Families Facing Cancer: The Forgotten Priority

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Familiarly: 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.

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 most at 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, 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.

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Concerted attempts to facilitate a good death should not be the sole purview of hospice professionals. For example, radiation oncologists, chemotherapy nurses, and intensive-care specialists should embrace the possibility of an optimum death with equal fervor as those consistently enmeshed in the dying experience. Cancer professionals have much to learn from their hospice and palliative-care colleagues. This learning should not be optional but required of the entire cancer team as we acknowledge that half of our patients will die of their malignancy.

Mentoring possibilities abound in mastering the dying trajectory. Look to colleagues who excel at providing family care in terminal situations, and emulate their competency. Suggest that the daughter lie in bed next to her restless mother to calm her in her last hours. Facilitate the temporary clearing of an overcrowded room so that each family member can spend a few minutes alone with the dying patient. Ask the husband if he wants to help you wash his wife’s face and hands and put on her nightgown after she dies. These are all learned interventions. Discuss as a team how well your group manages dying patients. Could data from a quality-improvement project provide your team with information needed to improve this aspect of cancer care? Solicitation of narrative descriptive data from family members is an effective avenue for change when perceptions about care during the final weeks, days, and hours of life are shared. Remember also that these family members eventually will die. Whether verbalized or not, their intimate observations about the dying they witnessed are highly instructive as they ponder their own death.

The term “family” applies liberally to clusters of people who share many varieties of lineage, housing, companionship, and belonging. As cancer nurses, we know that the projections cited earlier in this editorial severely underestimate the number of Americans affected by cancer. Spouses, children, siblings, grandchildren, nieces, nephews, cousins, neighbors, schoolmates, lifelong friends, partners, work colleagues, and church and volunteer comrades all comprise the heterogeneous term “family.” A more accurate projection of family members facing cancer most likely approximates the following.

- Four to five million Americans provide some type of support to a family member being treated for cancer annually.
- On a daily basis, 6,000 Americans must cope with the death of a family member from cancer. This equals the yearly total cancer death rates in individual states such as Colorado, Iowa, Arkansas, and Mississippi (Greenlee et al., 2001).

Nurses historically have acknowledged, supported, and championed the needs of the vulnerable and the underserved. Families facing cancer can be characterized as all of the above. As we face a future with the questionable provision of needed formal professional support in the home, a growing number of elderly people, and a dwindling number of family members available to provide care, families as a focus of care will assume greater prominence in our nursing ministrations. The time is now to begin to mobilize model programs to provide family-centered care and demonstration projects to test the effectiveness of novel nursing interventions with families facing cancer.

As we encounter cancer in our own families, our appreciation for the urgency to undertake these endeavors is intensified. Our struggles as sisters, daughters, spouses, friends, and colleagues can only be magnified as we attempt to appreciate what those with no experience with the chaos of cancer must master. As actress Anne Baxter once suggested, “See into life—don’t just look at it” (p. 131, *The Quotable Woman*, 1991). Oncology nurses have enormous potential to help families master the cancer experience with newfound vision and clarity. This evolving partnership benefits everyone—patients, families, nurses—touched by cancer, as “we are family.”

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**References**


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