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# Narrative Medicine and Health Care Ethics: Religious and Literary Approaches to Patient Identity and Clinical Practice

Tara Flanagan Tracy
*Loyola University Chicago*

LOYOLA UNIVERSITY CHICAGO


NARRATIVE MEDICINE AND HEALTH CARE ETHICS: RELIGIOUS AND LITERARY

APPROACHES TO PATIENT IDENTITY AND CLINICAL PRACTICE


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TARA FLANAGAN TRACY

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INTRODUCTION

This dissertation examines practices of narrative medicine and moral identity for end-of-life patients, with special attention given to Aristotle's *Poetics* and the work of Paul Ricoeur. While noting the genuine value of narrative medicine for clinicians, I examine the limits of self-narration for patients who are unable to offer a linear, coherent narrative of their lives due to cognitive deficits such as Alzheimer's disease. In chapter four, plays by Samuel Beckett, specifically *Rockabye* and *Krapp's Last Tape*, are approached as narrative case study to highlight the ways in which technology, structural space, attenuated relationships, difficult personalities, and limited verbal and cognitive ability come together to compound the challenges of approaching a patient with the assumption that they have a narrative arc.

For patients so challenged, I suggest that the practice of hospitality as it exists in the hospice model of care transcends the need for higher-level cognition commonly associated with narrative medicine. In the final chapter, I demonstrate how the hospice model of care recognizes both the value and the limits of narrative practices as they apply to end-of-life patients, and provides a treatment model for patients regardless of their verbal and cognitive abilities. Additionally, I detail the history of the hospice model of care, describing religious history of the model, as well as how Cicely Saunders interpreted hospice work as a religious vocation.

As an ethicist, my goal in this dissertation is to consider those patients who go unvisited and those who fall outside of the patient population considered in current models of narrative medicine. I examine the complications of approaching the clinical encounter with the expectation

that the patient will offer stimulating dialogue or dialogical reciprocity. Patients are often anxious, confused, suspicious, or in pain. Nevertheless, the premise of narrative medicine, that being a close reader of texts can develop the ability to attend closely to patients, remains useful. When the sources used in narrative medicine are expanded to include those found in modern literature—a genre known for disrupting language, character, plot, and the expectations of the reader—the joint study of literature and medicine can remain pedagogically viable for clinicians working with verbally or neurologically compromised patients.

Literature provides an especially valuable resource in the case of patients with impaired cognition, as they are not always able to provide coherent narratives or an understandable history. Therefore, in this research, I look to literature that describes the scene of patients at the end of life with the goal of demonstrating how literature can expand the scope of a clinician's understanding beyond the patient's spoken narrative. In particular, I look to dramatic works by Samuel Beckett, particularly those in which characters experience isolation, physical and emotional pain, and loneliness at the end of life.

Managing physical pain is a priority in medical care and rightly so. My concern in this work is neglect of the other dimensions of patients' pain:

1.      The social isolation and loneliness of the elderly and dying;

2.      Psychosocial and spiritual distress as a manifestation of total pain.

My argument is that patients who are not pleasurable or rewarding to visit, such as those with dementia or those who are angry or in distress as a result of life review, can go unvisited and unattended to because they are challenging to encounter. They do not provide the reciprocity that is celebrated in narrative medicine (which has focused up to this point on verbal, coherent patients). Drawing on the Matthean understanding of the vulnerable and marginalized, I see

these patients as the hungry, thirsty, naked, sick and imprisoned—the stranger; those that, in a medical field focused on health and healing, may have inward pain that goes unrecognized. My central question is this: What does care for the least of these mean for those at the end of life? Whose care might be overlooked when it comes to comprehensive pain management, care that goes beyond physical, bodily pain? Hospice offers an expanded concept of pain that includes, but expands beyond, the narrow view of pain as a physical experience. The definition of pain I use, "total pain," is defined by Cicely Saunders, founder of hospice, as physical, spiritual, existential, and psychosocial pain, pain that can be located in the body, mind, and soul. I look to hospice as a model for the treatment of pain in its myriad forms, and as a model for practicing hospitality and the corporal works of mercy.

I maintain that narrative medicine nevertheless continues to be useful for developing clinical skills with "difficult" patients, including those with intractable pain and those with verbal or cognitive deficits. Literature that portrays such individuals, those that present as agitated or with confused speech, for instance, can be used in narrative medicine to cultivate a clinician's tolerance for discomfort with such patients, leading to improved care for the "least of these." I use two of Samuel Beckett's dramatic works as narrative case study because he offers a clear portrayal of individuals that may be challenging for clinicians, chaplains, or non-professional caregivers to engage with.

Overall, my focus centers on the practices of narrative medicine, practices on the patient's part through the process of life review, and the growing body of practices available for clinicians who are committed to developing patient care skills. I demonstrate how methods in narrative medicine can be employed in clinical training for working with challenging patients. I then turn to theological models of presence with patients who may experience social neglect because they

make others uncomfortable. Drawing on the resources and modes of practice found in narrative

and theological approaches to patient care, my intention is to urge clinicians and caregivers to

practice sitting in that space of discomfort, thereby attending to the loneliness, isolation, and pain,

in its many forms, experienced by those facing the end of life.

CHAPTER ONE

NARRATIVE MEDICINE: IDENTITY AND PRACTICE

Medical practitioners, including physicians, nurses, chaplains, in the attempt to better their ability

to provide care, have turned to the study of narrative to develop their clinical skills. Resisting

an efficiency-model of medicine, such practitioners are concerned with treating patients as

individuals and deepening their ability to listen to patients as patients express their physical,

psychosocial, and existential concerns. Additionally, patients themselves have turned to narrative

methods to express their resistance to being treated as an object—as a body, a diagnosis, a subject

of research or experimental treatments—detached from their personhood and history. In this

chapter, I examine the history of medical care in the United States with the goal of tracing the

turn toward narrative practices in medicine. In the chapters that follow, I examine how life review

in hospice and palliative care portrays one of the ways patients engage in narrativity as a form

of ethical analysis, and then turn to the limits of narrative medicine for patients with limited

capacity to communicate verbally. In the final chapters, I explain how modern literature can be

used as a resource to address the limits of narrative medicine for such patients, and conclude with

a constructive, theologically informed approach to encountering patients that may present as

challenging to clinicians.

**The Need for Narrative: Positivist Medicine and Clinical Detachment**

Following the release of the Flexner report in 1910, commissioned by the Carnegie Foundation

under the auspices of the newly formed American Medical Association, medical education in the

United States was intentionally restructured to become both more uniform across the country and more science-based.[1] Abraham Flexner, familiar with the German model of medical training in which physicians were trained as scientists, evaluated medical schools in the United State and Canada, judging them based on the education levels of practicing physicians and on the quality of their laboratory facilities.[23] In his report, which denounced many U.S. hospitals as substandard, he recommended that medical education be amended to include laboratory training and research, moving toward a lab model of education rather than a lecture model of education. Research in cell biology, organic chemistry, and physiology were hallmarks of the German model, and, following the Flexner report—a catalyst for dramatic reform in medical education—these subjects were prioritized in the United States system as well.[4] The Flexner report is seen as the turning point in North American medical training, when medical education shifted from a focus on healing to a disease-based model focused on scientific research and curative treatment.

In addition to Abraham Flexner's role in medical education reform, the work of Morris Fishbein also created momentum for the pivot toward the science-centered focus of clinical education that exists today. Editor of the *Journal of the American Medical Association* from 1924 to 1950, Fishbein, similar to Flexner, became committed to defining medicine as a scientific

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1. Abraham Flexner and Daniel Berkeley Updike, *Medical Education in the United States and Canada : A Report to the Carnegie Foundation for the Advancement of Teaching* (New York City: Merrymount Press, 1910).

2. Thomas Patrick Duffy, "The Flexner Report—100 Years Later," *The Yale Journal of Biology and Medicine* 84, no. 3 (2011), 269.

3. Theodor Billroth, Leon Banov and Kellogg Speed, *The Medical Sciences in the German Universities : A Study in the History of Civilization* (New York: The Macmillan Company, 1924). Duffy notes that this text was central to Flexner's understanding of the German model of medical education.

4. Milton James Lewis, *Medicine and Care of the Dying : A Modern History* (Oxford; New York: Oxford University Press, 2007)., 46-47

pursuit that required substantial education in what would later come to be called evidence-based medicine.[5] Wary of medical fads and "quacks," he worked to inspire something of a Donatist approach to medicine, an approach oriented to the role of the physician as medium: it was the science that cured the patient not the doctor.[6] As a result, doctors qua scientists have "four fundamental tasks," based on problem-solving and research:

1.    Finding out what is the matter (diagnosis)

2.    Finding out how it happened (cause)

3.    Deciding what to do (treatment)

4.    Predicting the outcome (prognosis)[7]

Fishbein looked askance at homeopathic healers claiming to work under the aegis of medicine, but lacking a foundation of clinical medical education, and using ethically and medically questionable treatment methods, famously, snake oil.[8] Fishbein's dedication to the

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5.   The term "evidence-based medicine" (EBM) was first used by David M. Eddy in a 1990 article in the *Journal of the American Medical Association*. The turn toward evidence-based medicine began earlier than this, however, and Flexner and Fishbein's views of medicine align with those later asserted in EBM. David M. Eddy, "Practice Policies: Guidelines for Methods," JAMA 263, no. 13 (1990): 1839–41.

6.   Eric J. Cassell, *The Nature of Healing : The Modern Practice of Medicine* (Oxford; New York: Oxford University Press, 2013), 83. I use the theological language of Donatistism to point to the Augustinian idea that the personal failings of the priest are irrelevant to the nature of sacrament; the priest functions in a technical role where his personality does not come into play. Physicians can be seen similarly in a technical role as scientists.

7.   Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine* (New York: Oxford University Press, 1991), x.

8.   Morris Fishbein, *Medical Follies: An Analysis of the Foibles of Some Healing Cults, including Osteopathy, Homeopathy, Chiropractic, and the Electronic Reactions of Abrams, with Essays on the Anti-Vivisectionists, Health Legislation, Physical Culture, Birth Control, and Rejuvination* (New York: Boni & Liveright, 1925). For how his work applies to more current trends, see his text *The New Medical Follies: An Encyclopedia of Cultism and Quackery in these United States, with Essays on the Cult of Beauty, the Craze for Reduction, Rejuvenation, Eclecticism, Bread and Dietary Fads, Physical Therapy, and a Forecast as to the Physician of the Future* (New York: Boni & Liveright, 1927, New York: AMS Press 1977).

professionalization of medicine, and the megaphone that came with his role as long-time editor of the *Journal of the American Medical Association*, played a major role in medical education reform. The momentum toward reform at the turn of the 20th century culminated with the model of evidence-based medicine dominant in the United States today. The diagnosis-cause-treatment-prognosis model remains effective for meeting patient's acute medical needs, but the goals of care for other medical concerns, like chronic health conditions or terminal illnesses, do not necessarily fit a curative model. The turn toward narrative concepts of patient identity and clinical practice can be interpreted as a response to the efficient, yet mechanistic, treatment of patients, treatment that can result from a problem-solving model of care.

The reforms in medical education lead to the professionalization of medicine as a field marked by scientific rigor and high standards in clinical education. Yet, as medicine became systematized, patients began to feel overlooked or objectified, seen as experiments, body parts, diseases, scrutinized as objects of pathology. As early as 1910, patients were critiquing the detached impersonal care they received in hospitals.[9] Sophisticated care meant specialized, professional care, marked by a growing reliance on diagnostic technology, rather than on personalized care tailored to a patient's needs, experiences, and fears. What was perceived as impersonal care resulted from an institutional focus on administration, surgery, laboratory and X-ray tests, methods of treatment that made the hospital a place for technology-based treatment rather than human encounter.[10] In some hospitals, patients were known by their bed number rather than their names—this was intentionally done to keep a professional, yet therapeutic,

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9. Milton James. Lewis, *Medicine and the Care of the Dying: A Modern History* (Oxford: Oxford Univ. Press, 2007), 34.

10. Ibid., 33.

distance between the patients and nurses.[11] As a result of being treated as a body, a number, or

a diagnosis, patients became dissatisfied with treatment in which they were not seen, heard, or

recognized as a person. Consequently, patients voiced their critique through autobiographical

illness narratives, a turn I speak to later in this chapter. Patients might have been receiving higher

quality, more effective medical care, but their experience receiving this sophisticated clinical

attention was perceived as impersonal and dehumanizing.

### Clinical Detachment as a Practical Skill for Health Care Providers

The expression "clinical detachment" arose during the 1950's when sociologists observed how

medical students related to patients during their training.[12] Originally a descriptive term, clinical

detachment has now become normative in the field, a stance a clinician intentionally cultivates,

possibly to appear more professional, possibly avoid compassion-fatigue.[13] Research shows that

the empathic regard for patients that medical students start their training with begins to decline

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11. Ibid., 34.

12. Institute for Professionalism Inquiry Conference Proceedings et al., *Toward Healing: Virtuous Practice, Spiritual Care and Narrative Medicine* ([Akron, OH ]: Institute for Professionalism Inquiry, 2005): 6-22.

13. To describe the toll on clinicians that comes with repeatedly responding to complex medical needs, the term "compassion fatigue" was coined by Carla Joinson in the article 1992 article, "Coping with compassion fatigue," *Nursing, 22*(4), 118-120. The term was broadened to include other caregivers, such as those in behavioral medicine, or informal caregivers providing emotional labor by C.R. Figley in *Compassion Fatigue: Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized.* (New York, NY: Brunner Mazel, 1995). Compassion fatigue continues to play a role in clinician and caregiver burnout. See: T. Shanafelt, "Enhancing Meaning in Work: A Prescription for Preventing Physician Burnout and Promoting Patient-centered Care," *JAMA* 302 (2009): 1338–40. For a review of the literature on compassion fatigue, see N. Najjar, L.W. Davis, K. Beck-Coon, and C.C. Doebbeling, "Compassion Fatigue: A Review of the Research to Date and Relevance to Cancer-care Providers," *Journal of Health Psychology 14 (2009)*: 267-277.

as they progress in their studies.[14] Physician and poet Jack Coulehan identifies what he terms

the "hidden curriculum" in medical schools as the possible culprit, a curriculum oriented to

objectivity, suspicion of emotionality in patients and self, and a focus on empirical and technical

data, rather than patients' interpretations of their experience.

Not all physicians graduate medical school with diminished compassion for their patients.

Coulehan suggests that there are three possible scenarios for a clinician's approach to care when

they graduate: some leave as technicians, some leave with the empathic presence they came with,

and a large group leaves with what he calls "non-reflective professionalism."[15] These clinicians

are the ones that, over the course of their medical training, have become less compassionate

and more emotionally detached from their patients, resulting from the hidden curriculum that

teaches students that the objectivity that results from a posture of clinical detachment will allow

one to provide better care for patients.[16] Clinicians with detached concern are not unfeeling,

but they have learned to practice medicine with some distance from the world of the patient,

particularly the symbolic, meaning-oriented world of the patient. It is this world of meaning,

this inner world of experience, that interests those doing research and clinical practice based on

narrative medicine. Their hope is to close the gap between clinician and patient, developing what

Coulehan calls "clinical empathy" as part of the clinician's skill-set.[17] For physician-scholars like

Rita Charon, who examines literature and medicine, and Christina Puchalski, whose scholarship

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14. Jack Coulehan, "From Virtue to Narrative: The Art of Healing," in *Toward Healing: Virtuous Practice, Spiritual Care and Narrative Medicine* (Akron, OH: Institute for Professionalism Inquiry, 2005), 9.

15. Ibid., 11.

16. Ibid., 11.

17. Ibid., 15.

addresses religion and medicine, the goal is also to have an explicit curriculum centered on the use of resources that work to cultivate empathic regard rather than detachment in the way clinicians respond to patients.[18]

Due to the emphasis on empirical methods in medical training and the intentional cultivation of clinical detachment in residents, it is understandable that patients experiencing a health crisis may come to feel alienated by the biomedical model of care, a model focused on research, technologized treatment, and emotional distance, rather than on empathic concern and personal connection. The proliferation of illness memoirs, a form of protest literature in which patients reclaim their personhood and individual experience in the institutional model of medicine, can be seen as a result of patients not feeling heard or validated by their clinicians. Sayantani DasGupta's *Stories of Illness and Healing* speaks to medical treatment as fundamentally inhumane, particularly for women. For disenfranchised patients, writing can be a way of reclaiming agency in a time of powerlessness.[19]

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18.  Rita Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *JAMA* 286 (2001): 1897-902. See also Charon's forward in *Narrative in Health Care: Healing Patients, Practitioners, and Profession, and Community* (Oxford: Radcliffe Publishing, 2008), *ix-xii*. For more on the cultivation of empathy for clinicians, see the following by Sayantani DasGupta and Rita Charon, "Personal Illness Narratives: Using Reflective Writing to Teach Empathy," *Academic Medicine* 79 (2004): 351-56.

19.  Sayantani DasGupta and Marsha Hurst, *Stories of Illness and Healing: Women Write Their Bodies* (Kent, Ohio: Kent State University Press, 2007), 212. Additionally, Christina Puchalski writes extensively on the need to teach clinicians about the extra-medical needs of patients, particularly spiritual and religious needs. See the following articles: Christina Puchalski, "Spirituality and Medicine: Curricula in Medical Education," *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 21, no.1 (2006):14-18; Christina Puchalski and D. Larson, "Developing Curricula in Spirituality and Medicine," *Academic Medicine: Journal of the Association of American Medical Colleges* 73, no. 9 (1998): 970-974; and, S. Levin, D. Larson, and C. Puchalski, "Religion and Spirituality in Medicine: Research and Education," *JAMA : The Journal of the American Medical Association* 278, no. 9 (1997): 792-793.

## The Turn Toward Narrative in the Medical Humanities

The concept of narrative patient identity did not spring into existence in the 1990's, yet there is nevertheless a clear before and after when it comes to literature about a person's experience as a patient. Literature scholar Ann Jurecic names the AIDS epidemic in the 1980's as the cultural moment that lead to the burgeoning genre of illness narratives, noting that there were few accounts of the global influenza epidemic of 1918-1919 in comparison. Though more lives were taken by the flu than U.S. soldiers killed in World War I, and there were more deaths as a result of the flu in one year than there were from the Black Death over a century, there was very little written about it compared to the narrative accounts of those affected by the HIV virus.[20] Due to uncertainty about how one contracts the virus, and to the social stigma of AIDS as a "gay plague," activists responded by urging those infected to speak up about their diagnosis, recognizing that talking about AIDS would decrease the power of the taboo, lead to more funding for research, and possibly decrease infection rates. Activists used the catch-phrase "Silence = Death" to urge people to speak about their disease in the hopes of modifying the public perception of the virus. [21]

Clinicians came to be seen in a negative light around the same time as the turn toward narrative in the medical humanities, particularly in autobiographical illness accounts. The concept of a physician as detached, cold, and heartless, even malicious, became a familiar theme in illness narratives, a binary being created between the innocent, vulnerable patient, and the unfeeling, scientist doctor. When medical training transitioned from a healing model to a model based on the sciences, particularly chemistry and biology, the patient's experience moved from

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20. Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012), 1.

21. Ibid., 18-19.

the foreground to the background.[22] Medical education in the U.S developed into a type of "applied biology" as noted by philosopher and clinical ethicist Richard Zaner.[23] Patient narratives reveal that they felt unseen and unheard. Anne Hunsaker Hawkins sees a change in how medical testimonials changed over time. She notes that in the 60's and 70's patients' accounts were not necessarily critical of medical care and the medical system. However, testimonials in the 1980's had more of a decidedly angry, accusatory tone. She uses the language of "medically syntonic" and "medically dystonic" to describe the differences in patient accounts.[24] One could say that by the 1980's patients had decided that they would be the subject of medical treatment, rather than the object of medical treatment.

The proliferation of patient accounts coincides with academic interest in the clinical encounter. Michael Balint, inspired by Carl Rogers dedication to "client-centered" therapy, used the language of "patient-centered" medicine in 1970.[25] The turn toward narrative in the humanities and social sciences, particularly the turn toward narrative in medical anthropology, can be traced to the publication of Clifford Geertz' *Interpretation of Cultures* in 1973,[26] and, more specifically, to the publication of Arthur Kleinman's text *The Illness Narratives: Suffering,*

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22. Following standards set in place following the publication of the Flexner report.

23. Richard Zaner, "Medicine and Dialogue." *The Journal of Medicine and Philosophy* 15, no. 3 (1990): 303. Zaner critiques the medical materialism of "applied biology." The term originated with Donald Seldin in 1973.

24. Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Ind.: Purdue University Press, 1993), 21-22.

25. Cassell, *The Nature of Healing: The Modern Practice of Medicine*, xii.

26. Clifford Geertz, *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973). The concept of a medical culture, involving the experience of both patients and clinicians in the context of health care, took form after the publication of this text.

*Healing, and the Human Condition* in 1988.[27] Other notable figures in the history of narrative

medicine include psychologist Jerome Bruner and his influential work on narrative selfhood.

Bruner is famous for saying, "it is through narrative that we create and recreate selfhood," going

so far as to say that selfhood requires the ability to narrate.[28] Published in 1977, George Engel's

pioneering book on the biopsychosocial model of care also worked to draw attention to the limits

of biological positivism in medicine and the need to approach a patient contextually, taking into

account a patient's individual, psychological and concerns.[29] Cheryl Mattingly's work on narrative

reasoning in occupational therapy, and the work of medical anthropologists Byron Good and

Mary Jo Delvecchio Good, examines the clinical encounter itself, analyzing it as hermeneutical

exchange worthy of critical analysis.[30]

Philosophers Alasdair MacIntyre and Paul Ricouer also contributed to the turn toward

narrative in the humanities. MacIntyre examines the ways narratives are used to as devices for

individuals who need to reconcile their behavior with their ideal of selfhood. MacIntyre uses

the language of "epistemological crises" to describe the conflict between a person's expectations

and reality as they experience it. Narratives are then adapted to fit an individual's modified

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27. Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

28. Jerome S. Bruner, *Making Stories: Law, Literature, Life* (New York: Farrar, Straus, and Giroux, 2002). 85-86.

29. George Engel, "The Need for a New Medical Model: A Challenge for Biomedicine," *Science* 196, no. 4286 (1977): 129.

30. See Cheryl Mattingly's *Healing Dramas and Clinical Plots: The Narrative Structure of Experience* (Cambridge, UK; New York, NY, USA: Cambridge University Press, 1998) as a resource for narrative approaches to clinician-patient relationships in occupational therapy. Byron Good and Mary Jo Delvecchio Good investigate the general practice of medicine from an anthropological perspective.

worldview.[31] Both MacIntyre and Ricoeur see the self as a narrative self that engages in both

reflection on one's past self and projection about one's future self. Humans historicize their lives

and then plot their lives intentionally, working toward chosen or possible life goals—Ricoeur

uses the language of the kingdom of the "as if" to describe the realm of the possible.[32] Ricoeur's

words on emplotment, drawn from Aristotle's understanding of *mythos*, are relevant for clinicians

because clinicians are encountering patients whose lives have been disrupted by illness. Patients

are engaged in the operative process that Ricoeur lifts up, that of negotiating discordant elements

of their lives (breakdown of the external self, which cannot be neatly separated from the internal

self, via illness or accident) into their narrative. They can experience the loss of possibilities for

one's future self, and the anticipated loss of time.[33]

The turn toward narrative in the medical humanities coincides with the development of

formal bioethics and the focus on agency and autonomy in Beauchamp and Childress' principlist

model of medical ethics.[34] Similarly, agency and autonomy, and their limits, are common themes

in illness narratives, along with the persistent grievance that one's personhood is being neglected

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31. Alasdair MacIntyre, "Epistemological Crises, Dramatic Narrative, and the Philosophy of Science," *The Monist* 60, no. 4 (October 1977): 453–472; reprinted in Alasdair MacIntyre, *The Tasks of Philosophy*, Cambridge University Press, 2006. pp. 3-23.

32. Paul Ricoeur, *Time and Narrative* (Chicago: University of Chicago Press, 1984). Vol. 3.

33. Speaking to the loss of one's future self and the loss of one's potentiality, David Hall links to Ricoeur's idem/ipse view of the structure of the self. Hall writes: "Human existence is lived as possibility. Another way of putting this is to say that the being of the self resided in both actuality and potentiality. This then is the significance of Ricoeur's designation of the identity of the agent in terms of both sameness and selfhood. By relating these terms thought the concepts of character and self-constancy, he wove actuality and potentiality into the being of the self." In *Ricoeur and the Poetic Imperative: The Creative Tension Between Love and Justice* (New York: SUNY Press, 2007), 61-62.

34. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, 1979).

in medical care. With regard to bioethics, details about the inhumane treatment of medical research subjects cast a spotlight on the objectification and dehumanization of patients, leading to the formal recognition of medical ethics and patient rights in the Belmont Report, written in 1978.[35] Figures such as Peter Buxtun, whistleblower on the Tuskegee syphilis experiment, called attention to how those in need of medical care were surreptitiously being used to further medical research rather than receiving medical treatment.[36] Even the title of Paul Ramsey's classic text *Patient as Person*, captures the sense that the patient was being objectified.[37] Though studies such as the Tuskegee syphilis experiment, done on unknowing individuals who were withheld curative treatment, indeed reveal some physicians to have dubious motives in their interactions with patients, a cartoonish image of physician as villain came to have a life of its own in illness narratives. Storylines portraying the doctor as an unscrupulous villain and the patient as virtuous hero became common.[38]

Patients were not the only ones dissatisfied with the biological reductionism of medical

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35. "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of research," written in 1978, established guidelines for research on human subjects, laying the groundwork for regulations established by the United States Department of Health and Human Services and the establishment of Institutional Review Boards to judge the ethicality of research on human subjects. For the original Belmont Report see: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Department of Health, Education and Welfare. September 30, 1978. The Belmont Report. Washington, DC: United States Government Printing Office.

36. Susan Reverby, *Examining Tuskegee: The Infamous Syphilis Study and its Legacy* (Chapel Hill: University of North Carolina Press, 2009), 76.

37. Paul Ramsey, *The Patient as Person: Explorations in Medical Ethics* (New Haven: Yale University Press, 1970). This ethics text was published prior to the turn to narrative in medical anthropology.

38. B. Sharf and M. Vanderford, "Illness narratives and the social construction of reality," in Handbook of Health Communication, ed. T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Mahwah, NJ: Lawrence Erlbaum, 2003), 9-34.

care. Clinicians such as Eric Cassell, Edward Pellegrino, Arthur Frank and Rita Charon also expressed displeasure with the impersonal biomedical model. Rather than taking a positivist approach to medicine, these physicians highlight the value of care and healing in addition to the value of cure and treatment of disease. Dr. Cassell focuses on healing as the central concern of medicine, but he notes that even well meaning clinicians who want to be patient centered, do not know what this means or how to do it. The goal of care is ultimately the well-being of the patient. Yet well-being cannot be reduced to mere QOL (Quality of Life) measures.[39] For Cassell, well-being involves being able to live your authentic life rather than being only disease-free. He writes "well-being is related to feelings of being oneself (with oneself and in relation to others), being able to live life as desired, and feeling able to accomplish what is considered important"[40] While such care is commendable, the question of whether or not it is appropriate to expect physicians to assist us in pursuing our good life remains. For Cassell, the answer is plain: The doctor's role is humanistic and involves both cure of disease as well as the relief of suffering. For Charon, literature is the medium for developing empathy and awareness of the interiority of patients for clinicians, leading to the kind of care Cassell promotes.

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39. The original "Quality of Life Scale" was a measure created by psychologist John Flanagan in the 1970's for the purpose of identifying levels of physical, personal, relational, and social well-being. Similar quality of life measures are used to manage care for those who are terminal or live with chronic illness, including chronic mental illness. For early uses of the term, see the following: John Flanagan, "Measure of Quality of Life: Current State of the Art," *Archives of Physical and Medical Rehabilitation* 63 (1982): 56-59, and Kenneth Charles Calman, "Quality of Life in Cancer Patients--An Hypothesis," *Journal of Medical Ethics* 10.3 (1984): 124-127. For how the model has changed over time, see: Peter Fayers and David Machin, *Quality of Life: The Assessment, Analysis and Interpretation of Patient-Reported Outcomes*. (John Wiley & Sons, 2013). For how the measure is used for those with dementia, see: Rebecca Ready, and Brian R Ott, "Quality of Life Measures for Dementia, "*Health and Quality of Life Outcomes* 1 (2003).

40. Cassell, *The Nature of Healing: The Modern Practice of Medicine*, xiv.

## Narrative Medicine and the Patient: Self-Referential Practices

For psychologist Jerome Bruner, humans are narratival beings that tell stories to develop and sustain a sense of self. In his text *Making Stories: Law, Literature, Life*, Bruner speaks to the activity of "self-making" as a narrative process.[41] Bruner weaves together stories from literature, including religious literature, to speak to how selves are formed and reformed over time. Drawing on the research of psychologist Ulrich Neisser, Bruner names the following features of selfhood that can relate to life-review. Selfhood is "teleological and agentive," and the process relies on "selective remembering to adjust the past to the demands of the present and the anticipated future."[42] He notes that the self has a continuous narrative arc that extends over time, but also that selves change. A medical diagnosis, particularly an unexpected terminal diagnosis, can disrupt one's understanding of self, leading to personal crisis.[43]

To Bruner there are two modes of understanding narrative: narrative as paradigmatic (descriptive) and narrative as normative. The first mode reflects how things are; the second, how things could or should be.[44] The paradigmatic world is a world of concreteness and certainty. The normative world is a world of ambiguity and possibility. He speaks of the "dialectic of the established and the possible"—stories from the past and stories of the perhaps.[45] Speaking about the value of illness narratives he says, "tales from life—autobiography, self-referent narrative generally ('self-making')—have as their purpose to keep the two manageably together, past

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41.  Bruner, *Making Stories: Law, Literature, Life*.

42.  Ibid., 70-71.

43.  Bruner, *Making Stories: Law, Literature, Life*, 5.

44.  Ibid., 101.

45.  Ibid., 13.

and possible, in an endless dialectic"[46] Who was I? Who am I? Who do I want to be? These are

questions one can ask oneself when doing a personal account of one's life, and, in addition to

being connected to an understanding of time, as Bruner notes when he speaks about the dialectic,

they are also fundamentally ethics questions. In the next chapter, I speak to how life-review in

hospice can be interpreted as a form of ethical self-analysis.

Bruner, who sees narrativity as fundamental to selfhood, identifies those who are

clinically unable to fully engage in narrative self-making, a condition called "dsynarrativia," which

particularly affects those who have Korsakov's syndrome or Alzheimer's disease.[47] Individuals

afflicted with Korsakov's syndrome are unable to recollect past experiences, and they are

unable to read affect in others. They are unable to taking into account other's experiences or

to imaginatively inhabit the world of a separate person. As Bruner notes, those who have this

syndrome lack both a sense of self as well as a sense of other selves. To Bruner this points to

the deeply relational nature of the narrative self. If you cannot share who you are with another

person, or if you cannot connect with the very real, personal, inner world of someone separate

from you, your selfhood is diminished. Dysnarrativia is "deadly for selfhood" according to

Bruner; he continues, "The construction of selfhood, it seems, cannot proceed without a capacity

to narrate."[48] He says, in essence, without the ability to narrate, there is no self.

Galen Strawson in "Against Narrativity," strenuously disagrees with Bruner's claim that

selfhood requires narrativity. He notes that not all people engage in narrative thinking, making

a distinction between those who live diachronically, with a plotted life, and those who live

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46. Ibid.,14.

47. Ibid., 86.

48. Ibid., 86.

episodically, a more in-the moment type of existence.[49] He states that those who believe that

everyone functions narrativity are engaging in an individualistic fallacy, maintaining that how

they experience the world is how all people experience the world. Not so, says Strawson. Edging

on calling them narcissistic, Strawson describes narrative theorists as reductive, believing they

do not take into account the fullness of human experience. Strawson maintains that narrativity

emerges in two ways: descriptive, the "psychological Narrative thesis," and the normative, the

"ethical Narrative thesis" (capitalization his).[50]

Agreeing with Strawson, James Phelan uses the term "narrative imperialism" to critique

the assumption that narrativity constitutes the central feature of selfhood for all people.[51] The

view that narrativity is the hallmark of what it means to be human is directly named by Oliver

Sacks when he says that one's narrative is one's very self.[52] Strawson retorts, does this mean that

persons who do not function narratively are less of a self, less human? He says no. What Strawson

argues against is the claim that all humans are narrative beings that understand time in uniform

fashion. When it comes to the givenness of reflexivity, Strawson again protests, looking to his own

experience of life as an example:

> "I have a perfectly good grasp of myself as having a certain personality, but I am
> completely uninterested in the answer to the question, 'What has [Galen Strawson] made
> of his life?', or 'What have I made of my life?'. I'm living it, and this sort of thinking has no
> part of it."[53]

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49.  Galen Strawson, "Against Narrativity," *Ratio* 17, no. 4 (2004a): 428.

50.  Strawson, "Against Narrativity," 428.

51.  James Phelan, "Editor's Column: Who's here? Thoughts on Narrative Identity and Narrative Imperialism," *Narrative* 13, no. 3 (2005): 205.

52.  Strawson, "Against Narrativity," 435.

53.  Ibid., 438.

Strawson explains that he has more of a "present moment" awareness than a detached evaluation of himself as his self has existed over time. He concludes that one does not have to have a narrative, linear, third person sense of self to have an identity, and he urges those who celebrate narrativity to realize that their anthropology applies to some people, but not to all people. Strawson's work is useful for narrative medicine because he creates space for those who have a cognitive deficit or verbal deficit, those who would fall outside of narrative understandings of self according to Bruner's categories. I address the experience of such individuals in Chapter Three.

## Modalities of Narrative-Based Patient Practices

### Autobiographical Illness Narratives

Autobiographical illness narratives are first person accounts of an individual's experience with acute or chronic illness, including mental illness. They often present a critique of contemporary health care models by describing their experience as patients as dehumanizing. Autobiographical illness accounts provide a counternarrative to what is perceived to be the dominating voice of clinicians.[54] Some patients turn to online methods of sharing their personal experiences with health care providers.[55] I look to the published account of poet Audre Lorde as an example of an autobiographical illness narrative.

Audre Lorde's *Cancer Journals* exemplify the genre of autobiography in narrative medicine, with a distinct turn toward narrative medical ethics or how medicine *should* be

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54. Johanna Shapiro, *Current Controversy: Illness Narratives: Reliability, Authenticity and the Empathic Witness, Medical Humanities* 37, no. 2 (2011): 68-72.

55. P. Ressler, Y. Bradshaw, L. Gualtieri, and K. Chui, "Communicating the Experience of Chronic Pain and Illness Through Blogging," *J Med Internet Res* 14, no. 5 (2012):e143; C. Heilferty, "Toward a Theory of Online Communication in Illness: Concept Analysis of Illness Blogs," *Journal of Advanced Nursing* 65 (2009): 1539–1547.

performed.[56] Her work speaks to the phenomenological experience of having a mastectomy—

she began the journals six months after her surgery—and the social pressure to conform to a

normative vision of what it means to be a woman. Being pressured to wear a prosthetic breast

a "puff of lamb's wool" agitates her, as does how the treatment of cancer fits into the medical

market. The text is a mélange of journaling interspersed with self-analysis and social anaylsis; she

also uses poetry. She journals about fear, about anger, about support, sense of grief, of loss of self.

One of her primary interests is in what separates us from other people. She examines how pain

functions as a experience which creates distance, and she particularly examines the pressure to

wear a breast prosthesis. She chooses not to and, by making this choice, she feels set apart from

others who have had mastectomies.

For Lorde, narration functions as a form of self-healing with the potential to provide

healing for others through speaking openly about her experience, in a manner devoid of

sentimentality. She emphasizes that cancer is an experience that is not "unique"—it is shared by

many, but each person has a particular voice. The book testifies to her struggle of experiencing a

change in one's body and in one's relationships. Friends avoided her or treated her with distance.[57]

Some fawned over her in a way that felt inauthentic. One could say that at a time in which she

felt alienated and alone, the very act of self-narration and, more importantly, the act of sharing

her journals, was a way for her to create a sense of community to be present for her in a time of

loneliness.

## Ethnography

Primarily drawing on methods in the social sciences, ethnography attempts to describe the

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56. Audre Lorde, *The Cancer Journals* (San Francisco: Aunt Lute Books, 2006).

57. Lorde, *Cancer Journals*, 49.

patient's experience through in depth analysis of the patient's context, often using recorded

interviews as sources. The work of ethnographer Cheryl Mattingly is particularly relevant to

this dissertation because she looks at clinical encounters as having a narrative arc similar to

that of a drama. Drawing on Ricoeur's hermeneutics and applying his framework of thought to

occupational therapy, Mattingly examines what is implicit in the clinical encounter[58] She notes

that patients receiving occupational therapy engage in emplotment: Ricoeur's term for how

individuals maintain a narrative arc in their lives.[59] Mattingly describes how patients create a

narrative timeline to their lives, organizing the events that occur in their lives into a unified chain

of events. Ricoeur sees this activity as one that is teleological in nature; the activities serving

a type of end goal. Mattingly links Ricoeur's ideas to how treatment goals are understood in

therapy, noting that goals have more to do with intentions for a future self. Because my interests

are in hospice, I am less interested in future goals and more interested in how patients turn to

their past, reflecting not on how they should live into the future, but on how they did live. Their

telos is no longer on an abstract concept but a concrete reality that they can see on the horizon,

near or far. With a terminal prognosis, a patient turns to a narrative, ethical analysis of their lives.

The question changes from "What is my good life?" to "Did I live well?" This is the deep value of

narrative method for end of life patients. I will speak more to this in Chapter two on life review in

hospice care.

