Families Facing Cancer: The Forgotten Priority

Deborah A. Boyle, RN, MSN, AOCN®, FAAN

family: 1a. A fundamental social group in society typically consisting of one or two parents and their children. b. Two or more people who share goals and values, have long-term commitments to one another, and reside usually in the same dwelling place. 2. All the members of a household under one roof. 3. A group of persons sharing common ancestry

American Heritage Dictionary of the English Language, 2000

Each year, updated statistics are published citing the magnitude of the cancer problem for the American public. Specific cancers are quantified in the thousands, and sweeping graphic representations characterize changing patterns of incidence and mortality. What is not brought routinely to the public’s attention is the prominence of cancer in those Americans who lack a personal diagnosis of a malignancy but suffer the parallel consequences of anxiety, fatigue, depression, insomnia, financial burden, and overwork—the family.

Based on the most current population survey from the U.S. Census Bureau (2000), the average American household includes 2.61 people. In 2001, an estimated 1,268,000 Americans were diagnosed with cancer (Greenlee, Hill-Harmon, Murray, & Thun, 2001). One then could approximate minimally that at least another 1,268,000 Americans were “told” of a new diagnosis that mandated their coping with cancer. These family members did not require venous access procedures, lay under a radiation therapy machine for six weeks, or experience bone marrow compromise from chemotherapy. They were, however, mandated to respond to, struggle with, and integrate into their lives the turmoil that cancer creates. What are the needs, then, of these “unknown soldiers” who we recognize as important support for the patient but who infrequently are the recipients of formal interventions from nurses and other team members?

First, nurses must identify who in the family may be at most risk for suffering the consequences of the demanding cancer experience. Many family members may be present and supportive, but not all are actual caregivers. Who is contributing to or assuming the responsibility for the majority of the patient’s care outside of the office or the hospital? Who is overseeing the medications, managing doctor’s visits, planning meals, doing dressing care, waiting for phone calls about lab results, or providing explanations to family and friends about the patient’s status? Is this the same person who is trying to maintain full-time employment, respond to the children’s needs, clean the house, and pay the bills? Don’t just ask in passing in the hallway, “Hi, how are you?” Find 15 minutes to take this caregiver by the arm, sit down with him or her, and ask, “Do you have a minute to talk? I’m wondering how things are going at home and how you’re doing.”

This brief encounter, these simple words, and those genuine intentions all can have a profound effect on family members. Those who receive this quality of care feel the compassion engendered by nurses attempting to understand their equally pressing stresses within a life of chaos.

Many of the families with which nurses interact have never gone through the cancer experience. Hence, as a second option, family members can benefit from advice offered by nurses who can help them master the multiple intrusions imposed by a malignancy. Suggest letting friends bring in food, help with child care, and clean the house. Delineate strategies for triaging phone calls. Review the criteria for when to worry about suspicious symptoms at home. Most family members do not want hours of our time. Rather, they want to be heard when they are anxious, they want practical approaches to problems to help them feel in control of the seemingly uncontrollable, and they want us to listen to their loved one’s reports of distress.

Cancer statistics assume even more poignant implications when projections about families coping with the death of a loved one are considered. The American Cancer Society has estimated that 553,400 Americans died from cancer in 2001 (Greenlee et al., 2001). Again, even the minimum approximation of each patient having only one family caregiver would imply that 1,500 family members a day must cope with the cancer-related death of a loved one in America.

It is the dying that families remember, and for many, the experience of a good death from cancer is not their reality. My years of experience lead me to believe that contentment about feelings of closure and memories devoid of symptom distress do not characterize the majority of families’ experiences. To the contrary, many family survivors are left with ongoing queries about the nature of what they observed, anger about what was not done or managed well, and grief over unresolved relationship issues.

Deborah A. Boyle, RN, MSN, AOCN®, FAAN, is the advanced practice nurse liaison at the University of Texas M.D. Anderson Cancer Center in Houston.