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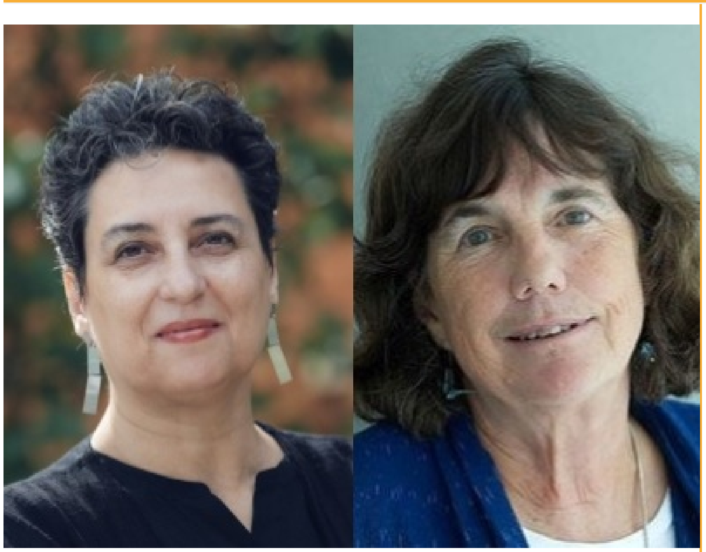
AACI Commentary

Changing Needs for a Growing Population: Shared Decision Making for People Living With Cancer as a Chronic Disease

By Gwen Darien and Christine Wilson, MA, MS



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Commentary Overview

- A growing number of patients are living with their cancers or remain under long-term treatment.
- The Patient Advocate Foundation has worked with three partners: VCU Massey Comprehensive Cancer Center, the Fannie Lou Hamer Cancer Foundation, and the Los Angeles Alliance for Community Health and Aging, to understand how patients living with cancer as a chronic disease make shared decisions about their treatment.
- Through workshops, discussion groups, and surveys, we learned that patients and their caregivers are seeking easy-to-understand information and support at all stages, from diagnosis through survivorship.

Brooke was 74 years old when she was diagnosed with advanced peritoneal cancer. She underwent aggressive neoadjuvant therapy, extensive surgery, and adjuvant chemotherapy. Before her diagnosis, Brooke had been a hiker and competitive tennis player, but after the second round of chemotherapy, she could barely walk for five minutes at a time. The cancer was in remission, but the treatment had left her weak, tired, and depressed. She reviewed the large packet her doctors provided on the potential benefits and side effects of the proposed therapy. But the one thing Brooke wanted was to feel good again – even for a short time, and even if it meant increasing her already high chance of recurrence. She decided against the maintenance regimen.

Today in the United States, an estimated 20 million people have been treated for cancer. While many have completed treatment and are now disease free, considered cured, or in long-term remission, a growing number are living with their cancers or are at high risk for recurrence and remain under treatment, sometimes for years.

These patients' information needs and communications with their health care team often differ from those who are newly diagnosed or who go through relatively short-term treatment regimens. We all learn from experience and cancer patients are no exception. Since the first days when they sat stunned as their doctors showed them the dark areas on their scans or explained what a mutated gene meant they have learned to speak the language of cancer. Most have acquired or improved their ability to advocate for themselves and often for others as well. They know how to identify and access resources and support. They understand that they have options for their treatment and care and want to participate actively, as partners, with their doctors and providers in making those decisions. They are fully capable of making rational choices in favor of *quality* of life over *quantity* of life.

Connected by Common Threads

In the last two years, the **Patient Advocate Foundation** has worked with three partners: **VCU Massey Comprehensive Cancer Center** in Richmond, Virginia; the **Fannie Lou Hamer Cancer Foundation** in Ruleville, Mississippi; and the **Los Angeles Alliance for Community Health and Aging** in South Central Los Angeles, to understand how patients living with cancer as a chronic disease make shared decisions about their treatment. In Year I, we co-created workshops with our partners to understand what matters to patients and caregivers and what barriers they face when accessing cancer care. We used discussion groups, narrative medicine sessions, and surveys to hear the voices of our participants. In Year II, we returned to the same partners and asked them to put together smaller working groups, largely drawn from the Year I participants. This time, we focused on understanding what kinds of information they value and how and when they want to receive that information.

