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Development and Testing of the Palliative Care-related Knowledge, Attitudes & Confidence (PC-KAC) in Home Health Care Questionnaires for Clinicians, Patients and Caregivers in the United States

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BACKGROUND AND STUDY AIM

- Several questionnaires exist that measure palliative care-related knowledge, attitudes, and confidence (PC-KAC).
- However, none have been developed for and tested in the home health care (HHC) setting.
- Here, we describe the development and testing of our PC-KAC questionnaires for U.S. HHC clinicians, patients, and caregivers.

METHODS

- Firstly, we conducted a comprehensive literature review and identified existing survey instruments measuring PC-KAC.
- Secondly, we developed two PC-KAC in HHC questionnaires: 1) for clinicians, and 2) for patients/informal caregivers.
  - Development was guided by the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP guidelines).
  - Existing scales/questions were adapted to the HHC setting.
  - New questions were created when no existing scales/questions adequately captured specific NCP guidelines.
- Thirdly, questionnaires were refined through feedback from experts in palliative care and HHC, as well as cognitive interviews with HHC clinicians, patients and informal caregivers.
  - Cognitive interviews were conducted individually over phone, Zoom or Facetime with 10 home healthcare clinicians (5 nurses, 3 therapists and 2 social workers) and 10 patients and caregivers who were given paper questionnaires to review prior to the interview.
  - During the interviews, we asked interviewees about: 1) questionnaire length; 2) understandability; 3) comfort; and, 4) suggestions.
- Lastly, pilot testing is being conducted online and over Zoom (via RedCAP) with 30 clinicians and 30 patients/informal caregivers from a large, urban HHC agency.

RESULTS

- Our PC-KAC questionnaires are organized by 3 main sections: knowledge, attitudes and confidence.
  - Most sections contain items relating to the NCP guidelines eight domains of practice (see **Table 1**).
  - There are core questions, as well as clinician role-specific (for nurses, therapists, social workers) and caregiver-specific items.
  - Questions about demographics, as well as preferred communication methods, information sources and location of palliative care services, are asked at the end.
  - Total number: 56 questions for patients/caregivers, 95 for clinicians.
- During cognitive interviews, we received specific feedback about:
  - Questionnaire length:
    - Time from start to completion ranged from 30-45 minutes for clinicians and 20-35 minutes for patients and caregivers.
  - Questions/topics included:
    - Questions were not confusing, but some patients and caregivers felt a few questions needed more clarification or they had no experience of what was being asked; some clinicians noted they are not that confident in providing palliative care, but understand hospice.
    - Physical therapists might have a harder time recognizing the generic pharmaceutical names cited in the knowledge section.
    - Talking about how palliative is different than hospice might be beneficial (in the survey's definition of palliative care) as people equate palliative care to dying.
    - It would be beneficial to provide more clarification or a definition regarding Medical Order of Life-Sustaining Treatment (MOLST) forms.
    - More questions about caregiver appreciation should be considered.
  - Response choices:
    - We should consider giving a directive that not all response choices may be true (for knowledge questions).
    - The terms "legal primary caregiver, Power of Attorney, or established healthcare proxy" were preferred in place of "surrogate decision maker".
- Pilot testing is underway to assess reliability and additional validity.

Table 1. Structure of the PC-KAC in HHC Questionnaires for Clinicians, Patients and Caregivers