<center>Case Studies</center>

Often dilemma-based, case studies are short descriptions that present the facts of cases and

have open-ended outcomes. Case studies are used to foster dialogue among clinicians, future

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58. Cheryl Mattingly, *Clinical Reasoning: Forms of Inquiry in Therapeutic Practice*, 246.

59. Ricoeur, *Time and Narrative*, vol. 1.

clinicians, and ethicists, to elicit responses to questions of ethics or questions of care. In many ways, case studies fall within the literature of fiction because, similar to thought experiments in philosophy, they are written accounts that radicalize or magnify situations that may not be likely. The scholarship of Tod Chambers addresses the content and function of literature and medical case studies. He is not attached to any one particular genre in his approach to narrative medicine, drawing on "classic" texts in the western cannon (he names James Joyce and F. Scott Fitzgerald) as well as popular fiction and film. He takes a ground-level approach to narrative medical ethics, believe that narrativity is something that all people engage in, not just literature scholars.[60] He believes there is value is using different sources and he has not hitched himself to one particular form, though he does say that he identifies more with structuralist approaches to narrative over poststructuralist approaches. Chambers is interested in both ethical reflection and in practical action, saying "ethical analysis out to concentrate as much on how one sees moral dilemmas as deciding how one should act in response to them."[61] Chambers also notes that there are different kinds of ethicists involved in doing the work of interpretation and in his analysis of case studies as literature he seeks to identify the implied author/ethicist/narrator of the case studies. [62] Rather than seeing case studies as come from a "view from nowhere" Chambers identifies the various authors and moves to discern the authors' intentions and intended audience in their composition of the case studies. He takes the veil away from the narrative data and shows that there is in fact an author behind them, even if case studies do not have an author listed. Chambers strives to

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60. Tod Chambers, *The Fiction of Bioethics: Cases as Literary Texts* (New York: Routledge, 1999), xiv, xv.

61. Ibid., 21.

62. Ibid., 60.

break down the binary between those that believe "real" patient accounts are more valuable than fictional ones. When it comes to on the ground care, he feels as though this binary distinction does not really matter. He is interested in how case studies function, not in their validity or epistemic value.[63]

<div align="center">Fiction</div>

Fiction is imaginative literature in the form of prose such as novels and short stories. The value of fiction is that it allows the reader to consider what "might be." Because fictionalized accounts are constructions, there is distance between the world of the reader and the world of the text. Regarding fiction, the great value of literary and dramatic works for clinical and ethical reflection is that characters function symbolically and can be read into by the reader as a participant creating the story. In comparison, case studies and certainly transcripts or interpretations of interviews are one-dimensional. It is much harder to project one's story onto another actual person's life or a thin case study—they do not function symbolically.

<div align="center">**Why Turn to Literature, not Patient Accounts?**</div>

In this dissertation, I examine literature, specifically the dramatic works of Samuel Beckett, as a source for developing clinical practice and pedagogy, rather than ethnographic accounts or illness narratives. Illness narratives can be deeply valuable for patients engaging in the process of critical reflection on their care and on what their life means. However, it is precisely the concreteness of illness narratives that ultimately limits their function for others. Because autobiographical illness narratives involve an individual person rather than a character, it is more challenging for a reader to project his or her experience onto that of the protagonist. Autobiographical illness narratives are less open to interpretation because they are not intended to function symbolically.

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63. Ibid., 176.

One can have an empathic response reading illness narratives, but there is not as much flexibility of interpretation on the part of the reader. Fiction, on the other hand, allows for multiple interpretations.

When literature is used I believe it is best used to point to ambiguity, to what is disruptive, strange, and unfair. Kathryn Montgomery in *How Doctors Think* speaks to how clinicians are trained to present themselves in a posture of certainty.[64] Patients can approach physicians with a desire for certainty, so the clinician, in ways, is meeting the needs of the patient. However, in many situations there is no certainty; there is only ambiguity, conflicting information, and misplaced hopes. Eric Cassell also adds that, in addition to physicians, medical technology is also seen as providing certainty.[65] In a culture that privileges autonomy and holds people responsible for their health and sickness, literature is particularly valuable for lifting up those situations where no person is at fault, no agent can be pinpointed, there is no one to blame. Cassell speaks to the recognition that in the history of medicine, "the belief has grown that individuals are responsible for maintaining their own health."[66] One sees this value system made manifest in the blistering judgment of people who are obese or those who smoke. In the debate about Obamacare there was talk that those who had lung cancer should not be covered because they "deserve to die" they "brought the disease upon themselves." This judgment is the dark side of virtue ethics in medicine and the dark side of privileging agency.

Literature can highlight and radicalize situations of lived experience. Because the content

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64. Kathryn Montgomery, *How Doctors Think: Clinical Judgment and the Practice of Medicine* (Oxford; New York: Oxford University Press, 2006) 199-200.

65. Cassell, *The Nature of Suffering and the Goals of Medicine*, 22.

66. Ibid.

of literature is inexhaustible, it offers limitless interpretation. Nonfiction or autobiographical narratives are valuable for offering information, but the persons in these narratives are not characters and cannot function symbolically. Unlike with characters, to read oneself into an autobiographical narrative risks commodifying or appropriating someone's story. An autobiographical account can be therapeutic for the patient and enlightening for the public, but a character offers much more in terms of interpretation. There is no "right" or "wrong" when you interpret a character; there can be when you interpret a patient. Because fictionalized accounts are constructions, there is distance between the world of the reader and the world of the text.

Some forms of narrative are both cognitive and noncognitive. For instance, in the Christian sacred texts, the Lord's Prayer and the twenty third Psalm serve as examples of material that contain, for some patients, words that are both known and unknown at the same time. The rhythm of these forms of biblical poetry can be deeply familiar, though the words may hold no coherent meaning for patients. The same can be true for lullabies, spirituals, and hymns—the value comes from the music and cadence of the language; the music may be deeply familiar and offer comfort though the words connote no meaning intellectually.

Similarly, some authors, such as absurdist playwright Samuel Beckett, write in a jarring, almost incoherent way, with bursts of random words in the text creating holes in the reader's understanding. Applying a narrative approach to medical education, reading Beckett's work can offer opportunities for clinicians to feel the confusion and discomfort that comes from straining to understand language that is nonsensical. For clinicians working with patients who have a cognitive or verbal deficit, the ability to be comfortable with uncertainty is particularly valuable. I address the value of his work in chapter four, examining two of his one-act plays as they relate to patient care. To answer the question, "Why literature?" the words of Jerome Bruner provide

insight: it is the "relative indeterminacy of a text" that allows for a "spectrum of actualizations."[67]

Aligning with Bruner, Anne Hunsaker Hawkins values fictional narrative accounts because she believe canonical literature provides paradigms for human experience.[68] One can then read oneself into the story, rather than take an empiricist approach to illness narratives as factual data.

### Clinicians and the Practice of Narrative Medicine

Narrative Medicine is an umbrella term that involves the study of different modalities of written texts, including dramatic works, with the overarching goal of understanding patients and their experience of the clinical encounter. According to Rita Charon, physician and literature scholar who coined the term, narrative medicine "provides health care professionals with practical wisdom in comprehending what patients endure in illness and what they themselves undergo in the care of the sick."[69] The underlying premise is that the study of literature will improve one's ability to provide care by developing one's listening skills and skills of clinical attention. Through reading literature one can become a better listener, a more empathic clinician, giving attention to understanding, reciprocity, and connection in the clinical encounter. With special attention given to the work of Henry James, who calls the act of listening a practice in being an "empty cup of attention," Charon maintains that learning to be a close reader of texts can be a way to develop one's clinical skills. Because reading fiction involves considering events from multiple perspectives, Charon maintains that developing narrative competence can in fact cultivate a

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67. Jerome S. Bruner, *Actual Minds, Possible Worlds* (Cambridge, Mass.: Harvard University Press, 1986), 25.

68. Hawkins, *Reconstructing Illness: Studies in Pathography*.

69. Charon, *Narrative Medicine*, vii.

person's sense of empathy.[70] As Tod Chambers notes in *The Fiction of Bioethics* there is no binary between theory and practice in narrative medicine.[71] For clinicians, practice is informed by theory, and theory is applied to care and models of education. The practice according to Charon is the "reading, writing, telling, and receiving of stories."[72] The conceptual framework behind this practice relies on an understanding of the person as a narrative being, an understanding of selfhood that I examine in this chapter. I use narrative medicine and narrative method interchangeably when talking about the practice of using literature as a resource for developing the clinical encounter, both for clinicians and patients.

For patients, narrative medicine can offer a vehicle to reflect on and share one's experience with illness and medical treatment. The rise of autobiographical patient narratives in the United States occurred largely in response to how patients were viewed and treated by their medical caregivers. Some patients felt neglected and unheard, and they believe this experience had an effect on their well-being. After examining the history of medical pedagogy in the U.S., one can assert that physicians were providing, and continue to provide, what they were trained to believe was medically appropriate clinical care at the time. Today, however, views on what promotes patient care have expanded to include an approach to patient identity that values more than just the body and a disease-model of medicine.

<div align="center">Clinical Pedagogy in Narrative Medicine</div>

At root, narrative methods in medicine are based on the following claims: one, that empathic

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70.  Teresa Thompson, "The Applicability of Narrative Ethics," *Journal of Applied Communication Research* 37, no. 2. (May 2009): 190.

71.  Chambers, *The Fiction of Bioethics*.

72.  Charon, *Narrative Medicine*, *vii*.

presence can be cultivated and, two, that the imagination is a valid source of moral understanding and not one to be discarded as subjective, relative and nonrational, as Mark Johnson claims so well in his text defending the place of the moral imagination in ethics.[73] Johnson and Ricoeur share the view that one can dwell within a story and approach literature as a source for ethical reflection. Similarly, literature can be used as a source for clinical reflection. As Johnson notes, "Narrative is not just an explanatory device, but it is actually constitutive of the way we experience things. No moral theory can be adequate if it does not take into account the narrative character of our experience."[74] Using narrative method in the clinical encounter calls for three primary steps: recognizing the human being as a narrative being, learning to be a close reader (of texts and human communication), and learning to invite the patient's story and engage in the work of interpretation along with the patient.

The goals of narrative method include cultivating the ability to demonstrate empathic presence with patients and deepening one's ability to listen to patients such that one can listen for what is being said beneath the words and to notice what remains unsaid. Ricoeur's words on the pedagogical function of narrative are easily applied to the clinical context. He looks to Aristotle's *Poetics*, noting that Aristotle "did not hesitate to say that every well-told story teaches something; even more, he said that stories reveal universal aspects of the human condition."[75] Though for Aristotle the form of knowledge offered through *poesis* is considered as a lesser form

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73. Mark Johnson, *Moral Imagination: Implications of Cognitive Science for Ethics* (Chicago: University of Chicago Press, 1993). Johnson, following Martha Nussbaum, looks to how literature can be a vehicle for moral reflection.

74. Johnson, *Moral Imagination*, 11.

75. Ricoeur "Life: A Story in Search of a Narrator," 123.

of knowledge than that provided by logic, it is nevertheless knowledge, as Ricoeur emphasizes.[76]

Ricoeur describes narrative intelligence as a type of "phronetic intelligence" distinct from

theoretical intelligence, making it particularly useful for clinicians doing the on-the-ground work

of patient care[77]

Using narrative methods in clinical education, through the use of literature or learning

to view the clinician/patient counter as one that is narratively-based, can develop empathic

awareness for clinicians, specifically the ability to recognize the separate, inner world of the

patient. Scholars in narrative medicine celebrate the work of novelist Henry James because he was

able to describe with nuance the distinct, though ambiguous and often inwardly held, points of

view of his characters.[78] His work highlights the variety of interpretations that can exist within

characters or readers. He describes the ways interpretations can vary in his preface to *Portrait of a*

*Lady*:

> The house of fiction has in short not one window, but a million . . . . [A]t each of them
> stands a figure with a pair of eyes, or at least with a field-glass, . . . insuring to the person
> making use of it an impression distinct from every other. He and his neighbors are
> watching the same show, but one seeing more where the other sees less, one seeing black
> where the other sees white, one seeing big where the other sees small, one seeing coarse
> where the other sees fine.[79]

A narrative pedagogy can point to the existence of, as well as the *limits* to subjectivity

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76.  Hille Haker in "Narrative Ethics in Health Care Chaplaincy" notes that Ricoeur is a bridge between Aristotelian poesis, in which stories are intended to represent reality, and postmodern and poststructural hermeneutics that focus on the limits of constructed stories. In *Medical Ethics in Health Care Chaplaincy: Essays* ed. Walter Moczynski, Hille Haker, and Katrin Bentele (Berlin: Lit, 2009), 160-161.

77.  Ricoeur, "Life: A Story in Search of a Narrator," 124.

78.  Rita Charon, "A Momentary Watcher, or the Imperiled Reader of 'A Round of Visits.'" *Henry James Review* 29 (2008): 275-86.

79.  Henry James, *The Portrait of a Lady 1 3. The Novels and Tales of Henry James* (New York: Kelley, 1970), *x-xi*. Quoted by Suzanne Poirier in "Voice in the Medical Narrative" in *Stories Matter*, 48-58.

for the physician, recognizing that one's diagnosis might be one possible interpretation among

others can be an awareness cultivated through the use of narrative-based clinical training. In

*The Fragility of Goodness*, Martha Nussbaum speaks to this possibility when she looks to using

literature as a source for moral understanding. Literature can teach the reader/clinician to

consider ethical quandaries or concerns from different perspectives, moving beyond one's own

limited understanding. In her interpretation of *Antigone*, Nussbaum looks to what the chorus

reminds us when they, considering the ethical crisis that Antigone and Creon are involved in,

say, "Looking at this strange portent, I think on both sides." For Nussbaum, a perspective that can

hold fragments within it, that can take on and embody different viewpoints, holds value when it

comes to deliberating well:

> The image of learning expressed in this style, like the picture of reading required by it,
> stresses responsiveness and an attention to complexity; it discourages the search for the
> simple and, above all, for the reductive. It suggests to us that the world of practical choice,
> like the text, is articulated but never exhausted by reading; that reading must reflect and
> not obscure this fact that correct choice (or: good interpretation) is, first and foremost,
> a matter of keenness and flexibility of perception, rather than of conformity to a set of
> simplifying principles.[80]

Because clinicians will be interpreting a patient's story from a medical perspective with the

patient, the clinician's ability to acknowledge the patient's experience and interpretation as valid is

one that can be developed using narrative methods in clinical education.

Wayne Booth offers suggestions for how medical practitioners can incorporate narrative

methods into the care they provide. Booth recommends that practitioners, in addition to their

diagnostic work (or as part of their diagnostic work), *attend* to the stories their patients tell and

that practitioners should be aware of how they are perceived by patients. He also encourages

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80.  Martha C. Nussbaum, *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy* (Cambridge: Cambridge University Press, 2001), 69.

practitioners to look to literature as a way of flexing their empathic awareness and as a means

by which one can increase self-awareness as a care-provider.[81] Julia Connelly speaks to how a

clinician can gain narrative knowledge:

> The physician must also struggle for a deep awareness and understanding of herself, both her personality and her true self. Here physicians need the capacity for being present with the patient, an understanding of their own personal intentions, beliefs, and values and the ability to set them aside in order to focus on the patient, the commitment to care for the patient as a person, and an acceptance of feelings as an integral aspect of patient care . . . To engage in practice designed to enhance self-knowledge is a commitment to improve health care. Without narrative, deep human contact is very difficult, especially in the setting of present-day medical practice.[82]

Charon uses the language of narrative competence to describe the ability to hear,

interpret and act on the story of another, and she maintains that this competence can be taught

to clinicians.[83] She views narrative competence as the ability to "recognize, absorb, interpret, and

be moved by the stories of illness."[84] Use of narrative method provides a way for the clinician to

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81. Wayne Booth, "The Ethics of Medicine," in *Stories Matter*, 18-19. Booth presents the play *W;t* by Margaret Edson, and Tolstoy's "The Death of Ivan Ilych," as texts that show the ambiguities of both patients' and clinicians' self-understanding. Regarding how to choose what literature to look to for when navigating bioethical issues, Booth recommends texts that address moral issues for both patients and clinicians rather than just advocating the stance of one side or the other.

82. Julia E. Connelly, "In the Absence of Narrative" in *Stories Matter*, 145. Connelly also speaks to the ability to hear the story of a person who has a cognitive deficit, particularly the memory lapses experienced by Alzheimer's patients. She urges the clinician to learn how to listen to what a person is attempting to communicate with their bodies, their emotional responses, and so forth without immediately moving one's attention to the patient's verbal family member, 141-142.

83. Rita Charon, "Narrative Medicine: a Model for Empathy, Reflection, Profession, and Trust," *Journal of the American Medical Association* 286, no. 15 (2001): 1897-902.

84. Rita Charon, "Narrative Medicine: Attention, Representation, Affiliation," *Narrative* 13, no. 3 (2005): 262.

practice the imaginative, empathic turn toward another through actively receptive listening[85] By

being heard a patient can feel recognized by the clinician. Hilde Lindemann Nelson makes a

similar claim about the power of recognition that can occur through narrative, suggesting that

many individuals, particularly women, feel invisible because their lives are named for them by

those speaking on their behalf.[86] By giving an individual patient an opportunity to offer his or her

own narrative, the clinician creates a space for recognition of the patient's individual value.

Ricoeur's understanding of the tasks involved in the hermeneutical approach to literature

does not have to be an approach limited to written documents. His recommendations for

engaging with literature can be applied to those who are engaging with patients. He says, "A

literary hermeneutics worth of the name must assume a threefold task . . . of understanding . . .

explanation . . . and application. In contrast to a superficial view, reading must not be confined to

the field of application even if this field does reveal the end of the hermeneutical process; instead

reading must pass through all three stages."[87] Similarly, a physician engages in a hermeneutical

process of understanding, explanation, and application when the physician attempts to interpret

the patient's medical concerns, explain what is happening medically, and applying a plan of care.

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85. Maintaining the value of the principlist framework for medical ethics, Charon sees narrative method not as an independent method, but as a means to supplement the encounter between clinician and patient. Rita Charon, "Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist," in *A Matter of Principles?: Ferment in U.S. Bioethics*, ed. Edwin DuBose, Ronald P. Hamel, and Laurence J. O'Connell (Valley Forge, Pa: Trinity Press International, 1994), 260-83.

86. Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Ithaca: Cornell University Press, 2001).

87. Paul Ricoeur, *Time and Narrative*, vol. 3. Quoted by Mario J. Valdes in his introduction to *A Ricoeur Reader: Reflection and Imagination* (Toronto: University of Toronto Press, 1991), 21.

The dynamic is one based on interpretation of the patient's needs and what will be therapeutic for the patient.[88]

Though a clinician can make the empathic step to understanding the world of his or her patient, this does not mean that the clinician has full access or can know with certainty what the patient experiences. Just as literature and sacred texts cannot be fully comprehended, offering boundless material for reflection and interpretation, the inner world of others cannot be fully known. Naming the plurality of interpretation that exists in literature can be a way of understanding the diversity of human experience that exists when one encounters another person. Ricoeur's concept of narrative identity and the process of emplotment can serve as a resource for examining models of patient identity in narrative medicine. A clinician's awareness of both the limits of one's own understanding and the existence of the separate world of the other can be developed through the use of literature in clinical education and through learning to view one's relationship with a patient as an interpretive encounter.

<div align="center">Narrative Methods in Health Care Chaplaincy</div>

Training for chaplains similarly incorporates narrative models of education to develop students' skills in empathic listening and understanding a patient's experience. Developed in 1925 Clinical Pastoral Education (CPE) is the process students engage in to become health care chaplains.[89] The training involves working directly with patients and reflecting on the clinical encounter in an educational setting. Because religious and spiritual dimensions of patient experience are

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88. Kathryn Montgomery Hunter in *Doctor's Stories: The Narrative Structure of Medical knowledge (*Princeton: Princeton University Press, 1991) speaks to clinician/patient relationship as an interpretive activity. See Part I in particular.

89. For a history of health care chaplaincy, see the work of sociologist Wendy Cadge in her 2012 text, *Paging God: Religion in the Halls of Medicine* (Chicago, IL: University of Chicago Press).

difficult to quantify or measure, CPE has not had to conform to the 20th century scientistic

trend in medicine that began. However, there are moves to make religious and spiritual care

more evidence-based to ensure chaplaincy's place in the health care domain.[90] It is unlikely that

training for chaplains will transition to the lab-based approach of medicine because the variables

involved in spiritual care cannot be fully controlled or projected to large populations.[91]

The founder of CPE, Anton Boison, promoted a field-based form of chaplaincy training

in which chaplains interact with patients and then write up a case study that is then reviewed

by other students and colleagues.[92] Rather than just reading and attending lectures, Boison

advocated for an educational model based on encounters with patients, a population he called,

"living human documents." The understanding of patients as living human documents connects

with the idea that clinical engagement can be a source of learning for caregivers, be they medical

caregivers or religious caregivers. Following these clinical encounters, chaplains in training use an

idiosyncratic form of case-study called a "verbatim" in which chaplains write down the dialogue

that occurred between chaplain and patient in script-form and conclude with a theological

and psycho-social analysis of the encounter. The goal is to learn how to improve their care by

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90. See the work of George Fitchett, associate professor and researcher in the Department of Religion, Health and Human Values at Rush University Medical Center in Chicago, IL, particularly "Evidence-Based Chaplaincy Care: Attitudes and Practices in Diverse Healthcare Chaplain Samples," by George Fitchett, Jason A. Nieuwsma, Mark J. Bates, Jeffrey E. Rhodes, and Keith G. Meador in the *Journal Of Health Care Chaplaincy* 20 , no. 4 (2014), and Barbara Pesut, Shane Sinclair, George Fitchett, Madeleine Greig, and Sarah E. Koss, "Health Care Chaplaincy: A Scoping Review of the Evidence 2009–2014," *Journal of Health Care Chaplaincy* 22, no. 2 (2016): 67-84.

91. Jeffrey Bishop addresses this challenge when critiquing spiritual care assessments in his text *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying* (University of Notre Dame Press, 2011).

92. Glenn Asquith, "Anton T. Boisen and the Study of "Living Human Documents,"" *Journal of Presbyterian History (1962-1985)* 60, no. 3 (1982): 244-65.

becoming aware of missteps and learning to hear what goes unsaid with patients. Clinical training takes into account the value of working both at the bedside and with written accounts of patient visits.[93] Medical clinicians devoted to narrative medicine share similar goals with health care chaplains, namely to learn how to listen at a deep level to patients, honing the ability to be able to hear what patients are struggling with so that healing becomes possible.

In addition to honing a chaplain's listening skills, narrative methods of education can train chaplains to consider multiple points of view, a useful ability when meeting with patients who are from other religious traditions than the one identified with by the chaplain. The pedagogical theory behind this approach claims that taking into account the different viewpoints of characters in literature and drama enhances a chaplain's ability to do the same with patients and family members. Additionally, the ability to consider multiple perspectives regarding patient care can inform a chaplain's involvement in family meetings and in decision-making in clinical medical ethics. At this point, narrative medicine addresses the work of medical caregivers, primarily physicians, but there is no reason to limit the use of methods involved in narrative medicine exclusively to medical clinicians, when the goals of care—meeting patients' needs—are shared by those in related disciplines, like chaplaincy and spiritual care.

### Narrative Approaches to Medical Ethics and Clinical Practice

Tod Chambers names two distinct approaches to narrative medical ethics, and, though the two are often conflated, they have different goals and methods.[94] One, developed by Kathryn Montgomery, situates itself as taking a distanced, more observational view of narrative medicine.

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93. Daniel Grossoehme, "Chaplaincy and Narrative Theory, A Response to Fisk's Case Study," *The Journal of Health Care Chaplaincy* 19, no. 3 (2013):99-111.

94. Tod Chambers, "Misreading Montgomery," *Atrium*, 46.

Descriptive in approach, Montgomery's style offers a philosophy of medicine rather than an ethical analysis of how medicine ought to be performed. Rita Charon presents another approach, one based on practice rather than observation. Charon's work, particularly her books *Stories Matter* and *Narrative Medicine*, is a confluence of literary theory, clinical application, medical pedagogy, and medical ethics.[95] [96] Offering an ethical analysis of how medicine could be improved, she calls the clinician to develop "narrative competence." Her interest is in how the clinical encounter can be improved through the use of literature. Specifically, her focus is on the use of literature in the education of clinicians. Charon's work falls into the domain of ethics, particularly virtue ethics, in the sense that she believes increasing narrative training in medicine will develop a clinician's sense of "humility, accountability, [and] empathy."[97] Through reading groups, narrating one's experience with patients, and the use of narrative curriculum in medical students training students learn to be close readers of text.[98] Anne Hudson Jones describes the questions that a narrative curriculum can teach medical students to ask:

> Who is the narrator? Is the narrator reliable? From what perspective or point of view is the story told? What does this perspective leave out? Who are the other potential narrators of this story? What might their perspectives add? How can differences between narrators' stories be reconciled? What do individual readers bring to the story that influences their interpretations? How can differing interpretations be reconciled? If they cannot be reconciled, how should a reader handle such ambiguity? What patterns emerge from the accumulating details, repetitions, images, and metaphors? That is, how does a skilled

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95. Rita Charon and Martha Montello, *Stories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002).

96. Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford Univ. Press, 2008).

97. Charon, *Narrative Medicine*, *vii*. See also Charon's "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *JAMA: The Journal of the American Medical Association* 286, no. 15 (2001): 1897–1902.

98. *Stories Matter*, 161.

reader learn to recognize significant details that cohere in a pattern of meaning that makes sense of the whole? [99]

Assumed in this approach to education is the correlation between attending closely to texts and attending closely to patients. Charon recommends parallel charting for clinicians, though one can argue that this activity is gratuitous and costly in terms of time, taking time away from engaging with patients. [100] A benefit of this approach is that those teaching in medical schools can then see how students are interpreting their patient's behavior, possibly overreaching in their interpretations, and the educator can then "diagnose" concerns having to do with the clinicians training.

According to scholars in the field, one of the benefits of clinical training in narrative method is that it will nurture an empathic response in a clinician. The premise underlying this view is that by learning to understand the world from a fictional character's or narrator's perspective, the clinician will be able to understand the patient's perspective of illness. As Rita Charon says, "to know what patients endure at the hands of illness and therefore to be of clinical help requires that doctors *enter* the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patients' point of view" [101] She is working to mitigate the clinical detachment that can result from scientistic medical training by working with physicians to take into account multiple points of view.

Charon recognizes that narrative competence is a sophisticated skill that requires some

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99.  *Stories Matter*, 160-161.

100.  Rita Charon, *Narrative Medicine–Honoring the Stories of Illness* (New York: Oxford University Press, 2006), 156. In parallel charting, the clinician, in addition to diagnostic charting, records the concerns of the patient in a more reflective, narrative manner. See also, Rita Charon, "Narrative Medicine: Form, Function, and Ethics," *Annals of Internal Medicine* 134, no. 1 (2001): 84.

101.  Ibid., 9.

self-awareness.[102] One has to have the desire to develop one's ability to listen and communicate. In ways, though, this is a reverse catch-22. The desire points to the reality that the clinician already has an awareness of the experience of the other. However, not all individuals have such awareness. "Alexithymia" is the term Howard Spiro gives to clinicians who are out of touch with their own emotions in addition to being detached or unaware of the emotional states of their patients.[103]

In a clinical encounter centered on narrativity, the narrative self manifests through dialogue with a clinician. Charon speaks to the intimacy that can exist in these encounters. Though honorable, some questions about narrative medicine call for consideration. Can a patient be fully known by a clinician? How does the asymmetry of power come into play? In what ways does narrative medicine inflate the role of the clinician and violate of a vulnerable patient's inner sanctum? The limited nature of relationality is also recognized by figures such as Judith Butler and Levinas, using the language of "otherness." Some, Eric Cassell, notably, believe this emphasis on distance, opacity, and otherness is overstated. Cassell believes patients can be known and that physicians can make excuses for their lack of engagement by emphasizing the unknowability of patients.[104]

Charon acknowledges that physicians cannot have the final say when it comes to understanding a patient's narrative—that there is a gap between the clinician and patient and that there is then a need to corroborate their interpretation of patient's experience. She says, "I have come slowly to appreciate that patients should be the curators of what we write about them." Thus

102. Thompson, "The Applicability of Narrative Ethics," 192.

103. Howard Spiro, "Empathy: An Introduction," in *Empathy and the Practice of Medicine*, ed. Howard Spiro, Mary Curnen, Enid Peschel, and Deborah St. James (New Haven: Yale University Press, 1993).

104. Cassell, *The Nature of Suffering: And the Goals of Medicine*, 232

she gives them a copy of her note and asks them to consider what she has written.[105] One can ask, though, is there even a need for empathy in the clinical encounter or is it nice but unnecessary, even intrusive? Some claim that it is ultimately not the role of a physician to provide emotional or metaphysical support and that not all patients are interested in their physician being present in this way. As Ronald Andiman notes in "Midrash and Medicine,"

> Patients have their own expectations of a doctor, and many patients would actually be impatient with an extended process of communication; they value efficiency over breadth or depth, especially if they don't think of their problem as complex. Some patients, because of a heavily defended psyche or because of their value system, merely want to get a brief 'answer'; they get their emotional support elsewhere or perhaps not at all. The point is, one size (of verbal discourse) doesn't fit all.[106]

The important thing to note about narrative medicine is that not all patients are interested in a dialogical encounter with clinicians. If we pull back from seeing the detachment of clinicians as a problem, we can ask whether a meaning-based response is necessary for the clinical encounter. Though the ability to listen and communicate well is a skill and can be, and in many cases is, taught in medical school, empathic presence that has a spiritual, emotional, or meaning-based value, is not what all patients prefer.

Physicians may not be trained or have the time available to listen to patients' narratives and to interpret them beyond the medical, yet there is nevertheless value in narrative training in that it teaches physicians to take into account information that falls outside the narrow domain of biological positivism. As Eric Cassell recognizes, physicians work with more than just medical facts; they also work with meaning and questions of morality. Larry Miller likens the work of

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105.  Charon, *Narrative Medicine: Honoring the Stories of Illness*, 190.

106.  Ronald Andiman, "A Physician's Response to the Midrashic Invitation." William Cutter, *Midrash & Medicine: Healing Body and Soul in the Jewish Interpretive Tradition* (Woodstock, Vt.: Jewish Lights Pub., 2011), 97-104.

medicine to the deductive reasoning of Sherlock Holmes, a type of speculative reasoning that creates a narrative out of disparate, but possibly related, pieces of evidence (source) Though a meaning-based response is ultimately not necessary for the clinical encounter to be successful (for diagnosis and treatment to occur), this dynamic can still be what the patient desires. Like attentive dialogue, touch can also be considered superfluous to the medical encounter, but it is nevertheless significant for patients and calls for taking into account.[107]

One of the values of using narrativity in clinical reasoning is there is recognition that a patient's life existed before the clinical encounter or medical event occurred and that it will continue to affect the patient's life afterward. A narrative understanding of care sees the medical moment as one moment in a patient's life. The concept of narrativity is particularly valuable for clinicians because it includes takes into account how selfhood is shaped in relation to time.[108] For some, time can be understood chronologically in a linear fashion, but others recognize that we move back and forth in time in terms of how we construct our understanding of self. Ricoeur, for instance, uses the language of mimesis—a process involving prefiguration, configuration, and refiguration—to build on and nuance the Aristotelian notion that we are agents in our own lives.[109] Time is understood in a linear way, but it is also understood as at the same time containing past, present, and future constructions of the self. That is, one can think of whom one *desires* to be. For

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107.  N. Guéguen, S. Meineri, and V. Charles-Sire, "Improving Medication Adherence by using Practitioner Nonverbal Techniques: A Field Experiment on the Effect of Touch." *Journal of Behavioral Medicine* 33, no. 6 (2010), 466.

108.  Michael White and David Epston, *Narrative Means to Therapeutic Ends* (New York: Norton, 1990), 3.

109.  Ricoeur, *Time and Narrative*, Volume 3.

Ricoeur, there is both the fixed, concrete self, located in linear time, as well as the fluid, imagined self, that exists, in ways, as a fiction.

Some scholars in narrative medicine understand time in terms of phases of life. Arthur Frank notes that illness narratives can be interpreted in terms of restitution, quest, dealing with chaos.[110] He identifies the post-modern self as the self that tells ones own story.[111] Kathlyn Conway describes some illness narratives as "narratives of triumph"—she recognizes a pattern in illness narratives and she finds this formula problematic because it can easily become prescriptive.[112] The "narratives of triumph" involve a patient experiencing what could be called a fall and redemption (though Conway uses secular language). The patient is well and in standard health, then experiences the rupture and shock of a diagnosis, then copes and conquers the process. Restoration and healing have been achieved.[113] She links her term "narratives of triumph" to Arthur Frank's term "restitution narratives" stories that share the same predictable pattern: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again."[114] Ultimately, this pattern does not hold for all patients, though, particularly chronically ill and terminal patients. This does not mean that restoration, healing, and hope cannot be redefined in a new way however. For some patients, their hope for a cure may transition to hope for intentional time

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110. Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995).

111. Ibid., 7. Frank builds on social theory and post-structural philosophy to make claims about the narrative self.

112. Kathlyn Conway, *Beyond Words: Illness and the Limits of Expression* (Albuquerque: University of New Mexico Press, 2013a).

113. Ibid., 1.

114. Frank, *The Wounded Storyteller: Body, Illness, and Ethics*, 5.

spent with family or a visit to a beloved park. The hope is still there, but the goal is no longer oriented to the body, but oriented to meaning. Again, the sense of self and agency assumed by both Conway and Frank is not available to all patients.

## The Limits of Principlism and the Contribution
## of a Narrative Approach to Medical Ethics

Principlism as a modality of decision-making in medical ethics formally began with the publication of Tom Beauchamp and John Childress' *Principles of Biomedical Ethics* in 1979.[115] Principlism, in brief, centers on four concepts: autonomy, beneficence, nonmalificence, and justice. While principlism undoubtedly did a great deal of good in creating a platform for patient's rights, particularly through the establishment of informed consent, the method can be seen as a minimalist approach to the complex dynamics that occur between patients and clinicians.[116] Principlism has also been critiqued as offering something of an ethical checklist for clinicians creating a scenario in which, once the four categories have been considered, other ethical issues are not taken into account, such as when two of the principles might conflict.[117] The principles can be critiqued for being both too neat and limited, as well as, on the other end of the

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115.  Tom L. Beauchamp and James F. Childress. *Principles of Biomedical Ethics* (New York: Oxford University Press, 1979).

116.  See Albert R. Jonsen's *The Birth of Bioethics* (New York: Oxford University Press, 1998) for a critique of prinicplism as the primary method in bioethics.

117.  See P. Gardiner. "A Virtue Ethics Approach to Moral Dilemmas in Medicine". *Journal of Medical Ethics* 29, no. 5 (2003): 297-302. Gardiner expands beyond the prinicplist model by looking at the virtue ethics framework as one that honors the complexity of the human being and one that can offer guidance when principals conflict or are not necessarily applicable to the patient in question.

spectrum, for being too general and open.[118] Again, the value of the principles is such that they are necessary in the medical model. Recognizing the limits of principlism does not mean that the model should be jettisoned entirely. However, the model can be improved by a more nuanced understanding of, to use Paul Ramsey's term, the patient as person.[119]

Many clinicians recognize the limits of principlism in terms of how much the framework can provide for informing the diagnostic encounter. The term "narrative ethics" is also used in various ways. Literary scholars like Wayne Booth use the term narrative ethics to describe how one can critically approach texts and use them as sources for ethical understanding and evaluation, recognizing that a reader can make claims about the ethical function of texts.[120] Martha Nussbaum looks to literature as a narrative source for moral understanding. Other scholars such as Hilde Lindemann Nelson, Arthur Frank, Howard Brody, and Rita Charon uphold the idea of the patient as a person whose being in the world is marked by narration. Their claims often have an implicit or explicit ethical appraisal of the medical model.

The narrative understanding of the self asserted by Paul Ricoeur, particularly in *Oneself as Another* and in the third volume of *Time and Narrative*, can supplement medical ethics, but

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118.  Martha Nussbaum in *Love's Knowledge: Essays on Philosophy and Literature* (New York: Oxford University Press, 1990) critiques modern philosophy for being overly abstract and scientifically-minded, presenting "a kind of all-purpose solvent in which philosophical issues of any kind at all could be efficiently disentangled, and any conclusions neatly disengaged," 19. Her critique could also apply to principlism in bioethics and the expectation the principlism covers the gamut of bioethical issues.

119.  Notably, Ramsey's text was published prior to that of Beauchamp and Childress. Ramsey in *The Patient As Person: Explorations in Medical Ethics* (New Haven: Yale University Press, 1970) speaks to the need for methodological structure in bioethics and Beauchamp and Childress' now classic text can be seen as a response to Ramsey's call.

120.  Wayne Booth, "The Ethics of Medicine, as Revealed in Literature," *Stories Matter: The Role of Narrative in Medical Ethics*, ed. Rita Charon, and Martha Montello (New York: Routledge, 2002), 10-20.

can also inform how patients are understood and treated in the medical model of care.[121] While

principlism highlights the autonomous mode of being of a person, Ricoeur, while not negating

this view, turns his attention to the narrative practices individuals engage in. A person engages

in taking the fragments of one's life and attempting to unify them into a coherent whole—

though this unity is never fully achieved as an individual continually engages in the process of

reinterpreting the past, present, and future. One can imagine how a patient might engage in this

narrative process after receiving a life-changing diagnosis that disrupts the narrative the person

envisioned for his or her future. Of note, these two concepts, narrativity and autonomy, are not in

opposition, and the respect for autonomy is crucial to medical ethics. However, the language of

autonomy does not take into account the rupture that can occur when one experiences physical

or mental illness, or the loss of autonomy that might concurrently be experienced with an illness,

the need of an ALS person to receive care as a dependent, for instance. Ricoeur's view of the

centrality of hermeneutics supplements, but does not replace, the centrality of autonomy in the

medical model. Ricoeur notes that narratives, while they can order lives in accordance with

moral norms, cannot "by themselves *found* ethics."[122] Through narrativity Ricoeur does not offer

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121. Paul Ricoeur, *Oneself As Another* (Chicago: University of Chicago Press, 1992) and the three volume *Time and Narrative* (Chicago: University of Chicago Press, 1984). Ricoeur describes the different foci of the two texts: "Whereas *Time and Narrative* was mainly interested in the role of narrative in the figuration of time, *Oneself as Another* is concerned with its contribution to a hermeneutics of the Self." He points particularly to the sixth study which looks to the dialectic of idem (sameness over time) and ipse (selfhood within time) as being central to his understanding of narrative identity. In Lewis Edwin Hahn's *The Philosophy of Paul Ricoeur* (Chicago: Open Court, 1995), 396-397.

