Recognizing Dying

Or… When does dying begin

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Die (Dying)

- To cease living
- **To cease existing, *esp. by degrees: Fade***
- To lose vitality, activity or force
- To cease existing completely
- To experience an agony or suffering suggestive of that of death <nearly died of despair>
- To desire greatly <dying to buy a house>

Webster II New College Dictionary

If you were dying?

- What would be important to you?
- How would this be different from your present (non-dying) state?

Organizing Concepts

- Whether a person is perceived as dying or not significantly affects attitudes toward decision making, relationships, and tasks
- Differing perceptions (dying versus not) underlie many conflicts toward the end-of-life
- Dying is more a matter of subjective than objective reality
- Skills exist to help resolve conflicts and improve care

Definitions and Distinctions

- **Terminal Illness** – an incurable illness that will eventually result in death (if something else does not sooner)

- **Life-threatening illness** – An illness with the potential to result in death (but not certain)

Neither synonymous with dying

Definitions and Distinctions

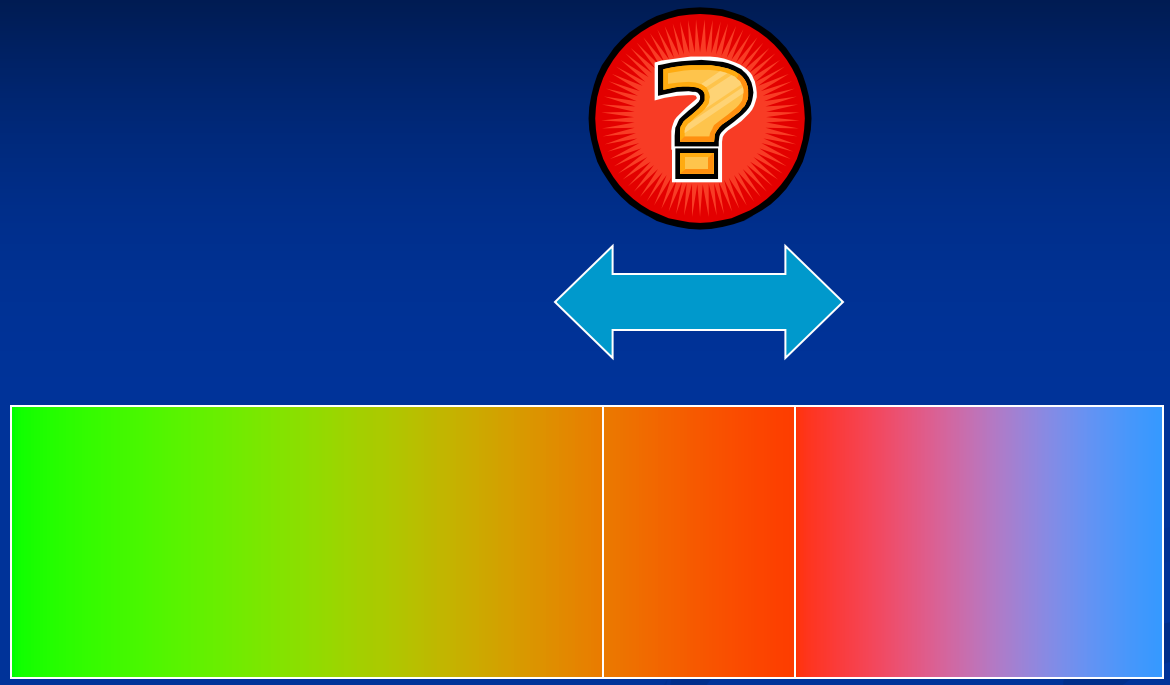
- **DYING** -An irreversible process moving toward death, like a wave - of increasing "amplitude" based on perceived:
  - Certainty (prognostic accuracy)
  - Rate of change (rapid > slower)
  - Proximity to death

