

Human Development at End of Life: Paths to Meaning and Transcendence

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Themes

Personal view and orientation to Hospice/Palliative Care

The “Cultural” View of Aging and Hospice

Potential at End of Life & Paradox-Hints & Assumptions

Beginning: Turn, Transformation, Transcendence

Maslow’s Hierarchy of needs to foster transcendence

Campbell’s Theory of the Hero—illness as a journey

Human Development and Transpersonal psychology



Reductio ad Absurdem

“I have learned that a culture that equates material possessions with success, and views the frantic, compulsive consumer as the perfect citizen, can afford little space for the aged human being. They are past competing, they are out of the game. We live in a culture that endorses “human obsolescence.” After adolescence, obsolescence. To the junk heap, the nursing home, the retirement village, the “Last Resort.”

Aging: The Fulfillment of Life, HJM Nouwen and WJ Gaffney

Current Cultural View

Negative experience, both individual and community, of terminal illness a theft, despair, bankruptcy transformed

Observation

- *“There is a hidden opportunity when we get very sick and have terminal illnesses: It is an opportunity to show the other our love for them.”*
 - RJZ

An Observation

- The opposite of living is not dying, but in fact is death or dead. Dying is part of living, and of living well.
 - Hospice is about living well until you die
 - Goal is not just comfort, but to preserve function for as long as we are alive. Together these constitute the quality of life.
 - How many times seen: the quality of life is so improved, that the will to live quickens, and one wonders whether time is extended.

Life Begins...

... with the awareness of my own mortality,
my own certain but future death.

Central Problem of Human Existence

*“What can be the meaning of a life
filled with loss and ending in death?”*

Weenolsen, P: Transcendence of Loss over the Life Span

Universal Truth...Ultimate Questions

“Can I be connected to the source of Being?”

“Can this connection survive death? By a love that transcends death, that exists after death?”

“Can I experience light in the inextricable abyss of death?”

Countercultural View: Universal Truths...Ultimate Questions

We are Born To Die

Therefore:

“From where have I come and To where am I going?”

“Why must I suffer and die”

“When my human form ceases to be, what happens to me?”

“When I die, how do I find peace and rest?”

Caring for the Patient

- *Howard Brody asserts that there are three things we must do as caregivers*
 - *Develop a jointly understood story among caregivers, patients, and families about the illness and condition between*
 - *Demonstrate that we care*
 - *Empower the patient to get relief of his illness*

Initial Approach to Caring

- By active listening to the patient, we enter their story, and bear their burdens with them. This in itself can be therapeutic
- By putting ourselves out to relieve their symptoms to start, we show that we care.
- By empowering them: we give them back some degree of mastery over their environment and illness—
prescription, telephone number, radiation therapy,
promise of commitment

Illness Trajectories

Sudden

Organ Failure

Metastatic Cancer

Frailty

Steps Along The Journey

The Three Ts:

The Turn ...toward awareness of mortality through a diagnosis of chronic fatal illness

Transformation of consciousness that follows the turn

Transcendence that can be approach following this transformation

New Paradigm: The Turn

An objective change in direction and a subjective awareness of the need or opportunity to take a new course in life's journey. Death is no longer something that happens to others, but to me.

Turn: Diagnosis of Fatal Chronic Illness

New phase of life

Ordinary routine of life is abruptly taken apart

Expectation of a present, connected to a past, extending to an unending future is broken, severed, destroyed.

Every assumption about life is taken away, unquestionable certainties become contingent possibilities; illness wraps the person in uncertainty and vulnerability

Immediate Consequences

Unable to buy life insurance

Unable to work

“To Do” list is in shambles, irrelevant or unachievable

Friends, spouse can become distant

“Open awareness” of fatal illness becomes a reality to oneself and society

The Turn

- Change in consciousness that occurs after the objective awareness of a having a terminal illness
- Stunning awareness of a disease that will take his life within a foreseeable time
- Michaelangelo's David
 - Faces Goliath, a monster symbolizing death
 - A need to face one's demons, no need to run, and that the monster will be overcome or transcended





Erickson's Crisis of Death

- My Life will End One Day
 - “Do I want to be in this job, relationship, or set of commitments until the end?”

