

Preferences of Individuals With Cancer for Patient-Reported Outcome Measures

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PURPOSE: Symptom monitoring and management using patient-reported outcome (PRO) measures improves outcomes for individuals with cancer. The purpose of the current study was to provide a qualitative assessment of preferences of individuals with cancer for PRO measures.

PARTICIPANTS & SETTING: 15 patients receiving systemic therapy at the University of Texas MD Anderson Cancer Center.

METHODOLOGIC APPROACH: Participants completed three PRO measures. Qualitative interviews were conducted, and content analysis was used to identify relevant themes.

FINDINGS: Identified themes were the importance of communicating various aspects of the disease and treatment experience to the oncology team, the importance of systematic PRO assessments, congruence among PRO questionnaires and questions clinicians ask at clinic visits, concerns about the length of PRO questionnaires, the importance of the response options available in PRO questionnaires, and willingness to complete PRO measures frequently.

IMPLICATIONS FOR NURSING: Oncology nurses are critical facilitators of the systematic use of PRO measures across the cancer care continuum.

KEYWORDS patient-reported outcomes; quality of life; symptom burden; patient-centered care

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Cancer is associated with distressing disease-related symptoms and treatment-related side effects that affect functioning and quality of life (QOL) (Kim et al., 2009). When symptoms are not well controlled, they can result in emergency department visits, unplanned hospitalizations, delays in treatment, and lack of adherence to an effective treatment course (Basch et al., 2017; Boehmke & Dickerson, 2005; Dodd et al., 2010; Kayl & Meyers, 2006; Mooney, Beck, et al., 2017; Mooney, Berry, et al., 2017; Spoelstra et al., 2015; van Herk-Sukel et al., 2010; Whisenant et al., 2017). Although national guidelines provide management strategies for cancer-related symptoms, no known best practices for routinely monitoring symptoms and responding to symptoms during outpatient cancer care exist (Barbera et al., 2015; Basch et al., 2016, 2017; Berry et al., 2011, 2014, 2015; Cleeland et al., 2011; Mooney, Beck, et al., 2017; Mooney, Berry, et al., 2017).

At the initiation of therapy, strategies for the self-management of symptoms may be discussed with patients with cancer; patients should be encouraged to contact the oncology team if symptoms are not well controlled. However, patients with cancer tend to notify clinicians about moderate to severe symptoms less than 5% of the time (Mooney, Beck, et al., 2017). In addition, clinicians often underestimate the severity of symptoms and their interference with daily functioning and QOL during cancer care (Basch, 2017; Basch et al., 2009; Williams et al., 2016; Xiao et al., 2013). Evidence suggests that systematically monitoring the symptom experience using patient-reported outcome (PRO) measures during treatment for cancer can improve QOL, increase adherence to therapy, and decrease emergency department use, as well as increase overall survival (Barbera et al., 2015; Basch et al., 2016, 2017; Berry et al., 2011, 2014, 2015; Cleeland et al., 2011; Mooney, Beck, et al., 2017). However, adding PRO measures to routine clinical