
NURSING ROLE IMPLICATIONS FOR FAMILY CAREGIVING

MARCIA GRANT AND BETTY FERRELL

OBJECTIVE: *To describe the clinical, education, and research roles of professional nurses caring for family caregivers.*

DATA SCORES: *Review of literature and Websites on the professional nursing role and family caregivers.*

CONCLUSION: *The growing number of family caregivers of cancer patients will need education and support. The professional oncology nurse is best suited to assess, teach, and support these family caregivers, as well as contribute to the evidence base of these areas of practice.*

IMPLICATIONS FOR NURSING PRACTICE: *Professional nurses caring for oncology patients need to expand their role to include additional support and education of family caregivers.*

KEY WORDS: *Professional nursing, nursing role, family caregiving*

FAMILY caregivers provide a staggering amount of unpaid care in the United States,¹ and this care will expand with the increasing number of patients needing this care. Who can prepare and support these caregivers? Do we know the best ways to provide this education and support? The profes-

sional role of the oncology registered nurse consists of clinician, educator, counselor, and researcher, and includes the education, support, and research that will address the family caregiver's ability to care for their loved ones. Based on the outstanding articles in this issue of *Seminars in Oncology Nursing*, this summary addresses the current status of family caregiving for the cancer population, the role of professional nursing in caregiver preparation and support, and the opportunities for nursing research to provide a scientific basis for educating and supporting family caregivers.

CURRENT STATUS OF FAMILY CAREGIVING

The number of cancer patients continues to increase, with approximately 1,638,910 new cancer patients expected to be diagnosed in 2012.² This increase involves both children and adults. However, the adult population is expanding at a more rapid rate because of the increased age of

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the general population and the resulting increased occurrence (prevalence) of cancer diagnoses (Fig. 1).³ Cancer patients are now being diagnosed earlier, treated earlier, and surviving longer. They frequently experience cancer as a chronic disease, with a recurring cycle of treatment, remission, recurrence, and additional treatment, remission, and recurrence, finally resulting in either disease-free survival or a declining health and resulting death from cancer (Fig. 2).⁴ Such a chronic disease picture illustrates how family caregiving of this population is more commonly not a one-time period commitment, but may continue for years with changing needs depending on the phase of care.

Coupled with this picture of increasing family caregiving needs is the continued pressure on acute care settings to discharge patients as early as possible to lower health care costs. This “early” discharge creates a challenge for family members to give care previously administered by hospital personnel. A third pressure comes from the changes in health care policy regarding hospitalization reimbursement. To minimize readmissions for Medicare patients, payment for hospitalization may be reduced if the patient is readmitted within 30 days following discharge.⁵ These trends in health care point to the importance of preparing family caregivers to manage complex symptoms (eg, pain, nausea, dyspnea, fatigue, lack of appetite, dehydration), coordinate medication administration, prevent and/or detect infections, and support functional rehabilitation, while making accurate judgments to contact health professional when needed. The health professionals traditionally involved with this preparation are professional nurses.

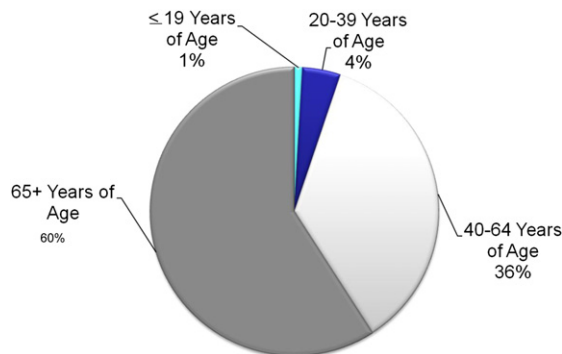


FIGURE 1. Estimated number of persons alive in the United States diagnosed with cancer on January 1, 2008 by current age (invasive/1st primary cases only, N = 11.9 M survivors). Data from Howlader et al.³

THE ROLE OF PROFESSIONAL NURSING IN FAMILY CAREGIVING PREPARATION AND SUPPORT

Family caregivers need preparation to meet the demands of their new responsibilities, including physical care as well as psychological, social, and spiritual support. This care varies considerably depending on the patient's cancer diagnosis. For example, patients with hematologic cancers treated with hematologic cell transplant are physically vulnerable when discharged. Their immune system is lowered, making them susceptible to potentially lethal infections. Their appetite and ability to eat is decreased and may result in dangerous dehydration and nutritional failure. The patient's emotional needs are great, and revolve around the potential for recurrence, readmission, and death. On the other hand, patients with early stage prostate cancer may be discharged with fewer physical changes, such as a potential for urinary retention, but with emotional concerns around a lack of continence, erectile dysfunction, and associated changes in social well-being. Patients with a late-stage lung cancer diagnosis may be treated completely in an ambulatory setting, with management of chemotherapy side effects and an increasing dyspnea presenting challenges for their family caregivers.

The recognition of cancer as a chronic disease, with treatment, remission, and recurrence leading to additional treatment, which starts the cycle again, occurs in many cancers and has changed the responsibilities of the family caregiver. These responsibilities are characterized by continued patient caregiving needs that may change and/or expand over the cancer trajectory, as patient remissions and recurrences take place. Maintaining and improving the health care status of the family caregiver has become a part of the support caregiver's need.

Studies have demonstrated that family caregivers suffer emotionally and may be susceptible to a variety of medical conditions. For example, high levels of depression occur in family caregivers.⁶ Increased risks for stroke and coronary heart disease have been reported in spousal caregivers of cancer patients.⁷ Routine health care may be delayed, resulting in missed primary care visits, delayed routine cancer screening, and postponed dental care.⁸ Thus, education and support of the family caregiver must address both how to

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