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Palliative care-related knowledge, attitudes & confidence in home health care: Results from a U.S. pilot study

Ashley M. Chastain[1], Jingjing Shang[1], Lori King[2], Charity Ogunlusi[1], Komal P. Murali[3], Jung A. Kang[1], Khadra Dualeh[1], Suning Zhao[1], Margaret V. McDonald[2]

[1]Columbia University School of Nursing, Center for Health Policy, New York, NY, USA; [2]VNS Health, Center for Home Care Policy & Research, New York, NY, USA; [3]NYU Rory Meyers College of Nursing, New York, NY, USA;
ac4192@cumc.columbia.edu, js4032@cumc.columbia.edu

Background: In the United States (U.S.), the rising use of home health care (HHC) services among people with multiple chronic conditions highlights a need for home-based palliative care (PC). However, only 7% of such programs in the U.S. are operated by HHC agencies. Integrating PC into the HHC setting could improve patient outcomes. Prior to integration, better understanding of clinician readiness for and patient/caregiver receptiveness of PC are needed.

Objectives: Develop 2 questionnaires to assess readiness for and receptiveness of PC among U.S. HHC clinicians' and patients/caregivers, focusing on knowledge, attitudes, and confidence (KAC).

Design: A cross-sectional pilot study guided by the 2018 National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care.

Methods: We adapted existing PC-related KAC scales and added new items to cover all eight NCP Guideline domains. Following expert review and 20 cognitive interviews, we refined the questionnaires. The final versions have 3 sections assessing KAC with 56 items for patients/caregivers and 95 for clinicians, including core and role-specific items. After IRB approval, pilot testing was conducted at a large, urban U.S. HHC agency. Descriptive statistics were calculated using Stata 17.

Results: 28 patients/caregivers and 30 clinicians (nurses, physical therapists, social workers) participated. Overall, 48.4% of patients/caregivers were unaware of PC. However, 31.3% of caregivers indicated they had some knowledge. Among patients/caregivers, knowledge gaps existed regarding pain management/opioid use, spiritual/cultural aspects of PC, and end-of-life (EOL) decision-making. Attitudes on pain management/opioid use varied. Caregivers were less confident in managing difficulty breathing and agitation, engaging in EOL discussions or providing EOL care. But 93.6% would consider PC for themselves or a loved one.

Overall, clinicians demonstrated adequate knowledge; however, several questions about pain management/opioid use and ethical/legal aspects of PC were answered incorrectly by >40% of clinicians. Clinicians held positive attitudes towards PC but had varying levels of confidence in PC provision.

Conclusion: We developed 2 PC-related KAC questionnaires for the U.S. HHC setting, laying the groundwork for PC integration. Broader questionnaire distribution will identify training needs and findings will enable tailored interventions for HHC patients, caregivers and clinicians.