The challenge is to move through the crisis of death and incorporate an awareness of death into life's time remaining.

“People Flourish when they face their mortality and live in congruence with their mortal condition”

Turn: Scientific, Artistic, and Spiritual Perspectives

■ Science

- Validating natural process through theory, observation and measurement, testing, scientific notation

■ Art

- Evocation of lived experience in aesthetic and metaphorical forms

■ Spirituality

- Search for ultimate meaning and the source of being through systems of belief and ritual processes

Turn Scientific Perspective

- Prognosis—classification, evidence, proof, probability
 - Dying trajectory and comorbidities and functional status
- Psychology
 - Kubler Ross's stages of death—denial, anger, depression, bargaining, acceptance & peace

Turn: Clinical Perspective

- Prognosis communicated
 - Awareness that it involves a crossing over
 - Sensitivity to the fears that the patient's life is ending, with many fears engendered and dreams, hopes, yearnings for the future ended
 - Responding to a need for hope and truth
- How
 - Honor, care and deep listening
 - To Honor—to show an unconditional positive regard for them in the broken conditions in which they find themselves
 - To create a space where it is safe to be himself
 - A commitment to be with them and care until the end

Turn: Clinical Perspective

- How
 - Deep listening calls for the person to be herself
 - It is listening that recreates the other rather than assesses
 - Follows how the person constructs his or her universality of experience
 - Without denigrating it as irrelevant to the medical process
- There must be timing to the prognosis
 - It's a prophesy, a speech act
 - To understand prognosis is to understand that it is the power to declare life and death-like the umpire declares safe or out
 - Balance both the prediction and the patient's ability to use this information

Spiritual Aspects of the Turn

- Kierkegaard remarked that Hegel explained everything under the sun except one small detail:
 - *What it means to live in a world where each of us must die*
- How does that fact that I am dying affect my relationship to my ultimate purpose or quest,
 - For many, to life that I have contributed in space-time, this planet
 - For some, to the Ultimate, the Creator, the God or Fountain of all Life

Transformation

- What is it?
 - Scientific, Artistic, and Religions meaning?
 - Can we understand its psychology and its expression?

Transcendence

- Scientific
 - Empirical observation—the near death experiences demonstrate the merging of a oneness
 - Psychological—Maslow—Various Meanings of Transcendence Spiritual—Various Meanings of Mortality

Definitions

Loss: anything that destroys some aspect of an individual's life and or self

Transcendence: the overcoming of loss and the recreation of self and/or life.

Weenolsen, P: Transcendence of Loss over the Life Span

Dreams of Mortal Beings



Maslow



Figure 1. Maslow's Hierarchy of Needs. The figure diagrams the dependence of higher on lower needs; the apex of the pyramid suggests that higher needs are less frequently realized.