122. Ricoeur, "Reply to Peter Kemp" in *The Philosophy of Paul Ricoeur* ed. Lewis Edwin Hahn (Chicago: Open Court, 1995), 397-398. He notes that norms such as the good and duty cannot be located within the narrative structure of the self, but can be added to it, facilitating a transition from narrative identity to the morally responsible self.

a replacement for principlist ethics; rather, he offers a way to include, but expand beyond, the category of autonomy as the salient feature of a patient's being.

Scholars in narrative medicine present a critique of medical pedagogy and practice and in so doing provide resources for ethical analysis. Behind normative claims that the practice of medicine can be improved by mindfully attending to a patient's narrative hides the claim that medicine offers an inadequate approach to patient care. When advocates of narrative medicine claim that reading literature nurtures empathic regard for patients, what then does this claim suggest about clinicians that have a science-based focus? Narrative approaches to identity formation and clinical practice create space for uncertainty; therefore, easy binaries between the virtuous scholar-physicians and the heartless scientist-physicians calls for nuance. A contribution of a narrative-based approach is that is offers resources for engaging with the gaps and grey areas in medical knowledge and in medical ethics. Drawing on an approach that allows for multivalent understandings of personhood, one can claim that there is no pure approach to clinical care, either on the side of empathic clinicians or on the side of those who prefer a posture of clinical detachment.

A view of the narrative self can serve as a reminder to take into account the complexity of a person's situation, one that may not have a solution or even a diagnosis for those with chronic illness. While there is a desire in medicine to have certainty, a desire made manifest though, for instance, over-testing patients, a narrative, hermeneutically-centered approach to the relationship between clinician and patient functions with the awareness that absolute certainty is not always possible when making a diagnosis or trying to understand the suffering of a patient. An understanding of the narrative self and the narrative encounter recognizes that in the diagnostic encounter and particularly in ethical dilemmas, there is not necessarily one "right" diagnosis or

one "right" answer. There can be multiple entry points into understanding a patient's experience. Laurie Zoloth points to the value of sacred texts as a reminder that ambiguity, not certainty, is what marks human experience. "Biblical texts," she says, "with their unsettled questions and the dark lacunae and the flawed heroes are a template for the lacunae of medicine and allow for a midrashic, interpretive and contextual analysis of the medical narratives that we are called on to reflect upon."[123]

Taking into account the particularity of an individual's story involves time and close attention. Being attentive to a patient's story can take more time than a physical exam. However, listening to the patient's concerns may save time by decreasing over testing and it also may reveal other medical concerns, such as psychosocial and spiritual concerns, that warrant treatment or referral to chaplains or mental health providers. Also, to continue the conversation about medical ethics, narrativity brings a human component to the rights-based structure of principlism. A narrative approach is not meant to replace principlism, only to supplement the model. If anything narrativity highlights the agency of a patient and falls under principle of autonomy. In Chapter Three, I consider the experience of patients who fall outside of narrative categories in clinical care and go on to address how care can be provided for them so that they are not a neglected subset of patients in narrative medicine.

## Conclusion

Western medicine is deeply teleological, a quest-based model structured on a linear process that includes diagnosis, treatment, and ultimately, cure. Patients, though, do not necessarily have a goal-based vision of care, or their goals may not be diagnosis and acute treatment, but

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123. Laurie Zoloth, "Faith and Reasoning(s): Bioethics, Religion and Prophetic Necessity." In *Notes from a Narrow Ridge: Religion and Bioethics,* ed. Dena S. Davis, and Laurie Zoloth (Hagerstown, Md: University Pub. Group, 1999), 261.

understanding and guidance about how to live with an illness when curative care does not exist as a possibility. This is particularly true for chronically ill or terminal patients who do not fit into a goal-based paradigm where cure exists as a possibility. My work takes into account both the value and the limits of narrative understandings of the self for patients who are unable to offer a linear timeline of self-development. The literature on narrative medicine depends a great deal on a concept of the self as narrating agent that originates with a particular reading of Aristotle. In the chapters to follow, I supplement this concept by describing elements of narrative selfhood that are marked by discontinuity and fragmentation. Some schools of thought in the medical humanities look to the patient as a more authentic or valid source of medical information, one that is closer to the truth than the accounts provided by clinicians. Patient narratives can also serve a therapeutic or social function for the patient, providing a means of taking back one's authority or a means of connecting a patient to others who have shared their experience of feeling dehumanized. As a source of ethical reflection, patient narratives can point to the need for systemic change in the medical system, offering a normative critique of care in the form of a personal testimony. Furthermore, patient accounts can also be sources of ethical self-evaluation, as I explore in the next chapter on life review in hospice. While many patients and clinicians find value in the narrative features of health care, there are patients who are cognitively unable to offer any sort of understandable narrative or account at all, and it is this group of patients that I address in Chapter Three.

In following chapters, I continue to examine narrative-based concepts of patient identity and practice and the value of narrative medicine for clinicians. I focus on the process of life review in hospice, and then turn to the limits of narrative practices for patients who are unable or limited in their abilities to engage in the process. Additionally, I explore the religious dimension

of patients as one that calls for recognition in the study of narrative medicine. When trying

to make sense of the world around us, particularly in times of unexpected distress, we look to

reasons why are bodies and minds are not working the way we would like them to. Some of the

reasons are medical, but many are religious, a reason why chaplains are including in medical care

teams in hospitals and hospice care. There are also deeply valuable sources of religious literature

that create space in narrative medicine for the recognition of darkness and ambiguity in the lives

of both patients and clinicians.

Many patients, especially those at the end of life, are unable to offer a verbal response to

caregivers and the needs of these patients can go unaddressed in narrative medicine as it exists

currently. Religious approaches to patient care also allow for a way of viewing patients that does

not rely on their ability to speak or respond to the clinician. My primary goal is to bring attention

to patients that may present as challenging for clinicians due to reasons related to physical,

personal, social and existential pain that affect patient behavior or due to the verbal or cognitive

limits of patients who are unable to offer a narrative account of their experience. I maintain that

the tools of narrative medicine nevertheless continue to provide value for such patients, and that

through learning how to stay engaged in difficult clinical encounters, clinicians will be able to

provide better care for patients experiencing various forms of pain beyond the physical to include

personal, social, spiritual, and existential pain.

CHAPTER TWO

NARRATIVE IDENTITY AND PRACTICE IN THE HOSPICE MODEL OF CARE: LIFE

REVIEW AS ETHICAL SELF-ASSESSMENT

Questions about ethics and morality for terminal patients often address the right to die or the

use of life-prolonging technologies. However, other forms of ethical analysis are present for

end of life patients that are not by nature dilemma-based. Instead, questions of morality, duty,

and appropriate behavior or life in accordance with personal, social, or religious virtues, can be

present for persons reflecting on the content of their lives. This reflection is often precipitated

by an unexpected medical event, and particularly by a terminal diagnosis. Narrative medicine

and narrative medical ethics offers a paradigm for understanding this mode of ethical reflection

that can occur when patients learn of their prognosis. Narrative medicine, because the concept

originated with a literature scholar and clinical professor of medicine, centers on the caregiver

or clinician and the development of his or her skills in attending a patient, what Charon calls

"narrative competence."[1] In Chapter 4, I attend to narrative medicine as the field relates to

clinical care; in the current chapter I examine how narrative medicine can offer methods of

ethical self-assessment for patients, specifically for patients at the end of life.

My concern in this section does not have to do with the empathic skills of the clinician,

also referred to as the moral imagination of practitioners, in which they learn to consider

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1. Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford Univ. Press, 2008).

the experience of the patient they encounter.[2] Rather, because narrative medicine is heavily

weighted toward the practitioner, my goal in this chapter is to turn to evaluative process of life

review engaged in by the patient particularly as it relates to narrative medicine. Because a patient's

interior world cannot be fully known, I look to themes that emerge from terminal patients at the

end of life both in literature and in reports from clinicians and patients; both offer rich reserves of

information for understanding the spectrum of human experience in the face of terminal illness

and death.[3] Not all of the patients are engaging in the structured process of life review, though

many are engaging in a similar, if informal, process of retrospective reflection and evaluation of

their lives.

Whereas previous research shows that life review has a therapeutic function, I maintain

that it also has a moral function.[4] To support this claim, I examine the philosophy of care in the

hospice model as one which asserts a concept of patient identity that supplements and furthers

concepts of identity that inform the biomedical model of patient care, and even the understanding

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2. John D. Engel, *Narrative in Health Care : Healing Patients, Practitioners, Profession, and Community* (Oxford; New York: Radcliffe Publishing, 2008).

3. The play *W;t* by Margaret Edson (New York: Faber & Faber, 1999) is just one example of the value of literature and dramatic works for considering the experience of terminal patients, even if fictional. Because the scholars I look to do not necessarily use interview or other qualitative forms of data collection, I do not describe the research I draw on as exclusively ethnographic. However, for detailed ethnographic research on illness narratives, see the scholarship of Byron Good, *Medicine, Rationality, and Experience: An Anthropological Perspective* (Cambridge; New York: Cambridge University Press, 1994. See also the work of Mary-Jo DelVecchio Good, *Pain as Human Experience : An Anthropological Perspective* (Berkeley: University of California Press, 1992).

4. Barbara K. Haight and Barrett S. Haight, *The Handbook of Structured Life Review* (Baltimore: Health Professions Press, 2007). Previous research also shows the value of the process: Barbara K. Haight, "The Therapeutic Role of a Structured Life Review Process in Homebound Elderly Subjects," *Journal of Gerontology* 43, no. 2 (1988), 40; B. Mastel-Smith, B. Binder, A. Malecha, G. Hersch, L. Symes and J. McFarlane, "Testing Therapeutic Life Review Offered by Home Care Workers to Decrease Depression among Home-Dwelling Older Women," *Issues in Mental Health Nursing* 27, no. 10 (2006): 1037.

of patient identity asserted in narrative medicine. The hospice philosophy of patient care, as established by founder Cicely Saunders, seeks to treat the patient in his or her wholeness with the recognition that patient identity includes their relationships, religious or spiritual identity and practices, and personal story. A hospice-based anthropology perceives the patient as a narrative being with an individual experience of pain. Further, the hospice anthropology offers an approach to patient identity that is more comprehensive than that presented in narrative medicine, because the hospice model of care includes the religious and spiritual dimensions of patient identity and experience, an aspect of personhood that goes unmentioned in narrative medicine scholarship. Nevertheless, such an anthropology aligns well with models of narrative medicine that view the clinical encounter as one structured by narrativity.[5]

In this chapter, I argue that life review in hospice is a form of ethical self-analysis for end of life patients who have the necessary verbal and cognitive capacities to do so. The central question being asked in this process of retrospection and self-analysis, either implicitly, or explicitly, is did I live a good life? This question is, in essence, is an ethical one, though the definition of the good life will differ depending on the person and context. My primary concern is with the process of evaluative retrospection rather than normative claims about what the good life is. It is the patient's attention to his or her individual definition of the good life that interests me in this chapter. Some reach the end of their life with a sense of well-being and satisfaction that they

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5. See the work of Cheryl Mattingly for her research on the narrative structure of the clinical encounter, particularly the following: *Healing Dramas and Clinical Plots: The Narrative Structure of Experience* (Cambridge, UK: Cambridge University Press, 2008); Cheryl Mattingly and Maureen Hayes Fleming, *Clinical Reasoning: Forms of Inquiry in a Therapeutic Practice* (Philadelphia: F.A. Davis, 1994); and Cheryl Mattingly, *Stories in Clinical Time: Narrative Theory in Medical Practice* (Cambridge, UK: Cambridge University Press, 1998). Rita Charon's scholarship similarly addresses the narrative aspects of clinical interaction, however, her work attends primarily to how narrative methods can deepen the clinician's ability to hear and understand patient concerns. Mattingly's research speaks to the patient's experience and to the narrative aspects of the clinician-patient relationship.

have lived well and are at peace with dying. But for many patients, life review evokes feelings with a negative valence—a sense of incompletion, regret, guilt, and fear, centering on the realization that they did not live their lives as they had hoped and that time is limited for making changes approximating the good life, as they define it. I connect their experiences of pain with how patient experience is conceived in the hospice model of care. To conclude, I make an ethical turn, examining situations in which patients may express their pain in ways that make them difficult to encounter leading to a problematic avoidance of challenging patients.

### Patient Identity in the Hospice Model of Care

In 1967, Cicely Saunders formally established the hospice model of care for terminal patients with the opening of St. Christopher's Hospice in London.[6] Florence Wald, nurse and Dean of the Yale School of Nursing, after hearing Saunders speak and working with her in London, established the Connecticut Hospice in 1974, the first of its kind in the United States.[7] Hospice is a model of end of life care, often residence-based, for patients with a prognosis of six months or less to live. The goals of care address physical, spiritual, and psychosocial dimensions of patient identity, as I speak to below. Pain management is a central feature of the hospice approach to care, and Saunders' definition of pain expands to include experiences of pain that are more than just physiological, observing that the end of life can be an experience of great pain for individuals and family members on a personal, social, and existential level. Her claims about the many dimensions of pain led to the Medicare requirement for hospices to include psychosocial support,

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6. Cicely M. Saunders, *St. Christopher's in Celebration : Twenty-One Years at Britain's First Modern Hospice* (London: Hodder and Stoughton, 1988).

7. James Lewis Milton, *Medicine and Care of the Dying: A Modern History* (Oxford; New York: Oxford University Press, 2007).

volunteer presence, and spiritual and religious professionals to meet with patients and family

members as part of the standard plan of care.

<div align="center">The Hospice Model of Care</div>

Hospice is a patient-centered model of care offering tailored treatment for an individual patient.

Though patient-centered, the model of care is not individualistic, but by nature relational, relying

on those in some relationship to the patient to provide ongoing care including physical care

such as feeding and bathing the patient, as well as non-clinical medical care such as providing

medication when ordered by the medical directory or needed by the patient. In fact, one cannot

enroll in hospice as an individual. Because hospice provides only episodic rather than continuous

care, to be accepted as a hospice patient in the United States, one has to have full-time caregivers,

either paid caregivers or unpaid caregivers in some form of relationship to the patient. While this

model can be seen as limited considering that for many patients having caregivers is a luxury,

there is nevertheless a relational component to this model of care that stands in contrast to

the individualistic model of care provided by the biomedical model as it exists today. Hospice

recognizes that total self-sufficiency may be an ideal for some, but the majority of individuals

who are ill cannot care for themselves and the effects of the patient's illness affect the entire family

rather than just the patient alone.

Underlying the hospice framework of care for terminal patients is an understanding

of patient identity that expands beyond biological reductionism, often connected with the

biomedical model of care, in which the patient's physical body is the focus of clinical attention.[8]

In hospice, the patient is assumed to have medical, psychosocial, and spiritual needs. Though

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8. Daniel Callahan, *False Hopes: Why America's Quest for Perfect Health is a Recipe for Failure* (New York: Simon & Schuster, 1998). Though binary, these categories can be helpful as a rhetorical device to analyze distinct medical epistemologies and how patient identity is framed within them.

autonomy remains key to patient rights in hospice, the patient is viewed as interdependent and as having social needs which, if left unattended to, can be a source of unmanaged pain.[9] As pain management is central to the hospice philosophy of care, techniques used to address all forms of pain, including but expanding beyond its physical manifestations, are employed in the interest of total patient care.

Hospice is distinct from palliative care in that hospice requires a six-month prognosis if the disease takes its natural course.[10] Palliative care models, which allow both comfort and curative clinical measures, are becoming more common, due to growing clinical education about palliative medicine and because the language of "hospice" continues to unsettle some patients, families, and even clinical caregivers. Because hospice requires a terminal diagnosis and the release of curative care, there is recognition by the patient, the patient's family and his or her caregivers that death is real and approaching soon. It is because of this honesty about a patient's terminal state that I focus primarily on this population of patients. I claim that a terminal diagnosis and honesty about impending death, combined with a retrospective narrative practice such as life review, creates a situation in which patients turn toward how they lived rather than how they hope to live. It is in this turn toward the past that patients engage in an ethical self-

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9. John Cacioppo, professor of Psychology at the University of Chicago, developed the field of social neuroscience and researches the effects of loneliness for the elderly. See his book written with William Patrick, *Loneliness: Human Nature and the Need for Social Connection* (New York: W.W. Norton & Co, 2008) as well as the following research on the health consequences of perceived isolation, primarily depression and death: J.T. Cacioppo, M. E. Hughes, L.J. Waite, L. C. Hawkley, and R. A. Thisted, "Loneliness as a Specific Risk Factor for Depressive Symptoms: Cross-sectional and Longitudinal Analyses," *Psychology and Aging* 21, no.1 (2006), 140-151, as well as Y. Luo, L. Hawkley, L. Waite, and J. Cacioppo, "Loneliness, Health, and Mortality in Old Age: A National Longitudinal Study," *Social Science & Medicine (1982)* 74, no. 6 (2012):907-914.

10. Diane E. Meier, "Palliative Care in Hospitals," *JHM Journal of Hospital Medicine* 1, no. 1 (2006): 21.

analysis about whether they lived well. While there can be language about how to prepare for a death on the patient's terms and there can be a reframing of what hope means at the end of life, I claim that because one no longer has a future *telos*, engaging in subjunctive understandings of future selfhood, patients then analyze how they in fact did live, according to their recollection and what they value. This ethical self-analysis is influenced by cultural understandings of what it means to fulfill one's social roles and be a good person. Patients are measuring whether or not they lived up to their standards of success.

### Life Review for End of Life Patients

R.N. Butler published the first document on structured life review in 1963, 4 years before the formal establishment of hospice by Cicely Saunders.[11] He claimed that older persons engage in a process of reflection about the course of their lives, particularly as they face life's end. He maintained that this is a universal feature of aging, stating:

> I conceive of the life review as a naturally occurring, universal mental process characterized by the progressive return to consciousness of past experiences, and, particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences can be surveyed and reintegrated.[12]

The process of life review is known by other names: reminiscence therapy, retrospection, guided autobiography, and, more recently, storywork.[13] Dignity therapy is another term form

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11. Robert Butler, "The Life Review: An Interpretation of Reminiscence in the Aged" *Psychiatry* 26 (1963), 65. Sharan Merriam questions the universal nature of Butler's claim and the connection he makes between death awareness and life review. See "Butler's Life Review: How Universal Is It?" in Jon Hendricks, *The Meaning of Reminiscence and Life Review* (Amityville, NY: Baywood Pub. Co., 1995).

12. Robert Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-76.

13. James E. Birren, Donna E. Deutchman, *Guiding Autobiography Groups for Older Adults : Exploring the Fabric of Life* (Baltimore: Johns Hopkins University Press, 1991); William Randall, "Storywork: Autobiographical Learning in Later Life," *ACE New Directions for Adult and Continuing Education* 2010, no. 126 (2010), 25.

of life review, specifically designed for end-of-life patients with the goal of achieving closure.[14]

For the purpose of clarity, I will primarily use the language of life review to refer to the process

of retrospective reflection on the course of one's life, particularly for patients with a terminal

diagnosis enrolled in hospice care. Barbara and Barrett Haight use the term "structured life

review" building on Butler's idea to create a short-term life review model for both caregivers

and clinicians.[15] They attend closely to Erik Erikson's developmental stages of psychosocial

development and offer a framework that applies to more than just hospice patients.[16]

Butler believed that a terminal diagnosis can prompt the process of life review; however,

one's advanced age alone, or an acute reminder of one's mortality, can similarly lead to this

process of reflection on one's life.[17] He describes a person's end of life as being a prime window

of time for self-reflection.[18] Recent studies show that there are marked differences in what is

considered salient for patients depending on their age and gender. For example, Ando, Morita,

and Connor in their study on life review for cancer patients note that the primary concerns

for 40 year-olds related to children, for 50 year olds, death, for 70 year olds, resignation about

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14. Harvey Max Chochinov, *Dignity Therapy: Final Words for Final Days* (Oxford; New York: Oxford University Press, 2012). The question of "achievement" is on that calls for analysis, particularly if vulnerable patients feel compelled to seek closure to satisfy his or her clinicians when this is not a goal or event that interests the patient.

15. Barbara K. Haight and Barrett S. Haight, *The Handbook of Structured Life Review*.

16. Erik H. Erikson, *The Life Cycle Completed : Extended Version with New Chapters on the Ninth Stage of Development by Joan M. Erikson* (New York: W.W. Norton, 1998). Haight and Haight, and others building on Erikson's developmental framework of selfhood, look to his stage "Integrity versus Despair" for concepts of identity in the elderly.

17. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 67.

18. M. Lewis and R. Butler, "Life-Review Therapy: Putting Memories to Work in Individual and Group Psychotherapy," *Geriatrics* 29, no. 11 (1974): 165.

their lives, and for 80 year olds, relationships with others were their primary concern.[19] Their

studies point to the reality that the focus is not merely on an answer to the question, "how did I

live?" particularly for younger terminal patients who may be concerned about how to establish a

framework of care for their dependent children who will survive them.

There are general themes that are shared for patients engaging in the process of life review,

however, Butler made no move to describe life review as one that has an internal structure or

order. He did not impose a formula or developmental timeline on the activity, noting that it can

involve "stray and seemingly insignificant thoughts about oneself and one's life history."[20] He

maintained that the process, for some can be inward and solitary, a process in which thoughts

happen upon individuals rather than being intentionally called forth.[21] Though Butler conceived

of the life review as more of a meandering of thoughts, the process has become formalized

in many hospice models. Life is divided into developmental periods connected with one's

chronological age. Major historical events are taken into account, shaping how one reflects on the

course of one's life.

Though I emphasize the social aspect of life review, that the process involves a dialogical

interaction often between patient and a nonprofessional visitor or caregiver, for Butler life review

can be done individually, even internally in silence.[22] The group process of life review as a shared

activity of piecing together and articulating the narrative of one's life is also an option that exists

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19.  M. Ando, T. Morita, S. O'Connor, "Primary Concerns of Advanced Cancer Patients Identified through the Structured Life Review Process: A Qualitative Study using a Text Mining Technique," *Palliative & Supportive Care* 5, no. 3 (2007): 265.

20.  Butler, *The Life Review*, 68.

21.  Ibid., 65.

22.  Ibid., 67.

as a way to engage in the process.[23] Butler's primary interest was in what he perceived to be the fact that individuals do engage in this process, rather than the modes in which they do it. In hospice, any attempt to engage in life review would follow attention given to pain and symptom management.[24]

In addition to claiming that life-review is a universal activity of reflection, he maintained that life-review correlates with advanced age and an awareness of one's mortality. However, the deaths of others, dramatic health or ability changes, and relational or professional disappointments can also trigger a sense that one's life calls for analysis or review. Butler notes that the condemned and that young people with terminal diagnoses engage in this process of reflection; his primary research interest is in the aged population because these are the more ordinary cases, and he felt that there was some neglect of this demographic in clinical research.[25] One of his goals appears to be depathologizing the life review process, noting that it is not an indicator of maledict psychological concern, but an ordinary, and he adds universal, reflective exercise.[26]

<div align="center">Reminiscence versus Life Review</div>

In his article, Butler makes a distinction between reminiscence and life review, defining

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23. James E. Birren and Kathryn N. Cochran, *Telling the Stories of Life through Guided Autobiography Groups* (Baltimore: Johns Hopkins University Press, 2001).

24. Robert A. Neimeyer, *Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved* (New York: Routledge, 2012).

25. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-67.

26. Ibid., 65. He notes: "The prevailing tendency is to identify reminiscence in the aged with psychological dysfunction and thus to regard it essentially as a symptom." His research strives to normalize the process of life review. David Haber describes him as successful in his work to minimize the stigma against reminiscence in the elderly. See David Haber, "Life Review: Implementation, Theory, Research, and Therapy," *International Journal of Aging and Human Development* 63, no. 2 (2006): 153.

reminiscence as a process of recollection and life review as a process of evaluation. However,
the term reminiscence has come signify what Butler intended to point to when he described life
review. Jeffrey Webster prefers the term reminiscence therapy or reminiscence work to describe
the process of evaluating one's life over time. Webster, disagreeing with Butler's claims about the
timeline for retrospective reflection, believes that reminiscence occurs throughout a person's
lifespan rather than just at the end of life.[27] The primary difference between reminiscence and life
review is that reminiscence does not involve the interpretive move.

Language about life review often sounds positive—the process is described in language
that connotes feelings of well-being, harmony, justice, and closure. The romantic ideal of the
bedside narration of a life well lived comes to mind. However, Butler, a realist about the process
based on his experience with it, notes that life review is not necessarily positive and can include
experiences of regret, loss, and despair.[28] Haight in her review of the literature following
Butler's article notes that almost all the descriptions of the results of life review tend toward
the positive.[29] The process of reminiscence is described as healthy, therapeutic, adaptive, and
integrative.[30] Haight sees this positive spin as a limitation in the research. Though hospice has an
overarching goal of minimizing pain, life review is not necessarily presented as a mode of therapy
for patients as a means to address unresolved issues. One could say that the primary form of pain
management that life review attends to is the pain that comes from social isolation of the elderly

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27. Jeffrey Dean Webster and Mary E. Mccall, "Reminiscence Functions Across Adulthood: A
Replication and Extension," *Journal of Adult Development* 6, no. 1 (1999): 73.

28. James E. Birren, *Encyclopedia of Gerontology* (Amsterdam; Boston: Academic Press, 2007).

29. Hendricks, *The Meaning of Reminiscence and Life Review*.

30. Ibid., 25

and infirm. Accordingly, there is no need to have the goal of resolving past emotional or relational

issues through life review; its purpose is to meet the social needs of patients that can be met

through conversation. There is not necessarily a therapeutic goal—i.e. "closure"—involved in the

process.[31]

     Butler described life review as a process of interpretation in which there is a

"reorganization of past experiences" that includes recognition and evaluation by the self. [32] This

evaluation includes recognition of one's "past inadequacies" that may have gone unexamined if

not for the reality of the patient's impending death.[33] To aid in this process, hospice organizations

have created guides for retrospection. For instance, the Hospice Foundation of America published

"A Guide for Recalling and Telling Your Life Story"; in Europe the Age Concern Society offers

"Reminiscence and Recall: A Guide to Good Practice" and "The Reminiscence Trainer's Pack"

online to assist those interested in the process. [34]

     Ultimately, life review as it functions in hospice is a process of reflection, interpretation,

and preparation. Through reflection on the course of one's life, a person engages in the activity of

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31.  Describing the popular concept as a myth, Nancy Burns disputes the very existence of closure in her book, *Closure: The Rush to End Grief and What it Costs Us* (Philadelphia, PA: Temple University Press, 2011). To address closure from an ethics perspective, one could say it stems from a well-meaning, but paternalistic, desire for the clinician to facilitate justice or harmony for a patient in distress.

32.  Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-76. He uses the language of the ego to talk about the self's perspective, 68.

33.  Ibid., 66.

34.  *A Guide for Recalling and Telling Your Life Story.* (2001). Washington, D.C.: Hospice Foundation of America; Gibson, F. (1998). *Reminiscence and Recall: Second Edition.* United Kingdom: Age Concern.; Gibson, F. (2000). Reminiscence Trainer's Pack. United Kingdom: Age Concern. Robert Butler offers a succinct overview of life review in. "Age, Death, and Life Review" in *Living with Grief: Loss in Later Life.* ed. Doka, Kenneth J., John Breaux, and Jack D. Gordon Washington, DC: Hospice Foundation of America, 2002.

interpreting these experiences according to both internal and external standards.[35] Additionally life reviews a process of preparation for death as one evaluates the time one spent in the world as it stands in the face of the limits of one's time, coming to terms with how one lived. Though life review does not require a terminal diagnosis, or even advanced age, hospice presents an opportunity to engage in the process by explicitly speaking about life review as an activity one can engage in using volunteer services. Also, in hospice, honesty structures the conversation about the time one has left. When one knows time is limited, they may be more inclined to do an assessment of how they lived.

<div align="center">Modalities of Life Review</div>

**Dignity Therapy**

Dignity Therapy, developed by Canadian psychiatrist Harvey Chochinov, is a dialogical model of psychosocial care for terminal patients that focuses primarily on legacy. Chochinov discovered that patients often experienced distress over the recognition that they would no longer exist and would not be remembered by those still living. Dignity Therapy serves as a way to therapeutically address this need by creating a record of the person's narrative as a form of legacy, something that will exist even after they die.[36] Dignity Therapy addresses some of the same questions as Life Review—questions regarding social roles and matters of pride and acceptance; however, there are two distinct points of difference between the two modalities of narrative medicine. One, Life Review does not have a purported audience; no one else, aside from the volunteer who serves as facilitator will necessarily hear or read the words of the patient.

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35. Hilde Lindemann, *Damaged Identities, Narrative Repair* (Ithaca: Cornell University Press, 2001).

36. Chochinov, *Dignity Therapy: Final Words for Final Days*.

Two, the approaches have different goals. The goal in Dignity Therapy is to create something

to leave behind, something that will live on after the patient has died as a testament to their

lives. By design, this would make the narrative established in Dignity Therapy more selective,

bringing forward what a patient is most proud of as a signifier of his or her legacy.[37] In contrast,

the narrative that emerges in Life Review is less structured to be positive. Because a person is

engaging in self-analysis the result may not be one that the patient is proud of. Rather, the patient

may feel deep regret and disappoint due to the realizations that emerge in life review. The very

term "Dignity Therapy" can shape the course of conversation; Life Review, a more neutral term,

allows the process to be more patient-directed and open with regard to content. Furthermore,

Dignity Therapy is a therapeutic technique, intended to address and mitigate patient distress (the

distress that results from the fear of being forgotten). Chochinov reports that in his research on

Dignity Therapy, 76% of patients reported a heightened sense of dignity following the experience;

68% reported feeling an increased sense of purpose in their lives; 67% reported a heightened sense

of meaning; and 81% reported that it had been or would be of help to their family.[38] Overall, 91%

of participants reported satisfaction with the process. Alternatively, Life Review in hospice may

be less of a therapeutic intervention; in fact, patient distress can increase with the recognition

that a patient did not live up to his or her standards combined with the urgency that can attend a

terminal diagnosis.

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37. Ibid. Interview questions include, "What about your self or your life are you most proud of?" and "How do you want to be remembered?" See Table 2.1 on page 39. These questions structure the type of responses that follow, skewing to the positive. Chochinov does note that for some individuals their "legacy" is that their lives serve as a warning to others, a cautionary tale about how not to live.

38. H. Chochinov, T. Hack, T. Hassard, L. Kristjanson, S. McClement, and M. Harlos, "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life," *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology* 23, no. 24 (2005): 5520.

**Guided Autobiography**

Guided Autobiography similarly has a therapeutic function though the purpose includes motives such as striving to "strengthen identity" and to "help older persons come to terms with the lives they have led" which can have a positive or negative valence depending on the person's interpretation.[39] While it is possible that a person's autobiography is one of regret and analysis of moral failings, the guided aspect to the process involves structuring dialogue according to the person doing the guiding. If they believe they "can help older adults build greater understanding and self-worth" in the process, their desire to make the experience positive for the person involved can limit the person's opportunity to do an honest self-analysis, particularly because the narratives written via guided autobiography are shared in a group setting.[40]

**Illness Narratives**

The term "illness narrative" originated with Arthur Kleinman's text *The Illness Narratives: Suffering, Healing, and the Human Condition* in 1988.[41] Kleinman, both a psychiatrist and an anthropologist, was intrigued by the differences between how illness is interpreted by patients and how it is interpreted by clinicians in the biomedical model of care. Kleinman expands beyond biophysical interpretations of illness to discuss how they shape a person's sense of self and a

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39. James E. Birren, Donna E. Deutchman, *Guiding Autobiography Groups for Older Adults: Exploring the Fabric of Life* (Johns Hopkins University Press, 1991). *x.*

40. James E. Birren and Kathryn N. Cochran, *Telling the Stories of Life through Guided Autobiography Groups* (Johns Hopkins University Press, 2001), 1.

41. Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

person's relationships with others. The text was written at approximately the same time as the turn toward narrative in the medical humanities.[42]

Audre Lorde's *The Cancer Journals* is an example of an illness narrative.[43] In this autobiographical account, she writes about how it feels to be unsupported by one's clinical caregivers and it was precisely this feeling of rejection and alienation that motored her to write the text. For Lorde, narration functions as a form of self-healing with the potential to provide healing for others through speaking openly about her experience, in a manner devoid of sentimentality. Lorde's *Cancer Journals* exemplify the genre of autobiography in narrative medicine, with a distinct turn toward narrative medical ethics or how medicine should be performed in her analysis.[44] In this illness narrative, Lorde describes the inner experience—the sense of loss, rage, and abandonment—she feels after her cancer diagnosis and surgery. Lorde uses self-writing and the memoir genre to mourn the changes in her physical body, to recreate her sense of self post-surgery, and to urge other patients, particularly women, to share their individual experiences.[45] By sharing her story, she believes she is removing the veil from what it means to have a "normal" body, that is, a healthy, fully functioning body.

In many illness narratives, Lorde's as an example, one of the author's goals is to express dissatisfaction with care rather than with one's life. Additionally, illness narratives, as the name of the genre expresses, concern how the patient's illness affected or affects his or her life, sense

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42. Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012). Jurecic credits the AIDS epidemic and the campaign to reshape social understandings of the disease as the signpost for when illness narratives emerged as a genre.

43. Audre Lorde, *The Cancer Journals* (San Francisco: Aunt Lute Books, 1997).

44. Audre Lorde, *Cancer Journals*.

45. Ibid., 24-25.

of self, and relationships.[46][47] In Life Review, the focus is on the patient's life, sense of self, and relationships, but does not necessarily include how the reality of illness informed the patient's interpretation of his or her life. Though some terminal patients have a diagnosis such as cancer or congestive heart failure, this is not the case for all patients. Some are admitted to hospice care with an unspecified diagnosis; they may be dying of advanced age with no categorizable illness to speak of. In these cases, patients do not gain a sense of identity from their illness in the manner that those writing illness narratives do.

Arthur Frank's *The Wounded Storyteller* comes the closest to the concept of the self and the ethical analysis involved in life review. He views the ill person not as a passive recipient of care, but as an agent in how his or her illness is interpreted and shared.[48] It is through the narrative process that the patient reclaims agency. Additional modalities of reminiscence and reflection include videos, memory books, scrapbooks, and communicating via social media; however, these forms of self-narration do not necessarily have the evaluative component that Life Review elicits.[49]

**Differences Between Other Modalities and Life Review**

A primary difference between autobiography and life-review is that there is not necessarily

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46. Jurecic, in *Illness as Narrative*, attends to the content of illness narratives, noting neglect of critical attention to the genre by literary critics who may feel the need to treat illness narratives with care rather than critical analysis or who, alternatively, view illness narratives as motivated to elicit sympathy rather than literary criticism.

47. Talcott Parsons, "The Sick Role and the Role of the Physician Reconsidered," *The Milbank Memorial Fund Quarterly.Health and Society* 53, no. 3 (1975), 257. In this article he emphasizes that, though the patient and doctor are in an asymmetrical relationship, the patient is not passive in the role as "sick person."

48. Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995).

49. M. Lewis, *Life-Review Therapy. Putting Memories to Work in Individual and Group Psychotherapy*, Geriatrics 29, no. 11 (1974): 165-73.

a documented or recorded product that comes as a result of the process. Life Review quite simply can involve a patient discussing memories or unrealized plans with a hospice volunteer. There is no established goal beyond the process itself. Similarly, there is no intended audience in life review; however, some do chose to document their experiences for those who follow. In illness narratives and autobiographies there is an assumed audience; knowing this may inform the content of a patient's narrative. A patient may share his or her regrets and disappoints during the process of life review whereas if a book were being written the negative appraisal one has of one's life may not be discussed. Additionally, life review often occurs with volunteer companions or family members interested in documenting life history. Because the conversation does not occur in a professional context, there is freedom for the patient to speak without worrying about clinical judgment. Ultimately, the process is self-based and the person is his or her own judge of moral behavior.

## Life Review and Narrative Practices in the Hospice Model of Care

"Life review" is the term for a process of reminiscence for hospice patients, often facilitated by a volunteer companion. Volunteers are a required part of the care team in the hospice model of care. In addition to skilled nursing care, Medicare requires that 5% of patient hours be provided by volunteers.[50] If a patient or a patient's caregivers accept volunteer support, volunteer-time is then ordered by the medical director on the patient's official plan of care. When volunteers visit patients, their primary goal is to provide social support for patients or respite for caregivers. Because they accompany patients in a non-clinical role, a patient may feel free to speak with more openness than if a professional caregiver were there, working with the patient toward a specific

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50.  NHPCO Fact Sheet, 2012 "Medicare Hospice Conditions of Participation Volunteer 5% Cost Savings Match Information Sheet: A Resource for Volunteer Managers" http://www.nhpco.org/sites/default/files/public/regulatory/Volunteer_Cost_Savings_Information.pdf

goal of care. When a patient accepts a volunteer for social support, engaging in life review in one

of the activities that can be available for them. Butler noted, however, that life review is often

spontaneous rather than being the product of an intentional conversation.

