

*Special Article*

# The Selection and Use of Outcome Measures in Palliative and End-of-Life Care Research: The MORECare International Consensus Workshop

Catherine J. Evans, BSc (Hon), MSc, PhD, RN, Hamid Benalia, BSc, MA, Nancy J. Preston, BSc, PhD, RN, Gunn Grande, BA, MSc, MPhil, PhD, Marjolein Gysels, BA, MA, PhD, Vicky Short, MPhil LLB (Hons), Barbara A. Daveson, BA, PhD, BMUS (MUSTHY), Claudia Bausewein, MSc, MD, PhD, Chris Todd, BA, MA, PhD, and Irene J. Higginson, BMBS, BMedSci, PhD, FFPHM, FRCP, on behalf of MORECare

*Department of Palliative Care, Policy and Rehabilitation (C.J.E., H.B., M.G., B.A.D., C.B., I.J.H.), Cicely Saunders Institute, King's College London, London; School of Nursing, Midwifery & Social Work (N.J.P., G.G., V.S., C.T.), University of Manchester, Manchester; International Observatory on End of Life Care and Faculty of Health & Medicine (N.J.P.), Lancaster University, Lancaster, United Kingdom; Centre for Social Science and Global Health (M.G.), University of Amsterdam, Amsterdam, The Netherlands; and Interdisciplinary Centre for Palliative Medicine (C.B.), Munich University Hospital, Munich, Germany*

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## Abstract

**Context.** A major barrier to widening and sustaining palliative care service provision is the requirement for better selection and use of outcome measures. Service commissioning is increasingly based on patient, carer, and service outcomes as opposed to service activity.

**Objectives.** To generate recommendations and consensus for research in palliative and end-of-life care on the properties of the best outcome measures, enhancing the validity of proxy-reported data and optimal data collection time points.

**Methods.** An international expert “workshop” was convened and an online consensus survey was undertaken using the MORECare Transparent Expert Consultation to generate recommendations and level of agreement. We focused on three areas: 1) measurement properties, 2) use of proxies, and 3) measurement timing. Data analysis comprised descriptive analysis of aggregate scores and collation of narrative comments.

**Results.** There were 31 workshop attendees; 29 recommendations were included in the online survey, completed by 28 experts. The top three

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*Address correspondence to:* Catherine J. Evans, PhD, MSc, BSc, RN, Department of Palliative Care, Policy and Rehabilitation, Cicely Saunders Institute, King's

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College London, Bessemer Road, London SE5 9PJ, United Kingdom. E-mail: [catherine.evans@kcl.ac.uk](mailto:catherine.evans@kcl.ac.uk)

*Accepted for publication: January 28, 2013.*

recommendations by area were the following: 1) the properties of the best outcome measures are responsive to change over time and capture clinically important data, 2) to enhance the validity of proxy data requires clear and specific guidelines to aid lay individuals' and/or professionals' completion of proxy measures, and 3) data collection time points need clear identification to establish a baseline.

**Conclusion.** Outcome measurement in palliative and end-of-life care requires the use of psychometrically robust measures that are clinically responsive, with defined data collection time points to establish a baseline and clear administration guidelines to complete proxy measures. To further the field requires clinical imperatives to more closely inform recommendations on outcome measurement. *J Pain Symptom Manage* 2013;46:925–937. © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### **Key Words**

*Outcome assessment, evaluation studies, research design, palliative care, consensus*

## **Introduction**

Widening access to palliative and end-of-life (EOL) care services is advocated with corroboration of patient<sup>1</sup> and carer benefits,<sup>2</sup> greater potential for health service cost savings,<sup>3,4</sup> and increasing demand with an aging population.<sup>5</sup> A major barrier is the requirement for better selection and use of outcome measures to demonstrate the effectiveness of services. Commissioners of health and social care services increasingly require service providers to use patient, carer, and service outcomes to demonstrate a service's safety, effectiveness, and quality as opposed to detailing service activity.<sup>6,7</sup> In research and clinical practice, a multitude of measures are used, and frequently these measures are not validated with palliative care populations.<sup>8</sup> This hampers meta-analyses, limits responsiveness to change in outcome, evaluating service effectiveness, and developing the evidence base to inform best practice.<sup>9</sup>

Trials and nonrandomized designs in palliative and EOL care are often compromised by the use of untested outcome measures,<sup>10,11</sup> measures not developed for palliative care populations,<sup>12</sup> uncertainty as to the best measurement time points,<sup>13</sup> and the use of measures for symptom change with less use of measures encompassing the multiple domains of palliative care (e.g., Palliative care Outcome Scale [POS], Edmonton Symptom Assessment System).<sup>12</sup> These limitations are not unique to palliative and EOL care. The COnsensus-based Standards for the selection of health

Measurement INstruments is a comprehensive checklist for assessing the quality of the measurement properties of health status questionnaires. The checklist was developed in response to the rapid increase in health status questionnaires and the need for quality criteria to compare measures in systematic reviews, identify shortcomings, and design studies validating measures.<sup>14,15</sup>

Palliative and EOL care involves people with increasing debility associated with advancing disease and has a broad mandate of care provision, with intended outcomes of improving quality of life for patients and their caregivers.<sup>16</sup> The nature of palliative and EOL care requires measurement properties that accommodate the following: the multiple domains of palliative care; to change over time and increasing levels of fatigue; the use of proxies, particularly when individuals are near to death; and timing to detect change and monitor sustainment of change. These challenges are well reported, and international advancements to address them are evident: projects such as the Palliative Care Outcomes Collaboration in Australia that uses national standardized assessments of palliative care outcomes<sup>17,18</sup> and a European collaboration, entitled PRISMA, focused on promoting best practice in the measurement of EOL care (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)<sup>11</sup> working with a European Association of Palliative Care (EAPC) Taskforce on patient-reported outcome measures (PROMs) in palliative care to

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