The Role of the Family in Treatment Decision Making by Patients With Cancer

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Purpose/Objectives: To examine family disagreements about treatment decisions for patients with advanced lung cancer.

Research Approach: Descriptive, qualitative study.

Setting: A large comprehensive cancer center in Cleveland, OH.

Participants: 37 patients with stage III or IV lung cancer and 40 caregivers (24 primary and 16 secondary) from 26 families were interviewed.

Methodologic Approach: Open-ended audiotaped interviews were transcribed verbatim. NUD*IST (non-numerical unstructured data indexing, searching, and theorizing) computer software (QSR International, Melbourne, Australia) was used to perform content analysis.

Main Research Variables: Vast differences in opinions between patients and family caregivers about treatment decisions and care.

Findings: Sixty-five percent of families reported various family disagreements that mainly concerned routine treatment decisions, discontinuation of therapeutic treatment, and use of hospice care.

Conclusions: Family disagreements about treatment decisions for patients with advanced lung cancer are common and include a wide range of issues. Family members play an important role in the selection of patients' doctors, hospitals, treatment options, and provisions of care.

Interpretation: The findings suggest that nurses need to be aware of differences of opinion between patients with advanced cancer and their caregivers. Knowledge of family disagreements about treatment decisions can help nurses' efforts to integrate families into decision-making processes in clinical settings to facilitate family communications and improve patients' and caregivers' satisfaction with treatment decisions.

Key Points . . .

- ➤ Patients with advanced cancer and their caregivers are likely to move from fighting to accepting cancer at different paces. Caregivers' personal understanding, knowledge, and experiences of death influence their empathy with patients' wishes.
- ➤ Family relations affect the degree of family concordance in making treatment decisions. Prior family dynamics set a tone for current treatment decision making in the family.
- ➤ In most situations, caregivers act as patient advocates in ensuring quality care. Family opinions have a significant impact on patients' treatment decisions and psychological well-being.

Lung cancer is the leading cause of cancer deaths among women and men (American Cancer Society, 2003). Difficulties in the early detection of lung cancer often delay its diagnosis. At the time of diagnosis, most patients with lung cancer are older than age 65 (Edwards et al., 2002). The older age of most patients with lung cancer imposes physical limitations on their ability to endure suffering and accustoms them to being more passive than younger patients in making treatment decisions (Petrisek, Laliberte, Allen, & Mor, 1997; Siminoff, Ravdin, Colabianchi, & Sturm, 2000). Spouses of patients with lung cancer often are deceased or in frail health themselves. Although adult children usually do not live at or near home, they often are actively involved in making treatment decisions, despite their limited insight into the physical and social needs of the patients (Lederberg, 1989). Given the numerous treatment decisions that need to be made in a short time period, families' impact on patients' treatment decision making can be profound. As cancer progresses and treatment outcomes become more uncertain, disagreements between family members and patients become more frequent. Family members may take increasingly proactive roles as decision makers when patients become further debilitated. Thus, treatment decision making centers on patients' and family members' concordance.

The existing literature sheds light on several contextual factors that may affect family behaviors in treatment decision making. Patients with cancer and their family caregivers experience tremendous stress (Akechi, Okamura, Nishiwaki, & Uchitomi, 2002; Cameron, Franche, Cheung, & Stewart, 2002; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). The experience can cause patients and caregivers to have different perceptions of patient stress and symptoms (Lobchuk & Degner, 2002; Porter et al., 2002; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002) and contribute to family disagreements about treatment. Based on individual physical, functional, and psychological states, patients and caregivers develop their own needs (Longman, Atwood, Sherman, Benedict, & Shang, 1992; Silveira & Winstead-Fry, 1997; Steele & Fitch, 1996). Differing needs may contribute to disagreements during treatment decisions. In addition, existing family relationships can affect decision making. A family that

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