

Issues in Palliative Care:
*Why a "good" death could
be a bad thing*

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Anatole Broyard
1920 - 1990



Art Buchwald
1925 - 2007



Morrie Schwartz
1916 - 1995

"In this world nothing can be said to be certain, except death and taxes."

Benjamin Franklin

What is a good death?¹

- **Institute of Medicine**
 - Free from avoidable distress and suffering for patients, families, and caregivers
 - In general accord with patients' and families' wishes
 - Reasonably consistent with clinical, cultural, and ethical standards

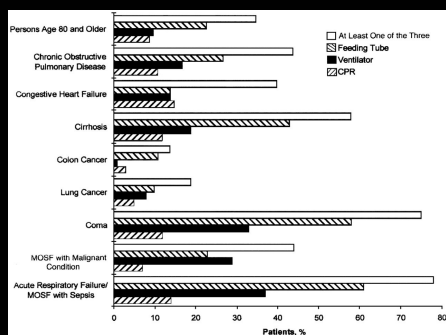
Research on a Good Death²

- Optimizing physical comfort
- Maintaining a sense of continuity with one's self
- Maintaining and enhancing relationships
- Making meaning of one's life and death
- Achieving a sense of control
- Confronting and preparing for death

EOL Developmental Tasks³

- **Affirmation**
 - “I love you” – “Do you love me?”
 - “Thank you”
- **Reconciliation**
 - “I forgive you” – “Do you forgive me?”
- **Saying Goodbye**
 - “This is my legacy to you.”
 - “This is the legacy I want from you.”

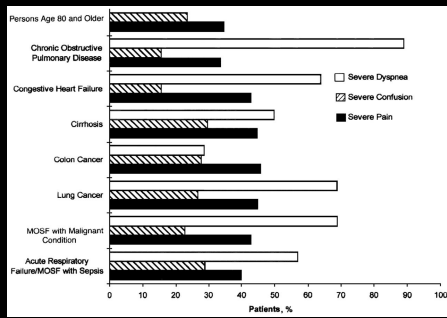
Treatments administered during the last 3 days of life, as reported by family members⁴



Lynn, J. et. al. Ann Intern Med 1997;126:97-106

Annals of Internal Medicine

Rates of severe symptoms in patients 3 days before death, as reported by family members⁴



Lynn, J. et. al. Ann Intern Med 1997;126:97-106

Annals of Internal Medicine

Problems with a Prescriptive Approach to EOL Care

- Patient's perceptions of "good" deaths, "bad" deaths, and end-of-life scenarios are heterogeneous⁵
- Minority and non-minority perspectives of a good death differ⁶
- Perceptions of patients and professional caregivers concerning what is a "good" death differ^{7,8}

Problems with a Good Death

- What is "good" entails a value judgment
- Determining whose values should prevail is not always easy
 - The patient? = patient autonomy
 - The caregiver?
 - The physician/care team?
 - The insurance company?

Evolution of the Concept of a Respectful Death

- Based on qualitative research into the perceptions of physicians, patients and their caregivers regarding quality end-of-life care⁹
- 39 family medicine faculty clinicians
- 42 patients of those clinicians
- 39 caregivers of those patients

Assumptions in Developing the Respectful Death Model

- Death is an **inevitable event** to be lived and not a problem to be solved
- Death is an **ongoing process** occurring within a community
- The role of professionals providing end-of-life care is to **help each member** of that community—patient, family and care team—to **live the best quality life possible** while a singular life comes to an end

EOL Study Domains⁹

- **Awareness** – the process of interpreting and embracing the impact of terminal illness on life experience
- **Management/Coping** – the necessary regimen or tasks that must be accomplished in order to get through each day
- **Relationships** – bonding through time with self, others and the environment
- **Personal Experience** – the individual's living through the dying process

“A Cross-Cultural Perspective”

• Patients

- Emphasized the personally overwhelming impact of serious illness
- Awareness of death infused every moment of their lives to become the context in which each day was lived
- Tasks
 - Coping with physical, financial, psychosocial and spiritual challenges of illness
 - Maintaining relationships: change, conflict, growth
 - Experiencing suffering, loss, spiritual growth, uncertainty, reconciliation and physical discomfort

“A Cross-Cultural Perspective”

• Family Caregivers

- Overwhelming impact of serious illness but with a focus on “my loved one’s death”
- Preparing to live in forever changed conditions
- Tasks
 - Maintain stamina to provide caregiving
 - Garner appropriate community resources
 - Accommodate change and loss of relationships
 - Experience suffering, loss, spiritual growth, uncertainty and reconciliation
 - Advocate physical comfort for their loved one