How Chaplains and Spiritual Counselors Utilize Life Review

When a patient is admitted to hospice, Medicare guidelines require a comprehensive

care plan to be established within the first five days of admission.[51] The role of the hospice

chaplain can be conceptualized as a spiritual or religious counselor available for the patient

and those close to the patient to discuss their beliefs or values; an assessment of the patient's

preferences to discuss their concerns with a spiritual counselor is one of the required measures

for assessment as of 2016, along with an assessment of pain, dyspnea, and bowel responses to

medication.[52] The inclusion of a spiritual assessment early in the patient's admission, if the

patient chooses one, supports Cicely Saunders's claim that spiritual pain is a dimension of total

pain. If the goal of hospice is comfort and the management of total pain for patients, this then

would require professional attention given to emotional, social, and spiritual pain, alongside the

attention given to physical pain. Physical pain includes nausea and agitation and other forms of

physical discomfort. Regarding clinical goals of care, the major distinction between the approach

to physical pain as distinct from spiritual pain is that physical pain is meant to be fully treated,

if possible and if preferred by the patient. Some patients prefer not to experience the sedating

effects of opioid medication, choosing the benefit of clarity over the experience of pain. However,

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51. "Medicare Hospice Conditions of Participation: Spiritual Caregiver," NHPCO, 5. https://www.nhpco.org/sites/default/files/public/regulatory/Spiritual_tip_sheet.pdf

52. "Hospice Payment System," Department of Health and Human Services: Centers for Medicare & Medicaid Services," 7. https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/hospice_pay_sys_fs.pdf

the goals of care for spiritual counselors are not necessarily focused on the elimination of pain.

Rather, when physical pain is sufficiently managed, the patient then has the capability to examine

one's life, via processes like life review or dignity therapy, common interventions for chaplains.[53]

Such reflections may actually be a source of emotional, social, or spiritual pain for the patient, but

the chaplain's role is to work with the patient as the patient examines these concerns, rather than

attempting to end or solve this pain.

For Cicely Saunders, physical pain must be managed so that other forms of pain can

be attended to. The goal is not to eliminate suffering in its entirety. The goal is to eliminate

physical pain so that a patient can encounter their suffering (their emotional, social, religious,

and existential suffering) and deal with it on their terms. A sense of peace and contentment can

occur, but it is not the primary goal of care. This is particularly the case for spiritual counselors

as compared to social workers because concerns regarding guilt, judgment, and confession, often

have religious tinges. Engaging in life review with a spiritual or religious counselor will thus

unearth concerns with God's judgment, punishment in the afterlife, guilt, penance, and lament;

language that is less likely to be used with a secular counselor. By acknowledging these areas of

pain and suffering with a chaplain or spiritual counselor, the patient may experience relief or

resolution of their spiritual and existential distress, but this is not a certain outcome. A study

on the nature of spiritual pain experienced by palliative patients found that patients wanted a

chaplain to listen, provide a sense of presence for them, and accompany them as they navigate

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53. George Handzo, Kevin Flannelly, et al., "What Do Chaplains Really Do? II. Visitation in the New York Chaplaincy Study," *Journal of Health Care Chaplaincy* 14, no. 1 (2008): 53.

their concerns.[54] Life review with chaplains can be initiated formally or occur spontaneously as a patient reflects on their sources of comfort and pain.

## Capabilities Necessary for Patient Life Review

Forms of life review in hospice include short-term life review and Dignity Therapy.[55] However, unofficial means of life review also exist in the form interview questions based on a person's lived experience. Life review serves multiple purposes: creating a legacy for those who remain, reducing isolation for terminal patients, and reducing depression for patients whose symptoms have reached the limits of pharmacological management. The researchers who developed structured short-term life review maintain that by participating in the dialogical process, patients experience lower psychosocial distress than patients who do not.[56] While not all patients experience a sense of harmony or satisfaction after participating in life review, the process nevertheless can serve as a vehicle for ethical analysis in that it is centered on answering the question, "How did you live?"

Two concepts underlying the process of structured short-term life review in the hospice model of care call for attention. First, the process relies on a linear understanding of time and human development. For instance, the Hospice of Cincinnati suggest an interview format divided into distinct life-periods: childhood (birth to 13 years), adolescence (14 to 21 years), young adulthood (22-35 years), middle adulthood (36-65 years), and older adulthood

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54. C. Mako, K. Galek, and S. Poppito, "Spiritual Pain among Patients with Advanced Cancer in Palliative Care," *Journal of Palliative Medicine* 9, (2006):1106–1113.

55. Ando Michiyo, et al., "Efficacy of Short-Term Life-Review Interviews on the Spiritual Well-being of Terminally Ill Cancer Patients," *Journal of Pain and Symptom Management* 39, no. 6 (2010): 993.

56. Ibid., 993.

(66 to 99 years).[57] Scholars such as Galen Strawson challenge the idea that humans share this developmental timeline when reflecting on their lives. Strawson, like Butler, believes memory can be more episodic and fragmented, and that self-narration, for some, centers on an in-the-moment experience of selfhood in time.

Also, the process of life review in the hospice model of care relies on a concept of narrative identity. Telling one's story, reminiscing, pondering one's choices in life, all of these activities require an agency-based understanding of selfhood. Furthermore, a narrative anthropology requires a high level of cognition and lucidity about past and present. Patients who are confused, aphasic, sedated or in pain may not be able to engage in this process.

Bereavement Care and Social Selfhood

In addition to the medical, psychosocial, and spiritual care provided to patients enrolled in hospice, the Medicare guidelines require that family members and friends have the option of receiving bereavement counseling services prior to the patient's death and following the death for a minimum of one year.[58] Bereavement care for family and friends begins before the patient's death to ensure that the counseling services provided are tailored to the individual person, rather than being a carte blanche kind of therapy.[59] Typically, bereavement needs of those close to the terminal patient are assessed by the social worker or chaplain on the interdisciplinary team who then communicate their clinical opinion to the bereavement counselor during the weekly team

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57. Hospice of Cincinnati, http://www.hospiceofcincinnati.org/life_review_info.shtml.

58. "Hospice Policy Compendium: The Medicare Benefit, Regulations, Quality Reporting, and Public Policy," National Organization of Hospice and Palliative Care, 2016. PDF accessible at https://www.nhpco.org/sites/default/files/public/public_policy/Hospice_Policy_Compendium.pdf

59. "Medicare Conditions of Participation: Bereavement," NHPCO, https://www.nhpco.org/sites/default/files/public/regulatory/Bereavement_tip_sheet.pdf

meetings.[60] Such an inclusive model of clinical care recognizes that a patient does not exist as an isolated, self-sufficient, self-defined entity, but that the majority of individuals exist in a matrix of relationships, positive and negative. The self in hospice is perceived fundamentally as a social self.

Regarding narrative identity and the social self, a concept of the social self proves important in those cases in which the patient is referred to hospice late in their disease progression. In situations of late referrals (understood here to mean referrals that occur seven days or less before death occurs), which according to the 2016 Medicare guidelines, were over 35% percent of patients receiving hospice care, attention shifts to prioritizing medical care for the patient with specific focus on pain management and arranging details regarding the context of care.[61] As a patient transitions, there can be less interest in the outside world and less energy to engage in the give and take of conversation and social interaction. The patient turns inward and may not speak or show signs of external awareness of others in the last days of life. In the context of a late referral where the patient is close to transitioning, the focus for the care team is less on the psychosocial or spiritual needs of the patient and more on ensuring that the patient's physical pain is appropriately managed and that they are comfortable.

In the event of a late referral to hospice, there may not be time for the chaplain, volunteer, or counselor to engage in a deliberate form of life review with patients. However, this does not mean that life review did not occur. In cases in which a terminal diagnosis is known by the

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60. The technical definitions of terms related to bereavement care are as follows: bereavement is the "objective situation one faces after having lost an important person via death." Grief is the internal experience in response to the loss; mourning is the outwardly expressed manifestation of the internal experience of grief. From the "Grief, Bereavement, and Loss" PDQ of the Supportive and Palliative Care Editorial Board. Bethesda, MD: National Cancer Institute, October 8, 2014. https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-hp-pdq.

61. 35.5% of hospice patients receive services for 7 days or less; the median length of care in 2014 was 17.4 days, a consistent figure since 2000. "Hospice Policy Compendium," 11.

patient, perhaps intuitively, they can begin to process their life and reflect on their choices, opportunities taken or missed, and relationships with their family and friends. The hospice team may not hear these accounts, but the person's companions often do in the period preceding hospice enrollment. Through bereavement counseling provided by hospice, the bereaved have an opportunity to communicate the individual's life review narrative in remembrance of the person, demonstrating the social dimensions of narrative selfhood. Social or secondary life review accounts reflect the variety of emotional responses that occur in relationships, not just positive reminiscences. According to Hooyman and Kramer, "An active confrontation with the loss—through rage, anger, and the honest expression of sorrow—is widely assumed to be necessary for deliverance from the past, as it requires recognizing all facets of the loss."[62] There can awareness on the part of the bereaved of the hopes or goals of the patient that were not realized because of their diagnosis. For parents experiencing the death of child, there is reflection on the life that might have been.[63] The proximity to the truth, or sense of self perceived by the patient as distinct from how it is perceived and described by the bereaved, matters less than the therapeutic value of the process.

### Life Review in Hospice as a Mode of Moral Reflection

In this section I attempt to demonstrate that life review is not merely a form of reminiscence;

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62. N. Hooyman and B. Kramer, *Living Through Loss; Interventions Across the Life Span* (New York Chichester, West Sussex: Columbia University Press, 2006), 44.

63. From Appendix E: Bereavement Experiences after the Death of a Child, "Children take on great symbolic importance in terms of parents' generativity and hope for the future. All parents have dreams about their children's futures; when a child dies the dreams may die too. This death of future seems integral to the intensity of many parents' responses." Institute of Medicine (US) Committee on Palliative and End-of-Life Care for Children and Their Families; Field MJ, Behrman RE, editors. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington (DC): National Academies Press (US); 2003.

rather it is a form of retrospective ethical self-evaluation. There are thematic elements that emerge for patients, disclosing the underlying process of moral reflection and evaluation. Whereas Butler uses the language of "reorganization" of one's understanding of self, I use the language of evaluation.[64] Both terms connote an interpretive move: Butler believes one interprets one's past based on a sense of self one is trying to confirm; I maintain that one evaluations one's past behavior and context based on perceived standards of what it means to be a good person (based on virtues, duty, one's religion, gender, or familial role) as well as standards for the good life, however this is defined by the patient.

Butler maintains that certain patients are more likely to experience depression, anxiety, and despair as a result of life review. Those who have a future-orientation, deferring culmination of selfhood to a point of time on the horizon—an "ever receding horizon" to use Karl Rahner's term, are often unsatisfied with the course of their lives.[65] In psychosocial literature, this tendency toward the future, or the fallacy of misplaced meaning, in which one neglects their present circumstances for the promise of future fulfillment shows strong connections with chronic anxiety.[66] The second group of those who have negative responses to life review includes those who have consciously caused harm to others during their lives and they are unable to consider "forgiveness and redemption" as possibilities in their respective futures. Finally, Butler names those who are "arrogant and prideful" as likely to experience distress during life review. Butler extrapolates that "their narcissism is probably particularly disturbed by the realization of

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64. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 69.

65. Ibid., 70. Karl Rahner, *Foundations of Christian Faith : An Introduction to the Idea of Christianity* (New York: Seabury Press, 1978).;

66. David H. Barlow, "Unraveling the Mysteries of Anxiety and its Disorders from the Perspective of Emotion Theory" *American Psychologist American Psychologist* 55, no. 11 (2000): 1247.

death."[67] His claims are speculative, based on his experience as a clinician working with terminal patients. Regarding Butler's third category, Paul Tillich similarly links anxiety and distress about dying with the fear of non-being in his text *The Courage to Be*.[68]

Butler repeatedly points to the image of the mirror and the activity of "mirror-gazing" as relevant to his description of life review. What calls for attention is not necessarily that the person is looking in the mirror, but that they do not recognize who they see. They see a stranger before them—the reflection does not depict the person they desire to see. Mirror-gazing prompts the questioning of identity, recognition, and satisfaction with one's sense of self that parallels the moral evaluation that occurs in life review.[69] A patient realizes that at the culmination of life, when there is no time left for future development of self, one's life was not fully lived. As Milton Lewis notes in his research on the retrospective turn, "life review, by its very nature, evokes a sense of regret and sadness at the brevity of life, the missed opportunities, the mistakes, the wrongs done to others, the chosen paths that turned out badly."[70] In addition to the moral analysis that occurs, distressing realizations emerge that can increase patient suffering at the end of life: fear of loss of self, of being a burden, loss of independence, and loneliness are reported by some patients.[71]

Not all patients engaging in life-review experience regret or disappointment in how

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67. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-76.

68. Paul Tillich, *The Courage to Be* (New Haven, CT: Yale University Press, 1952).

69. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 68, 75.

70. M. Lewis, *Life-Review Therapy*, 165-73.

71. M. Dees, M. Vernooij-Dassen, w. Dekkers, K. Vissers, and C. van Weel, "'Unbearable Suffering': A Qualitative Study on the Perspectives of Patients Who Request Assistance in Dying," *Journal of Medical Ethics* 37, no. 12 (2011): 727.

their lives took shape. Reports of regret signify the gap between how patients interpret how

they lived and how patients believe they ought to have lived, pointing to an ethical analysis at

work. However, satisfaction with one's life also points to an ethical analysis: a patient did in fact

achieve his or her "good life." Others may have a nostalgic version of the past, one in which they

romanticize their behavior and possibly long for a false utopia. Butler addresses this tendency

when he speaks about the construct of the "fantasy" of the past as utopian, pointing to this

interpretation as an example of how one retrospective organizes his or her sense of self.[72]

Even when a patient experiences a negative appraisal of self, there can be identity

formation at the end of life. Both Butler and Erik Erikson maintain that human development does

not end in adulthood—that ultimately it has no finish line, apart from death. Hospice clinicians,

volunteers, and bereaved family members similarly note that personal change can occur even

within a short time frame with the specter of death precipitating life review and attempts at

reconciliation, though they would have preferred an earlier referral.[73]

To make the religious turn in ethical self-analysis, when there is no concept of God in

one's moral or religious framework, this activity of weighing good and bad behavior shifts to the

person. For those who believe in a judging God (Christians and Muslims, in particular) the self-

judgment may feel preemptive; in such evaluative paradigms, it is up to God to decide at death

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72. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-76.

73. Susan C. Miller, Pedro Gozalo, and Vincent Mor, "Hospice Enrollment and Hospitalization of Dying Nursing Home Patients," *The American Journal of Medicine* 111, no. 1 (2001): 38. In this article the authors address the challenges of late referrals, particularly with regard to the limits posed on psychosocial and spiritual care for the patient.

how one lived one's life. However, patients can nevertheless anticipate "God's wrath" based on their own interpretation of their moral failings.[74]

## Themes that Point to Ethical Analysis

There are multiple themes that emerge in life review, both formally structured life review and informal moments of reminiscence and retrospective reflection that point to a process of ethical self-analysis. Through life review, one analyzes, interprets, and both celebrates and grieves one's choices in life. I categorize the themes that follow into two categories, an agency analysis and a context analysis. Agency refers to choices on the part of the patient in which they exercise the most control. Context refers to the patient's experience that they did not choose (family of origin, location of birth and dependent care, etc.). Both of these categories show an ethical analysis at work; the latter primarily using language of justice or fairness. There are three types of speech for end of life patients that point to this process of ethical self-evaluation: regret over choices and missed opportunities, the desire for forgiveness, and grief over lost time/longing for more time.

### Regret

Because hospice requires a terminal diagnosis, honesty structures conversation about one's prognosis. Awareness about impending death means that when patients are reflecting on ethical questions they turn their awareness to the past. Instead of asking, "How should I live?" a patient instead will turn the question to the past asking, "How did I live?" Life review thus becomes an on-the-ground form of ethical self-evaluation. A patient can reflect on his or her choices, inquiring as to whether he or she lived up to his own particular expectations. These expectations are influenced by social roles: was I a good mother? did I do the job I wanted to do? The person

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74. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged*, 65-76. Butler has a patient that uses this language.

is engaging in a role-based form of retrospective self-analysis, one shaped by social norms. As Daniel Sulmasy notes drawing from Aristotle's poetics, every ethos requires a mythos.[75] In other words, character-development requires a plot. Life review addresses both how one interprets one's character in an agency-based analysis as well as how one interprets one's context in an environmental analysis. One study on regret shows that there are two forms of regret: regret over one's choices and regret over one's "hard times" or the conditions one had no control over. For example, women experience regret related to their context report wishing they had had the opportunity to pursue their educations but were unable to do so because of external limitations.[76]

The feeling of regret for terminal patients demonstrates ethical self-analysis in action. In nurse Bonnie Ware's observation on the top five regrets of the dying, one of the primary regrets is not living one's authentic life--living the "good life" according to social expectations rather than living one's own good life.[77] Because time narrows for terminal patients, pointing them to their final *telos*, the reality that they no longer have behavioral choices in front of them is brought into sharp relief. The limits of autonomy related to action become starkly apparent. Choices related to how one interprets one's life are available, however, but one does not have the option of living a different life. Regret and self-reproach point to this recognition. For Ivan Ilyich, for instance, his suffering is compounded by his interpretation that he did not live the right life for him. His pain is more than just physical, a concept of pain that Cicely Saunders recognized in her formulation

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75. Daniel P. Sulmasy, "Ethos, Mythos, and Thanatos: Spirituality and Ethics at the End of Life," *Journal of Pain and Symptom Management* 46, no. 3 (2013): 447. Sulmasy expands on Aristotle's poetics to include religion in the category of mythos.

76. E. Timmer, G. Westerhof, F. Dittmann-Kohli, ""When Looking Back on My Past Life I Regret. . .": Retrospective Regret in the Second Half of Life" *Death Studies* 29, no. 7 (2005): 625.

77. Bonnie Ware, *Top Five Regrets of the Dying* (Hay House, Inc., 2012).

of "total pain." In fact, after he comes to the conclusion that his life was a lie, he can no longer speak coherently and only screams in pain.[78]

A scene from *The Death of Ivan Ilyich* captures this sense of regret and confusion, a time when one considers the possibility that perhaps the life one lived was not the best life:

> There was something good for me as a child, but that person is no more. Then in law school there was something genuinely good there—enjoyment, friendship, hopes. There were good moments in my Governor's service, and I remember love for women. As I think through my life, there is less and less good. My marriage—at first so happy, then disillusion. The hypocrisy, the anxieties about money all those 20 years.
>
> So what is this? What is it for? Surely it can't be that my life was so pointless, so wrong? And if it was that wrong and that pointless, then why die and die in pain? Something's not right here. Maybe I didn't live as I should. But how could that be, when I did everything I should have done?[79]

Ivan is in extreme physical pain; however, his distress is not limited to his physical experience. As the doctor notes, "his physical suffering is intense, but his spiritual suffering is worse, and that is what torments him most of all."[80]

Cicely Saunders categorizes feelings of regret under spiritual pain, noting that because of growing secularity in the western world, few patients will use explicitly religious language to describe their pain.[81] One could say that the desire to confess points to a form of spiritual pain; however, I am using the language of regret instead to demonstrate that one recognizes that one failed to live up to an assumed standard and that the individual becomes the judge of

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78. Leo Tolstoy, Lynn Solotaroff, *The Death of Ivan Illyich* (Toronto; New York: Bantam Books, 1985).

79. Ibid.

80. Engel, *Narrative in Health Care: Healing Patients, Practitioners, Profession, and Community*.

81. Cicely M. Saunders and Mary Baines, *Living with Dying : The Management of Terminal Disease*, 62.

moral standing rather than a divine being. Saunders also includes a feeling of meaninglessness

in her concept of spiritual pain.[82] Instead, a feeling of meaninglessness could come from a

non-religious awareness that one's life did not serve any larger purpose beyond the self. This

distress, then, is the result of a form of secular moral analysis rather than being a manifestation of

spiritual pain in the way that Saunders sees it. When a patient maintains that his or her life had no

meaning or was worthless, a normative ideal underlies this claim. This evaluation presumes that

there *should* be a purpose to one's life that transcends self-gratification. A patient is reflecting on

the gap between how one lived and how one thinks one ought to have lived.[83]

<div align="center">Desire for Forgiveness</div>

One action that speaks to the process of moral self-reflection for end of life patients is that of

asking for forgiveness.[84] While expressions of love and gratitude are also noted for end of life

patients, these have less to do with a moral self-analysis. The desire for forgiveness on the part of

patients shows that there is recognition of behavior in which a patient did not live up to his or

her expectations. In some patients, unexpressed requests for forgiveness (to receive or be offered

forgiveness) correlates with depression.[85]

Patient requests for forgiveness demonstrate this ethical analysis at play. Episodic

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82. Ibid., 63.

83. It calls for attention here, that not all persons believe their lives have value and therefore may not even have the luxury of expecting to think that their lives should "serve a purpose." The expectation that one should have a basic level of self-esteem is one that points to the assumption that all lives are recognized outwardly and inwardly as valuable.

84. Betty Ferrell et al., "Nurses' Responses to Requests for Forgiveness at the End of Life," *Journal of Pain and Symptom Management* 47, no. 3 (2014).

85. J. Exline, et al., "Forgiveness, Depressive Symptoms, and Communication at the End of Life: A Study with Family Members of Hospice Patients," *Journal of Palliative Medicine* 15, no. 10 (2012).

depression can also be linked to the awareness that one did not live up to one's expectations.

There is no universal "standard" here for a good life, there is only the claim that the patient has

a standard combined with the recognition that this standard is shaped by moral norms. For

example, a person may not have the "burden" of high expectations in life and may not feel the

gap between who they aspired to be and who they are. One could even say that this sense of

dissatisfaction of not being good enough is either a luxury or a sign of moral self-centeredness. As

Ira Byock says, "you die how you live" and a chronic sense of inadequacy that a patient feels in life

may also be present at death.[86]

Requests for forgiveness, while historically they may have been categorized as belonging

in the spiritual domain, point to an ethical self-analysis rather than exclusively a religious analysis.

It has been argued that whereas before the minister was seen as the arbiter of moral concerns, this

position transitioned to the doctor (as judge of whether one "lived well") or to the self.[87]

## Grief over Lost Time

There can be existential distress when a patient faces a terminal diagnosis. However, this distress

can involve more than just an awareness that one will die. One can also mourn the time they had

but that they did not use well, grieving missed opportunities, relationships, or a fullness of life.

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86. Ira Byock, *Dying Well: Peace and Possibilities at the End of Life* (Riverhead Books: 1998).

87. M. Therese Lysaught, *On Moral Medicine: Theological Perspectives in Medical Ethics.* (Grand Rapids, Mich.: W.B. Eerdmans Pub. Co., 2012), 12-21. Cited from Roy Branson's article "The Secularization of American Medicine" originally published in *The Hastings Center Studies* 1, no. 2 (1973): 17-28.

The question, then, is not how can I die well or have a good death, but rather, did I live well? Did I have a good life?[88]

To return to the scenario in *The Death of Ivan Ilyich*, when faced with death Ivan begins to question how he lived his life:

> "What if in reality the whole of my life was not done right? Could it be true that I have lived my whole life not as I should have done? It occurs to me that I never did fight against what people in high positions deemed good when they were wrong . . . I shrugged it off. And my work and the construction of my life and my family and my social and professional interest—all of them might not be the right thing. And if this is so, and I am leaving life in the knowledge that I have ruined everything that was given to me and it can't be put right, then what? All of my life was not the right thing, all of it was a dreadful, vast lie."[89]

In this form of analysis, patients evaluate how they lived their lives. There is no set standard for this analysis, no normative framework for "the good life." While no set standard exists, this does not mean that this process does not occur, a process adapted to the individual and one with various manifestations. If one asks oneself, "Did I live well according to my circumstances?" the circumstances will inevitably vary. Also, I do not mean to say that a person will explicitly ask oneself this question and then process his or her response externally, only that a from of ethical analysis occurs if the patient has the necessary cognitive ability to engage in the process.

A consequence of ethical self-analysis is a sense of deep grief over how one lived one's

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88.  My research attends to terminal adults; in the case of pediatric hospice care, parents may grieve over the loss of their child's potential life. The research of Ken Doka and Therese Rando offers nuanced scholarship on grief and mourning as it relates to the loss of a child. For instance, for parental loss of a child see the following representative example by Therese Rando, "An Investigation of Grief and Adaptation in Parents Whose Children have Died from Cancer." *Journal of Pediatric Psychology* 8, no. 1 (1983), 3.

89.  Engel, *Narrative in Health Care: Healing Patients, Practitioners, Profession, and Community*, 161.

life or a sense of a longing for more time so that one can live one's authentic life. Augustine's *Confessions*, for example, is a narrative of his grief over lost time with God. One can hear his longing in his words of lament, "Late have I loved you, Beauty, so ancient and so new."[90] With regard to the experience of grief, I am not including depression in this category, because, though depression often manifests for terminal patients there are confounding variables for this condition.[91] Depression can result from limited mobility, isolation, sleep deprivation and other physical factors unrelated to the process of ethical self-evaluation of life review. My overall claim that life review is a process of moral self-reflection corresponds with Cicely Saunder's recognition of the social and spiritual pain patients can feel at the end of life. I suggest that life review, though often presented as therapeutic or sweetly nostalgic, can unearth sources of pain for patients who reflect on their lives, and can be a source of pain itself.

<p style="text-align:center">Audience for Life Review</p>

The self-reflection and moral evaluation that occurs in life review does not have to be structured, encouraged, or elicited by a clinical caregiver such as a chaplain or social worker. Often the process occurs with a hospice volunteer, a person who visits a patient with no clinical motive or goal. Even in Tolstoy's story, it is not the clinician that serves the witness to Ivan's pain and death; instead it is the peasant child that stays with him. As Cicely Saunders notes in *Living with Dying*, "It is well known that interested ward orderly may hear more than anyone of matters which a

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90. Augustine, Gibb, John, Montgomery, W., *The Confessions of Augustine* (New York: Garland Pub., 1980).

91. B. Mastel-Smith, et al., *Testing Therapeutic Life Review Offered by Home Care Workers to Decrease Depression among Home-Dwelling Older Women*, 1037-49.

patient is unable to share with the professionals who surround him."[92] The volunteers offered by

hospice for social support are crucial members of the care team when it comes to bearing witness

to a patient's self analysis. The end of life is a time when patients can experience emotional, social,

and spiritual pain as well as a high level of depression.[93] One could argue that this depression

comes from one's prognosis, but also from one's awareness that time is short and that hopes for a

future self no longer carry the possibility of being fulfilled. This can be a time of anticipatory grief

over one's own life, the recognition that one's life will end before one is ready. Though her work

is frequently critiqued for establishing a formulaic 5-step model of how to respond to impending

death (Denial, Anger, Bargaining, Depression, Acceptance), Elisabeth Kubler-Ross's work proves

valuable for understanding the variation of emotional responses patients can have in response

to their awareness of death. Her patient-based research, in which she interviewed over 500

individuals in the early 1970's, published as *On Death and Dying* and printed as a popular text,

challenged the taboo on speaking about death in the U.S. and led to the recognition of the value

of home-based care for terminal patients.[94] The Hospice Medicare benefit approved in 1982 by

Congress and made permanent in 1986 was accomplished in no small part due to her research

92.  Cicely M. Saunders and Mary Baines, *Living with Dying: The Management of Terminal Disease* (Oxford; New York: Oxford University Press, 1983). 57.

93.  Carlos P. Zalaquett and Andrea N. Stens, "Psychosocial Treatments for Major Depression and Dysthymia in Older Adults: A Review of the Research Literature," *Journal of Counseling & Development* 84, no. 2 (2006), 192. Zalaquett and Stens report that up to 50% of nursing home residents show depressive symptoms.

94.  Elisabeth Kübler-Ross, *On Death and Dying* (New York: Macmillan, 1974). Her work addresses how individuals responded to their terminal status, yet her research became associated with stages of grief, a subject she barely addresses in the text. The value of her advocacy and scholarship has been unduly criticized for creating a standardized model of grief, when her research calls for commendation both for her emphasis on listening to patients and for promoting their preferences before the U.S Senate in 1972. Regardless of how her research was interpreted and directed, Kubler-Ross spoke openly about death and dying at a time when the subject was avoided in the public sphere.

and advocacy.[95] In her testimony, she spoke candidly about the marginalization of terminal patients and the need for reform for their medical care:

> "We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home."[96]

Curiously, her work is often linked with the bereaved, but her research was accomplished through direct interaction with terminal patients that she worked with while teaching at the medical school at the University of Chicago. She observed the spectrum of their responses to learning about and living with a terminal diagnosis. Denial, anger, bargaining, depression, and acceptance were emotional responses to one's terminal status.[97] Rather than maintaining that these emotions were required as a checklist for those grieving, she instead named the responses as possibilities for patients, expanding on the idea that one's grief responses are limited to feeling solemn. Kubler-Ross learned through speaking with patients that their responses to their terminal status involved more emotions than feeling "sad." She also learned that many would prefer to die at home rather than in an institution. Her research on the preferences of the dying and her

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95. "History of Hospice Care," National Hospice and Palliative Care Organization, https://www.nhpco.org/history-hospice-care. The timeline provided details the research and advocacy that led to the establishment of hospice as a Medicare benefit.

96. From her August 7, 1972 testimony before the U.S. Senate Special Committee on Aging, transcript of the hearings available at https://www.aging.senate.gov/imo/media/doc/publications/871972.pdf

97. Elisabeth Kübler-Ross, *On Death and Dying what the Dying have to Teach Doctors, Nurses, Clergy, and their Own Families* (New York: Macmillan, 1969).

public position advocating for them shaped policy that improved end of life care and worked to normalize discourse about dying, death, and grief.[98]

## Cicely Saunders and the Concept of Total Pain

Cicely Saunders established the hospice model of care in response to three deficiencies she observed in the medical model of care for dying patients. The first concerns comprehensive pain management for those who are dying. Attending closely to patients and drawing on their first-person reports in her research, she identified a pattern of inadequate pain control for the dying. In her text *Living with Dying: The Management of Terminal Disease*, she noted that patients voiced their symptoms to clinicians but nevertheless continued to receive partial treatment.[99]

The legacy of her critique of pain control for the dying can be seen today in the attention given to comprehensive pain management, particularly by pharmacists and clinicians working in hospice and palliative care. Hospice physician Dr. Ira Byock maintains that all physical pain can be successfully treated medically.[100] This is not to say that pain is fully treated—Byock will be the first to say it is not—only to say that it can be if clinicians make this their goal.[101] The work of Saunders combined with the confidence of physicians and pharmacists that pain can be fully treated can assure patients (or the general population) that they will not have to die in pain. Dying in pain remains one of the top fears of individuals when they consider their deaths.

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98. Laura Newman, "Elisabeth Kübler-Ross," *BMJ: British Medical Journal* 329.7466 (2004): 627.

99. Saunders and Baines, *Living with Dying,* 1983.

100. Ira Byock, *Dying Well: Peace and Possibilities at the End of Life* (New York: Riverhead Books, 1998).

101. Byock notes in *Dying Well* that not all patients prefer to die pain-free. As hospice is structured to honor patient preference, ultimately the decision to receive treatment for pain is left up to the individual patient in dialogue with the hospice care team and medical director.

Saunders' second concern also relates to pain management for terminal patients. Saunders recognized that not all pain manifests physically—pain can have an inward dimension and be oriented to emotional, social, and spiritual matters. She coined the term "total pain" to describe how pain is experienced three-dimensionally, in body, mind, and spirit.[102] Accordingly, if one is expanding beyond physical concepts of pain, not all pain can be treated pharmacologically. The different manifestations of pain call for a wide net of identification and treatment measures, transcending a pain management approach devoted entirely to the physical body. Yet, pain management for non-physical pain such as spiritual or emotional distress does not necessarily call for palliation; in many such cases, direct inquiry into the sources of a person's psychosocial or spiritual distress provides relief and a sense of recognition. Allowing the patient to examine his or her suffering, rather than attempting to assuage this pain, can offer succor to a patient whose pain may be avoided by others because the intractability of the person's pain discomfits them. Mere recognition that a person is in emotional pain can provide relief for those in distress. Also, physical, spiritual, social and emotional experiences of pain interconnect and impact each other; Saunders observed that after receiving spiritual and psychosocial attention to their concerns patients reported less pain.

Largely due to the research and advocacy of Cicely Saunders, medical treatment no longer relies solely on pharmacological treatment or the physician's independent judgment of the patient's experience of pain. Numerical pain scales (giving a number for the level of one's pain), face scales (choosing a face on the scale whose expression matches one's experience) and other

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102. Chi-Keong Ong and Duncan Forbes, "Embracing Cicely Saunders's Concept of Total Pain," *BMJ: British Medical Journal* 331, no. 7516 (2005): 576.

forms of naming the subjective experience of pain are now used by clinicians and caregivers.[103] Supplemental therapies are also increasingly used to mitigate pain for patients—massage, music therapy, and pet therapy, while still considered alternative modes of pain control, exist in the array of pain management possibilities available today. Saunders work on total pain accelerated medical interest in pain management and turned needed attention to extra-pharmacological forms of pain control for patients. Medical and non-medical forms of symptom management are not in conflict in her comprehensive view of patient care; her primary motive is to attend to what works to mitigate pain and suffering for patients, regardless of the source.

Finally, Saunders emphasized recognition of the dignity of terminal patients, recognizing that the treatment of patients calls for compassion and respect. She maintained that research on end of life care was a crucial part of demonstrating respect for the dying.[104] Accordingly, she called for new attention to pharmacological treatments for pain and prioritized patient comfort over a clinician's fear of opiate addition.[105] Saunders emphasized a shift in medical epistemology, envisioning a model of care devoted to the treatment of pain in all of its manifestations. Her normative vision for medical care for end of life patients led to increased attention given to pain management for dying patients receiving clinical care and encouraged a renewed focus on the spiritual and psychosocial aspects of end of life care. I speak to the latter in the next section on patient identity in the hospice model of care.

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103. Ellen Flaherty, "Using Pain-Rating Scales with Older Adults: The Numeric Rating Scale, the Verbal Descriptor Scale, and the Faces Pain Scale-Revised," *The American Journal of Nursing* 108 (2008): 40.

104. Caroline Richmond, "Dame Cicely Saunders," *BMJ: British Medical Journal* 331, no. 7510 (2005), 238.

105. Ibid.

Pain and Patient Identity

The hospice philosophy offers an alternative approach to patient identity that expands beyond

the biological reductionism found in medical models, particularly models in which clinicians

focus their care exclusively on the body. In contrast, the hospice model as designed by Saunders,

conceives of patient identity in three parts, including an inward, personal dimension, a social

identity formed by multiple strands of relationality, and, for many, a sense of identity that includes

a sense of the spiritual and a connection to organized religion, be this active engagement or

estrangement. Paralleling this view of identity, the concept of pain in hospice includes recognition

of personal suffering, relational tension, and spiritual or existential distress. The hospice team is

structured so that team members coordinate individual care for patients by creating a tailored

plan of care that addresses medical, personal, social, and spiritual needs, with specific attention

given to the sources of a patient's pain. Whereas the clinical goal in hospice is to manage physical

pain so that the patient is comfortable, comfort is not necessarily a goal for the personal, social,

and spiritual experiences of pain. Narrative practices such as life review can move a patient to

consider ways in which they fell short of their hopes and expectations for themselves and thus be

a contributing factor for an increase in emotional pain. The process can disinter painful memories

for patients or can bring into sharp relief the dysfunction that exists within families. Overall, the

goals of pain management within hospice differ depending on type of pain a patient experiences:

for physical pain the goal is comfort, but for the non-physical dimensions of pain, the goal may

be to allow the pain to be identified, named, and examined without an expectation of therapeutic

outcomes.

The Concept of Total Pain as it Relates to Life Review

One of the elements of total pain identified by Saunders is the pain that comes from isolation for

end of life patients. Because of the taboo against death and dying in the United States, and even the sense that death and misfortune can be contagious, terminal patients often go unvisited by friends and family members. Though many patients receive physical caregiving, they may receive little social stimulation via conversation or other forms of engaged activities. Mobility can be limited for terminal patients, restricting them to their place of residence. Some patients are bed-bound and placed in rooms in low traffic parts of parts of homes or hospital wings, receiving little human interaction. Though she did not use the language of "quality of life" common today, a term that can include social dimensions of patient experience, Saunders recognized the distress that comes from limited relationality and considered it worthy of attention in a patient's plan of care.

The attenuation of relationships for patients at the end of life can result in a near-solitary existence, even if patients reside in assisted living facilities they may experience isolation among others. Hospice addresses this form of social pain by offering volunteer companionship to patients, a visitor that comes in a non-professional role without even a plan of care. Though there is no set plan of care, a volunteer may engage a patient in a dialogical process of retrospection called "life review." Due to its social quality, the process can assuage the pain that comes from isolation and loneliness for patients at the end of life.

### The Ethics of Neglect: Failure to Care for Those in
### Spiritual and Emotional Pain as a Moral Concern

There are various sources of emotional, social, and spiritual pain for those facing the end of life. In addition to the emotional impact of receiving a terminal diagnosis, a person can be grieving an accumulation of losses: loss of health, abilities, and independence, future possibilities, relationships, loss of a job or the ability to engage in personal hobbies, and the losses of valued markers of identity or experience. There may be the radical fear that one has passed on a

inheritable terminal illness to one's children. Self-blame and condemnation can create anguish

for patients who believe they brought their illness on themselves due to behaviors or lack of faith.

One of the key differences between the pain of despair and physical manifestations of pain is

that the former cannot be easily assessed and efficiently treated. Physical pain can be reported

by the patient, but can also be observed by others in the form of clenched hands, a furrowed

brow, sounds of discomfort, wincing, and agitation. Inward pain, though it also has physical

manifestations through observable bodily tension, is primarily communicated through language.