Dying is a stage of living…

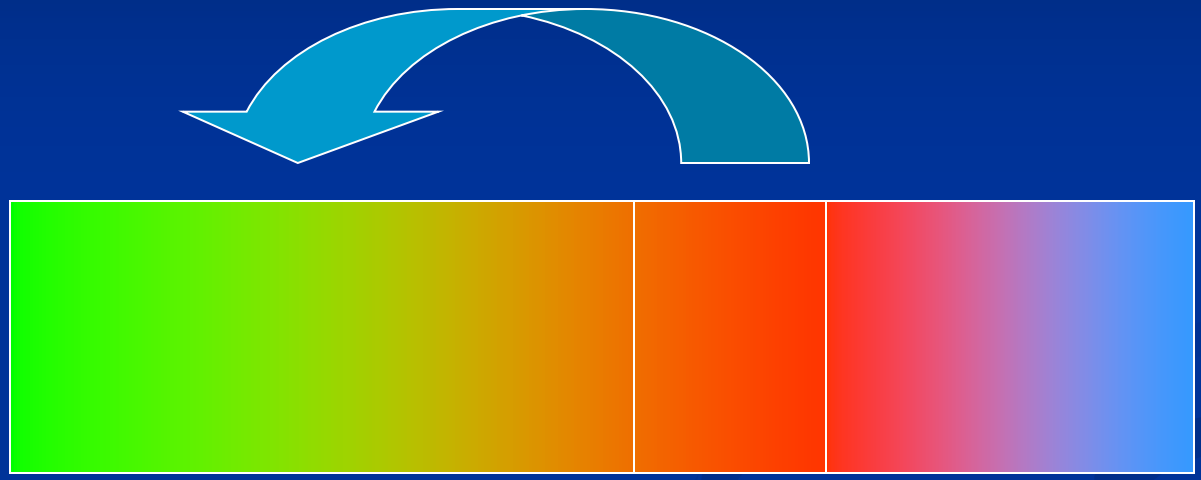
Implications of Dying as a Life Stage (beyond the obvious…)

- Medical
  - What therapies to take or stop taking
  - Where to receive care
- Tasks
  - Business
  - Relational
- Personal
  - Emotional – sadness, hopelessness, relief, resolution
  - Spiritual – Despair to transcendence

