Validity of the Patient Generated Index as a Quality-of-Life Measure in Radiation Oncology

Susan S. Tavernier, PhD, RN, APRN-CNS, AOCN®; Susan L. Beck, PhD, APRN, AOCN®, FAAN; Margaret F. Clayton, PhD, RN, FNP-CS; Marjorie A. Pett, MStat, DSW; and Donna L. Berry, PhD, RN, AOCN®, FAAN

Purpose/Objectives: To evaluate psychometric properties of an instrument designed to measure individualized health-related quality of life (HRQOL).

Design: Repeated measures of self-reported quality of life.

Setting: An outpatient radiation therapy department in the western part of the United States.

Sample: 86 adults with cancer receiving their first course of radiation therapy.

Methods: The Patient Generated Index (PGI), the National Comprehensive Cancer Network’s Distress Thermometer (DT), and the European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire–Core-30 (QLQ-C30).

Main Research Variables: Convergent validity, responsiveness, sensitivity, and response shift.

Findings: PGI scores were inversely correlated with scores on the DT (r = –0.49, –0.55, –0.44; p < 0.001), as well as the role (r = 0.31, 0.40, 0.38; p < 0.01), emotional (r = 0.33, 0.41, 0.33; p < 0.01), social functioning (r = 0.27, 0.49, 0.42; p < 0.05), pain (r = −0.29, −0.39, −0.39; p < 0.01), and fatigue (r = −0.35, −0.25, −0.47; p < 0.05) QLQ-C30 subscales at all measurement times. The PGI was responsive to those reporting high or low DT scores (t = 4.42, 3.32, 2.9; p < 0.05). A small-to-moderate effect size was detected in those who had an increase (effect size = 0.51) or decrease (effect size = 0.38) in HRQOL over time. Participants reconceptualized HRQOL over time.

Conclusions: Data supported the PGI as a valid measure of individualized HRQOL.

Implications for Nursing: The PGI potentially provides a more patient-centered measure of HRQOL in patients with cancer. Additional testing is needed in larger, more diverse groups.

Literature Review

Health-related quality of life (HRQOL) research has a rich history in oncology nursing. Its measurement is important for the evaluation of interventions designed to improve HRQOL, an outcome that is sensitive to oncology nursing interventions (Given et al., 2003). Several widely used and respected HRQOL instruments exist, and most are constructed of a set of items using Likert-type scale response options. Although the items usually represent domains of HRQOL (e.g., symptom severity, health status, functional levels), they do not allow the respondent to report the relevance or importance of the item to one’s HRQOL (Carr & Higginson, 2001; King, 2006; Moons, Budts, & De Geest, 2006). A need exists for HRQOL measures that allow patients to determine the constructs that define their quality of life. Such measures can have a significant influence on decision making in clinical practice (Donaldson, 2004; Efficace et al., 2007; Fitzpatrick, 1999; Levine & Ganz, 2002; Osoba, 2002).

The Patient Generated Index (PGI) uses a novel approach to measure HRQOL that can be adapted to disease and treatment conditions (Ruta, Garratt, Leng, Russell, & MacDonald, 1994). The PGI directs respondents to define and rate their own HRQOL by identifying important areas of life affected by illness and treatment, reporting the degree of impact during the past week for each area, and rating each area in terms of importance to quality of life. Use of the PGI in patients with cancer is minimal to date (Camilleri-Brennan, Ruta, & Steele, 2002; Lewis et al., 2002; Llewellyn, McGurk, & Weiman, 2006), with no reported studies of use in radiation oncology. The purpose of the current study was to examine the psychometric properties of the PGI in a radiation oncology patient population. Findings report the construct validity, sensitivity and responsiveness of the PGI.