

Partnering with Informal Caregivers: Meeting Needs, Tapping an Important Resource

Susan C. Cobb, PhD, RN-BC 07 February 2018

Executive Summary

Informal caregivers of adult patients with chronic illnesses can include family members, friends, neighbors, or other members of the community. These caregivers, often are unpaid and not trained as healthcare professionals, provide a critical link between healthcare providers/organizations and those receiving care. With trends toward outpatient care and extended survival rates for persons with chronic illnesses such as cancer, informal caregivers are now being recognized more for the important role they play in optimal health outcomes. Increased emphasis in nursing and other research has been placed on the needs and experiences of informal caregivers and how they can be supported and developed in their role. Fox Chase Cancer Center has partnered with patients, families, and caregivers to give caregivers more of a voice in healthcare and has implemented some innovative programming to help develop this important resource in oncology care.

Social Context

The role of family and other informal caregivers of adult cancer patients and others with chronic illnesses has been growing in importance and scope. With more therapy options for cancer patients and new ways to deal with side effects of treatment, cancer is now in many instances viewed as a chronic disease. Treatment is often handled primarily on an outpatient basis, such as oral chemotherapies and home injections, increasing the involvement of informal caregivers as an integral part of the patient team. While the majority of informal caregivers have been female, there is a growing proportion of males in the caregiving role (AARP, 2017). Many caregivers also work outside the home, compounding this already complex role. Despite the many challenges of caregiving, there are positive aspects which are gaining increased recognition, such as increased self-esteem, the feeling of accomplishment, and potentially closer relationships with the patient.

Innovative Model

At Fox Chase Cancer Center nursing and social work has innovatively partnered with informal caregivers to explore and strengthen the important role caregivers play in oncology care. Interdisciplinary research led by a nurse researcher in collaboration with a social worker has focused on the needs and experiences of informal

caregivers in an effort to identify ways to support and develop caregivers in their role. The researchers meet with the Patient and Family Advisory Council regularly to discuss their work and get input. An ad-hoc Caregiver Interest Group has emerged which consists of nursing, social work, and volunteers who are committed to helping caregivers.

Informal caregivers identify a need for information about resources available to assist them in their caregiving role. This information is best received early in the treatment process and prior to discharge when the patient is hospitalized. There is also a need to have information available throughout the course of treatment as needs change. Fox Chase Cancer Center (FCCC) developed a Caregiver Resource Guide which is available on the center's website. The guide includes information about social services, home care agencies, cancer organizations, tips for communication, financial and legal resources, and tips for caregivers including meeting their own wellness needs. The Caregiver Interest Group and the researchers found that many caregivers do not realize the guide exists. To help market the web guide, the Department of Volunteers developed a bookmark with information about the guide which was placed in the surgical waiting area along with other information and treats during National Caregiver Month (November). It is printed on lavender paper, the specified color for that special designated month. The bookmark has been very

well received and is now distributed at every opportunity to caregivers such as when they participate in research and in education sessions at the center. The Caregiver Resource Guide webpages were put on a regular schedule for review annually, with participation from members of the PFAC. The guide is also updated as needed throughout the year as new resources are identified, many times by caregivers themselves. This updating is coordinated by the Caregiver Interest Group in collaboration with the center's library staff. Recognizing that some informal caregivers prefer print format for information the guide has a print button enabling printing of each section.



The Resource and Education Center offers education sessions for informal caregivers and for patients. Courtesy of Fox Chase Cancer Center

Informal caregivers identify a need for support in addition

to information. Caregiving can be intense and all-encompassing for caregivers, leaving little time for participation in structured support groups held on certain dates and times. The center offers support groups for patients which are regularly open to caregivers as well. The Resource and Education Center (REC) at FCCC moved its location in the past year to a sunny, open space. The REC offers a large amount of print information such as booklets and print copies of the Caregiver Resource Guide. It also has computer stations and a phone charging station. There is comfortable seating and light refreshments available throughout the day. As part of their efforts to make the REC more widely known and accessible to patients and caregivers a monthly educational program was recently established by the REC staff. One of the first programs offered was "Caring for the Caregiver." A nurse facilitated the session which highlighted information, resources, and tips for caregivers, including the Caregiver Resource Guide. Adequate time was allowed for discussion and sharing among the attendees -- an area of need identified by caregivers who want time to share and learn from each other. Evaluations of the session were very positive. Ideas for other sessions in the future were garnered. Other topics offered so far have been on nutrition and spirituality.

Model Differentiation, Financial Insight

The approach at Fox Chase Cancer Center to involve

informal caregivers in identifying and meeting their own needs has been successful due to an innovative approach that is multifaceted, involving collaboration across departments and committees/other groups to enhance synergy. Being open to and seeking out assistance from caregivers themselves is another strategy for success. Getting started in partnering with informal caregivers in healthcare organizations requires minimal financial burden. As programs grow, opportunities for funding outside of one's own institution to explore could include groups involved in policy development and resources for informal caregiving such as the National Alliance on Caregiving, AARP, Family Alliance on Caregiving, and specialty organizations of professions such as nursing and social work.

Social Implications

While the time and scheduling limitations of informal caregivers are a reality, harnessing the passion and knowledge they have in their role can help organizations to enhance outcomes of care. Other ideas for consideration that have been gleaned from the work at FCCC include a web blog or support group for men in caregiving and development of a caregiver education program. Some informal caregivers express interest in sharing their expertise and giving back to organizations by offering to assist and/or participate in such programs. Informal caregivers are important partners in healthcare

whose voice is starting to be heard and whose potential is just beginning to be tapped.

Works Cited

Maisy Fernandez, "What is the Best-Kept Secret of Caregivers in America? 40 Percent of Them Are Men", American Association of Retired Persons (AARP) Bulletin (2017, November): 34-35.

Retrieved December 27, 2017, from AARP.Org/Bulletin: [Link](#)

Author bio

Susan C. Cobb is Director of Professional Development and Practice Innovation at Fox Chase Cancer Center in Philadelphia, PA. She earned her Bachelor of Science in Nursing from Binghamton University, her Master of Science in Nursing from University of Pennsylvania, and her PhD in Nursing from Duquesne University.