

Concepts and definitions for actively dying, end of life, terminally ill, terminal care, and transition of care: a systematic review.

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Journal of Pain and Symptom Management

Volume 47, Issue 1, January 2014, Pages 77-89

Review Article

Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminally Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review

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<https://doi.org/10.1016/j.jpainsymman.2013.02.021>

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Abstract

Context

The terms “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care” are commonly used but rarely and inconsistently defined.

Objectives

We conducted a systematic review to examine the concepts and definitions for these terms.

Methods

We searched MEDLINE, PsycINFO, Embase, and CINAHL for published peer-reviewed articles from 1948 to 2012 that conceptualized, defined, or examined these terms. Two researchers independently reviewed each citation for inclusion and then extracted the concepts/definitions when available. We also searched 10 dictionaries, four palliative care textbooks, and 13 organization Web sites, including the U.S. Federal Code.

Results

One of 16, three of 134, three of 44, two of 93, and four of 17 articles defined or conceptualized actively dying, end of life, terminally ill, terminal care, and transition of care, respectively. Actively dying was defined as "hours or days of survival." We identified two key defining features for end of life, terminally ill, and terminal care: life-limiting disease with irreversible decline and expected survival in terms of months or less. Transition of care was discussed in relation to changes in 1) place of care (e.g., hospital to home), 2) level of professions providing the care (e.g., acute care to hospice), and 3) goals of care (e.g., curative to palliative). Definitions for these five terms were rarely found in dictionaries, textbooks, and organizational Web sites. However, when available, the definitions were generally consistent with the concepts discussed previously.

Conclusion

We identified unifying concepts for five commonly used terms in palliative care and developed a preliminary conceptual framework toward building standardized definitions.



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Key Words

Actively dying; end of life; systematic review; terminal care; terminally ill; terminology; transition of care

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