Providing education and support to family caregivers of patients with cancer

Joanne P. Finley, RN, MS

BACKGROUND: The many burdens faced by caregivers of patients with cancer are well documented. Caregivers are asked to perform procedures, make assessments, coordinate care, and communicate with healthcare providers at an increasingly complex level. A caregiver quality improvement project, in the form of a Caregiver Café, was instituted at a National Cancer Institute–designated comprehensive cancer center.

OBJECTIVES: The objectives of the café are to (a) provide respite and a place for caregivers to relax and be nurtured, (b) provide a place for caregivers to meet and support each other, (c) provide answers to caregiver questions, and (d) recommend appropriate caregiver resources.

METHODS: The weekly Caregiver Café is led by an advanced practice nurse, and the format varies depending on the needs of the caregivers who attend.

FINDINGS: Caregivers have verbalized the importance of the café in helping them cope with their loved ones’ cancers and treatments, and many attend on a regular basis. The Caregiver Café provides support and information and a place to get away from it all.

CAREGIVERS OF PATIENTS WITH CANCER experience a higher level of burden than caregivers of older adults and a similar level of burden to caregivers of patients with dementia (Kim & Schulz, 2008). Today’s cancer treatments, including chemotherapy, radiation therapy, biotherapy, and stem cell transplantations, are primarily administered in outpatient settings. This is beneficial to patients who would prefer to remain in their homes but is more stressful for their caregivers, who perform much of their care without extensive preparation or education. Potter et al. (2010) documented the numerous learning needs of patients with cancer and their caregivers. The top three activities that caregivers said they would like to know more about were helping patients deal with their feelings about cancer, watching for infection, and managing side effects. An early study of caregiving burden (Carey, Oberst, McCubbin, & Hughes, 1991) found that providing emotional support for patients was the most demanding activity, as did a more recent study by Copley Cobb, Etkin, Nelson, Egleston, and Sweeney (2016).

Many researchers have identified the significant strain that a diagnosis of cancer, and the subsequent care and support that is needed, places on caregivers. Physical manifestations of this strain may include fatigue (Schumacher et al., 2008) and worsened general health (Bevans & Sternberg, 2012). Emotional manifestations include anxiety, depression, and stress. Halpern, Fiero, and Bell (2017) reviewed national survey responses of caregivers of patients with cancer and categorized their responses into emotional and psychological burden and relationship with the patient. Certain patient care tasks have more effect on different types of burden. For example, help with personal care and help with getting around were associated with a higher emotional burden for caregivers (Halpern et al., 2017). Mosher, Bakas, and Champion (2013) found that more than 50% of caregivers of patients with lung cancer experienced negative emotional effects. In addition, caregivers have jobs, children, and their own everyday household tasks to manage. In addition, they may feel isolated because of the lack of available time to socialize, exercise, and pursue hobbies when they most need support. All of these factors may negatively affect caregiver quality of life.

Two large meta-analyses of family caregiver intervention trials provide an overview of the types of interventions and their effects on caregiver outcomes. A meta-analysis by Northouse, Katapodi, Song, Zhang, and Mood (2010) listed the types of interventions primarily as psychoeducational, skills training, and therapeutic counseling. Interventions reduced caregiver burden, distress, and anxiety and improved coping, relationships, and physical functioning.
“Caregivers have formed special relationships with one another, particularly those without the normal support networks.”

In a guest editorial to the Clinical Journal of Oncology Nursing, Given and Northouse (2011) stated that there are a number of ways to help caregivers of patients with cancer. These include making the patient–caregiver dyad the focus of care, assessing caregiver needs and the ability to provide care, giving caregivers the information and skills they need, helping caregivers take care of themselves, and referring caregivers to appropriate websites if these resources are not locally available.

The Caregiver Café was established in December 2014 by the current author, who is an advanced practice nurse, to support caregivers of patients with cancer at the Sidney Kimmel Comprehensive Cancer Center. The objectives of the café are to (a) provide respite and a place for caregivers to relax and be nurtured, (b) provide a place for caregivers to meet and support each other, (c) answer caregiver questions, and (d) refer caregivers to resources. The Caregiver Café addresses the PEP recommended for practice interventions of psychoeducation/psychoeducational interventions and supportive care/support interventions and the likely to be effective interventions of caregiver training and skill development and multicomponent interventions.

