Personal health care experiences often propel individuals to pursue careers in health care. For me, it was the experience of caring for my father who had early-onset neurodegenerative dementia that set the stage for my current work. Now, with an advanced degree in health policy with a focus on caregiving policy and research, I am part of a research team studying the information needs of cancer caregivers.

Interest in family caregiving in the cancer context has grown over the past several years and is driven largely by the bubbling volcano that is older population growth in the United States. Due to a projected increase in the U.S. older adult population, a corresponding increase in cancer diagnoses is anticipated. A 67% increase in cancer diagnoses among adults 65 and older is anticipated between 2010 and 2030 (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). Meanwhile, a variety of factors contribute to the burden of care being shifted onto family caregivers, including a move toward more outpatient cancer care, advances in home-care technologies, and financial constraints (e.g., the cost of financing home aides or nurses).

Caregiving research is vital as it is the scientific story of many caregivers. Yet, the story of one still holds value. The following is my commentary on being a cancer caregiver for an 87-year-old woman. This woman is a nonbiological “grandmother” to me. She was never married and never had children. Thus, I formally fit within the family caregiver spectrum as a “friend.”

My official tenure as a cancer caregiver began when my pseudo-grandmother, Betty, noticed a large lump on her left breast. She immediately called her gynecologist and scheduled a mammogram. A mammogram was a test she had not had in years, which, unfortunately, is not uncommon of someone of her age and background. The mammogram verified what she knew—an abnormal growth. She moved on in the assembly line of...
good care and was scheduled for a biopsy. I, along with others, urged her to have patience and wait for the laboratory result. “It may be cancer, but it also may not be,” I offered in an attempt to be calm but not overly optimistic.

The biopsy result indicated cancer, a diagnosis that numerous other older women likely received that same day. Despite sharing a similar diagnosis with many other older women, Betty is no typical 87-year-old. Most notable is her number of prescription medications compared to the average adult 60 or older. A 2008 report indicated that nearly 9 of 10 adults 60 or older were taking at least one prescription medication, whereas nearly 4 of 10 were taking five or more (Gu, Dillon, & Burt, 2010). Betty’s number of prescription medications was zero. Her prescription card showed only a daily multivitamin and garlic pill. My pseudo-grandmother also owns her own car and, importantly, is exceptional at driving. On several occasions, she has driven my kindergarten daughter from school to home. Among her friends at the long-term care facility where she has an apartment, she is the designated driver (not that kind!) of many older women to and from church and other community events.

So here lies the conundrum as her family caregiver. Should her age or her health dictate her treatment protocol, and what is my role in ensuring that it is the latter? My role as her caregiver was not only to unobtrusively assist with information comprehension while tagging along at doctor appointments, but to also ensure that her clinicians knew she was an outlier.

What are the treatment considerations for an older, active, and able woman with breast cancer? This is the question I mulled over and over in days following Betty’s follow-up appointment with her surgeon.

Seeing too many friends run down and sick from chemotherapy, Betty’s one wish was not to have chemotherapy even if needed. “Two more years of life is not worth it,” she insisted. Betty viewed all other treatments as fair game. This included radiation therapy, as she could drive herself to and from appointments, which may influence treatment decision making for some older patients. The proposed course of care included lumpectomy, radiation if needed, and oral hormone therapy.

As it often does with primary caregivers, the weight of the world began to set on my shoulders. I turned to PubMed and soaked in every recent article on breast cancer treatment for older women that I could find. These few studies indicate that healthy older women can do as well as younger women with traditional treatments, including chemotherapy. The chance of toxic reactions, however, is still quite real in older populations (Hurria et al., 2011; Laki et al., 2010).

Needing more reassurance, I sought additional input from the health care professionals I knew and trusted in my local church community. One acquaintance is an administrator at a leading cancer center and the other is a breast cancer survivor and nurse. The first conversation reassured that the care being received was adequate, whereas the second conversation became a discussion on ethics of treatment. Yes, Betty might be a candidate for chemotherapy depending on the lumpectomy results, but does that mean it is the correct decision for her, given her wishes? No, we both agreed.

Betty’s lumpectomy went well, with her returning home within the day. Within 2 weeks we were meeting with a radiation oncologist to discuss whether radiation therapy was needed. Given Betty’s sturdy health, an abbreviated 3-week session of therapy was advised. Noting that Betty could very well live to be 100 or older, the radiation oncologist hinted that the 3-week course of radiation may be nothing more than an inconvenience and well worth the investment in the grand scheme. He openly admitted that he might not make the same recommendation to his father who is also 87 but not nearly as healthy.
Betty is now 6 months post radiation. She experienced little to no side effects from the radiation therapy. She now has one prescription medication on her list, and admittedly fears the likelihood of recurrence. Yet, she continues to thrive and drive.

This caregiving experience made me feel what it is like to be a cancer caregiver. Scared. Overwhelmed. Determined. It also pushed me to the information sources I valued most, including research findings and health care experts. More importantly, my experience put a spotlight to the importance of patient-centered care—even for those 85 and older—as no two patients of any age are ever exactly alike.

REFERENCES


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