Acceptance of Death as a Goal
Palliative Care

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End of Life Care: A Critical Clinical and Ethical Question

Is “Acceptance of Death” an Essential and Ethical Goal of Psychosocial Palliative Care?
Goals of Palliative Care: Beyond Symptom Control

Concepts of adequate palliative care must be expanded in their focus beyond pain and physical symptom control to include psychiatric, psychosocial, existential and spiritual domains of care; culminating in a peaceful acceptance of death.
Handbook of Psychiatry in Palliative Medicine
Second Edition
Edited by Harvey Max Chochinov & William Breitbart

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Palliative & Supportive Care

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Acceptance of Death: Kubler-Ross Stages of Dying

Denial
Anger
Bargaining
Depression
Acceptance

Kubler-Ross, 1969
Awareness and Acceptance of Death: Pattison’s Adaptation of Kubler-Ross’ Stages of Dying

- **Acute Crisis Stage** - Anxiety about dying, primitive or immature coping mechanisms
- **Chronic Phase** - Where Fears of the unknown and losses might be resolved
- **A Terminal Phase** - Associated with Acceptance and Withdrawal

Pattison EM, 1977
Existential and Spiritual Domains of Care
The 3 Fundamental Existential Questions Confronting Human Beings

Where did I come from?

Why am I here?

Where am I going? (i.e. what lies beyond death?)
Frankl’s Existential “Tragic Triad”

Cancer → Suffering → Death → Guilt → Enhance Meaning

Loss of Meaning → Maintain Meaning
The Four Basic Human Existential Concerns

1. **Death** – The Inevitability of Death
   - death anxiety, the limitations of life

2. **Freedom** – The Freedom to Make our Lives as We Will
   - groundlessness, responsibility, will, existential guilt

3. **Isolation** – Our Ultimate Aloneness
   - we are born & die alone, transcendence, love (standing vs. fallen)

4. **Meaninglessness** – Absence of Obvious Meaning to Life
   - search for meaning, uncertainty, values, why-how

Adaptations to the Inevitability of Death

When we are Young we Deny Death thru:
- Parental reassurance; secular and religious myths transform death through personifying it; detoxify death through taunting it, daredevilry desensitizing by exposure- ghost tales, horror films

When we are Older we Deny Death thru:
- Distraction; Transforming it to something positive – “going home” “rejoining God”, “Peace at last”; Deny it thru myths; strive for immortality through imperishable works, children, embracing religion
Common Methods Used by Cancer Patients to Allay Fears of Death

“Specialness” - The belief that one is invulnerable beyond the ordinary laws of human biology, destiny. A belief in personal specialness provides a sense of safety from within.

“Ultimate Rescuer” - We are watched and protected by an outside omnipotent force. A dialectic: emerge or merge

“Re-Define Death” - We re-define death thru beliefs in life after death, reincarnation, some type of continued existence, not “nothing”

Yalom I, 1989
“Middle Knowledge”: Between Acceptance and Denial

Avery Weisman pointed out that:

- Denial of Death is complex; it not only avoids the reality of danger but preserved important relationships.

- There are varying degrees of denying and denial of death.

- Coined the term “Middle Knowledge” for the state of unpredictable shifts between open acknowledgment of death and its repudiation.

Weisman AD, 1972
“It’s not that I’m afraid to die, I just don’t want to be there when it happens”

Woody Allen, 20th Century Writer and Filmmaker
“But there is another way - a long tradition, applicable to psychotherapy, that teaches us that full awareness of death ripens our wisdom and enriches our lives.”

“Although the *Fact*, the physicality, of death destroys us, the *Idea* of death may save us.”

Yalom, 1989
Defining “Acceptance of Death”
Acceptance of Death:
Kubler-Ross Stages of Dying

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Kubler-Ross, 1969
Acceptance of Death: Kubler-Ross’ Definition

Acceptance – coming to terms with the situation without feelings of hostility; allows time for facing the reality of death in a constructive way

“It’s going to be okay.”
“I’m ready, I don’t want to struggle anymore.”
<table>
<thead>
<tr>
<th>Awareness</th>
<th>Cognitive</th>
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<tr>
<td>Acknowledgment</td>
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<td>Insight</td>
<td>Behavioral</td>
</tr>
<tr>
<td>Acceptance</td>
<td>(Speech; Actions)</td>
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</tbody>
</table>
Acceptance of Death: Peaceful Awareness of Terminal Prognosis

• Cognitive acceptance: intellectual awareness of one’s terminal prognosis

• Emotional acceptance: peace and equanimity (i.e., absence of hostility) in facing death