The participants identified common themes across all three groups. They stressed the importance of having a relationship with their doctors and health care team. Mutual trust, good communication, and a provider who knows something about you as a person are critical to making shared decisions. Patients and caregivers in all three locations also talked about the hard issues they face: *How do you talk about changing treatments that are not working or ending treatment entirely? What is the impact of real or perceived judgments or biases about race, sexuality, and personal qualities on the patient/doctor relationship?*

Patients also expressed their fears of getting substandard care if they had certain types of insurance, were uninsured, or were unable to pay for their therapies. In all three locations, patients and caregivers raised issues about how to talk to their families about treatment decisions, especially when those decisions related to changing or ending treatment. Participants also expressed strong interest in becoming better self-advocates and in "paying it forward," using their experiences to help other people facing cancer.

Disparities in Access, Cost, and Awareness

There were also striking differences among the three sites. In Richmond, virtually all the workshop participants are being treated at the Massey Comprehensive Cancer Center and are aware of the quality of treatment and care they receive there. They spoke positively of having access to innovative therapies, clinical trials, and a system that supports their emotional and social needs. In Los Angeles, a city with a wide range of excellent cancer care facilities, the group expressed frustration with the problems they encounter in accessing this high quality care. They noted issues including difficulty in getting appointments with specialists; unwillingness of top doctors to accept MediCal, the California Medicaid program; lack of knowledge about existing options; and the day-to-day difficulty of getting from one part of the city to another.

It was in Ruleville, Mississippi where we learned how pervasive and deep the inequities in health care are in this country. The working group there, composed of community leaders, educators, businesspeople, and health professionals, had the highest education level of the three. These are knowledgeable people deeply involved in working to improve the health care and well-being of the Mississippi Delta. Mississippi is a state that has not expanded Medicaid. Patients, caregivers, and providers in this region understand what it means to make shared decisions about their cancer treatment and care, but frequently face enormous barriers in gaining access to that care. The largest hospital in the area is losing physicians and key services and teetering on the brink of closing entirely. Many people do not have insurance and cannot afford basic or preventive care. And patients with serious illnesses, including many cancers, must travel two hours to centers in Memphis or Mobile to get treatment.

Developing Health Literacy

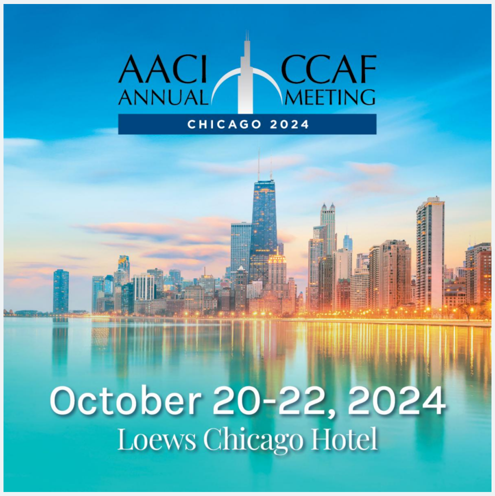
Regardless, the cancer patients and caregivers in our groups want information about their cancer at every key juncture in the illness journey. In the words of one participant, “We want easy to understand information that we can use to make decisions –but not dumbed down.”
They uniformly use their patient portals, search for information online, and use their smartphones—even in places like Mississippi, that have poor Wi-Fi availability—and seek support from other patients. They like information that is tailored to their specific situation, especially when it includes illustrations or visual explanations.

Very few people are “health literate” when they first hear their cancer diagnosis, but with time and experience, they gain knowledge, skills, and the ability to understand treatment options and make true shared decisions about their treatment and care. The challenge for health care providers is to work closely with patients and caregivers to develop decision support tools, information, and resources to make that partnership possible and mutually beneficial.

The Future is Here But Its Benefits Are Not Equally Distributed

Gwen Darien, a co-author of this AACI *Commentary*, recently discussed cancer disparities with AACI President **Robert A. Winn, MD**, director of VCU Massey Comprehensive Cancer Center; **Freddie White-Johnson**, founder of the Fannie Lou Hamer Cancer Foundation; and **Reginald Tucker-Seeley, ScD**, principal/owner of Health Equity Strategies and Solutions. A recording of their conversation will be available on demand as part of the President's Highlights on the **2024 AACI/CCAF Annual Meeting** app. AACI members must register for the annual meeting to access the app.

Register Today



Our Mission

The Association of American Cancer Institutes (AACI) represents over 100 premier academic and freestanding cancer centers in the United States and Canada. AACI is accelerating progress against cancer by enhancing the impact of academic cancer centers and promoting cancer health equity.

About AACI *Commentary*

To promote the work of its members, AACI publishes *Commentary*, a monthly editorial series focusing on major issues of common interest to North American cancer centers, authored by cancer center leaders and subject matter experts.

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