

Challenges and Opportunities in Cancer Survivorship Research

Karen Hassey Dow, PhD, RN, FAAN

Presenting the keynote address for the Seventh National Conference on Cancer Nursing Research was a distinct honor and pleasure. My focus was on the challenges and opportunities facing us in cancer survivorship research. We have witnessed major changes in cancer survival during the past three decades, with an increase in survival of all cancers combined. At the same time, we are at a unique juncture in our current scientific knowledge of late effects among childhood, adolescent, and adult cancer survivors. Accumulating evidence documents the existence of late physical and psychosocial morbidity from cancer and its treatment that challenges some of our prevailing notions, approaches, and paradigms. In addition, our lack of knowledge in other arenas presents tremendous opportunities for new and exciting research directions. This article focuses on four specific questions for which we have some answers.

1. Who are cancer survivors?
2. What is cancer survivorship research?
3. What do we know about cancer survivors?
4. How do we meet the challenges in cancer survivorship research?

It also will focus on some yet-to-be-answered questions.

Who Are Cancer Survivors?

Leigh (2001) suggested that differences exist in the culture of cancer survivorship. The population of cancer survivors and the concept of survivorship mean different things to different people. Answers to the question “Who are cancer survivors?” may differ depending on the perspective of the individuals—whether from the point of view of research, practice, personal experience, or family experience. Despite the differences in semantics, the National Coalition for Cancer Survivorship continues to define a cancer survivor as a person who is diagnosed with cancer (Clark & Stovall, 1996).

In the United States, cancer survivors total about 8.9 million people, representing 3.3% of the population (American Cancer Society, 2003). The population of long-term cancer survivors is increasing, with 60% of adults and 77% of children surviving beyond five years after diagnosis. As seen in Figure 1, 14% of all survivors were diagnosed more than 20 years ago. Of the 24,040 households in the 1992 National Health Interview Survey, 63% of respondents had received a cancer diagnosis more than five years previously and 10% had received a cancer diagnosis more than 25 years previously (Hewitt, Breen, & Devesa, 1999). Changes in the fundamental understanding of genetics, rapid translation of basic science to practice, modification of dose-limiting toxicities, an increase in screening and early detection activities, enhanced rehabilitation and support interventions, and changes in socio-cultural factors have contributed to the increase in cancer survivors (Rowland, Aziz, Tesauero, & Feuer, 2001).

We have reason to be optimistic: a decline in the cancer death rate from all cancers combined and from each of the four major cancer sites (Simmonds, 2003). Yet, tempered against the optimism of survival is that the burden of cancer in the United States is expected to climb. Two key trends—aging and diversifying population—are expected to increase the cancer burden. First, cancer rates increase with aging. Currently, about 60% of cancer survivors are 65 or older, and the current median age of male and female cancer survivors at time of diagnosis is 68 and 67, respectively (Rowland et al., 2001). However, the number of people with cancer in the United States is expected to double from 1.3 million to 2.6 million from 2000–2050. Thus, cancer in the elderly also is expected to double (Simmonds). Cancer in the elderly presents a challenge for several reasons. The elderly may have comorbid illnesses, making diagnosis, treatment, and survival greater challenges. In addition, caregivers of the elderly with cancer may be frail, which can increase the demand for additional supportive services.

At the same time, the population is diversifying. By 2050, Latinos and Hispanics are expected to comprise 25% of the U.S. population; African Americans, Asian Americans, and Native Americans are projected to constitute an additional 25% of the population. However, few studies have focused on the many multicultural needs of cancer survivors (Aziz & Rowland, 2002).

Figure 2 examines the different groups of cancer survivors by disease (National Cancer Institute [NCI], 2003). The largest group of survivors has breast, prostate, and colorectal cancers. When the data are broken down by gender, about 71% of the female survivors have histories of breast (40%), gynecologic (20%), or colorectal cancer (11%). Almost two-thirds (63%) of male cancer survivors have a history of prostate (38%), other genitourinary (e.g., testicular, kidney) (12%), or colorectal cancer (13%).

What Is Cancer Survivorship Research?

Cancer survivorship research encompasses the “physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment among both pediatric and adult survivors of cancer” (NCI, 2003). Cancer survivorship research focuses on (a)



Karen Hassey Dow, PhD, RN, FAAN, is a professor in the School of Nursing, College of Health and Public Affairs, at the University of Central Florida in Orlando. Dow presented this paper as the keynote address at the Seventh National Conference on Cancer Nursing Research in San Diego, CA, in February 2003.

Digital Object Identifier: 10.1188/03.ONF.455-469