

RESEARCH BRIEF

Measuring Subjective Side Effects and Symptoms in Palliative Photodynamic Therapy

Teresa Goodell, PhD, RN, CNS, CCRN, APRN, BC

Purpose/Objectives: To evaluate the reliability and validity of the Photodynamic Therapy Side Effects and Symptoms Scale (PSES) and to begin to describe patient-reported outcomes of photodynamic therapy (PDT).

Design: Repeated-measures instrument validation. The PSES uses a 10-point numeric scale to evaluate side effects or symptom trouble or burden on 13 items.

Setting: A Pacific Northwest community hospital.

Sample: 14 patients with end-stage lung or esophageal cancer undergoing palliative PDT.

Methods: Participants completed five PSES surveys (i.e., at baseline and once a week for four weeks after PDT). Weekly phone calls were made to assess functional status, operationalized as Karnofsky Performance Status.

Main Research Variables: Symptoms and functional status.

Findings: The PSES possessed acceptable internal consistency reliability and concurrent validity. Functional status declined in the first week after PDT, concurrent with an increase in side-effect and symptom burden. Photosensitivity became more burdensome over time but was never extremely burdensome.

Conclusions: The feasibility of measuring a diverse set of side effects and symptoms in end-stage cancer with a single-page, large-type instrument essentially was supported. The study provided preliminary information about side effects and symptoms in patients undergoing palliative PDT.

Implications for Nursing: Nurses often are called on to provide information to patients considering various treatment options. This study offers the first data on patient-reported outcomes of palliative PDT that clinicians can use to help in answering inquiries. The design of the PSES may be replicated by researchers working with other populations with end-stage disease to reduce respondent burden and decrease attrition.

Key Points . . .

- ▶ Tumor reduction has been achieved with photodynamic therapy (PDT), an endoscopic treatment for palliation of malignant dysphagia or dyspnea, but no patient-reported outcomes of this treatment appear in the literature.
- ▶ An instrument was developed to measure patient-reported trouble or burden from symptoms and side effects associated with palliative PDT for esophageal and lung cancer.

these indications (Diaz-Jimenez et al., 1999; Heier, Rothman, Heier, & Rosenthal, 1995; Lightdale et al., 1995; McCaughan et al., 1996; Moghissi, Dixon, Hudson, Stringer, & Brown, 1997; Moghissi et al., 1999). The patient outcomes evaluated in preapproval trials were performance status, tumor response, luminal diameter, dysphagia grade, and survival. Although PDT can offer rapid relief of obstruction, it carries potentially troublesome side effects, particularly intense ocular and cutaneous photosensitivity that may continue for as many as 10 weeks. Patients must remain indoors during daylight hours, avoid windows and skylights, and wear sunglasses and protective clothing outdoors for at least 30 days.

Clinical observations of people with late-stage cancer who have undergone PDT provided the impetus for studying the timing and magnitude of PDT-related side effects. Observed side effects and symptoms included worsening dysphagia, pain, and shortness of breath soon after treatment. The effect of prolonged, severe photosensitivity on quality of life,

Photodynamic therapy (PDT) is an endoscopic technique that involves the administration of a light-activated drug with subsequent exposure to wavelength-specific light, usually from a medical laser, to incite the formation of singlet oxygen and other reactive oxygen species to kill tumors. It was approved by the U.S. Food and Drug Administration for palliative use in 1996 for esophageal cancer and in 1998 for lung cancer. Palliative PDT relieves two major symptoms: dysphagia in obstructive esophageal cancer and dyspnea in obstructive lung cancer (Bruce, 2001). Objective safety and efficacy are well documented for palliative PDT for

Teresa Goodell, PhD, RN, CNS, CCRN, APRN, BC, is an assistant professor in the School of Nursing at Oregon Health and Science University in Portland. The study was funded by the Society of Gastroenterology Nurses and Associates and the ONS Foundation. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society. (Submitted March 2005. Accepted for publication October 3, 2005.)

Digital Object Identifier: 10.1188/06.ONF.647-650