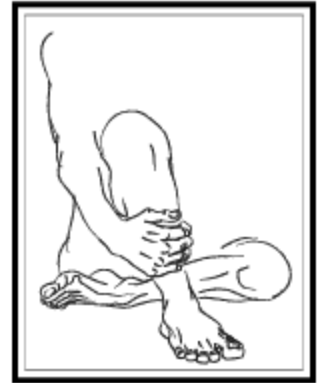


Exploring Human Stories of Illness
The Health Humanities Portrait Project

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Aging, End of Life & Narrative Ethics

Reading List

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Older adulthood is where “the life cycle weaves back on itself.” (Erik Erikson)

First Person Narratives: (presented during session)

- Gilbert J. *By Small and Small: From Midnight to 4AM*
- Carver R. *What the Doctor Said*

Scholarly Readings:

- Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: The National Academies Press, 2015. [Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.](https://www.nap.edu/read/18748/chapter/3#36)
<https://www.nap.edu/read/18748/chapter/3#36>
Introduction, pp. 21-44.
- Montello M. "Narrative ethics." *Hastings Center Report*. 2014: 44.s1, S2-S6. <https://doi.org/10.1002/hast.260>.
- Glossary of terms (see p. 3 of this Reading List)

Recommended Reading:

- Perry TE, Hassevoort L, Ruggiano N, Shtompel N. Applying Erikson's Wisdom to Self-Management Practice of Older Adults: Findings from Two Field Studies. *Res Aging* 2015;37(3): 253-274. <https://doi.org/10.1177/0164027514527974>.
- Leveen L. "Finding Purpose: Honing the Practice of Making Meaning in Medicine." *The Permanente Journal*. 2017: 21. [Finding Purpose: Honing the Practice of Making Meaning in Medicine.](https://doi.org/10.7554/2017.21.001)
- DasGupta S. "Narrative Humility." *The Lancet*. 2008: 371.9617, 980-981. [https://doi.org/10.1016/S0140-6736\(08\)60440-7](https://doi.org/10.1016/S0140-6736(08)60440-7).
- Gallop J. "The ethics of reading: Close encounters." *Journal of Curriculum Theorizing*. 2000: 16.3, 7-17. <https://journal.jctonline.org/index.php/jct/>.
- Halpern J. "The Therapeutic Effects of Empathy in Healthcare." *Emotion Researcher*. July 2017. [The Therapeutic Effects of Empathy in Healthcare.](https://doi.org/10.1007/s10804-017-9288-8)

Glossary

Decision-making capacity: “the ability to understand and appreciate the nature and expected consequences of each health care decision” and “to formulate and communicate a clear decision about health care.” (Veterans Health Administration. VHA Handbook 1004.1, Informed Consent for Treatments and Procedures. Revised January 29, 2009.)

Narrative humility: the sense of humility toward that which we do not know - the face of the Other, the face we cannot know but to which we are responsible; an acknowledgement that the patient’s story (or our own stories of caring for patients) cannot ever be comprehended in totality or mastered by another person.

Substituted judgment: a form of proxy decision-making whereby the proxy attempts to establish as accurately as possible the decision the patient would make if s/he could speak for himself or herself. Takes into consideration: “(i) the patient’s preferences (if any) as expressed in an advance directive or as documented in the medical record; (ii) the patient’s views about life and how it should be lived; (iii) how the patient constructed his or her life story; (iv) the patient’s attitudes toward sickness, suffering, and certain medical procedures.” (American Medical Association Code of Medical Ethics 2.1.2 Decisions for Adult Patients Who Lack Capacity,.... pg 30)

Advance care planning: “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.” (Sudore RL et al. “Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel.” *J Pain Symptom Manage*. 2017 May; 53(5), 821-832.e1. [doi: 10.1016/j.jpainsymman.2016.12.331](https://doi.org/10.1016/j.jpainsymman.2016.12.331). Epub 2017 Jan 3.)

Shared decision making: “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.” (Elwyn G, Coulter A, Laitner S, Walker E, Watson P, Thomson R. “Implementing shared decision making in the NHS.” *BMJ*. 2010; 341, c5146. [doi: 10.1136/bmj.c5146](https://doi.org/10.1136/bmj.c5146))

(Narrative) Projection: “the process of projecting our own ideas or opinions on how a writer's work should've been written” instead of how it is actually written (Gallop J. "The ethics of reading: Close encounters." *Journal of Curriculum Theorizing*. 2000: 16.3, 7-17. <https://journal.jctonline.org/index.php/jct/>).

Empathic curiosity... a model that puts “resonance to work in the service of learning more in order to better imagine how the patient is feeling and to communicatively connect in real time while co-imagining, in order to convey caring and appropriate worry.” [The Therapeutic Effects of Empathy in Healthcare.](#)

Hospice:

- “Medical care to help someone with a terminal illness live as well as possible for as long as possible, increasing quality of life.
- An interdisciplinary team of professionals who address physical, psychosocial, and spiritual distress focused on both the dying person and their entire family.
- Care that addresses symptom management, coordination of care, communication and decision making, clarification of goals of care, and quality of life.”

(Hospice Foundation of America (2019.) “What is hospice?”

<https://hospicefoundation.org/Hospice-Care/Hospice-Services>)

Palliative Care: “specialized medical care for people living with a serious illness. This type of care is focused on relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.” (Center to Advance Palliative Care. (2019).

“What is palliative care?” <https://getpalliativecare.org/whatis/>;

<https://platinumcarehhs.com/palliative-care/>.

Erik Erikson's Psychosocial Stages of Development ¹



Erikson's Psychosocial Stages Summary Chart



Stage	Basic Conflict	Important Events	Key Questions to be answered	Outcome
Infancy (0 to 18 months)	Trust vs. Mistrust	Feeding/ Comfort	Is my world safe?	Children develop a sense of trust when caregivers provide reliability, care and affection. A lack of this will lead to mistrust.
Early Childhood (2 to 3)	Autonomy vs. Shame and Doubt	Toilet Training/ Dressing	Can I do things by myself or need I always rely on others?	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feeling of autonomy, failure results in feelings of shame and doubt.
Preschool (3 to 5)	Initiative vs. Guilt	Exploration/ Play	Am I good or bad?	Children need to begin asserting control and power over the environment. Success in this state leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.
School Age (6 to 11)	Industry vs. Inferiority	School/ Activities	How can I be good?	Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feeling of inferiority.
Adolescence (12 to 18)	Identity vs. Role Confusion	Social Relationships/ Identity	Who am I and where am I going?	Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self.
Young Adult (19 to 40)	Intimacy vs. Isolation	Intimate Relationships	Am I loved and wanted?	Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, while failure results in loneliness and isolation.
Middle Adulthood (40 to 65)	Generativity vs. Stagnation	Work and Parenthood	Will I provide something of real value?	Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, while failure results in shallow involvement in the world.
Maturity (65 to death)	Ego Identity vs. Despair	Reflection on life	Have I lived a full life?	Older adults need to look back on life and feel a sense of fulfillment. Success at this state leads to a feeling of wisdom, while failure results in regret, bitterness, and despair.

¹ <http://www.ocfcpcourts.us/assets/files/list-758/file-1038.pdf>

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