Methods
Needs Assessment
Prior to implementation of the café, a convenience sample of 28 caregivers completed a 10-item learning needs assessment (see Figure 2). Caregivers waiting with patients or waiting for patients represented the population that would be served by the café. Results from the assessment were categorized into topics ranked in order of importance, with 1 being the most important and 10 being the least important. The topics the caregivers were most interested in were symptom management, supporting the patient emotionally, and equipment care. The needs assessment provided a starting point for topics to address in the café. The survey findings were similar to Potter et al.’s (2010) learning needs assessment results.
Establishing the Café
The café is held weekly for one hour from 11 am to noon in a lobby area near the visitor elevators. This location is visible and convenient. Oncology nursing leadership recommended the location and times when the café would be most useful. An advanced practice nurse coordinates and facilitates the café. Guest speakers are also invited. The advanced practice nurse introduces herself and lets the caregivers know that, if they have any questions, she is there to answer them or refer them to someone who can. The café is advertised on the cancer center’s website, in a paper calendar of events distributed throughout the center, on posters, and in an employee-wide monthly email of educational and support programs.

Café Format
The café format is fluid depending on who attends and what his or her needs are. Every caregiver and patient, if present, is offered a cup of coffee, tea, or cocoa and a snack. They are then asked how they are doing and if there is anything they need. Caregivers are introduced to each other, and if they are willing, they are encouraged to interact with each other. The format ranges from a guided coffee break to group discussion to individual counseling, depending on the caregivers’ needs.

A display rack with caregiver-specific materials is available at the café location to supplement discussions and provide answers to questions that are asked during the café, and to provide resources when the café is not in session or caregivers are unable to attend. These materials include information about talking to children and other communication tips, self-care, coping, spiritual and financial resources, and practical resources, such as discount parking and walking routes on the medical campus.

The café is funded by donations through the cancer center’s Development Office. The operations expenses for the year are estimated at $500. This covers the paper goods, coffee, tea, cocoa, cookies, granola bars, or other snacks. The single-serve coffee brewer and the serving and storage cart were donated.

Results
From 2015–2016, the café recorded 977 caregiver visits. The caregivers were mostly spouses, but also parents, adult children, other family members, and friends. The caregivers were primarily from four inpatient and two outpatient hematologic cancer units where patients received biotherapy, chemotherapy, and/or stem cell transplantation. However, caregivers also came from solid tumor, hematology, and surgical inpatient units and the medical oncology outpatient clinic. Johns Hopkins employee caregivers from other areas of the hospital have been referred to the café by the Managing Cancer at Work™ program staff. There usually are two to three repeat attendees each week. In addition, many caregivers have exchanged contact information with each other and continue to interact outside of the café.

A number of patients have attended with their caregiver. Some caregivers have made a point of bringing the patient to meet other caregivers and the nurse facilitator. During the two years of documented café visits, 103 patients have attended. Northouse (2012) encourages healthcare professionals to treat the patient–caregiver dyad as the unit of care. Because the dyad is interdependent, helping the caregiver also helps the patient. Patients generally view the café as the caregiver’s activity and usually do not stay for the group discussions.

Discussion topics range from self-care and communication skills to questions about central lines, dressing changes, and managing symptoms. Because lack of self-care is a major issue for caregivers, the nurse facilitator at the café has taken their blood pressures, referred them to local physicians if they are away from home, encouraged them to use the on-site gym, and distributed smoking cessation materials. The topics most commonly discussed are the experience of caregiver (what they are going through), stress and meaning (how it has affected their lives), and support and diversion activities (how to cope). Table 1 provides a complete listing of the topics. Discussion themes have

FIGURE 2.
CAREGIVER LEARNING NEEDS ASSESSMENT

CAREGIVER SURVEY
Are you caring for someone with cancer? We would like to offer information sessions for caregivers. Please rank the following topics from 1 (being the most) to 10 (being the least) in order of importance to you.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assisting with personal care (bathing, dressing, mouth care, etc.)</td>
<td></td>
</tr>
<tr>
<td>Assisting with medications</td>
<td></td>
</tr>
<tr>
<td>Helping patient move around</td>
<td></td>
</tr>
<tr>
<td>Nutrition and eating issues (weight loss, etc.)</td>
<td></td>
</tr>
<tr>
<td>Supporting the patient emotionally</td>
<td></td>
</tr>
<tr>
<td>Supporting self emotionally</td>
<td></td>
</tr>
<tr>
<td>Financial concerns</td>
<td></td>
</tr>
<tr>
<td>Toileting issues</td>
<td></td>
</tr>
<tr>
<td>Equipment care (dressing, tubes, catheters, succioning, etc.)</td>
<td></td>
</tr>
<tr>
<td>Symptom management (fatigue, pain, nausea, diarrhea, etc.)</td>
<td></td>
</tr>
</tbody>
</table>

Please list any other specific topics you are interested in:

Note. Courtesy of the Sidney Kimmel Comprehensive Cancer Center. Used with permission.
included feeling isolated, feeling stressed, feeling like a “nag,” and feeling taken for granted. Another theme is fear of making a mistake or missing something important in the patient’s care.