Maslow

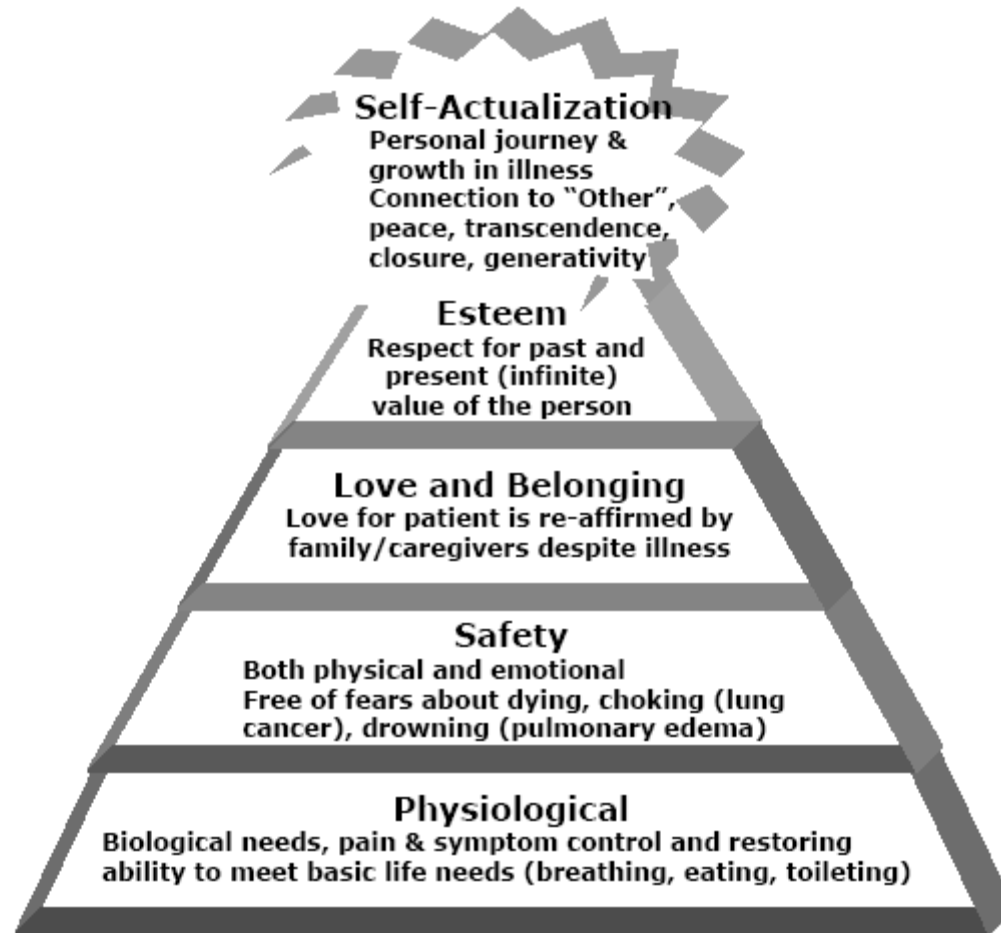


Fig. 2 Maslow's Hierarchy adapted to hospice and palliative care. The figure diagrams the dependence of higher on lower needs; the apex of the pyramid suggests that higher needs are less frequently realized.



St. Joseph's
Hospice

MB75 PNC



RECEPTION

PLEASE
WASH YOUR HANDS
WITH SOAP AND WATER
REGULARLY

Step inside the gates, just one step, and you will feel,
A special place upon this Earth, no fairytale, its real.
The peace the tranquility, serenity surrounds,
Camelot won't touch it, St. Joseph's still astounds.

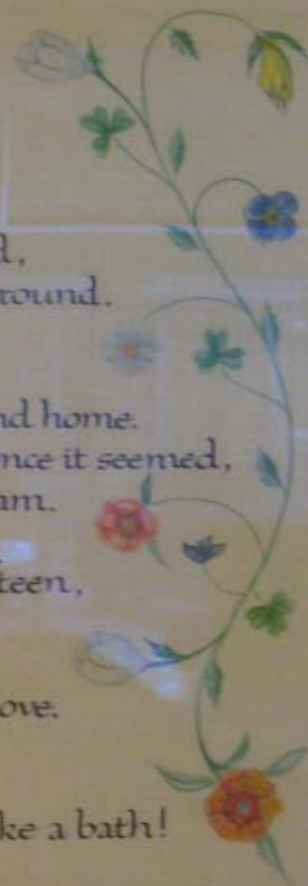
Step inside the doors and there's a calmness there,
The sisters and the staff, with all their loving care.
The happiness the laughter, no sadness to be found,
A little bit of heaven broke off and touched this ground.

I was there not long ago, for reasons of my own,
And as I stepped inside the gates, I found my second home.
My mind went back to years gone by, and all at once it seemed,
I'd never left this place at all, it wasn't just a dream.

The place I loved so long ago, when I was just fifteen,
Is still as solid as a rock, and precious still to me.
I will come back often, to the place I love,
To feel that special peace that's only given from above.

When I come back maybe, I'll be able to laugh,
Perhaps you will resist the urge, to make me take a bath!
But I love St. Joseph's, and all its people there,
I guess I'm saying thank you, for a special person who was there.

My heart's forever grateful, and it will always be,
For you gave comfort to the one, who meant the world to me.



