

PALLIATIVE CARE-RELATED KNOWLEDGE, ATTITUDES & CONFIDENCE OF HOME HEALTH PATIENTS, CAREGIVERS AND CLINICIANS: DEVELOPMENT AND TESTING OF QUESTIONNAIRES FOR A U.S. AUDIENCE

Ashley Chastain, DrPH, MPH^{1*}; Margaret V. McDonald, MSW²; Komal P. Murali, PhD, RN, ACNP-BC¹; Lori King, MPH²; Jung A. Kang, MSN, RN, AGACNP-BC, AGCNS-BC¹; Charity Ogunlusi, MD¹; Jingjing Shang, PhD, RN, OCN, FAAN¹

¹*Columbia University School of Nursing, 560 W. 168th St. Mail Code 6, New York, NY, USA*

²*Center for Home Care Policy & Research at VNS Health, New York, NY, USA*

**Corresponding author: ac4192@cumc.columbia.edu*

Abstract

In the United States, home healthcare utilization is increasing due to complex needs from patients with serious illness. Palliative care provides relief from serious illness-related symptoms and stress. However, it is unknown whether home healthcare clinicians are equipped to provide palliative care and whether those services would be accepted by home healthcare patients and informal caregivers. Here, we describe the development and testing of two questionnaires assessing palliative care-related knowledge, attitudes, and confidence for home healthcare clinicians, patients, and caregivers in the United States. We conducted the study with patients (or their caregivers) receiving home healthcare and clinicians from a large, urban home healthcare agency. We: 1) conducted a literature review identifying existing palliative care-related survey questions and instruments; 2) developed two questionnaires following the eight domains of practice from the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care; 3) refined the questionnaires through cognitive interviews with 10 clinicians and 10 patients/caregivers, and feedback from healthcare experts; and, 4) pilot-tested (using test-retest methodology) questionnaires with 30 clinicians and 30 patients/caregivers to assess validity and reliability. The questionnaires are organized into three sections: knowledge, attitudes, and confidence; they include core, clinician role-specific, and caregiver-specific items. There are 56 questions for patients/caregivers and 95 for clinicians. During cognitive interviews, we received feedback about questionnaire length, content, and comprehension. Pilot testing is ongoing. We developed the first home healthcare setting-specific questionnaires measuring palliative care-related knowledge, attitudes, and confidence. Broader dissemination of the questionnaires will identify gaps and inform future training.

Keywords: patients/caregivers; clinicians; home healthcare; palliative care; knowledge assessment