“A Cross-Cultural Perspective”

• Clinicians

- Works to help everyone reach consensus that life will be foreshortened while coping with the uncertainty of prognosis
- Tasks
 - Develop a common understanding with patient and family of medical future with specific goals and a treatment plan to support achieving those goals
 - Focus on treating disease, palliating symptoms
 - Manage relationships through the dying process and beyond
 - Commitment, Connection, Consciousness

Physician Roles in EOL Care¹⁰

- **Consultant**
 - Provides expert information based on the biomedical model, the diagnosis and the stage of disease
- **Collaborator**
 - Exchanges information with the patient and family to promote a common understanding of the diagnosis and illness experience
- **Guide**
 - Actively and personally seeks solutions for the patient based not only on the medical facts (consultant) and the patient's values and preferences (collaborator), but also on the guide's greater understanding of the medical context

What is a Respectful Death?

- **Process** vs. Prescription
- Emphasizes a **nonjudgmental relationship** amongst the patient, family and care team that **acknowledges differences**
- Allows for a **shared process of integrating differences** into as coherent a whole as possible
- Recognizes that the challenge is **weaving different perspectives into a whole cloth** that supports as many of the **common values** as possible for all parties

Elements of a Respectful Death

- Begins with **awareness of life foreshortened**
 - Not good at conveying this message/problems of prognosis¹¹
 - Would you be surprised if this patient were to die in the next year?
- **Values based** = a delineation of the values of each of the stakeholders
 - Gathering and understanding the stories by which patients and families make sense of their lives, provide continuity, and gain a sense of identity^{12,13}
 - Seeks to create a **common story** in which the lived experiences of the patient and family are at the center
- Focuses on the opportunity for **patient and family values to drive healthcare decision-making**

Respectful Death Protocol¹⁴

1. Meet the ill person/family in a **quiet setting**
2. **Include all** important participants
3. Make sure you have **adequate time**
4. Create a **safe therapeutic environment**
5. **Explore** the ill person's/family's **story**
6. **Listen fully** with intention to understand (with curiosity/openness to surprise)
7. **Verify** your **understanding**
8. Emphasize commitment to **integrate values and goals** into medical plan
9. **Develop care plan** that supports patient/family values/goals
10. **Acknowledge** that **suffering/loss** are part of end-of-life and be a compassionate witness when no solutions are possible

A Respectful Death: Requirements for Clinicians

- **Personal Insight**
 - Comfortable with death as a natural process
 - Capable of being a witness to suffering
- **Comfort with the limits of medicine**
 - Understand a medical role beyond curing
 - Ability to relinquish control
- **Expert communication skills**
 - Narrative competence – the ability to help patient and family write the end-chapter of their life narrative

A Respectful Death: Clinician Barriers¹⁵

- **Expert Certainty**
 - Valuing professional expertise above the life experience of patients/family
- **Conspiracy of Silence**
 - Trying to protect the patient and self by avoiding uncomfortable conversations
- **Fear of Uncertainty/Desire for Control**
 - Focusing on biomedical values rather than the patient's and family's values

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“For any culture which is primarily concerned with meaning, the study of death—the only certainty that life holds for us—must be central, for an understanding of death is the key to liberation in life.”

Stanislav Grof

Exploring Awareness of Dying

- Many patients with this condition tell me they think about the possibility of dying. They have questions about this. Do you?
- You say you will beat this illness. Is there any time, if only for a few moments, when you are not so sure?
- When you think about getting very sick, what worries you most?
- How does your cultural tradition approach a serious illness like this? What traditions, beliefs or rituals should we be aware of?

Exploring Issues of Coping

- How do you cope with the physical limits and challenges of your illness?
- How do you cope with the financial demands resulting from your illness?
- As you think about your current illness, what are the hardest issues for you?

Exploring Relationship Issues

- What roles and responsibilities do you want to maintain?
- What roles and responsibilities have you had to give up?
- How do you deal with changes in the way you relate to your relative or caregiver caused by your illness?
- Has this illness increased your appreciation of your abilities or potentials?

Exploring Personal Experience

- As you think about your current condition, what is the hardest thing for you? What do you fear the most?
- What are the hardest losses you have experienced with this illness?
- From what sources do you draw your strength? What role does spirituality play in your life?
- If you died tonight, is there anything you would leave unsaid or you would regret?
- Are you suffering physically in any way? Afraid of anything?

Nurturing Hope

- Let's "hope for the best, but plan for the worst"¹⁶

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