Maslow

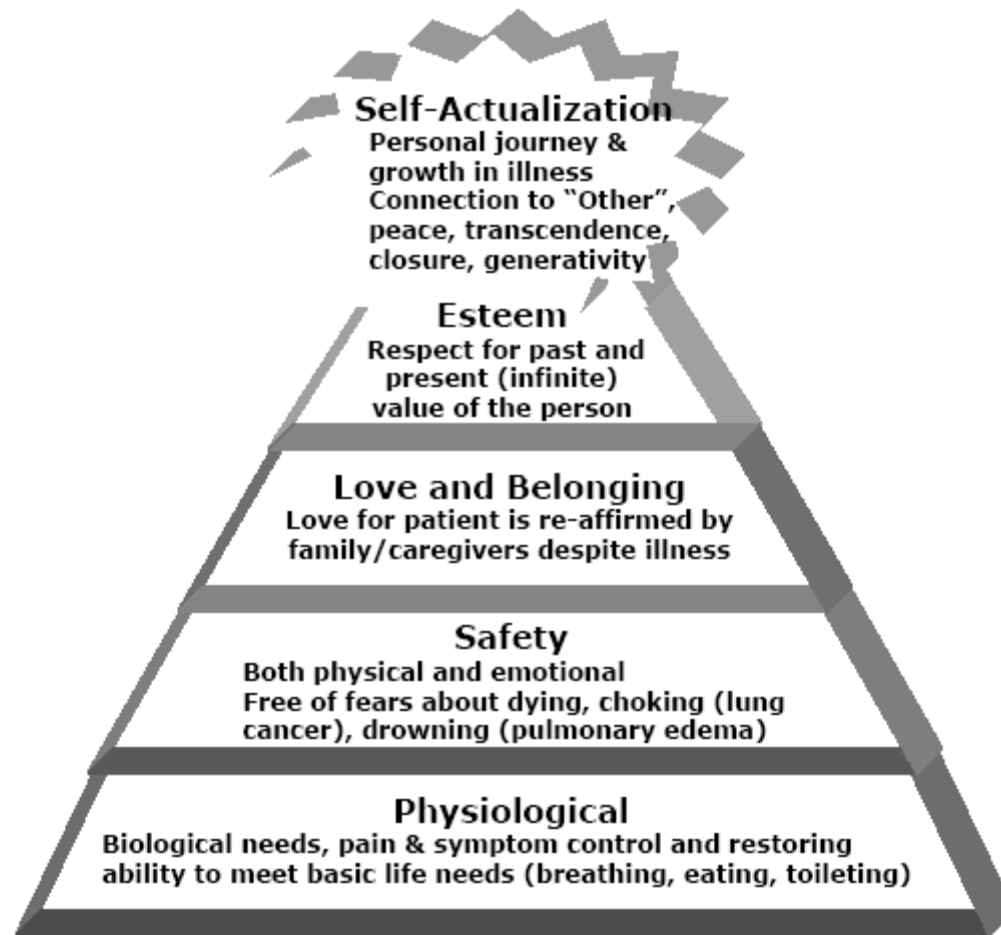


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St. Joseph's Hospice in Hackney

- Social Workers at St. Joseph's toured the terminal wards
 - “1. An absence of pain and drowsiness
 - “2. Liveliness and peacefulness
 - “3. An indefinable atmosphere which left one feeling that death was nothing to be worried about—a homecoming
 - “4. Patients, staff visitors of equal importance
 - “5. Simplicity of Approach to Pain
 - “6. Lack of narrow mindedness

Cicely Saunders

“Those who are dying are reached by the person who translates into the right depth of regard the lover’s explanation:

I love you because you are you.