Health (Illness) Narratives

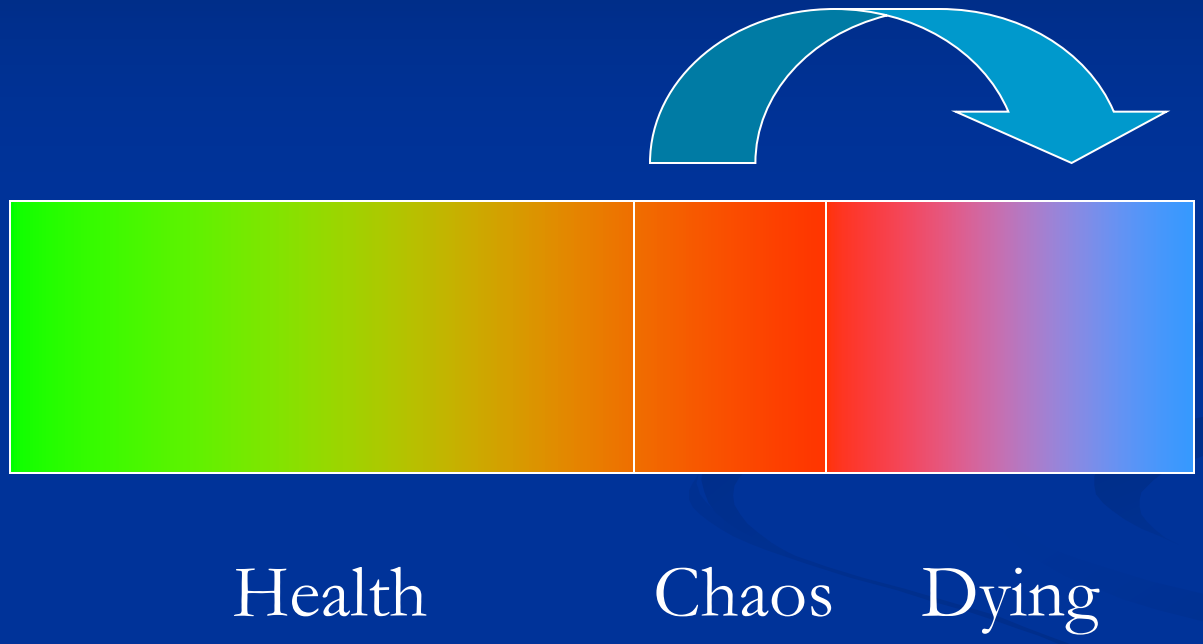


Restitution Narrative

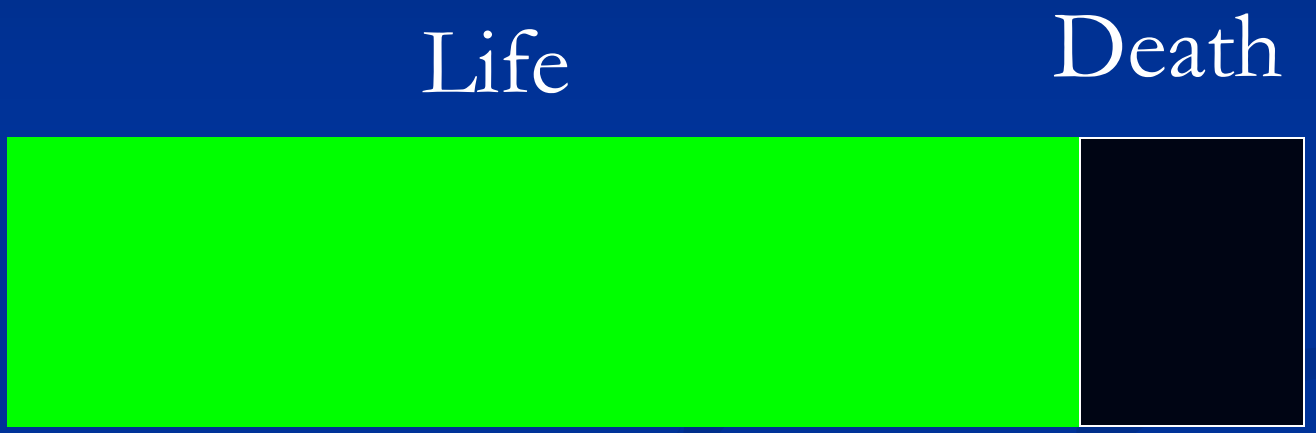


Frank A. The Wounded Storyteller – Body, Illness, and Ethics. Chicago. 1995

Resolution toward Dying Narrative

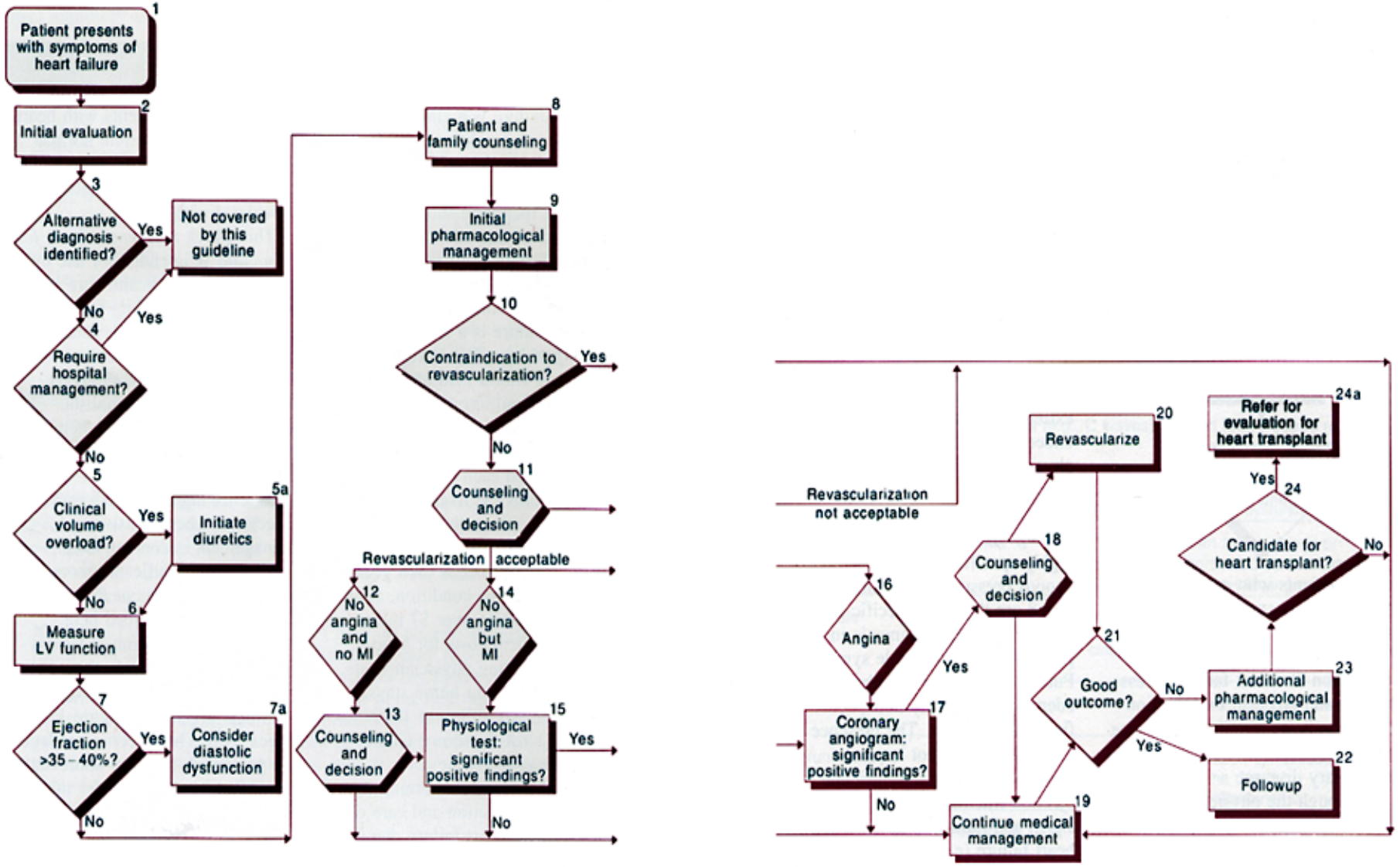


Common Fantasy
Rare Occurrence



Someday I hope to just wake-up, dead…

Figure 1. Clinical Algorithm for Evaluation and Care of Patients With Heart Failure



Note: LV = left-ventricular, MI = myocardial infarction.

"May I Talk with Your Dying Patients Please?" – Kubler-Ross

Response from Hospital Officials – 'Certainly – But we do not have any…'

In many hospitals, people do not die, they code…

Subjective Realities and Selective Presentations

- Internal Dissonance – beliefs in conflict
  - 'Sometimes I think I'm dying and other times I think I'm going to be cured'
- Selective presentations
  - Example: Clinicians, families or patients may "present" – as being on the path to health, while internally aware of dying = "*closed awareness*"

Closed awareness – Glaser BG, Strauss AL. *Awareness of dying*. Chicago: Aldine Pub. Co.; 1965.

"When my mother-in-law, Laura Foote, was dying from cancer, we all knew she was dying. At least one reason why our family never talked about her dying was that until two days before she died, we remained fixed on the incremental remedies that medicine continued to offer. However, clear her deterioration, there was always another treatment option. As long as small puzzles could be solved, fixing this or medicating that, the big issue or mortality was evaded. Each specialist carried out his task with some success, and the patient died."

