

## ARTICLES

# Helping Families of Patients With Cancer

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**Purpose/Objectives:** To discuss the impact of cancer on families of patients with cancer.

**Data Sources:** National reports on caregiving and research articles related to cancer and families.

**Data Synthesis:** Family caregivers are the bedrock of chronic care in the United States. They provide an enormous amount of unpaid care that is often invisible. Cancer can affect the emotional, social, physical, and spiritual well-being of family members.

**Conclusions:** Family intervention research can have a positive effect on patient and family caregiver outcomes. More intervention research with families is needed that is theoretically based, uses randomized clinical trial designs, and uses instruments that are sensitive to intervention effects.

**Implications for Nursing:** Although family intervention research is limited, descriptive and exploratory research has identified protective factors and risk factors that need to be addressed in clinical practice.

Families are deeply affected when one of their members becomes ill. Not only do they experience anxiety and worry about patients' recovery, but they frequently become the primary caregivers until patients recover. Although there is growing recognition that the family is central to the patient's recovery, information is limited on how to help families as they manage the demands associated with family caregiving. In this article, five areas will be addressed. First, the broader area of caregiving in the United States will be presented to provide a context for examining how cancer affects families. Second, research pertaining to the specific effects of cancer on the family will be reviewed. Third, family intervention studies will be discussed along with a brief summary of the family intervention research we have been conducting at the University of Michigan. Fourth, the article will discuss the implications of family research for clinical practice, and finally, it will identify directions for future research.

## Who Are the Caregivers in the United States?

This was a question asked by the National Alliance for Caregiving and AARP, who joined forces to describe unpaid caregivers in the United States. They formed a research team that conducted a telephone survey with 6,139 adults in the United States, from which 1,247 caregivers were identified. Caregivers were defined as anyone 18 years of age or older providing unpaid care for an adult who required help with at

least one activity of daily living (ADL) (e.g., bathing, dressing) or one instrumental activity of daily living (IADL) (e.g., managing finances, housework). Findings of this comprehensive study were reported in *Caregiving in the U.S.* (National Alliance for Caregiving & AARP, 2004).

Based on the proportion of caregivers and caregiving households identified in the national survey, researchers estimated that there are 44.4 million unpaid caregivers in the United States (National Alliance for Caregiving & AARP, 2004). These caregivers provide care to adults with a variety of conditions (8% reported providing care to someone with cancer). Most caregivers provide care to one person (69%), and an additional subgroup of caregivers (22%) provide care to two people. Because most caregivers (59%) are employed either full time or part time, caregiving is the "second job" for many. A sizeable number of caregivers (39%) report that they had "no choice" in becoming a caregiver.

According to the national survey, most caregivers in the United States are family members (83%). In more demanding care situations, family members are even more likely to be the caregivers (89%). Higher estimates have been reported by Emanuel et al. (1999), who found that among the terminally ill in the United States, 96% of the caregivers were family members. These high percentages underscore the central role that family members play in managing the care of people who are ill in the United States. It is no surprise that the family has been called the bedrock of our nation's chronic care system (Arno, Levine, & Memmott, 1999).

In regard to gender, a majority of caregivers in the United States are female. Although the number of male caregivers is increasing, women bear a greater responsibility than men with caregiving. When investigators compared the caregiving experience of women to that of men, they found that women provide more hours of care per week, provide care at higher levels of burden, are more likely to report "no choice" in becoming a caregiver, and report more emotional strain associated with the caregiving role than male caregivers (National Alliance for Caregiving & AARP, 2004).

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