

Developmental Landmarks and Taskwork for the End of Life

Ira Byock, M.D. www.irabyock.org

Introduction

A developmental framework occupies the center for much of my work and many of my writings. The concept of personhood and a model of life-long human development can be applied to understand the nature of suffering, as well as to comprehend experiences of enhanced well-being occasionally reported by dying patients.

Although symptom management is the first priority for palliative care, it is not the ultimate goal. True person and family-centered care strives not only to ensure comfort, but also to improve quality of life and preserve opportunities for people who are dying and for their families to grow through times of illness, caregiving and grief.

The specific characteristics of personal experience with advanced illness, dying and grieving vary widely from person to person. The conceptual framework and the language of life-long development effectively encompasses the broad range of human phenomenology related to these experiences — from severe suffering on the one hand, to a sense of profound well-being on the other.

Building from a foundation of human development within child psychology, education and pediatrics, I have worked to extend and apply life-long human development as a theoretical basis for the studying of end-of-life experience and shaping clinical care.

The specific work that a person has need for, or interest in, doing as they confront life's end will vary. A person's individuality is not diminished by recognition of elemental commonalities within the human condition as life ends. Issues of life completion and life closure are available to each individual, and one need not await serious, life-limiting illness for these issues to have relevance.

The end-of-life developmental landmarks and the taskwork that underlie them are intended to represent predictable personal challenges as well as important opportunities of persons as they die. I have provided the "working set" of developmental landmarks and taskwork below as an example of how this construct can be applied.

This "working set" of developmental landmarks and tasks evolved from notes that I kept in trying to make sense of clinical challenges in a way that would inform caring interventions. The actual landmarks and taskwork delineated invite refinement and modification. The general developmental approach can provide a valuable map to clinicians through the treacherous landscape of the dying experience and end-of-life care.

Importantly, within this model one need not sanitize nor glorify the experience of life's end to think of a person as having died well or, similarly, as having achieved a degree of wellness in their dying. Personal development is rarely easy. The touchstone of dying well -- the sense of growing individually or together in the midst of dying -- is that the experience is of value and meaningful for the person and their family.

Landmarks	Taskwork
Sense of completion with worldly affairs	<i>Transfer of fiscal, legal and formal social responsibilities</i>
Sense of completion in relationships with community	<i>Closure of multiple social relationships (employment, commerce, organizational, congregational) Components include: expressions of regret, expressions of forgiveness, acceptance of gratitude and appreciation Leave taking; the saying of goodbye</i>
Sense of meaning about ones' individual life	<i>Life review The telling of "one's stories" Transmission of knowledge and wisdom</i>
Experienced love of self	<i>Self-acknowledgment Self-forgiveness</i>
Experienced love of others	<i>Acceptance of worthiness</i>
Sense of completion in relationships with family and friends	<i>Reconciliation, fullness of communication and closure in each of one's important relationships. Component tasks include: expressions of regret, expressions of forgiveness and acceptance, expressions of gratitude and appreciation, acceptance of gratitude and appreciation, expressions of affection Leave-taking; the saying of goodbye</i>
Acceptance of the finality of life - of one's existence as an individual	<i>Acknowledgment of the totality of personal loss represented by one's dying and experience of personal pain of existential loss Expression of the depth of personal tragedy that dying represents Decathexis (emotional withdrawal) from worldly affairs and cathexis (emotional connection) with an enduring construct Acceptance of dependency</i>
Sense of a new self (personhood) beyond personal loss	<i>Developing self-awareness in the present</i>
Sense of meaning about life in general	<i>Achieving a sense of awe Recognition of a transcendent realm Developing/achieving a sense of comfort with chaos</i>
Surrender to the transcendent, to the unknown - "letting go"	<i>In pursuit of this landmark, the doer and "taskwork" are one. Here, little remains of the ego except the volition to surrender.</i>

Reference: Byock I., The Nature of Suffering and the Nature of Opportunity at the End of Life Clinics in Geriatric Medicine, Vol.12, No.2, pp 237-251, May 1996.