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Integrating Family Caregivers into Palliative Oncology Care Using the Self- and Family Management Approach

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Objective: *To describe the integration of family caregivers into palliative oncology care using the Self- and Family Management Framework.*

Data Sources: *Peer-reviewed journal articles.*

Conclusion: *The role of family caregivers in palliative oncology includes focusing on illness needs, activating resources, and living with cancer. Several factors may serve as facilitators of or barriers to these activities. A growing number of interventions support family caregivers' involvement in palliative oncology care.*

Implications for Nursing Practice: *Nurses should identify who the family caregiver is, confirm ability and willingness, discuss patients' and family caregivers' goals for cancer care, activate resources, and promote ongoing communication to support changing needs.*

Key Words: *palliative, oncology, cancer, caregiver, family, self-management.*

A family caregiver (FC) is a relative or friend whom a patient identifies as someone who assists with the management of cancer care.[1,2] In the United States, 2.8 million individuals serve as FCs to patients with a primary cancer diagnosis.[3] As a result of the increase in the number of patients with cancer, estimated to be 26.1 million by 2040,[4] the number of individuals serving as FCs is likewise expected to rise.

Because of improved patient survival and more cancer care occurring in the home, FCs are being integrated more regularly into the palliative oncology care team,[5] and there is increasing recognition of their dual role of supporting patients and themselves during the cancer experience. However, many feel unprepared and overwhelmed by the

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caregiving role[6,7] and report elevated stress[3] and distress, particularly when caring for patients with advanced disease.[8,9] The psychological burden of FCs may exceed that of patients, which can negatively affect the well-being of the FC and patient.[5,10] Integration of palliative care into oncology care, with the focus of palliative care on patients and FCs as a dyadic unit,[11] may increase support for FCs in coping with physical and psychosocial sequelae of caregiving and may enhance their ability to provide increasingly complex patient care.[2]

In this article, the Self- and Family Management Framework is used to discuss the role of FCs in palliative oncology care.[12] Facilitators of and barriers to the FCs' involvement in palliative oncology care are discussed, along with examples of interventions that support their involvement in palliative oncology care based on three main processes of self- and family management: 1) focusing on illness needs; 2) activating resources; and 3) living with a chronic illness.[13] Implications for future research and clinical practice that may assist oncology nurses in integrating FCs into palliative oncology care are also addressed.

FCs in the Context of the Self- and Family Management Framework

Self- and family management refers to the daily activities performed by patients and their FCs to manage a chronic illness.[14] The goal of self- and family management is for patients and FCs to develop and use cognitive, behavioral, and emotional strategies to maintain quality of life.[15] Patient self-management is not a solitary activity because, ideally, patients and FCs work together to manage the patient's health condition. Self-management has been defined as the activities of the patient "in conjunction with family, community, and health care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions."[16] Thus, FCs have a critical and dual role. They support patients in addressing patient self-management tasks (eg, symptom management), and they take on their own set of tasks (eg, helping the patient to make health care decisions) to assist in the management of the patient's health condition.

The Self- and Family Management Framework[17] was developed at the Yale School of Nursing (West Haven, CT) based on a literature review and on faculty research about patient and family management of chronic illness to guide self- and family management science. The Framework illustrates the interconnected roles of patients and FCs in performing self- and family management. The Framework was recently adapted[12] (Figure 1) to specify processes (ie, what patients do to manage a health condition), facilitators and barriers (ie, risk and protective factors that may help or hinder patient self-management), and health outcomes (eg, physical, emotional, family) based on two metasyntheses of patient-reported data.[13,18]

As shown in Figure 1, the three main processes of self- and family management are 'focusing on illness needs,' 'activating resources,' and 'living with the condition.'[12] *Focusing on illness needs* includes activities related to taking care of patients' physical needs and illness-specific concerns of a chronic illness. In a palliative oncology setting, these might include managing fatigue and encouraging a healthy diet. As part of focusing on illness needs, individuals learn about cancer, take ownership of health needs, and perform health-promotion activities to improve quality of life. *Activating resources* refers to accessing individuals and community services that support self- and family management. Individuals may include health care providers, clergy members, and friends. Services may include housekeeping or transportation support services. Activating resources can assist with management of medical, psychosocial, spiritual, and financial aspects of cancer. *Living with the condition* is the process of coping with cancer, including its physical, emotional, spiritual, and other effects. This process includes integrating cancer into one's larger life context and coping with the transitions that accompany a fluctuating course of illness.

As shown in Figure 1, a five categories of facilitators and barriers affect self- and family management: 1) personal/lifestyle characteristics; 2) health status; 3) resources; 4) environmental characteristics; and 5) health care system. The number and nature of operative factors within these categories varies by individual and over time.[19,20] Operative factors present somewhere on a continuum from being a facilitator to being a barrier. That is, the same factor may help or hinder self- and family management.[18] Consider the example of social support. Having social support in the form of a useful friend may help self- and family management by easing caregiving burden; however, an overbearing friend may hinder self-

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