
<td>Husbands (Partners) of Women with Cancer support group</td>
<td>Twice-monthly group for partners to discuss how to support their loved ones and take care of themselves</td>
<td><a href="http://bit.ly/1rtd0by">http://bit.ly/1rtd0by</a></td>
</tr>
<tr>
<td>Memorial Sloan Kettering Cancer Center</td>
<td>Caregiver self-care</td>
<td>A Guide for Caregivers</td>
<td>Document that addresses issues caregivers have said are of most concern to them: communicating with doctors, caring for the patient, dealing with financial and legal issues, taking care of themselves</td>
<td><a href="http://bit.ly/1f6Xqms">http://bit.ly/1f6Xqms</a></td>
</tr>
<tr>
<td></td>
<td>Caregiver self-care</td>
<td>Caregivers Clinic</td>
<td>Appointment-based counseling to help caregivers manage patient needs while attending to their own needs and other responsibilities</td>
<td><a href="http://bit.ly/MLY7nK">http://bit.ly/MLY7nK</a></td>
</tr>
<tr>
<td>Rutgers Cancer Institute of New Jersey</td>
<td>Marital and family care</td>
<td>Living with Cancer—Patient and Family Support Group</td>
<td>Twice-monthly group for patients and caregivers to facilitate sharing, encourage mutual problem solving, and improve education</td>
<td><a href="http://bit.ly/1nCLM77">http://bit.ly/1nCLM77</a></td>
</tr>
<tr>
<td>Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins University</td>
<td>Patient caregiving</td>
<td>Video Series</td>
<td>Videos for patients and caregivers that offer education and information about cancer, including chemotherapy, stereotactic body radiation therapy, and finances</td>
<td><a href="http://bit.ly/1xwY1XC">http://bit.ly/1xwY1XC</a></td>
</tr>
<tr>
<td></td>
<td>Patient caregiving</td>
<td>Managing Side Effects</td>
<td>Documents that provide tips to prevent bleeding and infection, and to manage side effects such as nausea and vomiting, diarrhea, constipation, fatigue, and pain</td>
<td><a href="http://bit.ly/1zpidvd">http://bit.ly/1zpidvd</a></td>
</tr>
<tr>
<td>University of Michigan Comprehensive Cancer Center</td>
<td>Patient caregiving</td>
<td>Cancer Center Education Clinic</td>
<td>Hands-on training that includes guidance on connecting, disconnecting, and caring for catheters and pumps; changing dressings; and giving injections</td>
<td><a href="http://bit.ly/1yuVAkP">http://bit.ly/1yuVAkP</a></td>
</tr>
<tr>
<td>University of North Carolina (UNC) Lineberger Comprehensive Cancer Center at UNC-Chapel Hill</td>
<td>Caregiver self-care</td>
<td>Single Fathers Due to Cancer program</td>
<td>Support group for fathers who have lost spouses or significant others to cancer and are learning how to become single parents</td>
<td><a href="http://bit.ly/1wYiqSs">http://bit.ly/1wYiqSs</a></td>
</tr>
<tr>
<td></td>
<td>Caregiver self-care</td>
<td>Writing and Healing for Caregivers group</td>
<td>Opportunity for cancer caregivers to find restoration and healing through the written word</td>
<td><a href="http://bit.ly/1wY10YF">http://bit.ly/1wY10YF</a></td>
</tr>
</tbody>
</table>
Review of the websites took place from August to September 2013.

Results

Most of the 61 NCI-designated centers reviewed had at least one program or service that could be categorized as fitting the evidence for reducing caregiver stress. Fifty-six of the centers had patient caregiving programs, 46 had caregiver self-care programs, and 42 listed marital and family care programs. More than half (n = 33) of the centers had programs in all three categories. The caregiver self-care programs identified included activities such as support groups, individual counseling, exercise and stress-relief sessions, and appreciation luncheons. Marital and family care interventions ranged from couples counseling to cognitive-behavioral therapy sessions, and from information concerning how to talk with children about cancer to quality-of-life screenings for families. Patient caregiving activities included hands-on skills training classes, numerous documents regarding the management of specific treatment side effects, videos introducing treatment modalities, and basic information (e.g., medical dictionaries). The authors selected six institutions with programs they considered to be exemplars (see Table 1). These programs demonstrate innovation and an obvious commitment to helping cancer caregivers, as well as highlight some of the means through which caregiver needs can be met.

Discussion

In this review of NCI-designated cancer centers, the authors found that many institutions already had programs in place that matched the evidence for alleviating caregiver anxiety and distress. This suggests that interventions that encourage caregiver self-care, teach problem-solving and coping skills, provide support for the patient-caregiver relationship, and offer training related to caring for the patient can effectively reduce caregiver distress (Northouse et al., 2010). Researchers have found that a combination of approaches, also known as multicomponent intervention, provides the largest positive effect for caregivers (Honea et al., 2008; Northouse et al., 2010). Making healthcare providers aware of the programs identified may help them to more fully leverage such resources to the benefit of beleaguered cancer caregivers.

Implications for Nursing Practice

Northouse, Williams, et al. (2012) proposed the concept of a caregiver champion and suggested that each cancer program designate one individual to carry the mantle of aiding cancer caregivers, who are crucial members of the patient care team. This champion could review the evidence for reducing cancer caregiver distress or anxiety, then identify programs already in place within the organization that fit those criteria. The current study’s findings provide a starting point for identifying the types of programs or activities that may exist in a cancer facility. This task is particularly important in large institutions where departmental or disciplinary boundaries may prevent optimal communication of existing efforts.

Conclusion

At various points in a patient’s healthcare journey, healthcare providers will interact with caregivers and may have the opportunity to influence their well-being. Helping caregivers to maintain their own physical, emotional, and spiritual health can help them continue to support the patient (Northouse, 2012; Northouse, Williams, et al., 2012). Engaged, informed, and encouraged caregivers can not only help patients cope with treatment and side effects but also help these patients move toward healthy survivorship (Northouse et al., 2010; Northouse, Williams, et al., 2012). Stressed, burdened, and overwhelmed caregivers may not be able to provide the same quality and quantity of informal patient care, leading to increased medical costs for the patient (Given et al., 2012; Northouse, Katapodi, Schafenacker, & Weiss, 2012; Skalla et al., 2013). Therefore, healthcare providers should consider the needs of the caregiver as they care for the patient (Given et al., 2012). Cancer centers wrestle with the financial, political, and organizational implications of instituting evidence-based interventions, but some of the pieces of the puzzle already exist. Most NCI-designated cancer centers have programs that address at least one component of effectively caring for the cancer caregiver: teaching patient caregiving, facilitating marital and family care, and encouraging caregiver self-care. Those pieces just need to be put together in a way that allows healthcare providers and caregivers the opportunity to readily learn about and access them.

References

Given, B.A., Given, C.W., & Sherwood, P.R. (2012). Family and caregiver needs over the course of the cancer trajectory. Journal of Supportive Oncology, 10, 57–64. doi:10.1016/j.suponc.2011.10.003

(Supportive Care continues on page 636.)