Frank, *The Wounded Storyteller*,.pp84.

Physician Selective Presentation

- 326 patients with cancer – physicians ask to formulate *internal* prognosis and the prognosis they would communicate to patients
- 22.7% of physicians would not communicate a prognosis *even if asked to do so by the patient*
- 40.3% of time communicated prognosis discrepant
  - 70.2% of these optimistic relative to internal prognosis

Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med.* 2001;134(12):1096-1105.

What if you're wrong…

- If not really dying…
  - Premature invocation of dying story – obvious dangers -shut-off from potentially life-saving therapies
- What if he patient "really can't handle the truth"…
  - Open awareness for some – loss of hope/face

What about dying 'outside of a dying narrative?'

- Therapies and side-effects of minimal, no benefit or possible harm
- Isolation
- Poor communication – unanswered questions
- Missed opportunities
- Dissonance between actual events and idealized dying story Example – dying story favors a peaceful death, actual dying involves CPR

Communication Skills

Chaos Stories

- Chaos is painful for all concerned
- Everybody seeks stability
- Strong temptation to "push" people out of chaos – either back toward health (restitution) or toward "acceptance" – resolution (doesn't work)
- While people in chaos need and want help they tend to resist being pushed, which is often perceived as further loss of control (chaos)

Chaos Stories

- Respect where the person is
- Bearing witness to suffering first, *listen,* before offering help
- Don't push your agenda
- Support control, where control is possible

"The need to honor chaos stories is both moral and clinical. Until the chaos narrative can be honored, the world in all its possibilities is being denied. To deny a chaos story is to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care." Frank. Wounded Storyteller

When Tensions Arise…

- Naming
  - Relevant Stakeholders
  - Stakeholders' position(s)
    - Stage – Health, Chaos, Dying
    - Process restitution, resolution
    - ? Selective presentation
    - Roles in illness management

Explore Different Understandings

- Stakeholder's understanding (explanatory model)
  - "What is your understanding of where Jim is in his illness?"
- Stakeholder's understanding of the *other's understanding*
  - "What do you think ***Jim's*** understanding is of his illness?"

Cultural Diversity

- Cultures vary in their understanding and communication styles about end-of-life issues
- May use "explanatory model" questions to explore understanding:
  - *What* do you call this illness and what causes it?
  - *What* constitutes proper care and by *who?*
  - *What is the natural course of such an illness?*
- *How* should people communicate about a life-threatening or terminal illness?

Listening "between the lines"

- Communication Cues – follow-up or drop
- Ambiguity – clarify or not
- Metaphor – co-construction or shift
- Identifying possible subtexts – raise to text or not

Raising the Subtext to the Text

- Common subtexts:
  - **Emotional** – "I can see you are very upset"
  - **Mistrust** – "It sounds like you don't fully trust the doctors"
  - **Guilt** "I wonder if she feels guilty about…"
  - **Dying** "Do you think he might be dying?"

What-if Questions?

- "How would you know if Sue is dying?"
- "If you were dying, how might that change your thinking or plans?"
- If your mother were dying, what important things would need to be done (or avoided)?

Less direct (toxic) approach: Ask about a third person – "If someone were dying, what kind of things would be important?"

Negotiation

Avoid		Encourage
Focus on differences	→	Common ground
Negative attributions	→	Positive framing
Person as the problem	→	Problem as the problem
Rigid positions	→	Interests
Means as ends	→	Goals
Fixed deadlines	→	Time trials
Treating "resistance" as a hearing deficit	→	Emphasize relationships

Fisher, Ury *Getting to Yes*

SUMMARY

- Dying is difficult under the best of circumstances
- If major participants in dying are "out-of-sync" with one another, dying become doubly difficult
- Communication skills can promote mutual understanding and lay the groundwork for coordinated approaches to dying