Ray et al, J Pall Med 2006
Empirical evidence suggests that cognitive and emotional acceptance of death leads to more desirable outcomes in terminally ill patients.
Positive Outcomes Associated with Acceptance of Death (Peaceful Awareness)

- Higher rates of advanced care planning
- Better quality of death
- More positive physical & mental health outcomes for bereaved family members

Ray et al, J Pall Med 2006
Insight into Illness

• What do you understand about your illness?
• How serious do you believe things are?
• 0… No information
• 1…. No insight: believes illness is curable; denies of terminal condition
• 2…. Limited insight; understands that illness is terminal, unrealistic time expectations
• 3…. Good insight; has full understanding of gravity of illness and imminence of death
Insight in the Terminally Ill

% Depressed

χ² (2) = 7.09
p = 0.02
Prognostic Non-acceptance - The Canadian National Palliative Care Survey

- A Canadian multicenter prospective survey of 381 advanced cancer patients with prognosis of 6 months or less receiving palliative care.

- Patients were rated on a 0-6 scale of difficulty in Acceptance of their terminal prognosis. Those scoring 3 or greater (moderate) were classified as Non-acceptors.

- Non-acceptors were more likely to have a diagnosis of a depressive or anxiety disorder, and reported significantly more hopelessness, and more suffering.

- Non-acceptors were younger, had more financial concerns, and smaller social connections.

Thompson, et al, JCO 2009
Goals of Palliative Care

Goals of Psychosocial and Existential Care at the EOL
What Should Be The Clinical Goals of Palliative Care?

To Prolong?

To Protect?

To Preserve?
What Should Be the Goals of Psychotherapy in Palliative Care?

• **Presence and Non-abandonment**: To escort the patient through the course of treatment and the dying process?

• **Support**: To provide support, ally with defenses including use of denial of proximity death?

• **To Accomplish Something More “Ambitious”**?
  Acceptance of a life lived, sense of life completion, meaning, coherence, legacy, acceptance of death
Existentially-informed EOL Goals: Growth in the Dying Process

- Sense of life completion
- Sense of coherent meaning about one’s life
- Leaving legacy
- Facing death with peace and equanimity
- Acceptance of death
- Acceptance of a life lived
Beyond A “Good Death”
Importance of Life Completion

- Be free of pain
- Be free of shortness of breath
- Be kept clean
- Name someone to make decisions
- Treatment preferences in writing
- Know what to expect about one’s physical condition
- Feel family is prepared for one’s death
- Have a doctor who knows one as a whole person
- Have a doctor with whom one can discuss personal fears
- Say good-bye to important people
- Resolve unfinished business with family or friends
- Share time with friends and family
- Remember personal accomplishments

Steinhauser et al, in press
Existentially-informed EOL Goals: Growth in the Dying Process

- Sense of life completion
- Sense of coherent meaning about one’s life
- Leaving legacy
- Facing death with peace and equanimity
- Acceptance of death
- Acceptance of a life lived
The “More Ambitious” Goal: Acceptance of a Life Lived and Acceptance of Death

• Facing death (and that time is finite) is the impetus for transformation—it forces one to turn around and face the life one has lived.

• This can enhance the process of pursuing a sense of coherence, meaning, and completion of one’s life.

• It allows for realization that the last chapter of one’s life is the last opportunity to live to one’s full potential—to leave behind an authentic legacy, to connect with the beyond, and to transcend life as we know it.
The “More Ambitious” Goal: Acceptance of a Life Lived and Acceptance of Death

The goal is to preserve the idea that there is still life to be lived, still time to become, so that one can die with a sense of peace, equanimity, and acceptance of the life one lived.

Through the acceptance of death, one can live life more fully, complete the tasks of living and dying, and preserve one’s own life.
The End of Life Dynamic

Acceptance of Death

Acceptance of Life Lived
How To Live (Be) in the Face of Death

Breitbart W, Palliative & Supportive Care. 2007

- **Upright**: Realization that one is Still Alive and Standing, not lying beneath the ground, Continuing to have Wants and Wishes, to Exert one’s Will, to have Courage

- **Whole**: To remain connected to all that gives meaning, value and purpose in life; to Relate not Isolate.

- **Careful**: To remember to Care for one’s self, one’s loved ones, one’s legacy, rippling effect
Counseling in Palliative Care: The Practices of Compassion

- **Hospitality**: Creating the setting for community and communication - recognizing we share the human condition and we are connected

- **Presence**: To give the other our full attention. "Attending” Physician; To be fully present for the other transcending our own concerns

- **Listening**: To hear and to respond in a way that makes the patient know they have been “understood”; empathy