

A Library of Instruments Endorsed by Published Systematic Reviews for Assessing Patients and Their Care Developed by the Palliative Care Research Cooperative

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Dear Editor:

Palliative care research encompasses a broad array of domains, care settings, and illnesses, and the instrument literature can be difficult and time consuming to navigate. The Palliative Care Research Cooperative (PCRC) has compiled a library of ~150 instruments for assessing patients and their care in palliative and end-of-life care research.¹ This library is a resource for investigators wanting to identify relevant and high-quality instruments.

This updated library was designed based on our experience with a preliminary version. Our primary challenge was to identify good quality instruments for a large number of domains.

The instruments now included in the library are those that were endorsed by published systematic reviews relevant to palliative care.² The 46 systematic reviews varied in their criteria and their rating method. Nonetheless, the instruments that were “recommended” or “highly scored” by the authors of each systematic review are included in this library. This method may omit some valid and reliable instruments that could be important in particular research studies, but does create a compendium of the highest quality and most commonly used instruments for the field. In a rapidly emerging field of investigation, further evidence for instruments will expand this library over time.

The instruments cover a wide range of topics, including communication, continuity of care, decision making, fatigue, function, grief and bereavement, multiple-domain scales, pain, quality of care, quality of care at end of life, quality of life, sleep, spiritual aspects of care, and physical and psychological symptoms. The library provides information about each instrument thought to be most useful to investigators who are seeking an instrument for a specific purpose,

such as the content, number of items, respondent, recall period, whether it requires an interviewer, estimated completion time, and key citations with links to PubMed abstracts.

The library is available to both PCRC members and non-members. Investigators who complete a brief online request form¹ will be immediately e-mailed a copy of the instrument library. The library is provided as an Excel spreadsheet that can be searched and sorted by attribute.

Instruments that assess caregiver needs and experience can be found in the PCRC Caregiver Research Core resources pages.³ Since palliative care involves both patients and their caregivers and other family members, investigators may want to consult both instrument resources.

In selecting instruments for a research study, investigators should consider whether the content of the instruments corresponds to what they want to measure; whether it has demonstrated validity, reliability, and responsiveness; and whether it is appropriate for the context of use (i.e., the study population, the disease condition, and the study environment). Information about instrument selection and study design with patient-reported outcomes can be found in the PCRC Measurement Core resource pages.⁴

A major focus of palliative and end-of-life care research is the patient experience of their disease and medical care, as well as their quality of life and quality of dying. This library was created to assist investigators in rapidly finding the best instruments for their research studies.

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