Guest speakers are arranged based on the learning needs assessment and concerns that caregivers have raised. The psychiatric liaison nurse, chaplain, and social workers have discussed providing emotional support for patients. The advanced practice nurse and other nurses have addressed symptom management and the use and care of equipment. Organizations, such as the Leukemia and Lymphoma Society, the Johns Hopkins Home Care Group, and the Image Recovery Center have shared their resources, and having them come to the café is easier for caregivers who are stressed and lack time to make contacts. One of the major benefits of the café is the ability to refer caregivers to other resources. Caregivers have stated that they did not want to bother the staff or did not know what resources existed. Table 2 lists the most commonly made referrals.

From the café interactions, caregivers have been instrumental in making suggestions and initiating changes to cancer center practices. Most of the suggestions come from the group discussions, whereas others have been specifically brought to the nurse facilitator. Two of the suggestions were related to documentation. Caregivers identified that a checklist specific for patients undergoing stem cell transplantation at the time of discharge would be helpful in preparing in advance for everything a patient might need at home. This suggestion was shared with the transplantation clinical nurse specialist and is under consideration. Caregivers requested a form to keep track of their patients’ medication administration, which was subsequently provided. In addition, a visually impaired patient’s caregiver suggested and helped write a list of resources for the visually impaired. A list of area grocery stores was provided to the out-of-town caregivers. In addition, a handout of caregiver resources was developed for all new patient binders (see Figure 3). Some suggestions, such as on-site day care for caregivers with young children and a Bible study, have not been implemented but have helped to identify areas in which resources are lacking.

**Discussion**

Applebaum and Breitbart (2013) conducted a systematic review of interventions for caregivers. The intervention categories were similar to the PEP caregiver strain and burden interventions (Oncology Nursing Society, 2017). Of the 49 interventions in their final sample, all categories, except supportive therapy alone, were found to be effective. Applebaum and Breitbart (2013) also stated that interventions that were integrative (e.g., combining psychoeducation and skills training) had multiple benefits for caregivers, including efficient use of time in their already stressful lives. They stated that a group setting provides social support even if that is not the focus of the group.

**Strengths of the Café Intervention**

The Caregiver Café is an integrative intervention provided in a group setting. Elements of psychoeducation and skills training have been included in the discussion topics, as have guest speakers. Caregivers continually express appreciation for the café. Many caregivers come weekly. They have formed special relationships with one another, particularly those who are from out of town and without their normal support network. Caregivers of patients who relapse have come back to the café as a source of support in a time of despair.

The strength of this quality improvement project centers on its flexibility and convenience. Caregivers are not asked to commit to a certain number of weeks, but they know they can...
count on the café being open every week. There is no pressure and no commitment at a time when the caregivers may feel stressed and overcommitted. They are encouraged to “take a break” from caregiving while their loved ones are being cared for by the staff on an inpatient unit or in the outpatient department. They are given permission to do something for themselves.

Another strength of the café is the format. Food and drinks are inherently social. Caregivers who may not feel comfortable attending a support group inevitably wind up supporting each other at the café. Having a facilitator who can assess the needs of the attendees is important and may include introducing them to each other, ideally based on knowledge of their individual situations. Another focus may include encouraging a group discussion by asking if they would like to sit down for a little while and talk. The café attendees are primary English speakers. Occasionally, someone does not speak English but still seems to enjoy the camaraderie and refreshments.

The nurse facilitator generally asks two simple questions: “How is it going?” and “Is there anything I can do for you?” If caregiver mental health is a concern, a referral can be made to a mental health professional, such as a psychiatric liaison nurse, social worker, or psychiatrist. Given, Given, and Sherwood (2012) stated that a caregiver who is overloaded or in crisis may not be able to provide care.

Next Steps
The Caregiver Café is now in its fourth year. Based on their comments, the caregivers wholeheartedly support the program. One caregiver stated, “If I lived closer, I would love to help you with this. This really helped me, and you are helping a lot of people.” The benefits of a caregiver-only program include the opportunity to be open about what caregivers are experiencing and to discuss issues that only they have in common (Northouse et al., 2010). The café has served as a model for creating similar programs in the Johns Hopkins Health System. Two other system hospitals have queried about the café, and there is discussion about expanding it to another day and location in the cancer center.