CONCEPT/AUDIENCE	KNOWLEDGE		ATTITUDES		CONFIDENCE		EXAMPLE QUESTIONS	
	PATIENT/ CAREGIVER	CLINICIAN	PATIENT/ CAREGIVER	CLINICIAN	PATIENT/ CAREGIVER	CLINICIAN		
DOMAIN (NCP GUIDELINES)	NUMBER OF QUESTIONS						PATIENT/CAREGIVER	CLINICIAN
1. Structure and processes of palliative care	19	5	5	9	1	4	K: Stress from serious illness can be addressed by palliative care.[2] (T/F/DK) C: Currently, how confident are you in caring for family members with serious illness? (1-4 Confidence Scale)	K: Palliative care should be provided for patients who have no curative treatments available.[5] (T/F/DK) A: Quality of care can be optimized with palliative care. (1-5 Agreement Scale)
2. Physical aspects of care	4	19	5	2	2	5	K: A goal of palliative care is to improve a person's ability to participate in daily activities.[2] (T/F/DK) A: Palliative care relieves pain and other symptoms.[4] (1-5 Agreement Scale)	A: Palliative care us as equally as important as curative treatments for patients with serious illness. (1-5 Agreement Scale) C: How confident are you in your understanding of insurance coverage for palliative care services in home health care? (1-4 Confidence Scale)
3. Psychological and psychiatric aspects of care	1	6	3	1	1	1	K: A goal of palliative care is to address any psychological issues brought up by serious illness.[2] (T/F/DK) A: Receiving palliative care services may help individuals with serious illness feel less isolated and alone. (1-5 Agreement Scale)	K: Delirium can be caused by medications.[6](T/F/DK) A: It is important to recognize and provide appropriate referrals when there are psychological and psychiatric health needs when caring for a seriously ill patient. (1-5 Agreement Scale)
4. Social aspects of care	0	2	0	3	0	1	N/A	K: Home-based palliative care includes an assessment of a safe home environment. (T/F/DK) A: Home-based palliative care services can be useful and supportive. (1-5 Agreement Scale)
5. Spiritual, religious, and existential aspects of care	1	2	0	2	1	1	K: Spiritual stress (no longer able to find meaning, peace, comfort, or connection in life) can contribute to the experience of physical pain. (T/F/DK) C: [CAREGIVER ONLY] How confident are you in your ability to discus your family members' spiritual needs with them? (1-4 Confidence Scale)	A: Identifying the spiritual and religious care needs of the seriously ill patient is important in home healthcare. (1-5 Agreement Scale) C: How confident are you in your ability to assess patient's spiritual/religious care needs? (1-4 Confidence Scale)
6. Cultural aspects of care	2	2	2	3	2	1	A: Cultural beliefs and values can affect healthcare decisions. (1-5 Agreement Scale) C: How confident are you that you can discuss your cultural beliefs and values with home health clinicians? (1-4 Confidence Scale)	A: Cultural beliefs impact medical decision making. (1-5 Agreement Scale) C: How confident are you in your ability to provide culturally sensitive palliative care to patients with serious illness? (1-4 Confidence Scale)
7. Care of patients nearing the end of life	2	5	3	10	1	2	A: I think it is better when people have the option to die at home. (1-5 Agreement Scale) C: How confident are you in your ability to have end-of-life discussions with your family member? (1-4 Confidence Scale)	K: Patients receiving palliative care and nearing the end of life always require higher calorie intake.[5] (T/F/DK) C: How confident are you in discussing the option of hospice care with seriously ill patients? (1-4 Confidence Scale)
8. Ethical and legal aspects of care	1	5	0	3	0	1	A: Health care proxies should always honor patients' wishes and preferences for treatment. (1-5 Agreement Scale) C: How confident are you in your ability to serve as a health care proxy (a person you authorize via a signed document to deal with medical situations when you cannot speak for yourself) for your family member? [CAREGIVER ONLY] (1-4 Confidence Scale)	K: A Medical Orders for Life-Sustaining Treatment (MOLST) form is a type of advance care planning. (T/F/DK) C: How confident are you in discussing designating a health care proxy with your patients? (1-4 Confidence Scale)

Legend: K= Knowledge; A = Attitudes; C = Confidence; T = True; F = False; DK = Don't know

References/Existing Scales: [1]Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med*. 2018;21(12):1684-1689; [2]Kozlov E, McDarby M, Reid MC, Carpenter BD. Knowledge of Palliative Care Among Community-Dwelling Adults. *Am J Hosp Palliat Care*. 2018 Apr;35(4):647-651; [3]Huo J, Hong YR, Grewal R, Yadav S, Heller IW, Bian J, Wilkie DJ. Knowledge of Palliative Care Among American Adults: 2018 Health Information National Trends Survey. *J Pain Symptom Manage*. 2019;58(1):39–47.e3; [4]Taber JM, Ellis EM, Reblin M, Ellington L, Ferrer RA. Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample. PLoS One. 2019 Aug 15;14(8):e0219074; [5]Nakazawa Y, Miyashita M, Morita T, Umeda M, Oyagi Y, Ogasawara T. The palliative care knowledge test: reliability and validity of an instrument to measure palliative care knowledge among health professionals. *Palliative Medicine*. 2009;23(8):754-766; [6]Yamamoto R, Kizawa Y, Nakazawa Y, Morita T. The palliative care knowledge questionnaire for PEACE: reliability and validity of an instrument to measure palliative care knowledge among physicians. J Palliat Med. 2013 Nov;16(11):1423-8. 2013 Sep 28.

CONCLUSIONS AND NEXT STEPS

- Palliative care is not reaching all who could benefit from it; there are calls for palliative care integration throughout the healthcare system, including HHC.
- To better understand the capacity to provide palliative care services in the HHC setting, it is critical to examine clinicians' readiness to provide and patient/caregiver willingness to accept palliative care in this setting.
- Through a rigorous process, we developed the first HHC setting-specific questionnaires assessing palliative care knowledge, attitudes and confidence in a U.S. audience with questions representing all eight domains from the NCP guidelines.
- While the NCP guidelines have not been adopted in other countries, our PC-KAC questionnaire could be adapted for use with other populations.
- Broader dissemination of the questionnaires will help identify gaps in PC-KAC, thus revealing areas for education and training for clinicians, patients and informal caregivers.
- Our next steps are to field the questionnaire: 1) using a larger sample size; 2) among more study sites (i.e., more HHAs); and, 3) to home health aides.

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