Maslow

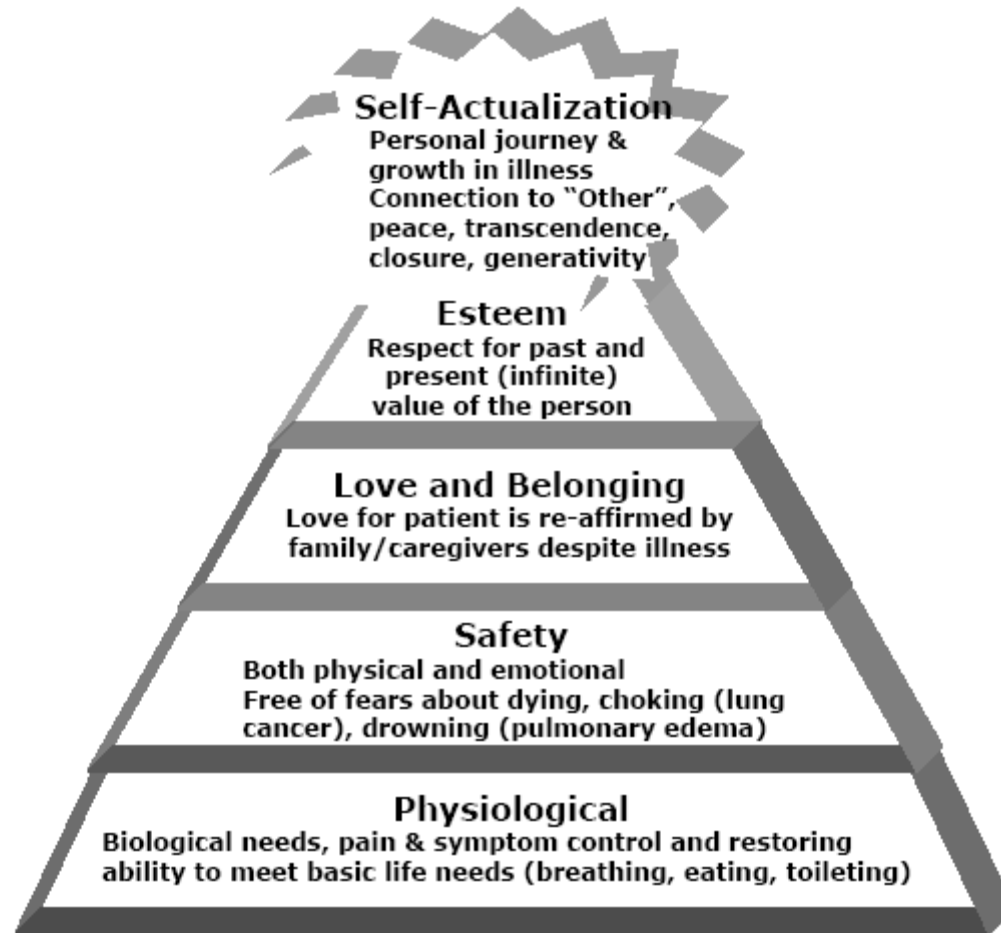


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Meaning and Esteem

Dignity Therapy

Campbell's the Hero's Journey

Joseph Campbell

The Hero with a Thousand Faces

Departure

Adventure and Transformation

Return

Joseph Campbell's Insight

- Things are not what they appear: the suffering patient is actually our savior: he or she draws us out of mundane lives and into a realm of compassion, total immediacy, and wonderful exultation.
 - We are grateful to be positioned (trained, available, well enough) to respond with compassion to the suffering of another

Maslow



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Transcendence and Mature Thought in Adulthood

Spiritual or transcendent experiences as momentary states—those states classified by Maslow as peak experiences are possible at any stage of development long before attainment of enlightenment.

Transcendence and Mature Thought in Adulthood, Miller ME and Cook-Grueter SR, Eds. Rowman & Littlefield, 1994.

Transcendent or Postrepresentational

...at this level ordinary reasoning (mentation) and symbolic representations can be transcended. The branch of psychology which deals exclusively with this tier calls itself transpersonal. Reality...is directly experienced without filters....Life is felt in its cohesive, fluid, incommensurable immediacy. ...The individual self is no longer seen as a separate entity, but as an unbounded part of a dynamic web—a universal, all-permeating consciousness.

Transcendence and Mature Thought in Adulthood

The Existentialist---

Rejects the existence of the *Absolute* and the importance or even the possibility of self-transcendence

The Human Condition: self determined choice in the face of a hostile universe

Can we foster the transpersonal and the Existential Views?

Conclusions

- Reconceptualization of Dying
- Partnership in the re-conceptualization of the care and the context of end of life care
- Vision: the dying experience be transformed from a curse to a blessing—a blessing because at this time, one thought they were thrown upon the rocks of life only to find that they had landed on sandy shores, where life was kind, and love was warm, and acceptance, safety, and love can be seen as a promissory note