Limitations
The project lacks a formal research structure. Despite this, very specific records have been kept, which have enabled the cancer center to identify caregiver needs and potential solutions. The results are not generalizable beyond the cancer center, but there were many similarities between the results and interventions and outcomes reported in the literature. For example, emotional support was found to be the most challenging activity for caregivers in Potter et al. (2010) and Copley Cobb et al. (2016). The experience of caregiving and support were the top two discussion topics at the Caregiver Café. Another limitation of the café is that the facilitators spoke English only. Interpreters for non–English-speaking café visitors were not provided and would be hard to implement given the uncertainty of who would be attending each week.

Implications for Practice
Nurses work closely with family caregivers and personally witness the stress they are under. Nurses are responsible for teaching intricate procedures to family caregivers, such as flushing catheters and changing dressings, as well as what important and possibly life-threatening symptoms to report. The Caregiver Café is an easily adapted model for nurses to implement in their settings to provide support and education for family caregivers without prohibitive costs. The café also provides a means for the caregiver to share their concerns and suggestions for improvement, as well as what is working. Nurses can implement their suggestions to improve care and enable the caregiver to feel they are a valued member of the healthcare team.

Conclusion
The many burdens faced by oncology caregivers have been well documented. They are asked to perform skills, make assessments, coordinate care, and communicate with healthcare providers at an increasingly complex level. Interventions like the Caregiver Café

<table>
<thead>
<tr>
<th>RESOURCE</th>
<th>TIMES REFERRED IN 2015</th>
<th>TIMES REFERRED IN 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing and transportation coordinators</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Chaplain</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Leukemia and Lymphoma Society</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Social workers</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Hospice and home care</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Image Recovery Center</td>
<td>4</td>
<td>--</td>
</tr>
<tr>
<td>Psychiatric liaison nurse</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Dietitians</td>
<td>2</td>
<td>--</td>
</tr>
<tr>
<td>Other nurses</td>
<td>2</td>
<td>--</td>
</tr>
<tr>
<td>Palliative care</td>
<td>2</td>
<td>--</td>
</tr>
<tr>
<td>Primary care physician</td>
<td>--</td>
<td>2</td>
</tr>
<tr>
<td>Ulman Cancer Fund for Young Adults</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Child Life Services</td>
<td>1</td>
<td>--</td>
</tr>
<tr>
<td>Financial counselors</td>
<td>1</td>
<td>--</td>
</tr>
</tbody>
</table>

TABLE 2. REFFERALS OFFERED TO CAFÉ VISITORS

CJON.ONS.ORG 

VOLUME 22, NUMBER 1 CLINICAL JOURNAL OF ONCOLOGY NURSING 95
Café may improve confidence and decrease stress for caregivers, and this type of intervention supports both caregivers and patients.

Joanne P. Finley, RN, MS, is the patient education coordinator at the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore, MD. Finley can be reached at finlej01@jhmi.edu, with copy to CJONEditor@ons.org. (Submitted February 2017. Accepted April 26, 2017.)

FIGURE 3.
CAREGIVER RESOURCES

PROGRAMS AND SUPPORT GROUPS
Caregiver Café
• Are you taking care of or supporting someone with cancer? You are invited to our Caregiver Café to relax, meet other caregivers, and ask your questions. Just stop by on Thursdays from 11 am to noon in the Weinberg Building 5th floor waiting area across from the visitor elevators. No reservations needed. All caregivers welcome.

Ask the Expert
• A place to ask your questions about taking care of your loved one (mouth care, nutrition, catheters, dressings, etc.) and yourself
Walking on Eggshells videos
• Covers a wide range of topics, such as communicating with healthcare providers and children, taking care of yourself, and finances
www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/videos/caregivers.html
Fine Print of Cancer caregiving video
• Shares what it is like to be a caregiver
www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/videos/fineprint.html#Caregiving

MEDICAL CARE FOR YOURSELF
If you need medical care, you can call Johns Hopkins USA at 1-410-464-6555 or 1-855-695-4872. The website is www.hopkinsmedicine.org/usa. Our social workers can also make the referral for you (call 1-410-955-8934).

WEBSITES
• www.cancercare.org
• www.caringbridge.org
• www.strengthforcaring.com/manual/index.html

RESOURCES
Caring for Your Loved One With Cancer
• www.cancercare.org/publications/1-caregiving_for_your_loved_one_with_cancer
Young Adults as Caregivers
• www.cancercare.org/publications/141-young_adults_as_caregivers

The author takes full responsibility for this content and did not receive honoraria or disclose any relevant financial relationships. The article has been reviewed by independent peer reviewers to ensure that it is objective and free from bias.

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. https://doi.org/10.1016/j.suponc.2011.10.003