Quality of Life, Uncertainty, and Perceived Involvement in Decision Making in Patients With Head and Neck Cancer

Miho Suzuki, PhD, RN, AOCNP®

Head and neck cancers only comprise about 3% of all cancers in the United States. The five-year survival rate is 61% for oral, pharyngeal, and laryngeal cancers, which is a better survival rate than that for stomach, esophagus, lung, liver, and pancreatic cancers (American Cancer Society, 2012). However, patients with head and neck cancer confront many functional problems with respect to speaking, breathing, eating, and swallowing, as well as difficulty maintaining a social life because of their altered facial appearance (Semple, Sullivan, Dunwoody, & Kernohan, 2004). Although all patients with cancer experience alterations in their quality of life (QOL), the challenges these particular patients face may result in a greater loss or change in their ability to take pleasure in life.

Uncertainty has been viewed as a common reaction to a cancer diagnosis (Molleman et al., 1984) and a major stressor to be addressed to maintain a person's well-being and QOL (Lazarus & Folkman, 1984). Mishel (1988) proposed the Uncertainty in Illness Theory to explain an adaptive process people use to maintain their QOL during unsettled time periods. Reduced uncertainty can facilitate patients’ adapting to an illness experience. Mishel (1988) also postulated that when healthcare providers offer information regarding the course of a disease and address patient concerns, patients may feel more comfortable dealing with symptoms and making treatment decisions, thereby decreasing uncertainty and improving their daily lives.

Researchers have found that patients with cancer are more satisfied with health care when their perception of their involvement in decision making matches their desire to be involved in decision making (Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002) and when patients perceive that they share decision-making opportunities with their physician, regardless of their preference for involvement (Gattellari, Butow, & Tattersall, 2001). Those findings suggest that assessing patients’ perception of their involvement in decision making in terms of evaluation of health outcomes is important. Despite a number of studies on QOL (Osoba, 2007) and patients’ treatment decision making (Hubbard, Kidd, & Donaghy, 2008) separately, little research

Purpose/Objectives: To explore the relationship among perceived involvement in decision making, uncertainty, and quality of life (QOL) in patients with head and neck cancer in pre- and post-treatment periods using Mishel's Uncertainty in Illness Theory.

Design: A prospective, correlational design.

Setting: Six outpatient clinics at urban hospitals in New York, NY.

Sample: A convenience sample of 52 adults newly diagnosed with head and neck cancer.

Methods: Data were collected by a self-administered questionnaire containing a demographic datasheet, the Functional Assessment of Cancer Therapy–Head and Neck, Mishel Uncertainty in Illness Scale (Adult), and Perceived Involvement in Care Scale, at pretreatment (Time 1) and six weeks post-treatment (Time 2).

Main Research Variables: QOL, uncertainty, perceived involvement in decision making.

Findings: Post-treatment QOL was lower than pretreatment. QOL was associated with uncertainty and employment status at Time 1 and Time 2. Uncertainty and QOL at the time of pretreatment were predictors of post-treatment QOL after controlling for unemployment, chemoradiation, and physician. Perceived involvement in decision making was not associated with uncertainty or QOL.

Conclusions: The higher a patient’s pretreatment QOL, the more likely QOL remains sound after treatment.

Implications for Nursing: Additional studies, including interventional evaluations to decrease uncertainty and to maintain employment and better income, are needed. Antecedents of Mishel’s Uncertainty in Illness Theory may need to be refined for patients with head and neck cancer.