Meeting with a chaplain can prompt conversations about personal distress that may not occur

with medical caregivers. However, it is imperative that clinicians learn when to make appropriate

referrals for patients in despair. Failure to diagnose and make proper referrals for patients in

emotional or spiritual pain signals an ethically-problematic neglect of their comprehensive well-

being because it does not attend to their total pain.

Patients in emotional or spiritual distress can trigger a sense of impotence for clinicians.

Trained to be diagnosticians and healers, the professional abilities of medial clinicians reaches

a limit-point for patients in despair because as there is no standardized treatment plan for a

patient's personal anguish. Also, when patients are angry about their health predicaments or

medical issues, they may lash out at caregivers and clinicians which can lead others to avoid them

or spend as little time as possible facing their distress. Nevertheless, difficult patients deserve

comprehensive care and sufficient attention despite their presentation, particularly as their

exacting state of being may be a symptom of unrecognized emotional pain, and concomitant

physical pain.

Recognizing Patients who are limited or unable to engage in Life Review

One can argue that the immediacy of pain does not allow one the to engage in a

retrospective ethical-analysis. Pain can cause a person to live in the moment; pain dominating

a person's attention such that the possibility of reflecting on one's life appears frivolous and

romantic.[106] Because pain has the power to limit one's thoughts to the moment, the philosophy

of care provided by hospice is all the more valuable. Physical pain-management is seen as

fundamental to care, so that other forms of interdisciplinary care—particularly, chaplaincy and

psychosocial care, become possible.

For patients with a high-level or functioning level of verbal and cognitive ability at the end

of life who have adequate pain management, the process of life-review and retrospective self-

evaluation can be a valuable enterprise, not necessarily a pleasurable one because it can disinter

uncomfortable moments in one's life, but one that nevertheless leads to an increase in narrative

material, personal information kept undisclosed until addressed during the dialogical process of

life-review. Some patients are referred to hospice too late in the process of physical and cognitive

decline to engage in the life review process.[107] Howarth, offering a class analysis of the "good

death" suggests that the concept of life-review, a model oriented to high-level verbal ability and

possibly the assumption that another person will have an interest in one's story, demonstrates

neglect of those who have more "stoic" deaths, often those who are poor or working class.[108] They

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106. Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985). Scarry describes how pain "undoes" language, though she does not advocate jettisoning the use of language to describe the experience of pain.

107. Carolyn Adams, Julia Bader, and Kathryn Horn, "Timing of Hospice Referral," *Home Health Care Management and Practice* 21, no. 2 (2009): 109.

108. G. Howarth, "Whatever Happened to Social Class? an Examination of the Neglect of Working Class Cultures in the Sociology of Death," *Health Sociology Review: The Journal of the Health Section of the Australian Sociological Association* 16, no. 5 (2007), 425.

may have the capability of talking, but it is not their preference to engage in conversations with strangers about their private concerns.

For patients with limited ability to communicate coherently due to physical, cognitive, or verbal limits, life review that requires first-person awareness of the self as it exists over time may not be feasible, as it requires a level of verbal communication not always available for these patient populations. For patients so limited, the process of life review can still occur, but via different modalities. For instance, it can be engaged in by those who knew the patient and can speak to his or her life as it was experienced by them. To use Ricoeur's language, those in some form of relationship with the patient, offer a testimony on his or her behalf as a form of narrative proxy. In the next chapter, I address the limits of the concept of narrative identity for patient populations with cognitive and verbal limitations.

Scholarship in narrative medicine largely addresses the clinical skills of the professional caregiver or the narrative structure of the clinical encounter. In this chapter, I turned attention to the narrative understandings of patient identity, particularly as they manifest in the process of life review. Life review can be engaged in by individuals at any time, formally or informally, but it frequently occurs in response to a milestone or turning point in a person's life. My stance in this chapter aligns with that of Robert Butler in his view that a terminal diagnosis brings the finality of one's choices and experiences into sharp relief. Hospice care in the United States, because it necessitates a terminal diagnosis for enrollment and because its clinical structure includes chaplains, volunteers, and social workers as fundamental providers of care, offers a context in which life review has a high chance of occurring. Due to the unfortunate reality of late referrals to hospice, a social understanding of patient identity offers another avenue for life review beyond the first-person narrative provided by the patient. In this chapter, I addressed the ethical components

of life review for the patient who is reflecting on the primary question in the study of ethics: What is the good life? This question moves from the speculative realm to the realm of concrete experience when the terminal patient considers how they lived and to what extent they did or did not realize their particular good life, due to choice and circumstance. In the next chapter, I examine the limits of practices of narrative medicine when working with patients who have cognitive or verbal limitations, considering ways in which narrative methods for understanding patient identity can still be used for patients with such challenges.

CHAPTER THREE

THE LIMITS OF NARRATIVE MEDICINE FOR END OF LIFE PATIENTS

In the previous chapter, I examined life review as a mode of moral analysis for end of life patients,

particularly for those enrolled in hospice care. My claim was that patients facing the end of

their lives often engage in a form of ethical analysis qua self-judgment in which they assess their

choices, contexts, roles, and limits in life retrospectively. The last chapter examined the practice of

life review as a narrative process of moral self-reflection for end of life patients, viewed through

the lens of narrative methods in medicine. Moral assessments incorporate culturally informed

categories—gender, marital status, family role, religious involvement, major life events, and other

culturally informed identity-markers that vary depending on how the person interprets his or her

experience, context, and life-events. The process is reconstructive, selective, and idiosyncratic.

Yet, themes emerge that demonstrate a preoccupation with judgment. Behaviors at the end of

life such as requests for forgiveness, an expressed longing for more time, and regret over missed

opportunities or past behaviors point to the function of moral evaluation for end of life patients.

The desire for confession and a fear of divine judgment or punishment points to the religious

dimension of retrospective life review. Though the method of analysis may vary from person to

person, especially taking into account demographics and social context, the process nevertheless

discloses a form of ethical self-evaluation.

In this chapter, I examine the limits of narrative methods for end of life patients that

have dementia.[1] While the merits of life review hold true for patients able and interested in the process, there are situations in which the process is compromised for certain populations of patients, particularly patients already marginalized due to their physical and cognitive states. In this chapter I identity these limits, noting the ways the process of life review can be expanded beyond verbal or strictly narrative methods. This chapter is structured into three parts, corresponding with three limits to the practice of narrative medicine. In the first, I identify limits related to a patient's ability to speak coherently in narrative fashion. In this section I address cognitive decline in end of life patients and address the impediments to verbal ability that can come with such decline, leading to unintelligible speech.

Next, I turn to the clinician's role in hindering communication in the clinical encounter, examining how a clinician's expectations for narrative coherence can artificially limit engagement with patients and family members. I look to Aristotle's *Poetics* as the source for understandings of identity held by those in narrative medicine and draw attention to those patients who do not fit the expectations of what it means to narrate their lives successfully according to Aristotle's narrative formula. On the clinician's side, I assert that moving beyond an Aristotelian understanding of narrative identity allows for engagement with a greater population of patients, whether the patient has full verbal ability or not. Additionally, an expansion on Aristotelian models allows life review to be a social process, rather than one that zeroes in on an individual as the main character that can offer a coherent, linear life narrative.

In the third section, I examine the ways in which context of end of life care can impede the

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1. Dementia is not a stand-alone diagnosis that makes one eligible for hospice care because a patient's decline can be gradual and is difficult to predict—a patient can have dementia for many years and not be terminally ill. However, many patients in hospice have a dual-diagnosis such as Congestive Heart Failure and a form of dementia, and it is these patients that I take into account in this chapter.

process of life review for terminal patients, including those with full semantic and neurological abilities. I identify common locations of care for end of life patients—specifically, the hospital, a residential facility, or a personal residence— noting the ways each of these contexts of care can enhance and further the process of life review for end of life patients, or can limit the process or exclude it entirely. Overall, I promote the value of life review as a narrative practice for end of life patients, not only as a therapeutic process, but also as an exploratory one that allows for ethical self-reflection and evaluation. Though I identify the limits of the process in this chapter, my goal is to expand on forms of patient-centered care within narrative medicine to include patients with cognitive and verbal limitations and patients who may be difficult to engage with due to their behavior or to constraints related to their context of care.

<div align="center">

**Cognitive Decline and its Effects on Narrative**

**Practices and Patient Experience**

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As life expectancy continues to increase in the United States, so does the likelihood of experiencing some form of cognitive decline as one ages.[2] Life review remains possible even with slowed or altered mentation; however, there are forms of cognitive impairment that significantly impede a person's ability to engage in the type of coherent verbal narration expected in encounters structured by the goals of narrative medicine. Alzheimer's disease, the most common form of dementia representing 60 to 80 percent of those affected, impairs cognition over time, compromising a patient's memory and ability to think and speak coherently.[3] The

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2. "Alzheimer Deaths Increased during the Previous Decade," *JAMA* 309, no. 17 (May 1, 2013): 1767–1767.

3. Alzheimer's Association, http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp.

disease leads to death, with progression of the disease often extending over many years.[4] Decline

in cognitive and motor function is inevitable; however, the disease progresses differently

and manifests distinct symptomology depending on the patient. A patient may demonstrate

disorientation and confusion regarding time, believing that he or she is experiencing a period

in the past, yet be able to describe this experience with clarity. The content of the account does

not align with reality; however, the structure of the account is coherent. In some cases there is

a blend of reality and a constructed reality. When a patient describes an event that occurred,

but embellishes or confuses the content of the account, details concerning location, subject

matter, and the players involved, a type of speech called "confabulation" exists.[5] Confabulation

describes an account that is partly true and partly constructed, recognized as such by the listener.

The person speaking in a confabulated manner typically defends the validity of the account,

possibly to protect a threatened sense of identity. As cognitive and verbal ability declines with

the progression of the disease, awareness of one's environment and the ability to attune to

conversation with others becomes impaired. Whereas in the beginning stages of the disease, a

person's speech was coherent even if the subject matter was disorganized, in the end stages of the

disease speech becomes progressively incoherent.

    In addition to Alzheimer's disease, other forms of cognitive decline can impede a

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4. Life expectancy with Alzheimer's Disease varies from 3 to 10 years, with some living up to 25 years with the disease. Death usually occurs due to choking, falls, or infection, rather than cognitive decline. "2014 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 10, no. 2 (2014), e59. However, current research shows that deaths due to dementia may be underreported: B. James, S. Leurgans, and L. Hebert, et al., "Contribution of Alzheimer disease to mortality in the United States," *Neurology* 82 (2014): 1-6. Dying *with* dementia or *from* dementia is often a hard distinction to make. For more on the distinctions see, M. Ganguli and E. Rodriguez, "Reporting of Dementia on Death Certificates: A Community Study," *J Am Geriatr Soc* 47 (1999): 842–9.

5. Linda Örulv and Lars-Christer Hydén, "Confabulation: Sense-Making, Self-Making and World-Making in Dementia," *Discourse Studies* 8, no. 5 (2006): 647.

patient's ability to narrate his or her life coherently. Vascular events such as strokes can impair

speech and neurological function, and degenerative diseases such as Parkinson's can similarly

limit communication, though neurological abilities may remain stable or have the potential for

improvement in such cases.[6] Additionally, a patient may present with dementia unspecified, a

general diagnosis for cognitive impairment, typically used for elderly patients. Dementia is not

a stand-alone disease, but an umbrella term for a constellation of symptoms such as memory

loss and impaired capacity for daily function.[7] Alzheimer's Disease is a form of dementia, the

most prevalent type of dementia for those aged 65-89, the old, and 90 and above, the oldest-old.[8]

While episodes of memory loss occur normally for aging patients; dementia is not understood to

be a natural part of the aging process and is instead considered a form of damaged neurological

function. A diminished ability to recall past events does not necessarily indicate dementia; such

decline is typical and non-pathological.[9] In these cases of ordinary decline, prompts such as

visuals or verbal reminders of either personal or historical events can rekindle a person's memory

such that they can engage in the recollective process of life review. With patients who have

dementia, the ability to understand verbal cues from another person deteriorates; therefore, direct

questions posed to encourage reminiscence are less productive, though certain prompts may elicit

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6. "2014 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 10, no. 2 (3, 2014), e47.

7. Alzheimer's Association, http://www.alz.org/what-is-dementia.asp

8. B. James, D. Bennett, P. Boyle, S. Leurgans, and J. Schneider, "Dementia From Alzheimer Disease and Mixed Pathologies in the Oldest Old," *JAMA* 307, no. 17 (2012): 1798.

9. The term for typical memory loss is Mild Cognitive Impairment (MCI). While it can be an indicator of Alzheimer's Disease, it does not always indicate a trajectory of further cognitive impairment. See the following text for more information: Glenn E. Smith and Mark W. Bondi, *Mild Cognitive Impairment and Dementia: Definitions, Diagnosis, and Treatment* (New York: Oxford University Press, 2013).

a coherent, if mismatched, response, notably familiar music and ritualistic or mannered language such as an exchange of a greeting or farewell.[10]

An Alzheimer's Disease or dementia diagnosis does not entirely rule out the possibility of life review. For the majority of those affected, cognitive decline occurs gradually over time and, with an early diagnosis, a patient can intentionally engage in the process of life review with the knowledge that the ability to engage in lucid reminiscence will inevitability become impaired.[11] In a form of tailored care called "therapeutic environmental design" clinical attention centers on the parts of the brain, and the patient's abilities, that are functional rather than focusing on the capabilities that have been lost.[12] As Robert Butler noted in his seminal work on life review, the retrospective process is often prompted by a terminal diagnosis.[13] However, a diagnosis of dementia or Alzheimer's Disease does not necessarily indicate that a person is imminently

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10. Mohamed El Haj, Virginie Postal, and Philippe Allain, "Music Enhances Autobiographical Memory in Mild Alzheimer's Disease," *Educational Gerontology* 38, no. 1 (2012): 30; Alison Wray, "Formulaic Language as a Barrier to Effective Communication with People with Alzheimer's Disease," *CMLR Canadian Modern Language Review/ La Revue Canadienne Des Langues Vivantes* 67, no. 4 (2011): 429. The latter article notes that the mannered or formulaic language used by patients does not always align with the structure of the conversation as understood by the caregiver and can lead to a caregiver choosing not to engage in further conversation with the patient.

11. Alzheimer's Disease is categorized as either early-onset or late on-set, depending on the age of the patient when diagnosed. The disease is then understood to be mild, moderate or severe, with seven intermediate stages of decline, depending on the patient's symptoms. "Seven Stages of Alzheimer's," Alzheimer's Association, http://www.alz.org/alzheimers_disease_stages_of_alzheimers. asp. The framework was developed by physician Barry Reisberg. The following article by Reisberg, et al, "Stage-Specific Behavioral, Cognitive, and in Vivo Changes in Community Residing Subjects with Age-Associated Memory Impairment and Primary Degenerative Dementia of the Alzheimer Type," *DDR Drug Development Research* 15, no. 2-3 (1988): 101.

12. M. Friedrich, "Therapeutic Environmental Design Aims to Help Patients with Alzheimer Disease," *JAMA* 301, no. 23 (June 17, 2009): 2430.

13. Robert Butler, "The Life Review: An Interpretation of Reminiscence in the Aged." *Psychiatry* 26 (1963), 65.

terminal (the six-month prognosis of death required by Medicare standards) and therefore

eligible for hospice admission.[14] Thus, while a patient in the early stages of cognitive decline may

have greater capacity to engage in the process of life review, they may be unaware of the process of

formal retrospection or they may find the preparations for their eventual decline in cognitive and

physical functionality to be more pressing than retrospective self-reflection.

<div align="center">The Loss of Socialization for Dementia Patients</div>

In addition to memory loss and the loss of day-to-day functional abilities, those with dementia

often experience a "social death."[15] One of the symptoms of the disease is a change in mood and

presentation, and such dramatic changes can fragment relationships.[16] Furthermore, the patient

may not recognize familiar and beloved friends and family members causing these individuals

to minimize contact with the patient.[17] Because those with Alzheimer's Disease and dementia

are frequently unable to respond to another person's facial expressions or nuances in language, a

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14. K. Yaffe, "Treatment of Alzheimer Disease and Prognosis of Dementia: Time to Translate Research to Results," *JAMA* 304, no. 17 (2010):1952-1953. The authors note that prognostic tools that would allow patients with dementia to be admitted to hospice are still in development. At this point, the rate of decline is too variable to accurate determine a diagnostic window that would make patients with dementia hospice eligible. For more information on the development of a prognostic tool, see the following: S. Mitchell, S. Miller, and J. Teno, et al., "Prediction of 6-month Survival of Nursing Home Residents with Advanced Dementia Using ADEPT vs Hospice Eligibility Guidelines," *JAMA* 304, no. 17 (2010): 1929-1935.

15. Helen Sweeting and Mary Gilhooly, "Dementia and the Phenomenon of Social Death," *SHIL Sociology of Health & Illness* 19, no. 1 (1997): 93.

16. "2013 Alzhiemer's Disease Facts and Figures, Symptoms of Alzhiemer's Disease," Alzhemier's Association.

17. Thomas Kitwood drew attention to the social aspects of dementia, emphasizing that they can often be just as, if not more, debilitating that the neurological and physical aspects of the condition. Tom Kitwood, "The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease," *Ageing & Society* 10, no. 02 (1990): 177.; T. M. Kitwood, *Coping with Dementia: The Person Comes First.* (Leicester: British Psychological Society, 1996).; Jan Dewing, "Personhood and Dementia: Revisiting Tom Kitwood's Ideas," *OPN International Journal of Older People Nursing* 3, no. 1 (2008): 3.

growing estrangement can occur leading to isolation for the patient. Social distance can occur for various reasons: the caregiver may expect a give and take from the patient, a reciprocal dynamic that may not be possible due to the patient's disease.[18] Additionally, caregivers are often unpaid and provide care without adequate respite or social recognition or acknowledgement from the patient; all reasons why a caregiver may limit their role to providing the fundamentals of physical care to the patient.[19] Unfortunately, the patient can experience social neglect even if his or her medical and physical needs are being met.

Commendably, there are other forms of interaction for dementia patients that extend beyond a verbal framework. Art therapy, music therapy, dance, and other forms of creative self-expression are available to patients falling on a spectrum of cognitive and verbal ability.[20] Such modalities of self-expression do not rely on a patient's ability to offer a narrative arc of selfhood. Due to being more experiential in nature than results-oriented, such activities may be more rewarding for patients whose cognitive capacities have declined, truly meeting them where they are and offering opportunities for stimulation, enrichment, and personal attention that extend beyond dialogical forms of personal interaction. Contemporary methods in narrative medicine

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18. Satisfaction can come from providing care to patients—the experience, while challenging, is not wholly negative. Adult children serving as informal caregivers for parents experience less satisfaction from providing care than do spouses. See the research of M. Lawton, et al., for research on the subject: "A Two-factor Model of Caregiving Appraisal and Psychological Well-being," *Journals of Gerontology* 46, no. 4 (1991): 181–189.

19. H. Kim, M. Chang, K. Rose, S. Kim, "Predictors of Caregiver Burden in Caregivers of Individuals with Dementia," *Journal of Advanced Nursing* 68, no. 4 (2012): 846.

20. B. Chancellor, A. Duncan, A. Chatterjee, "Art Therapy for Alzheimer's Disease and Other Dementias," *Journal of Alzheimer's Disease : JAD* 39, no. 1 (2014): 1; Heather Hill, "Journey without a Map: Dance Therapy with Dementia Patients," *How the Arts make a Difference in Therapy* (1993), 89; D. Duignan, L. Hedley, R. Milverton, "Exploring Dance as a Therapy for Symptoms and Social Interaction in a Dementia Care Unit," *Nursing Times* 105, no. 30 (2009): 4.

seek to be patient-centered, creating an environment in which clinical caregivers tune in with patients and engage in rich dialogical exchange. However, the structure of the clinical encounter as framed by narrative medicine is one that excludes the growing population of patients with dementia. Additionally, the model of care in narrative medicine is dyadic in nature; however, a patient's experience extends beyond the one-on-one, clinician/patient model found in narrative medicine. The social experience of patients lacks salience in narrative medicine, due to a focus on a patient as a "character," a concern I address in the next section.

Some clinicians that align with the narrative medicine similarly address the individualism in narrative medicine and in medical ethics in general. Jack Coulehan notes:

> The first difficulty with the narrow focus on individuals in a doctor-patient relationship is that it distorts who an individual is in our society. Each of us is embedded in a complex matrix of relationships—family, friends, coworkers, churches, community . . . Dyads are a convenient fiction in medical training, but a fiction that distorts young physicians' understanding of the values inherent in their work."[21]

Because the words and gestures of dementia patients are often hard to interpret for those who may not be familiar with the patient, such as clinicians who have only episodic encounters with them, there is need to expand the dyadic nature of the clinical encounter as it exists in narrative medicine to a social model that includes those who know the patient. In so doing, the limits of narrative medicine can be addressed such that the model still has value for patents who may not be able to engage in lucid dialogue.

Social enactment is another form of communication for those with semantic dementia. Though they may be unable to articulate their ideas with language, some can convey meaning

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21. Jack Coulehan, et al., "The Best Lack All Conviction: Biomedical Ethics, Professionalism, and Social Responsibility," *Cambridge Quarterly of Healthcare Ethics* 12, no. 1 (2003): 24.

through acting out what they are trying to say.[22] Usually, this form of communication is most effective with those who are familiar with the patient, such the patient's kin or a medical staff member in a residential facility that frequently and informally interacts with the patient to the degree that the staff member can interpret the patient's verbal and non-verbal cues. Hyden and Orulv note that the storytelling engaged in by those with Alzheimer's Disease can have a social and performative aspect. Caregivers familiar with the patient's stories can remind them of certain events and can serve as a responsive audience for the individual's account; they typically know the themes the patient values in the account and can support the development of the themes.[23] Dramatic arts are also useful for caregivers, usually non-clinical caregivers, in that the interaction enhances the bond a caregiver has with a patient, often a fraying bond due to caregiver burden.[24] Using drama has also proved efficacious as an educational tool for teaching clinicians how to understand and interact with dementia patients.[25]

## Moral Identity and Life Review for Verbally and Cognitively Compromised Patients

How does one understand narrative selfhood after taking in the limits imposed by cognitive

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22. Jacqueline Kindell, Karen Sage, John Keady, and Ray Wilkinson, "Adapting to Conversation with Semantic Dementia: Using Enactment as a Compensatory Strategy in Everyday Social Interaction," *JLCD International Journal of Language & Communication Disorders* 48, no. 5 (2013): 497.

23. L. Hyden and L. Orulv, "Narrative and Identity in Alzheimer's Disease: A Case Study," *Journal of Aging Studies* 23, no. 4 (2009): 209.

24. Margret Lepp, Karin Ringsberg, Ann-Kristin Holm, and Gunilla Sellersjö, "Dementia – Involving Patients and their Caregivers in a Drama Programme: The Caregivers' Experiences," *Journal of Clinical Nursing* 12, no. 6 (2003): 873.

25. Pia Kontos and Gary Naglie, "Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool," *Qualitative Health Research* 17, no. 6 (2007): 799.

decline? In the following section, I address the dimensions of narrative selfhood that concern

moral identity. Building on the last chapter, my specific research interest centers on moral inquiry

as it manifests in life review for the elderly. However, in this chapter, taking into account those

who have compromised ability to engaged in verbal narration, my research expands to include

other modalities of moral selfhood that include, but can move beyond, first-person written or

spoken accounts of identity. As I argued in the last chapter, ethical reflection relies on a mode

of narrativity that involves a reflexive turn, the ability to consider past behavior, and the ability

to engage in self-reflection about such behavior applying frameworks of moral reasoning, either

implicitly or explicitly. This chapter includes other forms of identity-expression that do not

necessarily require the components needed for written or spoken life review.

Specifically, I identify categories of narrativity that include those who are able to recall

events from their lives and can share these recollections with others as well as categories that can

include patients with limited ability to communicate with others. To make distinctions between

narrative capability for patients, specifically with regard to moral reflection, I use the terms Agent

Narrativity, Partial Narrativity, and Social Narrativity, addressing how these categories of agency

relate to moral identity in a narrative framework.

<div align="center">Agent Narrativity</div>

Agent Narrativity is the form of reflection such as that found in life review. Patients with Agent

Narrativity are able to recollect events from their life and to reflect on these events, offering a

moral evaluation of their circumstances or behavior, including missed opportunities or unfulfilled

desires. They can do this independently, documenting their reflections in an autobiography or

memoir, for instance; they can also do this in the form of structured life review with another

person in which the person asks the patient questions and has the option of recording the

response.[26] In such cases, it is the patient who is both the subject and the object of the analysis. They are the ones that generate the information, even if the remembrance is prompted or structured by another person, the other person functions in a secondary capacity as a catalyst for reminiscence. In Agent Narrativity, the patient can benefit from the presence of another person or a structure that facilitates their memory, but it is not necessarily for the process of recollection and review. For verbally and cognitively challenged patients, however, their ability to engage in reflection requires assistance in the form of the guiding presence of another person or the cues provided by reminders such as memory books and music. I address the modalities of reminiscence when describing Partial Narrativity.

**Moral Identity for those with Agent Narrativity**

Moral identity can be established in multiple ways. The topic draws on language that concerns selfhood: who am I? Am I the person I aspired to be? How did I live? These questions become particularly salient for hospice patients facing their final telos. As established in the second chapter, patients often engage in this process of ethical analysis via life review, engaged in either formally or informally. Some take into account the entire narrative arc of their lives, while others reflect on their experience with a present-moment analysis. Though a person may not explicitly state that an ethical analysis is occurring, the presence of normative language—was I a good father? Did I do what I wanted to do in life?—points to the activity of moral self-evaluation.

The interpretation of time comes into play in the process of life review; a patient engages in a self-assessment as the self functioned over time, with signposts in life marking significant event. Graduating high school, joining a religious body, starting a job, marrying one's spouse,

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26. Barbara K. Haight and Barrett S. Haight, *The Handbook of Structured Life Review* (Baltimore: Health Professions Press, 2007).

all serve as points of remembrance for individuals reviewing their lives. These events may be signified through mementos around one's home or through photographs, and can prompt life review for patients able to independently engage in the process. In ways, these events can serve as "chapters" to a patient's life, upholding the narrative concept of identity as it relates to life review.

Time can function differently for patients depending on their residence. For patients who are at home, they may have more control over how time is structured day-to-day. Social markers of time such as birthdays and anniversaries can serve as external reminders of life events. For those living in a residential facility, however, time for ordinary events is not necessarily in the patient's control. The schedule of bathing, eating, and recreational, therapeutic, or medical activities may be designed to serve a multitude of patients with the goal of institutional efficiency rather than accommodating individual desires. Small, home-style residence models can offer an alternative to this institutional structure, allowing for more tailored care.

Additionally, the tenor of social relationships can change. Some AD patients experience the consequences of stigma when they disclose their diagnosis to friends, coworkers, and family members. Though their cognition may be declining, in the early stages of AD there remains an awareness of other's perception of one's status as cognitively impaired. Consequently, individuals with AD may be infantilized or avoided because of their diagnosis. John Turner notes that this is problematic because our identities are both internally and externally constructed; our sense of self cannot be fully separated from how we are perceived by others.[27]

With regard to self-analysis, however, previous research shows that patients are able to separate their individual sense of self from their socially recognized self, particularly when

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27. John C. Turner, *Rediscovering the Social Group: Self-Categorization Theory* (Oxford, UK; New York, NY, USA: B. Blackwell, 1987).

stigma is involved. For instance, when patients experience memory loss, even though this may cause distress in their caregivers or social group, the individual may interpret their experience as an aspect of typical aging, a nonpathological consequence of human development. This ability to separate one's self-appraisal from one's social-appraisal suggests that patients do retain a recognizable sense of identity, in the early stages of AD at least.

The process of life review shows moral analysis at work for verbal patients who have the requisite cognitive and verbal capacity to engage in the task. However, moral identity for verbally and cognitively challenged patients calls for closer attention. Though some scholars maintain that the self is fundamentally a narrative self, patients with Alzheimer's Disease and patients with other forms of semantic dementia, though they may not have access to a linear store of memories, nevertheless demonstrate that they have a continuous sense of self.[28] Coherent use of first-person signifiers are present even for some in late-stage Alzheimer's.[29] Additionally, there can also be periods of lucidity that indicate to self-awareness.[30] Because patients claim that they have selfhood even though they cannot access all forms of selfhood (their married self or parental self, for instance): the question for consideration in such cases becomes, how then is moral analysis demonstrated for those with neurodegenerative status and a compromised ability to reflect on their lives?

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28. L. Tippett and D. Addis, "Memory of Myself: Autobiographical Memory and Identity in Alzheimer's Disease," *Memory (Hove, England)* 12, no. 1 (2004): 57.

29. R. Tappen, C. Williams, S. Fishman, and T. Touhy, "Persistence of Self in Advanced Alzheimer's Disease," *Image: Journal of Nursing Scholarship* 31 (1999): 121–125.

30. H. Normann, K. Asplund, and A. Norberg, "Confirmation and Lucidity During Conversations with a Woman with Severe Dementia," *Journal of Advanced Nursing* 39 (2002): 370–376.

Partial Narrativity

Partial Narrativity is a term that recognizes those patients who may not able to engage in life review in a structured way but still engage in reminiscence and reflection, both spontaneously and when prompted. In the following sections, I identify the multiple ways patients can engage in moral reflection even with verbal and cognitive limits. In the section following this one, I attend to forms of social narrativity that function even for patients who are mute, unconscious, or nonresponsive. Methods of social narrativity also apply to those who have died.

Moral analysis can occur for patients with early stage AD; however, for advanced patients or for patients with mutism or those who cannot speak coherently, moral analysis can occur via proxy. This is also true for patients with full verbal and cognitive capacity; however, the observers interpretation is then added to the patient's narrative, sometimes with the option of the patient correcting the content of either the observer's narrative or their own. With patients who are severely limited or who cannot speak, the narrative provided by the observer stands without the possibility of correction by the patient concerned. While someone who knows the patient may have access to more details of the person's life, a visitor may also be able to piece together elements of the person's moral identity through pictures, newspaper clippings, vocation, etc. This is all to say that the patient is not the exclusive source of moral analysis and that without the ability to self-interpret one's past behavior this behavior can nevertheless be interpreted socially.

**Confabulation as an Example of Partial Narrativity**

With AD patients or patients with unspecified dementia, there are degrees of language ability, ranging from mild, moderate, to severe. Those with on the advanced end of the spectrum

with severe dementia may speak in gibberish or become mute and nonresponsive.[31] In mild to moderate forms of disease progression, patients do not completely lose access to communication; rather, their vocabulary becomes less nuanced, words are repeated, and that language claims may contain tendrils of truth or be true thematically, while not being historically true.[32] For instance, in her article "Making Sense of the Stories That People with Alzheimer's Tell: a Journey with My Mother," Jane Crisp identifies confabulation as a meaningful form of speech exhibited by AD patients.[33] She draws on her conversations with her mother as representative of this type of speech. In confabulation, a patient blends past experiences or emotional states with their current experience. In her mother's case, she felt as though there were "danger" near and she spoke of the loss of children. Her daughter initially thought that her mother was fabricating these stories, especially because of their fantastic nature. However, she came to realize that her mother lived by hot pools and there was a "danger" sign near them that she saw everyday. She interprets her mother's language about the loss of children as pointing to the possibility that she had miscarriages that were not publically disclosed.

While Crisp's interpretations of her mother's account and other moves to interpret blended stories cannot necessarily falsified or verified, such interpretations work to erode the notion that AD patients are speaking nonsense and therefore do not call for being heard. Crisp listens to her mother's repeated concerns and responds with concern; linking her research about attending to AD's words to the research which shows that AD patients are aware of

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31. Wray, *Formulaic Language as a Barrier to Effective Communication with People with Alzheimer's Disease*, 429-458.

32. Ibid.

33. Jane Crisp, "Making Sense of the Stories that People with Alzheimer's Tell: A Journey with My Mother," *Nursing Inquiry* 2, no. 3 (1995): 133.

others' perceptions of them, there is call then to err on the side of listening to AD patients and attempting to interpret their language rather than dismissing their words as incoherent and disconnected from current reality. Crisp concludes in her research that family members often feel the impulse to correct patients and adjust the patient's claim to historical reality. She suggests that the impulse may originate from the observer's need to assert that they have uncompromised access to reality as it is.

Confabulation does not necessarily point to a process of ethical analysis; yet, it does point to the existence of content-based language for compromised patients to such a degree that their speech is worth taking into account. Language that does point to ethical analysis is language of evaluation of one's earlier behavior. "I was a good x" "I was proud of x" "I should have done x" "if only," phrases such as these and their variants indicate moral self-analysis. AD patients may not have full access to the entirely of their lives, though it is debatable whether persons without dementia have full access either; however, the process of recollection and evaluation and still occur. This process can occur in structured fashion through life review or can happen spontaneously. Butler identifies both as modalities of life review.

**Assisted Recall**

Partial narrativity also manifests in the form of assisted recall. With assisted recall, patients are prompted to engage in reminiscence with visual or auditory aids. Depending on how advanced their deterioration is, the patient may have only minimal recollection of the events; however, the cues assist them in partial narration of their past behaviors. Because memory, specifically the details of past events, becomes impaired over time, with the initial diagnosis, a patient with Agent Narrativity can then work to make a document or visual collection that

recounts the details of significant life events.[34] When the patient later experiences waning memory, the patient can be reminded of life events and either fill in the story of hear the story from others.

If no photos are available, caregivers can create generation scrapbooks based on the patients earlier context and time period in which they lived. With advanced dementia the patient may have no recollection of these events. Furthermore, the patient may show no discernable response to the person showing them the resource. A patient's flat affect can be difficult to encounter for visitors and caregivers who may be used to interpreting such a response as lack of interest. However, the social value of the interaction with the patient calls for engaging in the process even if the patient shows no recognition of the events in the book or does not demonstrate affirmative feedback about the process. Similar interactions could occur via video; however, because this is a more passive medium, the interaction may be less likely to occur. One of the benefits of video however, is that a patient in early stages of dementia can record messages to their loved ones that can be used once the patient is no longer able to function at the same cognitive level. The benefit of using video in this way is that the person has a living record of the person in a multi-dimensional way; they can see them and their body language, can hear their voice. A moment in time is preserved as well.

In addition to scrapbooks, music has been successfully used to generate recollection in AD and other dementia patients. Music from a patient's earlier life can bring up memories of one's youth and young adulthood and evoke descriptions about that time period in a person's life. In addition to increasing cognitive activity, the process can also be therapeutic for patients in

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34. Baddeley, et al. use the language of "clouding" to describe the loss of detail that occurs for those with dementia: "Dementia and working memory," *Quarterly Journal of Experimental Psychology* 38A (1986): 603-618.

that the music serves as a form of companionship when other visitors are not present. Hospices often recognize the benefit of such therapies as scrapbooking and music and include them as part of the plan of care. Additional art therapies such as using color to describe emotion (with the assistance of small, colored stones among other physical aids), allows those who have an eroding vocabulary of words to describe their emotional state to nevertheless communicate their inner state. Such approaches are also useful for grief therapy to elicit responses in the bereaved that they may not be able to fully articulate or may not feel as though it is socially acceptable to feel "red," for instance. Music therapy in hospice can take the form of soothing music played at a patient's bedside to the use of music to facilitate relationality between patients and volunteers. Additionally, chaplains may be able to identify familiar hymns from a patient's faith tradition and play those for patients, offering comfort through deep familiarity.

Social media and other technological tools can also serve to facilitate recollection, evaluation, and social connection for patients.[35] Some AD patients begin blogging when they learn of their diagnosis so that they can record the experience and share it with others.[36] Real time narration such as that that occurs via blogging can be an approach that includes moral reflection such as that found in life review. However, though it can also be a more in-the-moment form of observation and appear to be stream of consciousness, if it is a public blog, attempts to engage in comprehensive review that includes regrets may be lessened because of the audience-

35. J. Rodriquez, "Narrating Dementia: Self and Community in an Online Forum," *Qualitative Health Research* 23, no. 9 (2013): 1215.

36. For instance, "Silverfox" blogs about his experience with Lewy Body Dementia due to Parkinson's Disease: http://parkblog-silverfox.blogspot.com/. The blog creates a record of narrative self-expression, shows how he copes with his changing cognitive state, and serves as a vehicle for social interaction as he can see how many people have viewed his site and can interact with readers via comments and email.

factor.[37] A person may instead offer an edited presentation of self rather than participating in a form of review that includes negative components of one's history and interpretations of moral identity.

In addition to social media, other forms of social support include groups in which AD patients meet with each other to talk about their experiences with the disease. Such groups can be more intimate because they are centered on those who have the disease (groups also exist for family members and caregivers of those who have they disease. They are often invited to the former meetings as well) Though my research on life review tends to have a retrospective focus, the social gatherings of those diagnosed with AD may be more oriented toward one's future self. Employing normative language, one can speak about the kind of person one wants to be and the kind of life one wants to have before and as they decline. This future orientation also represents a form of moral self-analysis in projected rather than review form.

**Familiar Texts**

The use of familiar texts can also facilitate partial review for patients. Favorite books from a person's childhood, familiar poems, sacred texts that they may have heard repeatedly, all can serve a therapeutic function, providing comfort even if the patient may have lost the ability to comprehend the meaning of the words. As with familiar hymns and common songs from the patient's earlier life, the rhythm of the language may be recognizable though the meaning is incomprehensible. Whereas, the formal process of life review relies on the ability to access one's previous history, those engaging in the process can also draw on means of assistance such as those

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37.  A benefit of the publicness of online social media is that it can connect individuals to each other who may otherwise be isolated as their disease progresses. Online support groups are also valuable for caregivers of those with dementia who may be unable to physically leave the patient alone to attend in-person support groups. Alzheimer's Association, "Caregivers Support Groups," http://www.alz.org/care/alzheimers-dementia-support-groups.asp

used in partial review. In so doing, the use of aids then does not become linked with a stigmatized

disease and remains a neutral means of fostering reminiscence and possible reflection.

