

Paper Session B3: Pain Control and Palliative Care

Palliative Care Outcomes: Meaning, Research, and Policy Implications

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Purpose: To clarify the concept of palliative care in outcomes research so as to promote scholarly discourse, contribute to methodological rigor, and inform the development of rational health policy.

Background: The 2004 National Consensus Project (NCP) Guidelines established a broad scope for palliative care as care that helps to align treatments with patient preferences and is appropriate early in the disease trajectory, but a variety of definitions continue to be used. To properly evaluate programs and to meaningfully guide policy, it is essential that we develop a common language to describe palliative care and the measurement of its outcomes.

Methods: Dimensional analysis holds that the meaning of a concept is socially constructed through its scholarly use (Caron & Bowers, 2000). MEDLINE, CINAHL, EMBASE, and PsycINFO were searched for studies of outcomes of inpatient palliative care in the U.S. ATLAS.ti was used to explore explicit and implicit meanings by coding palliative care dimensions and analyzing how relationships among the dimensions change across multiple perspectives and contexts.

Results: Nineteen articles from 2005-2010 comprised the final sample. The 215 initial codes were consolidated into 89 attributes and grouped into 6 dimensions: Interventions, outcomes, patient population, timing of intervention, team members, and principles of care. The analysis showed variation in palliative care descriptions. Symptom management, goals of care communication, and psychosocial support were common components, but spiritual and cultural components of care were rarely described. Economic outcomes were prominently featured and patients in most studies had end-stage illness or were dying. Many of the studies lacked representatives from medicine, nursing, and social work and in 6 cases the team was not described.

Conclusions and Implications: This dimensional analysis shows a lack of consistency between definitions of palliative care in recent outcomes research and consensus guidelines. Well-designed research is warranted to establish optimal interventions, team composition, and outcomes for palliative care. Study design and the language used to report findings should be chosen carefully to avoid communicating that palliative care is about decreasing the cost of dying rather than improving the care of the seriously ill.