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Special section on measuring quality of care at life's end II

Evaluating the Quality of Dying and Death

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Abstract

We propose a model for evaluating the quality of dying and death based on concepts elicited from literature review, qualitative interviews with persons with and without chronic and terminal conditions, and consideration of desirable measurement properties. We define quality of dying and death as the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others. Expected level of agreement is modified by circumstances surrounding death that may prevent following patient's prior preferences. Qualitative data analysis yielded six conceptual domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns. These domains encompass 31 aspects that can be rated by patients and others as to their importance prior to death and assessed by significant others or clinicians after death to assess the quality of the dying experience. The proposed model uses personal preferences about the dying experience to inform evaluation of this experience by others after death. This operational definition will guide validation of after-death reports of the

quality of dying experience and evaluation of interventions to improve quality of end-of-life care.



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Keywords

Dying; death; palliative care; quality of life; outcomes; terminal diseases

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Facing death without tradition, stratification, in the first approximation, spontaneously.

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