All of these forms of assisting recollection contribute a person's ability to demonstrate

partial narrativity. The patient may not be able to bring forth a narrative account of his or her life

when asked a direct question. However, prompts may facilitate dialogue and reflection on the part

of the patient. When a patient has partial narrative ability, there can be moments of recognition

from the patient that indicate a response of familiarity. However, even if no response occurs, the

process nevertheless has therapeutic value for the patient because it involves social interaction, an

activity that is repeatedly shown to decrease depression and agitation in patients.[38]

## Social Narrativity

Social Narrativity relies exclusively on others speaking on behalf of the patient. In cases of

social narrativity, the patient is physically or cognitively unable to express selfhood is therefore

is unable to express any form of retrospective moral analysis. However, a form of narrative

identity still exists for such patients. It can take the form of family members describing the

patient as they knew them over time; it can also include the reports of coworkers who may have

encountered another side of the patients' behavior. One form of Social Narrativity occurs by

means of bereavement care for those surviving the patient's death. The hospice benefit offers one

year of post-death bereavement care for family members and those close to the patient. In many

cases, bereavement care begins before the patient dies. Doing so increases the likelihood that

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38. Additional forms of supplemental therapies include massage and pet therapy. While valuable for sensory stimulation and social interaction, these were not addressed directly as they do not designed to create opportunities for narrative self-reflection. L. West and J. Polubinski, "Implementation of a Massage Therapy Program in the Home Hospice Setting," *Journal of Pain and Symptom Management* 30, no. 1 (2005):104.; M. Maleske, "Hospice Care. Pet Therapy," *Hospitals & Health Networks / AHA* 78, no. 11 (2004).

bereavement services will be used and creates a sense of continuity because those who cared for the patient continue to be available to share their experience with and memories of the person.

A concept of social narrativity allows for a concept of narrative identity to be viable even for patients who are unable to narrate. This mediates the concerns raised by figures such as Jerome Bruner who maintained that individuals who are unable to articulate a sense of self through narration literally do not have selfhood. Though Bruner did allow for a social understanding of narrativity, his primary interest was in a person being able to take into account the narration of another person, to be able to hear another as a separate individual. Without this ability, one's independent selfhood is compromised in his rubric. My understanding of social narrativity does not concern the ability to hear another's narrative as much as it concerns the observer's attempt to construct or recreate the narrative of another. It also includes the moral assessment of another's life according to one's terms as an observer. For instance, a son may say that he knew his mother identified as a good mother, but according to his expectations, his mother did not meet his social needs. Both appraisals are a form of Social Narrativity as it relates to moral identity.

The benefit of Social Narrativity is that it does not require functioning cognition on the part of the person being considered. A drawback is that the assessments cannot be verified by the person. They can, however, be verified by others who knew the person, other family members, other coworkers, other clinicians, and so forth. Moral analysis occurs through the interpretation of those who knew the individual. Ultimately, there is no one true moral assessment made by observers, or even by the individual person demonstrating Agent Narrativity for that matter. As with life review, my concern is not the veracity of the moral evaluations, merely that they occur and indicate ethical analysis.

One of the primary limits of narrative medicine is that the method of clinical care promoted in the model applies to a limited subset of the patient population. The patient has to be verbal and cognitively aware of self, others, the environment around them, and they also need to have a retrospective sense of selfhood within time. Patients with semantic dementia are not taken into account in methods of narrative medicine because the model relies on a dialogical relationship between caregiver and patient. Ultimately, the patient has to be perceived as a rational agent for a narrative clinical encounter to operate. Rita Charon uses the language of mutuality and reciprocity to describe the equalization of roles within a clinical session framed by narrative medicine.[39] By focusing care on a portion of the patient population that has high-level cognitive abilities, other patients and their experiences can go unattended. Patients who cannot speak or think according at a level that corresponds with the clinician's expectations can be marginalized and rendered exempt from care. In the next section, I attend to the expectations clinicians bring to the clinical encounter, expectations that can exclude or disregard patients with cognitive and verbal deficits.

### The Limits of Narrative Medicine Due to Clinicians' Overreliance on Patients' Verbal Abilities

Narrative methods in medicine (attending to a patient's story, parallel charting, life review, etc.) are valuable for some patients, but ultimately limited in scope, and often impractical given the growing population of those with dementia.[40] Not all patients are able to offer a self-narrative or understandable verbal response, due to a cognitive deficit such as Alzheimer's disease, aphasia,

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39. Rita Charon, "Narrative Reciprocity," *Hastings Center Report* 44, no. 1 (2014): S21.

40. Rita Charon, "Narrative Medicine: Form, Function, and Ethics," *Annals of Internal Medicine* 134, no. 1 (2001):83-87.

or lack of consciousness. Physically and cognitively some patients cannot think along the lines of a linear narrative and are unable to share their narrative with another. A patient with a cognitive deficit can also engage in behaviors that are interpreted by clinicians and caregivers, behaviors such as picking in the air or at themselves, nodding, rocking, staring, and other physical behaviors that may or may not have meaning. In a clinical context built on a dialogical model of patient-interaction, patients who are unable to meaningfully interact with others are needlessly forced into a position where they cannot adequately provide what the clinician seeks.

Expanding beyond narrative accounts that rely on verbal abilities, other forms of self-expression exist for patients that can supplement the dialogical model of narrative medicine, such as art-based therapies. Such therapies are also valuable because, as they do not rely on recollective storytelling. Rather, they allow a patient to be his or her current self, rather than focusing on a past sense of self, an aspect of identity that may be lost to the patient. Moving beyond a narrative-based patient encounter allows for greater patient involvement in comprehensive care in which a patient's experience is central. Additionally, methods of social narrativity in which those who know the patient and can speak to how the patient lived allows patients who cannot speak for themselves to benefit from attention given to their personal identity. This is particularly valuable for older patients, as many experience social isolation as they age.

Undoubtedly, narrative medicine can be mutually beneficial, both for caregivers who value the practice, and for care receivers who value being heard. The model of care can create space for recognition, connection, and genuine relationality in a clinical context often described as impersonal. Training in the field can enhance a clinician's ability to attend very closely to what a patient is communicating, the premise being that a close reading of text correlates with detailed attention to patients, or, to use Ricoeur's language, methods in narrative medicine can create a

context in which the "world of the text can meet the world of the reader." Many patients feel as though their personhood is overlooked by clinicians focused on physical care and efficiency.[41]

The critiques raised in this chapter are not intended to dispute the overall value of methods and training informed by the principles of narrative medicine, but to demonstrate the ways in which the approach is limited and can be supplemented by other models of engagement in and beyond clinical sessions.

<div style="text-align:center">Limits Concerning the Clinician's Training and

Expectations for Reciprocity and Meaning</div>

In this section, I speak to the limits of narrative method on the clinician's side, specifically those who are trained in narrative medicine. Narrative medicine relies on a concept of patient identity that does not always align with how a patient presents in a clinical context. There are two primary features of patient identity as it exists in narrative medicine that I address in this section, time and agency. While not always conscious or intentional about their use of this model, clinicians trained in narrative medicine approach time and patient identity from an Aristotelian perspective, as I explain in the following section. Aristotle's poetic framework is deeply embedded in Western literature; however, its structure, particularly concerning the acts involved in character development, is not always relevant to patient identity. Paul Ricoeur offers an expansion on Aristotelian models of time and agency that can hold value for a concept of patient identity in narrative medicine that is inclusive of verbally and cognitively compromised patients.

In this analysis, I examine the ways in which clinicians trained in narrative medicine can impose standards from Aristotle's *Poetics* to clinical encounters with patients. Clinicians may

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41. D. E. Epner and W. F. Baile, "Patient-Centered Care: The Key to Cultural Competence," *Annals of Oncology* 23, no. suppl 3 (April 01, 2012): 33.

not consciously or intentionally approach dialogue with patients in this way; however, clinicians

trained in narrative medicine can bring with them expectations of the patient's side of dialogue

that do not necessarily align with the patients desires or abilities.[42] On a basic level, there can be

expectations of linearity, unity, and coherence with regard to the patient's narration of history and

identity--all are features of Aristotle's concept of tragedy in his *Poetics*. These expectations, often

taken as a given by the clinician, may not be achievable by patients with compromised speech or

memory issues, or they simply may not be elements of how a patient reflects on his or her life.

I now turn to the elements of Aristotle's *Poetics* that clinicians or clinical scholars of narrative

medicine apply to the clinical encounter.

<center>How Aristotle's Concept of Character Informs Concepts</center>

<center>of Patient Identity in Narrative Medicine</center>

In Aristotle's *Poetics*, a text on the elements and function of drama that serves, in part, as a

response to Plato's suspicion of poetry in *The Republ*ic as a seductive distraction, he names

different types of poetry (drama), distinguishes poetry from history, and outlines the components

of poetic narratives that make them successful. For the purpose of this chapter, his description of

tragedy is where I will look to note the ways scholarship in narrative medicine interprets patient/

clinician dialogue. Aristotle responds to Plato's negative appraisal of poetry in *The Republic* as

being estranged from the real, by claiming that poetry does not strive for precision, accuracy,

immutability, or any approximation of the real. Rather, poetry is representational, a reflection

of aspects of reality, that ultimately does not strive for a correct description of objects or ideas.

Poetry attempts to intentionally provide an imitation of an action. By imitation (mimesis),

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42. Rita Charon, "The Great Empty Cup of Attention: The Doctor and the Illness in the Wings of the Dove," *Literature and Medicine* 9, no. 1 (1990): 105.

Aristotle means the experience of connection that can result from the detached experience of observation. For instance, in Emily Dickinson's poem about encountering the "narrow fellow in the grass," a snake, and feeling "a tighter breathing, and zero at the bone" she provides the reader with an opportunity to mirror, remember, or consider this experience of primitive fear without actually being in the presence of any danger. This experience of fear is satisfying, in a safe, detached way; the reader knows the snake is a literary figment. It is satisfying in a way that coming across a real snake would not be. Aristotle uses the example of a dead body—we can be in the presence of a dead body in drama and experience a sense of appropriate consummation, whereas encountering a dead body in real life would be disturbing, deeply upsetting precisely because it would be real, even if the death itself was perceived as inevitable or just. The imitation of poetry/drama does not attempt to portray reality, but instead offers an opportunity to dwell in a separate, obviously constructed space—a set, a stage, a theater, a story—to experience a response to the content, and then leave that space and return to the social order.[43]

After speaking about the goals of poetry/drama, Aristotle distinguishes between different types of poetry and then presents a detailed taxonomy of tragedy. Tragedy consists of six features; in order of most important to least important for dramatic success, tragedy includes an emphasis on plot, character, diction, thought, sound, and spectacle. Dramatic success is the arousal of pity or fear in the viewer, one that results primarily from the movement of the plot, and stemming from a sense of connection with characters who present as relatable, neither wholly moral nor thoroughly vile. The structure of the plot is crucial to successful tragedy, and the moral state of the character, while important, is second to plot because it attends to qualities or states of being rather than actions. His work on tragedy comes the closest to components of dialogical interaction in

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43. Richard Kearney, "Narrating Pain: The Power of Catharsis," *Paragraph* 30, no. 1 (2007), 61.

the clinical encounter, particularly his understanding of plot, though the other elements come into play as well, and I will address their role after examining Aristotle's attention to plot.

Plot (mythos) has three components: reversal, recognition, and suffering on the part of the protagonist. A successful plot involves the movement of a generally respectable character from fortunate circumstances to a state of misfortune. In a complex plot, there can be a moment of surprise when this reversal (peripetaia) occurs, but from the perspective of the viewer, narrator, or author, this transition from high to low was logical and nigh inevitable. The unstoppable climax and unraveling of events in the narrative is precisely that which leads to pity or fear in the viewer, a successful tragedy for Aristotle. When the truth of one's place in the world is revealed to or realized by the character, there is an experience of recognition (anagnorisis) on his or her part, though this awareness does not change the impending consequences of the character's actions, consequences that result in an experience of suffering (pathos).

In addition to the principles of recognition, reversal, and suffering, Aristotle emphasizes the linear structure of narrativity in his *Poetics*. In tragedies, there is a distinct beginning, middle, and end, and the plot progresses as an unfolding of the coil of possibilities that existed from the beginning of the storyline. Aristotle also emphasizes thematic unity in dramatic works, and promotes a narrative in which events follow from each other and are logically connected. According to the *Poetics*, a plot must be shaped by unity, wholeness, and linearity. Modern forms of literature, whether dominated by fragmented dialogue or lacking a linear frame, would not satisfy his expectations of successful drama. He specifically addresses episodic accounts as deficient, lacking in thematic unity of action. I argue that patients with compromised speech or cognition would be better served by those trained in literature that rejects Aristotelian principles of successful drama. The dramatic works of Samuel Beckett, for instance, in which repetitive,

disjointed, confused speech prevails, applies directly to the experience of patients with dementia. In Chapter Four, I examine Beckett's work in detail as an option for case study in narrative medicine.

Also, in Aristotle's delineation of drama he identifies the necessity of denouement in the structure of the plot, the resolution which follows the culmination of events experienced by the protagonist. The denouement is the "end" to linear structure of drama, for the viewer, the signal to leave the mimetic space and return to the social order. For the protagonist, the denouement is the resolution of the drama. It is this expectation of resolution that I believe is placed on patients in the clinical encounter, especially for patients at the end of life. The clinician's expectation of a sense of harmony for patients, manifesting in the form of recognition of past wrong doing, or the reunion of family members, may be insensitively imposed on a patient. For instance, regarding the reunion of family members, counselors may work toward reconciling a patient's disconnected family members through group therapy sessions in the hope of creating what can be called "restorative justice." However, the patient may not share the social worker's impulse toward reconciliation. In patient-centered care, then, there would be need for the clinician to withhold or suspend his or her desire for denouement or resolution in the patient's life.

Janelle Taylor notes that Ann Fadiman's *The Spirit Catches You and You Fall Down*, now considered a classic in the medical humanities, stands as a text that follows the Aristotelian formula for tragic drama to the letter.[44] The Spirit Catches You is an anthropological account of a young Hmong girl diagnosed with epilepsy. The conflict involves what Taylor describes as a "clash of cultures", the Hmong culture, represented by the child's parents, and the scientistic medical

44. J. Taylor, "The Story Catches You and You Fall Down: Tragedy, Ethnography, and ''Cultural Competence," *Medical Anthropology Quarterly* 17 (2003): 159–181.

culture, represented by her doctor's. Ultimately, Taylor critiques the account for its oversimplified description of culture, one that can unintentionally reinforce stereotypes about minority communities (i.e., the Hmong are "defiant" as a people, and the clinicians were not appropriately sensitive to why a child's parents would refrain from giving their child life-saving medicine). In the text, it is this clash of cultures and misunderstanding on both sides that leads to the child having a grand-mal seizure that puts her in a coma, an event that was impending from the beginning of the narrative. Hence Taylor's identification of the narrative as one that exemplifies Aristotelian tragedy.

As it stands today, the field of narrative medicine relies solidly on Aristotelian standards for drama as they are outlined in the *Poetics*. On a basic level, there can be an expectation of coherent speech, that the patient will be able to respond to the clinician's prompts and, one could say, satisfy the clinician's desire to flex his or her skills in narrative medicine. Rita Charon emphasizes the skill-set model of narrative medicine, that being trained in the model of care will allow a clinician to develop empathic regard, close listening, and a more reflective clinical practice. A parallel can be made to Daniel Callahan's understanding of medical technology: any tool that can be used will be used, regardless of genuine medical need. His maxim is one explanation for the ballooning use of dubiously necessary medical testing and treatment. This is all to say that a clinician trained in narrative medicine may approach conversation with a patient with expectations informed by Aristotelian tenets of successful narratively and attempt to engage with the patient in a tool-based manner that does not correspond with the patients abilities or preferences. The clinical encounter then becomes one in which the clinician is the main character rather than the patient, compromising the likelihood of patient-centered care. Ironically, the

clinician trained in narrative medicine believes he or she is being a close listener, but it is precisely this training that limits the clinician's ability to be genuinely present with a patient.

Regarding the role of diction in the *Poetics*, one benefit of the Aristotelian model as it relates to narrative identity for verbally and cognitively compromised patients is that there is recognition that language serves a greater function than just providing facts. Aristotle identifies to the value of metaphorical speech and normative speech, that language can describe what ought to be rather than what is, asserting that this type of diction has the same epistemic value of descriptive speech. When making a distinction between history and drama, he notes that history involves descriptive speech addressed to particular periods of time and experience, whereas drama attends to human experience in a shared, general way, attending to broad themes that speak to the human condition. Relating his thoughts on diction to the speech of patients with dementia, while the patients may not be speaking in a manner that attends to concrete experience as others understand it, their language may nevertheless communicate states of being, personal preferences, or reflections on the past. Recognition of the epistemic value of their speech may lead to less "correction" of what is perceived to be inaccurate speech by caregivers or those communicating with the patient.

Aristotle lists character as his second category of development in tragic drama. The details of his thoughts on character relate to narrative identity in multiple ways; however, for the purpose of this chapter I draw attention to one unstated aspect of his description of character. While also attending to the place of the chorus and other characters, Aristotle concentrates on the role of a single protagonist in his account of tragic drama. He does not directly state that there must be one character in the spotlight; however, his description attends primarily to a single figure (Antigone, Odysseus, Oedipus, Iphigenia). The language of "tragic hero," not specifically found in the

*Poetics*, is nevertheless derived from Aristotle's concept of the protagonist and the protagonist's sympathetic flaw (hamartia).[45] A reversed form of this concept is Talcott Parson's idea of the "sick role" in which a diagnosis, illness, or disability can exclusively constitute an individual's sense of personhood or how they are perceived by society.[46] The challenge with this focus on a single character (one mirrored in medical ethics by the attention given to patient autonomy) is that an person's experience of illness is both individual and social. A terminal patient, in most cases, depends on care from other people, and he or she will leave others bereaved after death. When attention is directed primarily to an individual and his or her experience, there can be neglect of the person's fullness of identity, and a diminishment of comprehensive care. Additionally, if a patient has limited verbal or neurological function, the person may not be able to speak to caregiver in an understandable way. In such cases, there is value in looking beyond the individual patient's experience, to that of the patient's family and greater network of relationships.

## The Presumed Desire to Connect in the Clinical Encounter

Turning now to an analysis of how the clinical encounter can be shaped by the clinician, whether implicitly or explicitly, according to an Aristotelian paradigm, I first want to speak of the value of the approach and then take into potential problems that can arise. A distinct value is that the clinician approaches dialogue with a patient in a listening posture, rather than approaching the patient as a dominant authority figure speaking to a benighted patient or in a provider-consumer dynamic. When a clinician approaches dialogue with a patient with an ear to listen deeply, the asymmetry of care that can exist between clinician and patient can be minimized in an approach

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45. Though Aristotle maintains that his concepts apply to drama rather than other forms of literature or "narrative" nevertheless, the principles have been foundational to the western cannon.

46. Talcott Parsons, "The Sick Role and the Role of the Physician Reconsidered," *The Milbank Memorial Fund Quarterly.Health and Society* 53, no. 3 (1975): 257.

to dialogue informed by values of narrative medicine. A form of authority is granted to the patient in a context when patients can be perceived as or can self-interpret their role as a passive recipient of care. Furthermore, research shows that training in narrative medicine correlates with empathic regard for patients.

A common complaint among patients in the United States is that physicians provide an insubstantial amount of time for their concerns and that their experience in the clinical context is one dominated by a depersonalized approach to care. Being heard by a physician who is listening with full attention to details and shades of meaning can deepen and enhance a patient's experience of care in the clinical context. On a related note, studies show that when clinicians meet with patients in a spirit of reconciliatory conversation, the patients are less likely to sue for malpractice—a common response to why they did not pursue litigation is that they just wanted to be heard. Clearly, there is a longing for connectivity for some patients when it comes to clinical care. Clinicians who are trained in the practice and methods of narrative medicine can attempt to meet this need for patients so interested.

For other patients, however, a clinical visit structured on narrative medicine is neither desired nor tenable. Some patients are private and view their doctors as service-providers trained to attend to matters of the body, not the person. Others are unable to offer the kind of high-level conversation the physician may expect. My concern is how training in narrative medicine prepares clinicians for attending to patients who are unable to offer a coherent narrative. If they are trained in providing care for fully verbal and neurotypical patients, how do they respond to patients who are unable to engage in sophisticated dialogue? Applying concepts of linearity and recognition of one's place as an agent are Aristotelian concepts of narrative identity that do not apply to all patients.

**Ethical Analysis of Narrative Medicine**

In "Narrative Reciprocity," Charon writes about how listening to patients and writing about one's experience can create a dynamic of "reciprocal reciprocity." However, this term is not adequately addressed in her account. It is possible that what she calls reciprocity is actually a form of objectification of the patient. Take, for instance, her metaphorical use of the word "mirror." She uses the language of a mirror to describe how she views her patients: "I discovered that writing not only helped me to see the couple with clarity but also enabled me to see myself in the mirror of their gaze as a dependable and affiliated clinical partner.[47]

The challenge here is that the "mirror" merely reinforces the clinician's appraisal of his or her own work—because the mirror offers a self-reflection, there is no true reciprocity involved. Reciprocity would include the patient's ability to challenge or critique the clinician, not merely the function of reinscribing the clinician's interpretation of being an exceptional clinician. Rather than a scenario of reciprocity, what appears to be a reciprocal relationship on the part of the clinician is a variation of objectifying the patient for the clinician's purposes.

She also uses the language of "gaze," in part, a refiguration of the Foulcaldian concept of the medical gaze: "As I gaze at a patient, trying to recognize his or her situation, I am "gazed back at," recognized as someone who can recognize.[48] Charon's misstep is equating her gaze and the patient's gaze as a connection grounded in reciprocity. There is an asymmetry in the clinician-patient dynamic that does not create the conditions for a reciprocal gaze. A better term may be "mutually beneficial," but the gaze is not reciprocal, particularly if the patient is viewed as an object or a mirror. Additionally, when she tries to recognize the patient's situation, there is an

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47. Charon, *Narrative Reciprocity*, S21-S24

48. Ibid., S23.

assumption that the present can be fully known rather than a recognition that the patient has an inner life inaccessible to the clinician.

In the clinical encounter with patients, who are often in a vulnerable position and experiencing powerlessness and fear, there is a need for humility not reciprocity. Additionally, clinicians risk objectifying patients by turning them into artistic objects of study or as there to meet the needs of the clinician. Consider, for instance, Charon's reflections on her clinical presence:

> "So in the midst of my clinic session, I've taught myself to attend—to behold and to separate the beholding from the acting. I literally sit back in my chair. I do not turn the computer on at the beginning of the visit. I do not write or type. When I gaze at my patient, I find that I do what I do while gazing at the Baie de Marseilles, vue de l'Estaque of Cézanne, while attending a jazz piano recital of Fred Hersch, or while standing at Ground Zero. I receive these works or this place and am summoned out of my ordinary self by virtue of their integrity, their solemnity, and their beauty."[49]

In addition to the danger of objectifying the patient, lurks the danger of romanticizing the patient. Describing the patient's integrity, solemnity, and beauty limits the patient's ability to be broken, ordinary, and sick. When the clinician expects the patient to be beautiful, the patient has to perform a model-function for the clinician, creating a potential burden for an already physically, emotionally, and often, financially drained person. The patient comes to the clinician in need of receiving care, rather than as a figure meant to serve the clinician's needs.

Bioethics emerged as a formal response to the objectification of patients in a medical or medical research context, demonstrated in the Nuremberg trials and the ethical code developed in the wake of the trials. In documents such as the Belmont Report, an emphasis on patient autonomy was dramatized to counter historical practices of human objectification and to prevent future occurrences. The objectification of patients also emerged in conversations about clinical

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49. Ibid.

regard and patient dignity. Referring to patient's by their room number or diagnosis is an example

of this form of objectification: "the cancer in room 1341"[50] for instance. Jack Coulehan notes

that dignity, rather than being connected with the intrinsic value of the patient, has narrowed

to mean respecting a patient's rational choice. Dignity has been reduced to autonomy.[51] What

began as an effort to protect a patient's personhood and subjectivity in the genesis of bioethics

became a reduction of such personhood to mere choice. Coulehan notes that children and those

with cognitive impairment are not included in such a concept of human dignity, as it relies on

functioning rational agency.[52]

Methods of clinical interaction informed by narrative medicine seek to honor a patient's

personhood and narrative particularity thereby maintaining a deeper understanding of patient

dignity, one that extends beyond autonomy. One of the goals of this approach is to reduce the

objectification of patients as objects and to approach them as subjects in their own right, in

Martin Buber's language, as a "thou" rather than an "it." However, when a patient is referred to

as a mirror or as serving to reflect back to the clinician the clinician's listening skills, the patient

continues to be seen in a functional manner. While the structure appears to be one based on

personal relationality and mutual reciprocity, the role of the clinician nevertheless continues to

be dominant. Though well-intentioned, the clinical posture promoted in narrative medicine does

not necessarily reduce patient objectification. For instance, Arthur Frank names three themes

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50. Jack Coulehan, ""They Wouldn't Pay Attention": Death without Dignity," *American Journal of Hospice and Palliative Medicine* 22, no. 5 (2005): 339-340.

51. Ibid.

52. Ibid., 341.

prominent in patients' narratives: restitution, chaos, and quest.[53] If a clinician approaches a

clinical session with these three themes in mind, the clinician is likely to find them in the patient's

dialogue, thereby framing and interpreting the patient's experience. However, the patient may

have a very different interpretation of his or her life that does not involve restitution, quest,

or chaos. Similarly, a patient's narrative may not include Aristotelian elements of recognition,

reversal, or suffering. Such themes create compelling drama, but the themes found in written texts

do not necessarily have a one-to-one parallel in patients' narratives.

A clinician trained in narrative medicine can be present in a way that some patients seek

and prefer. For such patients, a clinician only interested in the medical aspect of their care may

come across as brusque and impersonal. For other patients, however, a clinician who aspires to

engage in reciprocal reciprocity may be met with resistance.[54] In addition to objectifying patients

and approaching patients with high-level expectations of reciprocal dialogue, narrative medicine

is highly individualistic, often maintaining focus on the patient as the hero of a narrative, an

approach informed by Aristotle's *Poetics*. Patients who have dementia or verbal limitations

are excluded from such models of care. To honor a patient's preferences, it is best to assume

neutrality and to inquire as to whether or not the patient would prefer a more personal clinical

session. Approaching patients this way maximizes their agency, important in a time when many

experience a diminishment of agency, and minimizes the chance of intruding on a patient's

personal sphere.

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53.  Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995).

54.  S. O'Mahony, "Against Narrative Medicine," *Perspectives in Biology and Medicine* 56, no. 4 (2013): 611. See also Galen Strawson's article, "Against Narrativity," *Ratio* 17, no. 4 (2004a): 428.

**Applications to Nonclinical Caregivers**

Directed foremost to clinicians, the concerns I address here also apply to nonprofessional

caregivers; some caregivers can have expectations of a bedside reminiscence that is idealized and

disconnected from the patient's desire or ability. For instance, some patients show no interest

in discussing the lives of their children, grandchildren, or even of their own past, and instead

focus on day-to-day life in their residence. A caregiver familiar with the patient may find this

disinterest upsetting. I maintain that this distress stems from an interior desire for the patient

to display a normative narrative identity, a concept of identity shared by those who approach

the clinical encounter from the perspective of narrative medicine. There are occasions where

approaching a patient from this perspective limits one's ability to be authentically present with

a patient, especially if the patient does not fit neatly into Aristotelian categories of narrative

selfhood. Demented patients may be dwelling in a domain of time in which the caregiver either

did not exist or did not matter. The caregiver can either listen with attention given to the patient's

understanding of time and identity or approach the patient with the attempt to impose his

or her understanding of time and identity. When the latter occurs, dissatisfaction on the part

of the caregiver and emotional distress on the part of the patient can result. An unfortunate

consequence of this discomfort is that a nonclinical visitor may reduce interactions with the

patient to avoid the experience of incoherence.

**Ricoeur's Expansion of Aristotelian Models of Narrative Identity**

In the following section, I look to Paul Ricoeur's understanding of narrative identity, making

connections between his thought and life review in hospice. Ricoeur's concept of the self

ultimately allows for narrative-based understandings of personhood even for verbally and

cognitively limited patients. His work expands on Aristotle's concept of narrative identity in ways

that make narrative identity applicable to the caregiver-patient dynamic. Overall, while there are concerns with narrative medicine on the clinical side, narrative identity continues to be a valuable framework for concepts of the self, particularly for those engaging in life review. I understand Ricoeur's framework as one that can include all of the categories of narrative agency for patients—agent narrativity, partial narrativity, and social narrativity.

<p style="text-align:center">Narrative Identity through the Lens of Paul Ricoeur</p>

Due to his interest in narrative identity, his understanding of the limits of self-awareness, and his concept of radical passivity, Ricoeur's work can deepen an understanding of the moral identity for patients, particularly those at the end of life. Ricoeur uses the language of "life plan" rather than life review, maintaining that we project the concept of our selfhood into the future, taking into account our past and present concept of self. His work on the alterity of the self also provides value for an understanding of both the physical body and selfhood for those with a terminal diagnosis. For Ricoeur there will always be an opacity present when it comes to self-understanding; one's own self is perceived as another. Thus the achievement of complete self-awareness is not possible. Nevertheless, even though self-knowledge is not fully possible, selfhood is based on narration, only a form of narration that blends history with fiction. To further connect his thought with the moral identity of end of life patients, the process of narration as Ricoeur describes it does not rely on a sole person considering one's own history; rather it is both an individual and a social process.

Ricoeur takes as his foundation Aristotle's understanding of plot, that we narrate stories with a distinct beginning, middle, and end. To distinguish his understanding of narrative identity he prefers the term "emplotment" as a word that points to narrative identity as one based on a process of selfhood that functions over time, an activity of self-making. He notes

that narrative identity is based on interpretation, and interpretation that takes into account one's history, including fictional history and how one envisions oneself.[55] For Ricoeur, fact has a fictional component and fiction has a factual component. He supplements Aristotle's model by expanding on the concept of mimeses, dividing it into three parts: prefiguration, configuration, and refiguration.[56] Additionally, the understanding of the passivity of the self that he presents in *Oneself as Another* adds another way of looking at personhood that does not rely exclusively on individual agency.

Ricoeur's work is valuable for an understanding of narrative moral identity for end of life patients because he views the self fundamentally mediated, marked by interpretation, both social interpretation and self-interpretation, noting the limits of interpretive activities on both sides. Ricoeur points out that we are not accurate self-reporters, and we may not have reliable insight into our own behavior. There is no "pure" autobiography in his view. The subject's claims are not epistemically superior merely because the person is offering a self-narration. Nevertheless, the question, "Who am I?" is a compelling one for Ricoeur, particularly in *Oneself as Another*.[57] At the end of life, I claim that patients no longer as the question "Who am I?", and instead turn this question into one centering on reflection and ethical analysis, asking, "Who was I?" This is the turn toward ethical self-analysis that occurs via life review in hospice. For those patients unable to even consider this question, their family members or social cohort answer the question instead either on behalf of the patient while the patient is still alive or during the period of bereavement support following the death.

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55. Paul Ricoeur , *Oneself as Another* (Chicago: University of Chicago Press, 1992), 114.

56. Paul Ricoeur , *Time and Narrative* Vol. 3 (Chicago: University of Chicago Press, 1984).

57. Ricoeur , *Oneself as Another*.

Concepts of personhood in narrative medicine often rely on a derivative of the Aristotelian concept of identity, assuming that individuals are heroes of their own narrative and that they are fundamentally agents with regard to how life unfolds within the arc of their lives. However, not all patients narrate their lives as if they were the "hero" of an individual story.[58] Furthermore, not all lives have plots or a narrative arc. Some do; for instance, some patients can experience distress precisely because their "plot" has been interrupted by a diagnosis or catastrophic accident. They then have to reformulate a new life plan after this shift. Aristotle uses the language of *peripeteia* to describe this experience, one in which a person encounters a "reversal" in life, a tragedy that also allows for discovery. Many patients who are confused or have dementia, however, do not fit into Aristotle's concept of narrative identity as it is presented in his poetics. They may have a slow decline, rather than an abrupt shift in circumstances. They may exist in the liminal space of a medicated haze with dulled cognition and limited awareness of the environment. In a basic sense, the possibility of constructing a plot is not possible for those who are unable to express a current sense of self. Ricoeur's concept of narrative identity and the moral self supplements how Aristotelian understandings of selfhood are used in narrative medicine because he expands beyond an individualistic model.

<div align="center">Life Review and the Limits of Ricoeur's Concept of "Life-Plan"</div>

Ricoeur uses the language of "life-plan" to describe his understanding of agency. Though it would appear as though one could make a parallel here to life-review in hospice, a direct comparison does not precisely exist. Ricoeur's interest is in how the ethical self is understood in ways as a projection toward the future. He speaks of the ethical "aim" for instance, in his petit ethics, aiming

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58. Alice Hendrickson Eagly, *Sex Differences in Social Behavior: A Social-Role Interpretation* (Hillsdale, N.J.: L. Erlbaum Associates, 1987).

for the good life, with and for others in just institutions. In hospice this future-orientation can be present, for instance, one can desire to repair relationships, go on trip, or plan one's funeral or last wishes for care; however, I suggested in the last chapter that a terminal diagnosis often compels a person to look backward, analyzing how one did live instead of how one plans to live in the future. When one makes the retrospective turn, the relevance of "aim" speak diminishes; the future self, the agent of Ricoeur's "life plan" becomes less compelling. One's historical life, embellished by memory or fiction as it may be, exists then as more content-based, more fixed in time, than one's idea of a future self. One then makes the backward turn and analyzes how one lived according to a moral framework.

This analysis, however, does not require a life-plan. It requires only the recognition that one did not live the way one could have lived or ought to have lived. Ricoeur's "I can" understanding of agency reaches its earthly limit and one realizes that there was lost time or opportunity in one's life, regardless of whether or not these opportunities were a part of someone's life-plan or plot. That is to say, one can engage in this form of ethical self-analysis without comparing how one lived to a fixed ideal of how one hoped to live according to an established life-plan. One can consider the course of one's life and feel deep satisfaction that one did in fact live an authentic life (this model does not have to be achievement-based). Reflecting on the question, "How did I live?" is distinct from reflecting on the question, "Did I achieve my life plan?" Also, it is debatable whether or not one even has a "life-plan;" for some limited by trauma, they can experience a sense of fore-shortened future, having no expectation of a projected self. Others, as Galen Strawson argued, have a more episodic concept of self in time.[59]

For Ricoeur, the "I can" concept of capability has four parts: I can speak, I can act, I can

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59. Galen Strawson, "Against Narrativity," *Ratio* 17, no. 4 (2004b): 428.

recount, and I can impute (and be imputed).[60] For those able to recount, they can interpret their

lives according to how they spoke, acted, and were responsible. For those terminal patients who

cannot speak or cannot recount their lives, it is the interpretation of others that contributes to

their identity. When applying Ricoeur's understanding of agency to the process of life review

as it exists in the hospice philosophy of care, it becomes clear that the ability to recount is an

important one. To expand on Ricoeur, a patient engaging in life review will use their ability to

recount their story, naming and analyzing the ways in which one spoke and acted (shifting the "I

can" understandings of "I can speak" and "I can act" to the past tense, thus reflecting on how one

spoke and acted). The first three capabilities Ricoeur names—speaking, acting, and recounting—

function as key features in life review. For patients challenged by cognitive and verbal limits, the

ability to speak, act, and recount contracts or disappears entirely. However, Ricoeur's modalities of

narrative selfhood continue to be relevant, particularly when looking at the activity of recounting

and the activity of imputation.

The activity of recounting continues to hold value for concepts of narrative selfhood for

end of life patients because this activity does not have to be engaged in by the person involved.

A patient's family members, friends, and colleagues, even neighbors or professional caregivers

can narrate the person's life and work to create narrative identity on the person's behalf. This

is not to say that a witness's testimony is accurate, only that the activity of recounting as it

relates to narrative identity remains possible for patients who are unable to narrate their lives

themselves. Though there may be some epistemic distance between the life of the patient and the

observer describing the life of the patient, this distance does not call for rejecting the observer's

perspective. Furthermore, the accuracy of a person's first-person narrative is also questionable,

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60.  Paul Ricoeur , *Memory, History, Forgetting* (Chicago: University of Chicago Press, 2004).

particularly in medicine.[61] The clinical encounter is by nature goal-based, though the goals of the patient and the goals of the clinician may differ, and because the encounter is goal-based, information is selected to represent and support one's goal. By goal, I do not mean "agenda" such as a treatment agenda on the part of the clinician or drug-seeking behavior on the part of a patient; rather, in an admittedly general sense, the goal of the clinician is a diagnosis followed by a plan of care, and the goal of the patient is to receive care and make sense of the events occurring to the body or mind.

This is all to say that narrative identity continues to be possible for end of life patients who are themselves unable to offer an account of their lives. These accounts can be offered vicariously and work to establish a narrative identity for patients. In ways, the analysis offered by witnesses can be perceived as more substantial than the one provided by the patient. If the question for analysis is what kind of parent was the patient—the best person to answer this question may be the child, not the parent. Ricoeur noted this situation in his fourth capability, that of imputation. Imputation is a category of narrative identity that creates space for accusing and being accused. Ricoeur includes misconduct, neglect, even malevolence into the category of imputation, recognizing that identity includes brokenness and the possibility of evil.[62]

Narrative identities constructed by those who speak on behalf of the patient also point to the social aspect of Ricoeur's understanding of selfhood: that all identity is mediated, both by ourselves and by others. Identity is filtered through memory, interpretations provided by others,

61. Kathryn Montgomery, *Doctors' Stories: The Narrative Structure of Medical Knowledge* (Princeton, N.J.: Princeton University Press, 1991), 62.

62. Ricoeur's concept of the misuse of freedom and its attendant guilt that he speaks to in both Paul Ricoeur , *Fallible Man* (New York: Fordham University Press, 1986).; Paul Ricoeur , *The Symbolism of Evil.* (New York: Harper & Row, 1967). Butler notes that such individuals have a particularly challenging time when evaluating their lives (Butler, *The Life Review*, 70).

and through a conflation of one's sense of self with the characters that exist in our imagination, characters that we encounter through fiction that we relate to on a deep level. When it comes to applying Ricoeur's concept of selfhood to compromised patients, there are some gaps, however. The places where Ricoeur's concept of narrative identity reach their limits are cases in which patients appear to lack self-awareness or self-recognition (the term self-esteem is used in *Oneself as Another*, but that connotes a positivity that does not accurately portray Ricoeur's view of identity). Though the question, "Who am I?" captivates Ricoeur, this question assumes a level of cognitive ability that does not exist for all patients. While self-recognition may not be possible for such patients, there is still value in Ricoeur's concept of attestation when it comes to understanding narrative identity through relationality, even for patients who are unable to offer a coherent narrative themselves.

Ricoeur's concept of the self holds value for analyzing the process of life review and for how to approach the epistemic value of the narrative accounts provided in the process because he recognizes that memory involves a fictional component—that our stories can never be pure fact, just as fictional narratives rely on a truth-base and are not complete inventions of the author. The issue at hand is not whether the patient's claims represent a "true" biography; facticity is not the concern. The concern, rather, is with the value of the process for the patient, with the additional value of possibly having a first-person record of an ordinary person's life that would be lost with the person's death. The person's memories, therefore, do not necessarily have to be true to be valuable because the standard of evaluation is not one based on external verification. Ultimately, it is the process of reflection and ethical evaluation that is valuable, rather than the veracity of the patient's claims.

## Context of Care and the Effects on Narrative Practices

In the second section I addressed the ways in which methods of narrative medicine can be

limited by a clinician's expectations of the process. In this section, I address how the patient's

context of care enhances or limits narrative methods in medicine, with special attention given to

the process of life review for terminal adult patients. One's context of care, be it at home or in a

hospital setting, crucially shapes the likelihood of this process occurring for patients. Specifically,

I examine home-based care, hospital care, and residential care as areas that call for attention, as

these are the contexts of care for most hospice patients. For hospital care and residential care I

identify different modalities of care within these contexts: acute care and standard care, such as

the ICU and home-like or institutional facilities respectively. Though the majority of patients

claim to prefer receiving care and dying at home, hospice services and the location of death often

occur in non-residential contexts such as the intensive care unit.[63]

In Robert Butler's research on life review, he claimed that older persons engage in a

process of reflection about the course of their lives, particularly as they face life's end.[64] He

maintained that this is a universal feature of aging, one that is often prompted by a terminal

diagnosis. I would add that an early diagnosis of Alzheimer's Disease, Parkinson's Disease, or

other forms of neurodengernative diseases can also move a person to reflect on and morally

evaluate his or her life while they still have cognitive and verbal capabilities. As stated in Chapter

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63. Fischer, Stacy, Sung-Joon Min, Lilia Cervantes, and Jean Kutner. "Where Do You Want to Spend Your Last Days of Life? Low Concordance Between Preferred and Actual Site of Death Among Hospitalized Adults." *Journal of Hospital Medicine* 8, no. 4 (2013): 178-183.

64. Butler, *The Life Review: An Interpretation of Reminiscence in the Aged.*, 65-76. Sharan Merriam questions the universal nature of Butler's claim and the connection he makes between death awareness and life review. See "Butler's Life Review: How Universal Is It?" in Jon Hendricks, *The Meaning of Reminiscence and Life Review* (Amityville, NY: Baywood Pub. Co., 1995).

2, I focus on hospice care because the model promotes direct conversation about the patient's impending death. This frankness about the patient's prognosis often leads to life review for a patient because they shift from a future concept of selfhood to a retrospective concept of selfhood. I suggest that the context of home-based care and home-like residential facilities offers the optimal living conditions for the manifestation of narrative moral identity through the process of life review when done informally. However, the formal process, because it is structured, limited, and timed, can be successfully undertaken regardless of context. While I include patients who have verbal and cognitive limitations, the patient population I address here is more general in scope.

<div align="center">Home Care</div>

## Home with Unpaid or Paid Caregiver

Hospice appeals to patients who prefer to remain at home in a familiar context with familiar caregivers. A benefit of remaining at home is that patients will receive personalized attention from a person that knows their history. In such cases, the likelihood of informal life review and individualized care may increase. However, patients can nevertheless go untended to by family members depending on their location in the home. For instance, if a patient is in a bedroom in the back of the house; he or she may only experience human contact when a specific need arises. One way to increase interaction with family life is to place the hospital bed in the living room of the home or another room where ordinary interactions occur. Doing so allows patients to be involved, even if through observation and physical presence, in the day-to-day household conversations. Having the patient's bed in the main room of the home may encourage family members to speak to the patient or to reminisce about the patient's life. Such encounters may prompt an informal process of life review for the patient.

For some patients, the possibility of unpaid, family caregivers there to provide continuous attention to their medical and nonmedical needs is not a realistic option. In such situations, paid caregivers can assist in a patient's activities of daily living and serve as a point person for the hospice care team. These more clinical relationships may not provide an ideal context for life review, as the caregiver is often paid by the hour to perform necessary care-tasks such as bathing, feeding, and ambulating the patient. However, the non-familial relationship does not preclude a dialogical mode of relating for the patient and the caregiver; this relationship would exist on a case by case scenario depending on the desire and the personality of the patient and the personality of the caregiver.

**Home without a Paid or Unpaid Caregiver**

Though prioritizing patient autonomy and preference with regard to many of the specifics of care, hospice is not a model that is fundamentally oriented to the individual patient. Admission requires the presence of a caregiver; only in exceptional cases will an independent patient be enrolled in hospice.[65] The assumption is that as the patient declines, independent living will become untenable. The hospice care team, then, strives to prepare for the patient's future caregiving needs even if they are functioning sufficiently on their own when they are admitted.

If one is able to pay for their services, it is possible to have contingent caregivers provide assistance with a patient's daily needs. For some patients, however, a caregiver, either paid or unpaid, is a luxury that they do not have. Some patients may be homeless or not have a

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65. Andem Effiong and Stephanie Harman, "Patients Who Lack Capacity and Lack Surrogates: Can They Enroll in Hospice?" *Journal of Pain and Symptom Management* (2014).

permanent home.[66] Others may live alone for their safety, such as those enrolled in the Witness Protection Program, a program where a patient's former identity is "erased" and replaced with a new formal identity. In addition to having limited access to models of care such as hospice, the process of reminiscence and moral self-analysis that occurs in life review becomes complicated because the fractured nature of their lives.

<div align="center">Hospital Care</div>

**Hospital: Acute Care**

Though the majority of patients claim they would prefer to die at home either with unpaid or paid caregivers, deaths commonly occur in the hospital.[67] This occurs for a variety of reasons; a patient may be receiving care at home, but when the person begins to actively die his or her caregivers will call an emergency number, rather than the on-call team in hospice. Additionally, a patient may experience a fall or an acute event such as a stroke that warrants a hospital admission and during this short-term stay the patient expires. There are some clear advantages to receiving end of life care in the hospital, a salient reason being that care is continuous and pain management options are immediately available. However, interactions in a hospital setting, particularly in an acute-care environment, are by necessity and design short and goal-oriented. Once the objective is achieved, for instance, administering a medication, the encounter ends without much opportunity for dialogue. An exception to this may be visits by nursing assistants there to take vital signs, an activity that allows for some level of verbal encounter that is not goal-

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66. Erica Wilson, "Dying Without a Home: Understanding and Responding to Palliative and End-of-Life Care Needs of Homeless Patients (SA516)" *Journal of Pain and Symptom Management* 45, no. 2 (2013): 403-403.

67. Derek Angus and Robert Wood Johnson Foundation ICU End-Of-Life Peer Group, "Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study," *Critical Care Medicine* 32, no. 3 (2004): 638-643.

based (conversations that occur while taking blood pressure, for instance). Physician Christine Puchalksi notes that it is often the janitor or the nursing assistant (roles that are seen as lower in the medical hierarchy) that the patient will speak to about his or her fears or desires, rather than the medical staff in the hospital.[68]

**Hospital: Non-acute care**

In non-acute care contexts, such as the oncology unit in a hospital, opportunities to engage in repeated dialogical encounters are more likely to occur. One caveat is that hospice patients are unlikely to be in such environments because the model of care stipulates that patients receive no curative treatments. Some exceptions include treatments that sustain life, but do not prolong it, such as therapeutic radiation or dialysis treatments. Patients receiving daily care may be more likely to form relationships with clinical caregivers and hospital staff that they frequently see. Due to such day to day encounters, the possibility of a narrative process is more likely to occur. The patient can build a history with the person and they pick up where they left off in their next encounter. Additionally, the caregivers will then know the appropriate questions to ask to move into a more personal conversation with the patient. One of the limits of hospice is that these encounters are less likely to occur because of the model's limits on non-acute care. However, hospice visits for patients living at home or in long term residential facilities allows for similar continuity of relationships with the hospice care team.

<div align="center">Residential Care and Other Contexts of Care</div>

**Long term Residential Care**

For patients who do not have family members, friends, or paid caregivers attending to

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68. Christina Puchalski, ed. *A Time for Listening and Caring: Spirituality and The Care of the Chronically Ill and Dying* (New York, NY: Oxford University Press, 2006).

their non-clinical medical and physical needs, the option of long-term assisted living facilities

exists as an option for residential care. Additionally, patients can move to residential nursing

units, though there can be time restrictions in such contexts because they are reimburse by

Medicare. With regard to narrative identity, a benefit of long term residential care facilities is

that they offer social opportunities for patients so inclined. A patient will have close neighbors

living nearby and there is a higher chance for ongoing relationships to form. Furthermore, a

patient's personal affects will be in the room (pictures, gifts, mementos, etc.) that can serve as

prompts for conversation. Such contexts can provide an optimum environment for narrative

identity to emerge. Unfortunately, long term residential care facilities have few regulations in

the United States and can function on a business model rather than one oriented to patient care.

Many facilities also allow mentally and physically compromised patients to pay to live there when

the patient needs a higher level of care than is provided in the residence.[69] More research and

oversight is called for when it comes to the management and goals of such facilities, especially

with regard to patients who may require a higher level of care than is provided in long term

residential assisted living facilities.

**Other Contexts of Care**

Other contexts of care call for attention when it comes to analyzing moral identity for end

of life patients. Not all patients have the benefit of caregivers or even of a permanent residence.

Hospice does serve incarcerated patients; additionally, some prisons have fellow prisoners provide

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69.  Robin Stadnyk, Susan C. Jurczak, Vanessa Johnson, Haley Augustine, and Russell D. Sampson, "Effects of the Physical and Social Environment on Resident-Family Member Activities in Assisted Living Facilities for Persons with Dementia," Seniors Housing & Care Journal 21, no. 1 (2013). This study skews toward a positive appraisal of assisted living facitlites for those with dementia. For a critique, see the PBS Frontline expose, "Life and Death in Assisted Living" episode. Transcript can be accessed here: http://www.pbs.org/wgbh/pages/frontline/social-issues/life-and-death-in-assisted-living/transcript-48/

care and companionship for those who are terminal.[70] However, for patients who are homeless

or do not have a permanent home, care options are limited. Though patients may not be able

to engage in the formal process of life review through the hospice model of care, bereavement

services are available for those in community who knew the person. Through bereavement

care a form of narrative construction of identity occurs. Utilization of such resources may be

low, however, due to limited awareness about availability, financial constraints, transportation

concerns, and other variables that limit access.

## Narrative Identity in the Clinical Encounter

## Taking Context into Account

Narrative identity in the clinical encounter is more likely to flourish in the patients home, a

residential facility or in non-acute care wings in a hospital setting. The following conditions

are conducive to the emergence of narrative moral identity through the process of life review:

unstructured interactions, continuous relationships with caregivers, and relationships that exist

over time. Fortunately, there are models of care structured to facilitate social interaction for

patients who may not otherwise have it. For instance, in home based environments, contexts

intended to simulated a residential family-model, occasions of interactions such as conversations

occurring while making a meal or doing the dishes can develop organically. The value of such

conversations is that they are not limited to the medical structure expected in hospital care. For

example, checklists are part and parcel of hospital care, fundamental to charting. The checklists

serve a valuable purpose in reminding clinicians to cover all of the bases while meeting with

patients. However, the checklist approach can also limit conversations to only that which is on the

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70.  Kristin G. Cloyes, Susan J. Rosenkranz, Dawn Wold, Patricia H. Berry, and Katherine P. Supiano, "To be Truly Alive Motivation Among Prison Inmate Hospice Volunteers and the Transformative Process of End-of-Life Peer Care Service," *American Journal of Hospice and Palliative Medicine* (2013).

list. A similar critique is made of principlism in medical ethics: that a "check-list" approach can then be used to recuse oneself from further moral analysis.

Hospice provides care for patients regardless of where they reside, though there is an expectation that the patient has a caregiver. Narrative identity is likely to manifest in hospice care because the model offers volunteer companionship for patients which will provide the unstructured interactions needed for narrative identity to manifest in the form of life review. Additionally, hospice provides spiritual care via professional chaplains who visit the patient in the patient's residence.[71] While hospitals also provide chaplains, chaplains in the hospital context usually function in an on-call basis. Alternatively, pastoral care visits in the hospice model are often regularly scheduled, thereby allowing for both continuous relationships and for unstructured interactions (though they are scheduled, they are not necessarily "goal-based"). On an individual level, moral identity for hospice patients involves a process of evaluation centered on a fundamental ethics question: How did I live? Theologically, a patient may include what they perceive to be the perspective of the divine when they engage in this evaluative process. For instance, they may inquire as to whether they lived in a way that honored God, asking the question, "Did I live according to God's plans for me?" or they may feel deep guilt and regret at the recognition that God was aware of their ambiguous choices. Therefore, regular pastoral care visits can deepen a patient's moral inquiry, furthering the process of life review for patients. Hospice is a model that provides optimal conditions for narrative identity to emerge regardless of the patient's primary residence, be it at home or in a residential care facility.

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71. Allan Kellehear, "Spirituality and Palliative Care: A Model of Needs," *Palliative Medicine* 14, no. 2 (2000): 149-155.

**Conclusion**

Narrative medicine structures the clinical encounter such that attentive listening can be practiced by the clinician and concentrated attention can experienced by the patient, valuable in the times of isolation, fear, and vulnerability experienced by patients when seeking care, often in a highly technologized and impersonal environment. Listening closely to patients, appreciating their words the way one would a work of literature, is often deeply valued by patients when they experience such care and when it is absent the likelihood of litigation or of neglecting the pursuit of medical care can result. The style of narrative-focused clinical care has roots in the western intellectual tradition. Narrative approaches to care, whether implicitly or explicitly, are often embedded in an Aristotelian concept of dramatic form, particularly with regard to how time and identity are understood. Such an approach can limit the applicability of narrative-based care for certain patients, particularly those with verbal and cognitive limitations. Paul Ricoeur's offers and expanded model of the Aristotelian standard as it is presented in the *Poetics* inclusive of patients so challenged. Ricoeur's extends Aristotle's concept of narrative time and he allows for a form of social narrative identity that includes but stretches beyond a model focused on an individual person.

Additionally, forms of person-centered care that do not rely on coherent verbal narration are available for patients who may not be able to engage in a dialogical clinical encounter. Forms of art therapy and social narrativity are accessible to a greater variety of patients, including those who are marginalized in narrative medicine, and patients do not have to perform in a context shaped by high-level dialogue. Such forms of care address many of the needs met narrative medicine, particularly the need for personal, individualized care. Due to the burgeoning demographic of those considered old (both "young-old" and "old-old"), there is reason to attend

to the ways in which cognitive decline and compromised verbal ability intrude upon the ability to engage in narrative practice, including specified practices such as life review in hospice. Limited ability not only affects the patient's capacity to self-narrate, it also influences a clinician's ability to comprehend what a patient is attempting to communicate. In Chapter 4, I address the ways clinicians can exercise the ability to attend to patients with compromised verbal and cognitive abilities, specifically through the use of modern literature in clinical training.

Finally, the context of a patient's care can radically influence the prospects of a narrative-based clinical encounter. If a patient is receiving care in an ICU, for instance, primary attention is given to a patient's acute medical needs rather than a patient's concept of self over time. Further, patients receiving care in their homes may be seen as having more access to personal attention. However, this is not always the case as patients can reside in a room in the back of a home or receive care from an burdened caregiver who is physically, emotionally, and financially taxed to such an extent that time spent in dialogue or art therapies may be seen as an impossible luxury or as another wearying duty.

Though challenges exist when it comes to providing care to certain patients under the aegis of narrative medicine, patients with cognitive challenges or patients with behavioral concerns, for instance, the benefits of the model in deepening a clinician's attention to patients remain relevant to clinical practice. However, the sources used in the context of narrative medicine need to be expanded to include characters that portray the limitations that many patients may be struggling with, such as confusion, disoriented speech, and agitation. Patients who are perceived as difficult or challenging may receive less clinical and social attention than they need. In the next chapter, I demonstrate how the practice of narrative medicine can be used to teach clinicians how to remain present with patients perceived as difficult. My claim is

that, through the use of modern literature that conjures such figures, characters with disrupted, fragmented speech and characters acting out aggressively in existential or physical pain, clinicians can practice the experience of encountering difficult patients thereby increasing their tolerance for difficult clinical encounters.

CHAPTER FOUR

THE DRAMATIC WORKS OF SAMUEL BECKETT AS LITERARY CASE STUDY IN

NARRATIVE MEDICINE

Narrative medicine seeks to develop the communication skills of the clinician, to enhance the

clinician's ability to listen deeply and glean detail from each patient interaction such that the

outcome of the clinical encounter is that the patient feels respected and heard in addition to

being assessed for medical needs. Learning to be a close reader of texts, according to Rita Charon,

likewise teaches a clinician to be a close reader of patients. In the previous chapter, I described the

ways in which narrative modalities of patient care reach a limit point for patients with cognitive

or verbal limitations. In this chapter, I address the ways in which modes of patient care shaped by

narrative medicine can still be a resource for clinicians working with patients unable to engage in

coherent speech or participate in a dialogue characterized by recognition and reciprocity.

In this chapter I look to the dramatic works of Samuel Beckett, a writer who radicalizes

the limits of language and understanding in a way that can prove useful for those hoping to

practice narrative medicine with cognitively and verbally challenged patients. I maintain that

by working with such literature clinicians can become comfortable with patients who may not

be able to communicate coherently. Additionally, reading Beckett's texts and applying them to

the clinical encounter can help one become aware of the expectations one brings to the patient

dynamic, expectations that carry ethical concerns that may have gone unexamined otherwise.

Though practices of patient care informed by narrative medicine can be challenging in the context

of speech-impaired patients, I maintain that the practice can still be useful and find insight in Beckett's productive disruption of high-level speech.

Samuel Beckett, recipient of the Nobel prize for literature in 1969, dramatizes the distance between language and understanding and reconfigures classical understandings of the form and structure of drama. His plays often have no identifiable plot and no developed characters; in some cases, his plays feature just a mouth, as in *Not I*, or a head, as in Happy Days, in which the character Winnie, eventually becomes buried in sand past her shoulders. Language is fragmented in his plays and his characters speak at each other, periodically interrupted by insistent bodily needs—urinating in *Waiting for Godot*, eating and drinking in *Krapp's Last Tape*—and by cognitive intrusions like fragments of song lyrics or involuntary memories. Nevertheless, the characters do try to communicate, either with each other or with a remote being. Connected with what Martin Esslin called the "theater of the absurd" his work portrays characters struggling with the human desire to communicate and the limits of this ability.[1] Often set on an empty stage, the reader or viewer is given no context to place the character in space and time. The lack of historical specificity enables his texts evergreen meaning; his stories occur nowhere and anywhere, his characters are no one and anyone.[2] The blank or inaccessible histories of his characters allow the spectator to experience the discomfort of incomprehension.

Beckett's dramatic works allow for a plurality of interpretations, rendering his work ideal for the interpretive activity involved in narrative medicine. The many interpretations of

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1. Phrase coined by Martin Esslin in his article, "The Theatre of the Absurd." *The Tulane Drama Review* 4, no. 4 (1960): 3-15.

2. Beckett was clear that the genders of his characters were not interchangeable, however. When asked if Vladimir and Estragon in *Waiting for Godot* could be cast by women, he gave a definitive no: "Women don't have prostates." Beckett's response is quoted in "Introduction" to Ben-Zvi, L., (ed.) *Women in Beckett: Performance and Critical Perspectives* (Urbana and Chicago: University of Illinois Press, 1992), x.

his texts, ranging from the religious, neurological, linguistic, political, historical, psychological, autobiographical, among countless other niche perspectives, reveal the inexhaustible nature of his writing. In this chapter, I draw on his work for a specific purpose within the framework of narrative medicine. My goal is to demonstrate how these texts can be used as a resource for clinicians working with patients that present as challenging. My objective in using Beckett's work is to allow the clinician to practice enduring the discomfort that can arise from working with challenging patients, so that the patient's total pain—emotional, spiritual, social, and existential—can be fully observed.

The plays I examine here are two of his later dramatic works: *Krapp's Last Tape* was first performed in 1958 and *Rockabye* was first performed in 1981. I engage in two uses of these plays in this chapter:

1. To demonstrate the practice of life review as a narrative mode of self-understanding and ethical analysis, and the pain that can accompany the process in Part 1: *Krapp's Last Tape* and Life Review in Narrative Medicine.

2. To show how Beckett's work can be used for clinicians training in narrative methods and working with patients experiencing cognitive decline or verbal limits in Part 2: Applying Samuel Beckett's *Rockabye* to Dementia Patients: The Use of Modern Literature in Clinical Education and Narrative Medicine.

**Turning to Literature to Address Clinical Concerns**

What is the value of turning to literature as a source for reflection on clinical practice when the material is several degrees removed from the patient-clinician experience? First is the tremendous value of practicing sitting with the experience of discomfort and uncertainty, of "not-knowing," particularly for individuals who are trained to speak with authority like clinicians. Second,

characters in works of fiction and drama can be analyzed, critiqued, rejected, judged and disliked to a degree that would be inappropriate with living patients. Critically engaging with literature rather than learning from patients helps prevent the objectification of patients as mere objects of study, and it also has the potential to teach clinicians how to recognize their trigger points with patients before they emerge in the clinical encounter. Finally, the use of literature in clinical education functions as a reminder that the application of medical care extends beyond the empirical, and provides a reminder that medical care exists to serve, in Paul Ramsey's words, the patient as a person, not as a medical specimen. The use of literature addresses patient concerns that fall outside the boundaries of evidence-based medicine and the scientism that can constrict such a limited epistemology. While it may seem counter-intuitive to use literature as a source for understanding how to engage with patients who have dementia or other impairments, the style of contemporary authors can correspond with the disrupted speech of such individuals, connecting the scholarship to the clinical encounter in a constructive way.

Beckett's minimalist writing style, particularly in his later plays including and following *Waiting for Godot*, confounds and destabilizes dialogue. His narratives often lack any kind of identifiable plot or context, and his characters speak in a stark, repetitive way, obliquely referring to figures or past events unknown to the reader. Yet his characters seem familiar in their struggle to understand and relate to others, and their words demonstrate the ways speech both connects and radically separates humans from each other. In the two plays I analyze in this chapter Beckett depicts two solitary, aging figures that can serve as resources for literary case study in narrative medicine. In *Krapp's Last Tape*, the eponymous Krapp engages in the retrospective self-analysis of life review that I describe in Chapter 2. In *Rockabye*, Beckett works with themes of memory, particularly memories of a character's past self, in a way that can be relevant for clinicians

working with patients with Alzheimer's disease or other forms of dementia, challenges I speak to in Chapter 3.

Beckett wrote other plays that demonstrate the fragility and involuntary nature of memory and feature characters that engage in life review. Like *Krapp's Last Tape*, *Endgame* includes a character, chair-bound Hamm, engaging in life review, what he calls his "chronicle." In regard to cognitive deficits, Estragon and Lucky in *Waiting for Godot* demonstrate memory gaps and confused speech marked by confabulation and coherence mixed with incoherence. Beckett's *Trilogy: Molloy* (1951), *Malone Dies* (1951), and *The Unnamable* (1953), presents characters with maladies physical and mental and examines the limits of accurate recollection. This chapter focuses on *Krapp's Last Tape* and *Rockabye* because they feature solitary figures, isolated and in emotional distress, whereas in the other plays, aside from the *Trilogy*, the characters spend their time in the company of others. Loneliness and isolation of the elderly and dying are dimensions of patient experience that call for ethical analysis in medical ethics. Both *Krapp's Last Tape* and *Rockabye* demonstrate the existential pain that can accompany unchosen solitude. The main characters also exhibit qualities that would make them difficult to engage with if a clinician approaches them with the desire for meaningful, reciprocal communication.

Because interacting with brusque or incoherent patients can create discomfort for caregivers, reading Beckett's work can normalize this experience before meeting with patients. Elderly, confused patients are often isolated, even if they live in social environments like assisted living facilities. If caregivers become more comfortable with patients who cannot interact in lucid, reciprocal, and socially acceptable ways, such patients may then have more social interaction, including longer and more frequent clinical encounters. I suggest in this chapter that narrative methods in clinical education can develop a clinician's ability to be present with patients that may

be experienced as difficult, patients that speak in a confusing manner in the case of *Rockabye*, and patients that present in a way that is coarse or belligerent in the case of *Krapp's Last Tape*.[3]

In the following section, I examine Beckett's play, *Krapp's Last Tape*, analyzing the ways the play can apply to narrative methods in health care. I demonstrate how the play represents the process of life review for a person at the end of life and, in an attempt to show the value of the play for clinicians, I describe the themes present in the play that clinicians such as health care chaplains may encounter in their work. Beckett's dramatic works address isolation, caregiving, and the desire to connect with other humans, particularly the plays, *Endgame*, and *Krapp's Last Tape*. Whereas *Rockabye* portrays a character with disrupted speech, *Krapp's Last Tape* uniquely addresses the themes that emerge in the process of life review that I highlight in Chapter 2, and because of this I examine this play as it applies to narrative methods in medicine.

**Krapp's Life Review**

In Chapter 2, I speak about the process of life review as a process of self-analysis; specifically I claim that individuals are engaging in a form of ethical self-evaluation through the process of reminiscence. Often this retrospective turn is prompted by a terminal diagnosis. Yet it can also occur when a person faces a health crisis, significant life event, or a landmark birthday. In the play I examine here, the main character engages in a ritual of reflection on his birthday. This yearly ritual can be interpreted as a form of life review—Krapp asking the question, "How did I live?" and then giving his appraisal of his year. While Krapp engages in the activity of retrospective

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3. The "difficult patient" is a term found in scholarship on clinical interactions; see "The Difficult Patient: Prevalence, Psychopathology, and Functional Impairment" Hahn, S.R., Kroenke, K., Spitzer, R.L. et al. *J Gen Intern Med* (1996) 11: 1. The designation comes from the clinician's perception that a patient is noncompliant, combative, accusatory, suspicious, and hostile. Difficult patients typically have functional impairment, psychological dysfunction, and substance abuse. Regarding patients with dementia, it is the interaction that is difficult or challenging, not necessarily the behavior of the patient.

reflection every year, due to his increasing age and decreasing abilities this year may be his last time doing life review. The future no longer lies before him full of possibility and promise: professionally, he has failed, and relationally he has failed as well, paying to see "an old whore" whose presence he merely tolerates. Spiritually he is disengaged.

Through literary construction, some of the features of life review become visible, such as regret and other forms of self-judgment. How personhood and pain are understood in the hospice model of care—as including physical, social, psychological, and spiritual dimensions—proves useful in describing how this self-evaluation is structured. A person might be reflecting on his or her body, its appetites and abilities, reflecting on what used to be enjoyable but is no longer available, convenient, or even possible. For example, John Milton, poet and lover of language, lost the ability to read and had to have his daughters read aloud to him, a task they resented. A person might reflect on how socially narrow his or her world has become in terms of the loss of family members, romantic relationships, friendships, and professional colleagues. Depression and grief can result from or precipitate the process of self-evaluation or extended rumination. In life review, one might reflect on the presence or absence of God, blaming, lamenting, or yearning for divine intervention. Beckett's characters in the two plays I examine speak to all of these dimensions of selfhood in their narrations—loss, regret, anger, frustration, nostalgia, and a desire for companionship are features of their expressions.

*Krapp's Last Tape* and Life Review in Narrative Medicine

*Krapp's Last Tape* premiered in London in October 1958, as an introductory play for *Endgame*, another minimalist play that addresses end of life concerns, including the challenges of caregiving. Beckett wrote *Krapp's Last Tape* in English, later writing the French and German

translations of the text.[4] The play, a variation of a one-act monologue, presents a man engaging in a process of reminiscence, a ritual he performs on his birthdays. He is alone on stage, with a tape recorder as a type of mechanical companion. He is the primary character in the play, though the presence of his younger self speaks through the tape recorder. The compact play features a solitary man, 69-year-old Krapp, listening to recorded stories of his early days on his tape recorder. The play occurs, "A late evening in the future" on his birthday. One of the tapes he listens to is narrated by his younger self on his 39th birthday. Krapp views his young self with derision, puffing at his younger self's vanity and hopes for the future. Even in his earlier days, we see lament about wasted time and regret over his choices. These regrets are amplified on his birthday at 69--he berates himself for his choices then, considering his situation now, and he finds his younger self ridiculous, a pompous fool who thought he knew everything. Aging, alone, and bitter about his choices and his circumstances, Krapp displays a self-indulgent narcissism through his process of reflection and rumination. He is the center of his world, even if his self-judgment is negative.

<div align="center">Tragedy and Comedy in *Krapp's Last Tape*</div>

Krapp's appearance and behavior in the play can evoke pity and sympathetic regard for his predicament. However, through the use of ludicrous attire and crude humor, Beckett's portrayal resists any attempt to sentimentalize Krapp. In addition to the character's scatological name, Beckett's stage directions highlight the tragicomic features of Krapp's appearance:

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4. Beckett was significantly involved in the production of the play from its the premier at the Royal Court Theatre in London in 1958, where he attended rehearsals, to directing the Paris Revival production in 1975 at the Théâtre d'Orsay. See James Knowlson's "Krapp's Last Tape: The Evolution of a Play: 1958-1975," *Journal of Beckett Studies* 1 (Winter, 1976). Knowlson was Beckett's friend and official biographer; see his biography for details on Beckett's life and work: James Knowlson, *Damned to Fame: The Life of Samuel Beckett* (New York, NY: Touchstone Press, 1997).

*Sitting at the table, facing front, i.e. across from the drawers, a wearish old man: Krapp*

*Rusty black narrow trousers too short for him. Rust black sleeveless waistcoat, four capacious pockets. Heavy silver watch and chain. Grimy white shirt open at neck, no collar. Surprising pair of dirty white boots, size ten at least, very narrow and pointed.*

*White face. Purple nose. Disordered grey hair. Unshaven.*

*Very near-sighted (but unspectacled). Hard of hearing.*

*Cracked voice. Distinctive intonation.*

*Laborious walk.*

With his over-sized shoes, purple nose, short pants, and unruly hair, Krapp has the exaggerated features of a clown. At the same time, Krapp is an ordinary aging man, experiencing the loss of his physical abilities, discontentedly reminiscing about his past and feeling the pressure of time indicated by the "heavy silver watch and chain" he carries. Throughout Beckett's revisions of the play from the original version performed at the Royal Court in London in 1958 to later versions of the play staged in 1975, the watch remained present even as Beckett had removed most of the other props and the production became increasingly unadorned.[5] James Knowlson notes that Beckett kept the silver watch because Krapp wanted to begin his reminiscence at precisely the minute he was born.[6] Yet, the watch, in its heaviness, also represents Krapp's proximity to death or the end of how he marks time, this being his "last" tape. Though the play uses props like banana peels and includes the fumbling actions and exaggerated emotions and expressions of a clownish figure, the play is not comic, evoking pity more than humor.

Krapp is a failure in his eyes; he has accomplished nothing in the past year worth narrating on his birthday ritual: "Nothing to say, not a squeak. What's a year now? The sour cud

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5. Knowlson, *Krapp's Last Tape.*

6. Knowlson, *Krapp's Last Tape.*

and the iron stool." He is an author, but his self-proclaimed "magnum opus" goes unread and

he is disgusted with himself for his lack of success and his poor choices. In his reminiscence he

wonders whether he could have had a good life if he had chosen relationality over his literary

endeavors, especially as his aspirations resulted in professional failure. [X] notes, however, that

taking into account Krapp's personality, he probably would have self-flagellated regardless of his

choice; considering his temperament, if he had chosen love over work he would likely be dwelling

on the lost possibilities with his writing and literary fame.

## Connections to Life Review

The act of recording his voice on his birthday is an example of the process of life review. Though a

terminal diagnosis is often a catalyst for the self-reflection and evaluation involved in life review,

birthdays can also serve as a time that calls one to intentionally reflect on how one has lived. The

difference is one of degree: whereas on an ordinary birthday a person can lament past choices

and resolve to live differently in the future, when one receives a terminal diagnosis he or she is

faced with a foreshortened future that makes past choices much more final and can make the

corresponding self-judgment more severe. Krapp is "sifting" the events and choices of his life. The

title of the play is *Krapp's Last Tape*, suggesting either the end of the process of life review, the last

birthday tape he makes, or the end of his life, the last birthday he has. Julie Campbell notes:

> On this day, the day of *Krapp's Last Tape*, we have a kind of judgment taking place. The grain is being separated from the husks, and the thing "worth having when all the dust has settled" is the experience on the punt. All the rest is discarded; Krapp "sweeps boxes and ledger violently to the ground"; all the rest is waste, crap. His life, all hoarded up in tapes, is rejected, the boxes scattered over the floor.[7]

> In Chapter Two, I claim that this self-judgment is a primary feature of life review, a

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7. Julie Campbell, "The Semantic Krapp in *Krapp's Last Tape*," *Samuel Beckett Today/ Aujourd'hui: An Annual Bilingual Review/Revue Annuelle Bilingue* 6 (1997): 63-72.

process in which individuals reflect on and assess the choices they made in life. Facing the end of one's life increases the wattage of these choices because they become more final—there is limited, if any, time to make changes, and the past is fixed. With a terminal diagnosis, the hard reality of one's finitude can no longer be pushed to the horizon. The 69 year old Krapp listening to the voice of 39 year old Krapp recognizes this limit and finds his younger self profligate in his rejection of the goodness in life, particularly intimacy. Sixty-nine-year old Krapp does not have much to narrate on his birthday. He is inside and alone; it is unclear how or if he will be remembered. From his tape at 39:

> "Here I end this reel. Box--(*pause*)--three, spool--(*pause*)--five. (*Pause*. Perhaps my best years are gone. When there was a chance of happiness. But I wouldn't want them back. Not with the fire in me now. No, I wouldn't want them back."

> *Krapp motionless staring before him. The tape runs on in silence.*

CURTAIN

Previously I spoke about a sense of satisfaction that individuals can have when they sift their lives. In the self-evaluation that occurs in life review, one can determine that the life he or she lived was the preferred life, a good life. Even if there are regrets, losses, and failures, one can interpret them as detours or opportunities for learning and growth, rather than as the defining features of a wasted existence. However, Krapp's words do not indicate satisfaction with his current state, only a fixation on his past state when physical pleasure was more of a possibility. He speaks of his former resolutions—to drink less, to limit his sexual indulgences—and he laughs, "Jesus! And the aspirations! . . . And the resolutions!"

Krapp's views his younger self as, in a sense, an entirely different self. The 39 year man he is listening to on his tape recorder is simultaneously him and not-him. In another paradox, the memories conjured by the voice of his younger self are both a source of pleasurable recollection

and painful self-judgment. Jeanette R. Malkin's essay "Matters of Memory in *Krapp's Last Tape* and *Not I*" identifies the complexities and contradictions of personal memories:

> It is not the memories revealed or the words which suddenly "come" that are of the essence. Rather, it is the complex net of memoried states of being--the interplay of inner voices, the pluralisms of self-perception, the complexity of agency, of volition or its lack, the simultaneity of pasts and present, the multiple modes of repetition and recall, of traces and patterns: which evoke a sense of our own trivial yet inevitable multiplicity, simultaneity, fragmentedness.[8]

In Chapter 2, I spoke of the themes that emerge in life review—regret, desire for forgiveness, and grief over lost time. The themes of regret and grief over lost time are evident in Beckett's play as Krapp reflects on his younger self and his current situation at the time of his 69th birthday:

> Just been listening to that stupid bastard I took myself for thirty years ago, hard to believe I was ever as bad as that. Thank God that's all done with anyway. (*Pause.*) The eyes she had! (*Broods, realizes he is recording silence, switches off, broods. Finally.*) Everything there, everything, all the--(*Realizing this is not being recorded, switches on.*) Everything there, everything on this old muckball, all the light and dark and famine and feasting of . . . (*hesitates*) . . . the ages! (*In a shout.*) Yes! (*Pause.*) Let that go! Jesus! Take his mind off his homework! Jesus (*Pause. Weary.*) Ah well, maybe he was right. (*Broods. Realizes. Switches off. Consults envelope.*) Pah! (*Crumples it and throws it away. Broods. Switches on.*)

Beckett repeatedly describes Krapp as "brooding" as he listens to the narrations of his younger self. To demonstrate his feelings of regret, in this passage about the death of his mother, Krapp wishes he had kept the ball he had been playing with when his mother died, as a way of remembering her.

> All over and done with, at last. I sat on for a few moments with the ball in my hand and the dog yelping and pawing at me. (*Pause.*) Moments. Her moments, my moments. (*Pause.*) The dog's moments. (*Pause.*) In the end I held it out to him and he took it in his mouth, gently, gently. A small, old, black, hard, solid rubber ball. (*Pause.*) I shall feel it, in my hand, until my dying day. (*Pause.*) I might have kept it. (*Pause.*) But I gave it to the dog.

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8. Jeanette R. Malkin, "Matters of Memory in *Krapp's Last Tape* and *Not I*," *Journal of Dramatic Theory and Criticism* 11.2 (Spring 1997): 25-39.

*Pause.*

Ah well . . .

*Pause.*

Like W., the main character in *Rockabye*, Krapp is alone and full of recriminations, though Krapp's are turned inward to a greater degree than W.'s. Both characters also reflect on the death of their mothers, again evidencing regret about their current contexts and showing grief about their losses. In particular, Krapp regrets giving a dog the ball he found on the day his mother died, wishing he had kept the ball as a reminder of her life. There are multiple props in the play, both seen and conjured through memory, that suggest Krapp's arrested development. A toy, a dog, a banana peel, the "pop" of a cork, even Krapp's appearance with a bumbling manner and disheveled hair, all suggest comedy. Yet laughter does not seem appropriate. Krapp is a clown and a fool, and a self-serious, sad ordinary figure in a tragic situation. He is alone, and full of regret and longing for a life he wishes he had lived, but now cannot. His body has changed and does not function according to his will, with his "sour cud and iron stool". Krapp uses the tape recorder as a device that records the highlights of his personal history, but in his 69th year he has nothing of note to record. His time has become waste, crap. Instead of giving an account of his events of his year, he records silence and switches the tape to revisit one of the physical experiences.

*Krapp's Last Tape* allows one to be a witness to life review as it is happening and demonstrates the process of self-evaluation that I speak to in chapter two. His experience is solitary and the tapes allow the audience to participate in listening to his self-talk. Life review can be both internal as a process of self-reflection, and external as a process of reminiscence that occurs through dialogue, be it informal conversational dialogue or structured interviewing. Though Krapp engages in reminiscence, he remains connected to the immediacy and

concreteness of his environment. His experience is both internal, through his memories of his previous days, relationships, and choices, and external, his memories kindled by the tape recorder and hearing his voice from prior birthdays. The account of the toy ball and the dog at the event of his mother's death, another comic/tragic episode, points to the relationship between the inner world of memory and the exterior world that animates memory.

<div align="center">Augustine's Imprint on <em>Krapp's Last Tape</em></div>

Beckett was a student of the writings of Augustine, and in *Krapp's Last Tape* one can see the imprint of Augustine's theological anthropology and cosmology. Like *Krapp's Last Tape*, Augustine's *Confessions* can be read as a form of life review and moral judgment and self-evaluation: for example, both Krapp and Augustine experience regret over lost or wasted time. However, it is unclear whether or not Krapp has the experience of recognition and conversion to another way of life as Augustine did. Krapp's last words in the play, "Perhaps my best years are gone. When there was a chance of happiness. But I wouldn't want them back. Not with the fire in me now. No, I wouldn't want them back" suggest he would not make changes in how he chose to live, but his last act is to let the tape run on in silence with Krapp "motionless staring before him." Whereas Augustine can write of his youthful transgressions with the knowledge of his subsequent redemption, maybe Krapp's life, at its end, truly was wasted, and he is sitting with this knowledge as the tape runs on in silence. Krapp's is not a conversion narrative of confession-redemption-judgment, only one of judgment without redemption.

Before Augustine converted to Christianity, as he narrates in the *Confessions*, he was a follower of Mani, aligning with the dualistic cosmology of Manichaeism in which there is an evil force of darkness and a good force of light and the two are in battle with each other. Similarly, Krapp views life as in extreme polarities, particularly love or work; Krapp chooses work and on

his 69th birthday he longs for his past encounters with women. Krapp established an either/or approach to work and relationality. A meticulous writer and director, Beckett describes exactly how he envisions the binaries in the play. In his stage notes for Beckett, he writes about the dualities he wants to see on stage: light and dark, young and old, male and female, birth and death. As seen in his stage notes, Beckett writes "Mani" next to his lighting directions.[9] In "*Krapp's Last Tape* and the Mania in Manichaeism" Sue Wilson claims that Beckett presents a modified version of Manichean dualism in *Krapp's Last Tape*, specifically in his later German translation for the Berlin performance. To support her claim, she shares the details Beckett writes in his stage notes in which he calls for "explicit integration light dark" in the translated play. His earlier English version had more of a stark contrast between light and dark on stage. [This paragraph re: dualism may need a bit more explanation.]

Like Augustine, particularly in the *Confessions*, Krapp is disgusted with his inability to control his physical appetite. For Augustine, this disgust and self-loathing manifests primarily with the body and sexual desire. From the beginning of Book II of The Confessions:

> And what was it that I delighted in, but to love, and be loved? but I kept not the measure of love, of mind to mind, friendship's bright boundary: but out of the muddy concupiscence of the flesh, and the bubblings of youth, mists fumed up which beclouded and overcast my heart, that I could not discern the clear brightness of love from the fog of lustfulness. Both did confusedly boil in me, and hurried my unstayed youth over the precipice of unholy desires, and sunk me in a gulf of flagitiousnesses. Thy wrath had gathered over me, and I knew it not. I was grown deaf by the clanking of the chain of my mortality, the punishment of the pride of my soul, and I strayed further from Thee, and Thou lettest me alone, and I was tossed about, and wasted, and dissipated, and I boiled over in my fornications, and Thou heldest Thy peace, O Thou my tardy joy! Thou then

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9. Stefano Rosignoli,"Dreaming through the Confessions: On the Intertextuality of the Augustinian Excerpts in Samuel Beckett's 'Dream' Notebook," *Journal of Beckett Studies* (Edinburgh University Press) 25, no. 1 (April 2016): 39-55.

heldest Thy peace, and I wandered further and further from Thee, into more and more fruitless seed-plots of sorrows, with a proud dejectedness, and a restless weariness.[10]

For Krapp his disgust is a response to his weak will with food (bananas), alcohol, and sexuality. He continues to binge on bananas and drink on his 69th birthday, and he meets with a prostitute to address his sexual appetite, so he has not developed a stronger will as he had hoped when he was younger. Like Augustine, Krapp castigates himself for his past weaknesses, denouncing himself with relish: "Just been listening to that stupid bastard I took myself for thirty years ago, hard to believe I was ever as bad as that. Thank God that's all done with anyway. (Pause.)" Augustine speaks with similar self-abasement about his younger self and his proclivities toward the flesh and satisfying his bodily appetites, with similar dramatic flair:

> I will now call to mind my past foulness, and the carnal corruptions of my soul; not because I love them, but that I may love Thee, O my God. For love of Thy love I do it; reviewing my most wicked ways in the very bitterness of my remembrance, that Thou mayest grow sweet unto me (Thou sweetness never failing, Thou blissful and assured sweetness); and gathering me again out of that my dissipation, wherein I was torn piecemeal, while turned from Thee, the One Good, I lost myself among a multiplicity of things. For I even burnt in my youth heretofore, to be satiated in things below; and I dared to grow wild again, with these various and shadowy loves: my beauty consumed away, and I stank in Thine eyes; pleasing myself, and desirous to please in the eyes of men.

<div align="center">Memory</div>

*Krapp's Last Tape* speaks to the complications of memory, demonstrating that memory is both voluntary and involuntary; some is lost memory. He cannot access all of his past, and what he does access upsets him. Beckett's play disrupts the narrative of the poignant reminiscence experience. Krapp is not satisfied with his retrospective reflections on his 69th birthday; as he listens to his reflections when he is turning 39 he similarly responds with scorn to his self in his twenties. Whereas in his past reflections, he had the future to look forward to, another year to

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10. E. B Pusey, *Confessions of Saint Augustine*. Masterpieces of American Literature. Collector's Edition (New York: Pocket Books, 1951), *Book II*.

recount at his next birthday, at this session the possibilities of future birthday-recordings are ambiguous. The title of the play, "*Krapp's Last Tape*," speaks to this ambiguity. It is unknown whether the word last indicates, the most recent tape he made or listened to, or the final tape he will make or listen to. Is this his last tape because he will not live to see his 70th birthday to engage in his ritual of remembrance? In early versions of the play, Beckett directly references death in *Krapp's Last Tape*, having Krapp sing the hymn, "Now the Day is Over;" in later editions the song is removed, but Krapp's actions, twice nervously looking over his shoulder in the darkness as if someone is lurking behind him just out of sight, reflect Beckett's intention to suggest death's closeness. When rehearsing for the Berlin performance, Beckett directed the actor Martin Held to portray Krapp as knowing on some level about the nearness of death: "'Old Nick's there. Death is standing behind him and unconsciously he's looking for it."[11] The finality of this birthday tape, that Beckett is not only reflecting on his past year of life since his last birthday, but potentially his last full year of life, indicates that this life review has the intensity of moral judgment that can come with life review for hospice patients, in which one assesses choices made in life without the escape-hatch of resolving to act differently.

In Krapp's process of life review, he is digesting his previous experiences, "ruminating" on them, like a cow chewing its cud. One can almost imagine Krapp taking a bite, chewing, considering what he's taking in, making a sour face and complaining, and then eating some more. Michiko Tsushima makes direct parallels to the process of ingestion, digestion, and elimination to the play.[12] Tsushima's research shows the connections between Beckett's understanding of

11. "Martin Held talks to Ronald Hayman" *Times Saturday Review* April 25, 1970, quoted by James Knowlson in *Krapp's Last Tape*: *The Evolution of a Play, 1958-75.*

12. Michiko Tsushima, "'Memory is the Belly of the Mind: Augustine's Concept of Memory in Beckett,"*Samuel Beckett Today / Aujourd'Hui*, vol. 19 (2008):123–132.

memory as presented in *Krapp's Last Tape* and Augustine's understanding of memory as the belly

of the mind. You cannot entirely control memory; reminiscence can be invited and encouraged,

as Krapp does listening to his tapes, but memories can also just occur seemingly at random, by

encountering a familiar smell, sound, taste, person, or for no obvious reason.[13] Digestion is a

similar process. Like the experience of memories, it happens, for the most part, involuntarily. In

addition to being difficult to control or manage, and like the process of eating and digesting, the

experience of reminiscence can be uncomfortable. Further, eating, like reminiscence, can be both

a source of enjoyment and a source of discomfort when the pleasure of eating the food inevitably

turns to the involuntary process of digestion. Augustine sees memory as separate from experience

and separate from the mind—the mind being that which one can order and control. Beckett

transcribes Augustine's words on memory in his 1930-1932 *Dream* notebook:

> When with joy I remember my past sorrow, the mind hath joy, the memory hath sorrow;
> the mind upon the joyfulness which is in it, is joyful, yet the memory upon the sadness
> which is in it, is not sad. . . .The memory is the belly of the mind & joy & sadness the sweet
> and bitter food; which, when committed to the memory, are, as it were, passed into the
> belly, where they may be stowed, but cannot taste.[14]

While Tsushima focuses on the process of ingestion and digestion in her analysis of

Beckett's concept of memory in *Krapp's Last Tape*, Julie Campbell, in "The Semantic Crap of

*Krapp's Last Tape*," details the next phase of the eating process: elimination.[15]. Campbell begins

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13.  Beckett's concern with memory can be found in his other works as well. He writes about
voluntary and involuntary memory in his 1930 essay on Marcel Proust; Proust's *Remembrance of Things
Past* is an extended memory animated by the experience of eating a madeleine steeped in tea. Both Proust
and Augustine recognize the involuntary nature of memory, that it is not fully controlled by the will or
intellect, hence Augustine calling memory "the belly of the mind." Just as digestion is not controlled by the
will, memories, likewise, can be activated and operate without conscious control or direction.

14.  Tsushima, quoting Beckett's notebooks on Augustine, 124.

15.  Campbell, "The Semantic Crap in *Krapp's Last Tape*," 63.

with Krapp's name, detailing the etymology of the homonymous word "crap". Crap, a vernacular word for waste, comes from the Dutch words krappe/krappen which means "to pluck off" or to "cut off". The old French word crappe means "siftings" and in Middle English crap means "the husk of grain." Campbell connects the meaning of "siftings" with Krapp at 39, who speaks of "separating the grain from the husks." She notes, "Krapp is like an empty husk at the end of his life, and he is sifting through his recorded past in a way which is strongly at variance with the way the younger Krapp assessed the events he recorded." Campbell's attention to waste in her analysis of *Krapp's Last Tape* corresponds with Krapp's interpretation that his life has been a waste due to his short-sightedness and quixotic ambition. The process of life review, a process of sifting the choices and events of one's life, can similarly lead patients to the judgment that their life has been wasted—it is this judgment that points to the moral dimension of life review.

<div align="center">Satisfaction and Pleasure in the Moment</div>

In addition to the toy he wishes he had kept to remember his mother, Krapp's actions and reflections speak to the value of objects of physicality in life, including food, technology, and bodies. Krapp shows some intimacy with his tape recorder, hugging it in some adaptations of the play. In a reversal of Augustine's conclusions in his *Confessions*, that physical desires ultimately leave one unsatisfied and that fulfillment comes from God, Krapp believes instead that by not choosing relationality and intimacy with women he chose in error. His primary pleasures in the play, and in his retrospections, are physical, and he longs for more of them. Augustine idealizes a life of abstinence with regard to sexuality and intimate relationships; in contrast, Krapp's regret is that he did not appreciate the value of human intimacy when it was available to him.

Krapp still has his pleasures, though. In the play, and in his recorded narrations, Krapp eats and enjoys bananas, rubbing his hands in anticipation, and he relishes his spools of tape

for the recorder. He speaks and listens to his tapes, his longtime companions. Most of the play involves Krapp sitting and listening to his tapes, pausing them to think and rewinding them to consider again. He listens, pauses, responds, occasionally gets a drink, ponders, and experiences the gap between what his younger self narrates and his current knowledge, looking up a word, "viduity," he used when he was younger but that he no longer knows. His experience is not one of total despair and regret. By looking at his behaviors—rubbing his hands, making expressions of pleasure—one could say he finds satisfaction and momentary enjoyment in immediate bodily activities: drinking, eating his bananas, engaging with his tape recorder, using his dictionary, hiring the "old whore.". He possibly experiences a pleasure-pain as he listens to and reflects on his younger self, calling him a fool, while being wincingly amused by his younger self's fatuity. Krapp might have lost the opportunity for a relationship and have unrealized hopes for literary success, but his ritual behaviors demonstrate some satisfaction in his life.

## Grief

In addition to recounting his earlier experiences and his self-judgments, Krapp chronicles his losses in his recordings, the loss of his relationships with women as noted earlier, and the losses of his parents. With the loss of his mother, he wishes he had kept the black ball he was playing with as a memento. The ball would also be something material that would remain after his mother was gone and his memory of her became patchy. Krapp experiences the fragmentation of memory that comes with age—he loses words that he knew before and loses episodes that once held significance for him: one of the tapes is titled "memorable equinox" but he looks at it blankly. He also loses the ability to move freely, shuffling and tripping when he walks. Control over his appetite, his craving for alcohol, and the function of his bowels remains limited. He also experiences the absence of the professional success he once imagined for himself. His writing goes

unread. We see in Krapp a representation, if radicalized, of how an individual might experience life review as a chronicle of losses: relationships squandered, professional opportunities closed off, physical and mental abilities slowly diminished.

## Legacy

The significance of legacy can emerge when one is aging or facing a late birthday. Legacy is what one leaves behind after death, that which will testify to your existence when you are gone. Legacy can be in understood in various ways, but the essence of a legacy is the answer to the question, "how will you be remembered?" It can include your surviving family, your professional record, what is willed to others after your death, and your "name". A legacy can be seen as a marker of your existence in its particularity. Krapp may have sought to establish his legacy through his writings or his tape recordings. He might have planned to will them to a friend or relative. Yet Krapp has no living family as far as one knows from the play, and the play ends with the tape running on in silence, Krapp sitting, still, silent, and alone. The prospect that Krapp is remembered by the literary public or even family and friends seems unlikely. In this sense, *Krapp's Last Tape* presents itself as a tragedy about an isolated man who feels as though he wasted his life and is worthless. What might be interpreted as comic--the near-slip on the banana peel, his name--become pitiful in his context. It is hard not to view him as pathetic. He has no family, no social recognition, and he views the self in his tapes, his legacy, as ridiculous.

## Social Isolation and a Longing for Relationality

Krapp inhabits a solitary world. Like W. in *Rockabye,* his isolated existence is not entirely by choice: indeed, both individuals long for the company of others. W hopes to see another person, "another living soul," out of the window of her apartment and so disrupt her isolated existence, and Krapp demonstrates a desire for companionship in his bitterness about his younger self who

foolishly took romantic company for granted. Stanley Gontarski observes that Krapp's world progressively becomes smaller and more isolated as he ages; he moves from enjoying the company of others in outdoor settings to a constricted, solitary existence in his home.[16] Krapp's experience reflects the narrowing of relationships that can occur for many as they age and lose mobility.[17] Connecting W and Krapp's reflections to the process of life review in hospice, the value of another person there to navigate the terrain of loss becomes evident.

<div align="center">Life Review in Health Care Chaplaincy</div>

Life review demonstrates a narrative mode of self-understanding for patients. Because they have the time and opportunity to address the spiritual, emotional, and social dimensions of a patient's experience, chaplains are likely to hear patients engage in life review or to invite them to do so. I speak to the role of chaplains here specifically, because they are most likely to engage in the process of life review as an intentional dimension of their plan of care. Therefore, literature like *Krapp's Last Tape* that models the process of life review holds special value for chaplains and pastoral caregivers in developing their clinical skills. Clinical Pastoral Education is an action-reflection mode of education in which patients are considered "living human documents."[18] A

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16. S.E. Gontarski, *Crapp's First Tapes: Beckett's Manuscript Revisions of Krapp's Last Tape* (Philadelphia: Temple University, 1977).

17. John Cacioppo, neuroscientist at the University of Chicago, examines the health consequences of loneliness, which he defines as perceived social isolation. His research connects the self-centeredness of loneliness to the drive for self-preservation in "Reciprocal Influences Between Loneliness and Self-Centeredness: A Cross Lagged Panel Analysis in a Population-Based Sample of African American, Hispanic and Caucasian Adults," by John T. Cacioppo, Hsi-Yuan Chen and Stephanie Cacioppo in *Personality and Social Psychology Bulletin*. Applying his research to Beckett's work, Krapp, an unambiguously self-centered figure, can be perceived as engaging in a form of self-preservation through his annual ritual of recording his account of the year.

18. Anton T. Boison, founder of the clinical pastoral education model, describing the subject of case studies in chaplaincy and pastoral care education.

person like Krapp is a figure that can prove useful for clinical pastoral education for chaplains because he engages in life review, speaks about the loss of religion in his life, and touches on his grief over his losses in life, including the loss of his parents and the losses of his romantic relationships. He also engages in ritual behavior through listening to his tapes every year on his birthday, an activity a chaplain may interpret as worthy of reflection. Dramatic works like Beckett's offer a valuable source of narrative analysis for chaplains who will likely encounter such patients in their work. A literary work makes explicit, through staging, exaggeration, characters' names, props, and other details, what is not so explicit in real life narratives.

<div align="center">Connections to Narrative Methods in Medicine</div>

On the clinical caregivers side, narrative methods are used to train clinicians to become better listeners for their patients, learning to attend closely to what is being communicated to them. In this dissertation, I speak to both narrative practices on the part of patients looking to life review as an example. Additionally, I look at narrative methods of education and professional development for clinical caregivers, such as physicians, nurses, and chaplains. *Krapp's Last Tape* is valuable for educating clinicians because it portrays a person that may be considered a difficult, challenging, or non-compliant patient. Krapp is a bitter, angry man. His emotional presentation is one that may lead to his social isolation over time. Even clinical caregivers may limit their time with patients like Krapp that appear hostile.

Krapp curses, sighs, paces, throws objects, and conveys disappoint and disgust with his situation. Scholars and clinicians trained in narrative medicine, by romanticizing the clinical encounter and focusing on mutuality, may leave clinicians unprepared for encounters with figures like Krapp. In reality, many patients are defiant, entitled, angry, suspicious of doctors and institutional medicine, anxious about finances, or in pain—thus many will not be interested in

narrating their life history in an agreeable way, if at all. By reading texts like *Krapp's Last Tape*, clinicians can develop the skills of being present with challenging patients. Krapp has physical ailments—constipation, and possibly addiction—that may cause him to be peevish and ill-tempered. If a clinician has learned how to be patient with such an unpleasant individual, the clinician may be able to learn about any underlying physical causes that contribute to the patient's poor health, leading to more effective care for the patient. They may also be able to identify dimensions of a patient's total pain, expanding beyond physical pain.

As one form of practice, a clinician could describe how they respond to patients that are harsh or difficult, like Krapp, writing down how they might respond to a figure like him if they encountered him in life. How would they assess his pain? Would they be able to recognize existential pain and the ways it manifests, such as the feeling that one's life was a waste? If a belligerent patient like Krapp says he does not have physical pain, would he then be left alone because he is challenging to be around, and then miss the possibility of having his personal and existential pain examined. Krapp represents patients whose existential pain warrants attention, but may go unnoticed because time is limited with such patients. Turning now to the second part of this chapter, I show how Beckett's work can also be used for patients with disrupted speech or cognitive limitations, patients similar to Krapp in that they can be challenging to work with and avoided or unconsciously neglected.

### Applying Samuel Beckett's *Rockabye* to Dementia Patients: The Use of Modern Literature in Clinical Education and Narrative Medicine

Visitors and clinical staff can become uncomfortable in the presence of those who are non-verbal, non-responsive, or have disrupted or confused speech. As a result of this discomfort, such patients receive less personal attention and human interaction, becoming more and more isolated.

They are visited less, their doors remain closed and the person inside largely goes unseen. My claim in this section is that by engaging with literature such as Samuel Beckett's *Rockabye*, a clinician can practice the discomfort that comes with reading Beckett's work, with the clinical goal of being able to sit with this discomfort in encounters with patients who cannot speak clearly. Because clinicians are trained as diagnosticians, and are expected to have the answers to patients' wide-ranging medical questions, they may experience not-knowing as uncomfortable, potentially avoiding patients with chronic conditions or concerns or dismissing questions that do not have clear answers. Yet, many patients have medical predicaments with no clear or obvious solutions, such as those who have dementia. Building on the scholarship in the field of narrative medicine, I propose that Beckett's work can address some of the limits of narrative medicine that I examine in previous chapters. Additionally, I address the ethical implications of neglecting socially isolated patients. My goal is to show that by encountering literary works that portray fragmented speech and disjointed conversational patterns, such as questions posed and left unanswered, the reader may sit with the experience of not-knowing and the discomfort that comes with leaving a question unanswered, thereby increasing their tolerance for this discomfort. I argue that increasing tolerance for this discomfort can work toward mitigating the social isolation of patients perceived as difficult.

Patients who present with disrupted speech or who are unable or engage in everyday conversation are socially marginalized, even if unintentionally. In a verbal economy of conversational give and take, such patients can make others feel uncomfortable or agitated when their question goes unanswered or when the patient responds in an unexpected manner. Due to a limited ability to respond in an exchange structured by reciprocity, such patients can become isolated, exacerbating a situation in which they are already socially isolated due to age

or ability. When a patient's clinician or non-professional caregiver expects the person to respond in a coherent, reciprocal manner, the caregiver may, unconsciously, be expecting to be rewarded by the patient, to be affirmed as a dialogical partner. When their question or comment goes unacknowledged, the caregiver may decrease interactions with the patient thereby increasing a patient's sense of loneliness and social isolation.

Because medical school has been shown to reduce students' sense of connection to patients, programs in narrative medicine strive to cultivate, or rekindle, empathic regard in clinicians. To work toward this goal, students learn to closely engage literature and develop the ability to attend to nuance and detail in their sources, looking for meaning that may not be explicitly expressed in the text. Recent research shows that empathic regard does increase when students engage in the practice of narrative medicine. However, by reading literature in which characters speak in a sophisticated manner, students may find themselves limited in their ability to engage with patients that speak in a confusing way or with patients that do not present as satisfying dialogue partners.

In this section, I suggest that the practice of narrative medicine can address this limitation through the use of modern literature, specifically texts that include characters with disrupted speech. Samuel Beckett's dramatic works model this type of speech and I look to his late play *Rockabye* as a potential text for the study of narrative methods in medicine. Because they often speak in a baffling, fragmented manner, the characters in his plays serve as a useful resource for clinicians interested in developing their ability to attend closely to patients with disorganized speech. Beckett's work serves as a needed supplement to the literature already used in narrative medicine programs. His characters closely resemble those that clinicians will encounter in their work, especially clinicians working with elderly patients. Whereas the literature used in narrative

medicine programs can idealize how patients may speak in a clinical context, Beckett's portrayal

of lonely, fading individuals presents a decidedly unromantic view of human experience.

Background for Beckett's Interest in Dementia

and Autobiographical Memory

After an extended decline, Beckett's mother, May Beckett, died of Parkinson's disease in 1950 at

age 79. Visiting her in the nursing home where she died, he noted in correspondence with a friend

that, "Most of the time her mind wanders and she lives in a world of nightmares and delusions."[19]

Thirty years later, Beckett, living in France at the time, was commissioned by the State University

of New York at Buffalo to write a play for a theater festival held in his honor. In 1980, when

Beckett finished the play, *Rockabye*, he was also in his 70's (75 when the play premiered in Buffalo,

NY, in April 1981). There are close similarities between the single character in *Rockabye* and May

Beckett with regard to their confused mental state and their turn toward death. The woman on

stage, named W., sits alone in a room in a rocking chair that rocks her slowly (Beckett specifies

that the chair rocks her mechanically—she does not rock it), the movement bringing her body

back and forth, her face in and out of a meager beam of light on a dark stage, the light fading as

the play progresses. Beckett's mother, sharing W's state of confused mentation, similarly preferred

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19. Adam Piette, "Ending the Mother's Ghost: *Beckett's Ill Seen Ill Said* and *Rockabye*,"
*Complutense Journal of English Studies* 83, no. 22 (2014): 81-90.

a rocking chair toward the end of her life.[20] W's experience, steadily declining, disoriented and socially isolated, reflects that of Beckett's mother in the nursing home until her death.[21]

Beckett's characters cause the reader to face common fears: dementia, abandonment, isolation, institutionalization, death. Due to the peculiar affect of his characters and their stark, uncanny "nowhere" settings, like the windowless, padded cells in *Murphy*, Beckett's work gets categorized as absurdist drama, a genre popularized in post World War II European literature and recognized by Hungarian-born Martin Esslin in his 1962 essay, "Theatre of the Absurd." Yet, the fragmentation of language, the rarity or impossibility of reciprocal conversation, the anxiety about losing one's sanity or mental abilities and control over one's body and its functions, are common human concerns. Beckett presents humans in caricature, but their challenges and concerns are ordinary.

In many of his plays, Beckett's characters use confused speech, have disjointed conversations, where answers do not match questions and language does not match actions (From *Waiting for Godot*: Vladimir: "Well? Shall we go?" Estragon: "Yes, let's go." *They do not move*.), and where fancy, overwrought language is punctuated by farting, scratching, coughing, and other course moments of physicality. Whether Beckett intended his characters to be absurdist or realist does not matter for the use of his writings in narrative medicine; regardless of the author's intention, his characters depict behaviors that clinicians will undoubtedly face in their

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20. Piette, 83.

21. James Knowlson notes that to prepare for his play *Murphy*, Beckett toured the Bethlehem Royal Hospital, an institution for mental illness, and source for the term "bedlam. " The Bethlehem Royal Hospital treated those with various forms of mental ailments, including psychiatric illness and individuals with dementia. Beckett was also familiar with the Newcastle Sanatorium, where he went to see his uncle Boss Sinclair (Knowlson, 191). The abusive patient-caregiver dynamic he witnessed in institutions can be seen in his literary work as well, particularly the relationship between Hamm and Clov in *Endgame*.

work with patients. Encountering the discomfort, the impulse to laugh or recoil, in response to the challenging characters in Beckett's dramatic works allows clinicians to become aware of their immediate responses to such individuals or contexts where they might experience concentrated discomfort. The goal of using confounding literature like Beckett's is to allow clinicians to practice sitting with discomfort so that they can remain present for patients who may go neglected because they perturb others.

<div align="center">Rockabye</div>

*Rockabye* is a short play that uses repetitive speech and few words. In the play, though there is only a single character on stage, there are in fact two voices: W.'s voice and V's voice (V.'s voice is W.'s recorded voice). Their voices overlap throughout the play until the final movement where V.'s voice is no longer present and only W.'s voice remains. While W. is sitting and rocking, V. narrates W.'s action in the past, with W. occasionally responding in echo, particularly one line that is repeated throughout the narrative: "time she stopped." V.'s recorded voice could be W.'s thoughts or her memories, that she modifies as she considers them. The line can be heard as "Time, she stopped" or "Time she stopped" with Time as the subject in the former and she as the subject in the latter. "She" could be W. or "she" could be W's mother. Beckett's language is marked by indeterminacy in the play creating disequilibrium for the reader or viewer.

To highlight her mental and social disorientation, and possibly her turn toward death, Beckett specifies that W is to wear a black dress, seemingly mismatched with her context: "Costume: Black lacy high-necked evening gown. Long sleeves. Jet sequins to glitter when rocking. Incongruous flimsy head-dress set askew with extravagant trimming to catch light when rocking."[22] The eerie effect of her dress serves to remind us both of her estrangement from

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22. Samuel Beckett, *Complete Works*, 433

ordinary social life, she is fundamentally disconnected from the world, and of her closeness to death—she could be dressed in her "best black" to indicate mourning or funeral attire. She could also be longing lost connectedness, the dress potentially having been used for a formal social event before she ceded to a solitary life.

There are four movements in the play, each marked by the motion of the chair which rocks mechanically, but then stops and starts again, like a pulse that slows and stops but then feebly returns as a person nears death, or like breathing that stops and then starts back with a gasp as a person fishmouths for air as they die. The movements are also marked by state of W.'s eyes which at the beginning of the play are equally open and closed until then middle of the fourth movement when they are closed completely. Her closed eyes possibly signifying her turn inward and her final separation from the external world. Set in a bare, dark stage, the play evokes fears of bodily diminishment and loneliness. W.'s voice loses energy and becomes quieter as the play moves toward its conclusion. The chair stops four times and each time she calls out "more" at first loudly like a demand and then quietly, like a plea. When the final stop occurs, she does not speak or move. She is dead, or possibly asleep. This is ambiguous in the work, she could very well wake up and ask for more; however, though it is unclear whether or not W. dies at the end of the final movement, she certainly experiences a kind of slow social death in the account narrated. The rocking motion of the chair creates a constant rhythm like a heartbeat (maybe make connection that a cradle's rocking simulates a heartbeat). The rhythmic language reminds one of a lullaby.

W, live and via V's voice, speaks in a repetitive, non-linear way, revising her narrative as she recounts her thoughts and activities aloud. The play begins in media res, with W asking for "more" and V's recorded voice speaking with what sounds like the conclusion to a story: "till in

the end / the day came / in the end came / close of a long day / when she said / to herself / whom

else / Time she stopped / *Time she stopped*."

Hunter Groninger and Marcia Day Childress note the following about Beckett's word

choice in the play:

> The first movement establishes a base vocabulary of just 41 words; subsequent movements
> build on this base by introducing new words and word patterns. In the English version,
> single-syllable words predominate, with occasional two-syllable words (*herself, creature,
> window, only, other, famished, never, alone, rocker, mother*) virtually all of which are crucial
> thematically, and but two words of three syllables (another and the title, *Rockabye*).[23]

They also note that there is almost no subject throughout the entire narrative. There is this

self-evacuation that has occurred, a loss of self as a result of a loss of recognition by others and

any form of social existence. "Time she stopped" can be understood in a few ways: it can be time

that stopped—this may be the case when W. recalls the death of her mother (who died in her best

black, as W. is now dressed, in sequins even). But the phrase can also be understood as "It's time

she stopped" looking for another person like herself because she ultimately will not find one. W.

decides to stop her search for another, and she is now alone, with the voice and the chair and her

memories for company.

V. narrates W.'s movement from a world of social interaction to a world of isolation. As W.

is rocking, V. says the following about W.'s prior life: "going to and fro / all eyes / all sides / high

and low / for another."

W. is looking, searching all around, for another living soul, for another creature, as she

says, like herself. W. moves from looking for another outside to looking for another from within

her room, looking out the windows. She, keeping her blinds up, looks out her window at other

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23. Hunter Groninger and Marcia Day Childress, "Samuel Beckett's *Rockaby*: Dramatizing the
Plight of the Solitary Elderly at Life's End" *Perspectives in Biology and Medicine* 50, no. 2 (2007): 260-275.

windows—and sees all the blinds down in windows facing hers. All she wants is to see another blind up, to know that there is another person across from her, even if separate from her: "Sitting at her window / Quiet at her window / All eyes / All sides / For a blind up / One blind up / No more / Never mind a face / Behind the pane / Famished eyes / Like hers / To see / Be seen."

As in the play *Endgame*, windows and eyes are connected with each other in Beckett's dramatic writings. Windows on the set can be interpreted as eyes and the stage is one's skull, reflecting the interiority of one's mind.[24] W. sits looking out from within her inner world, and sees no one like herself. She then, as V. narrates, chooses to move even more inward. Going down the "long stair" to sit in the chair where her mother sat and died, after going "off her rocker." W. never does see another, but she does have this voice, even if it is her own voice narrating her life in the world. She also has the memory of her mother, but she does not encounter the presence of another living soul like herself. She lives and dies in isolation, in the arms of her rocking chair "those arms at last", alone. In both *Krapp's Last Tape* and *Rockabye* the characters present as solitary figures, but they demonstrate intimacy with the technological devise they live with, the tape recorder for Krapp functions as a longtime companion and the rocking chair for W. holds her body close.

There is no evidence in the play that W. experiences any physical pain, though one can say that not being seen or touched can create an ache for this experience. While there is no indication of physical suffering, W. does experience the suffering that comes with chronic isolation, an isolation that can be seen as both chosen and unchosen in her case. Many themes emerge in the play that relate the experience of the character to the experience of end of life patients—social

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24. Katherine H. Burkman, *Myth and Ritual in the Plays of Samuel Beckett* (Rutherford, N.J.: Fairleigh Dickinson University Press, 1987).

isolation of the elderly, the unreliability of memory and the revision of narrative, the desire for companionship, preparing for one's own death, and the connections between birth and death. Her pain, the kind of total pain that Saunders names, goes unrecognized. W. is left alone, in an unchosen solitude, where she may die alone. Her experience dying or even existing in this manner, represents in fiction what many fear will happen to them in life. Through encountering the existential distress of characters like W. in literature, clinicians may better understand the emotional and existential pain of their patients.

Beckett's other dramatic works share some thematic elements that are salient in *Rockabye*. The stage is often bare with only one or two characters present. One gets few clues as to where the play is set beyond what is present on the stage (usually just a bed, a chair, or a window). Similarly, one is not provided with a panoramic understanding of the character involved—we don't know her full name, only an initial, we don't fully see her body as she is sitting in the rocking chair the entirety of the play. The viewer or reader gets only a partial view of her. In *Not I*, Beckett shows only the main character's mouth and nothing else, no context; in *That Time*, only a face. In *Endgame*, Hamm is in bed and his parents, Nagg and Nell, (names connoting sounds one does want to hear) are in dustbins, signifying the reality that the elderly are often hidden away out of sight or discarded when they are no longer socially useful or rewarding. Beckett's characters are detached from the outside world, and not by choice; rather, they are trapped in the confines of a room, a bed, a dustbin, or the mind.

## Significance of *Rockabye* for End of Life Care

In *Rockabye*, Beckett presents a character that is elderly and alone, with compromised cognitive and verbal skills. While she articulates no overt medical concerns in the play, her plight is one shared by many patients that clinicians will encounter in their day to day clinical context.

The value of examining this play in the domain of narrative medicine is that in *Rockabye*, one encounters the radicalization of a context that is ordinary life for many patients. Such patients are not only socially neglected, they can be neglected in literature as well. Because the classic Aristotelian dramatic categories do not apply to such individuals, as they have limited ability to engage in retrospective reflection, characters such as W. remain scarce in the Western canon. If a clinician exclusively studies how to interact with verbal, highly cognitive and self-aware patients, he or she may be challenged by engaging with patients who cannot speak coherently or respond in a dialogical manner. The discomfort that arises from encounters with the patients may then lead the clinician to limit time with the patient in the future, thereby exacerbating the individual's experience of isolation.

Additionally, throughout the entirety of the play she is ensconced in the rocking chair, a technologized machine-like apparatus that rocks her. The chair can serve as a reminder of the highly technologized environment of many patients at the end of life. Though this is less the case with clinical staff who are familiar with medicalized environments, the very presence of the machinery can make some visitors uncomfortable. This discomfort can similarly lead to fewer visits with patients who are already socially isolated.

<div align="center">

The Value of Narrative Medicine When

Working with Alzheimer's Patients

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There is specific value in examining *Rockabye* in the context of narrative medicine because W. can be read as a character that has a form of dementia. She is able to revise her narrative (which she does in response to V.'s recorded voice), but many of her speech patterns resemble those of patients with compromised neurological function. She engages in repetitive, rhythmic speech, and demonstrates confusion about past events. Additionally, her labile mood ("fuck life!") is

symptomatic of neurological concerns; in many cases, dramatic mood changes that seem out of character for an individual is one of the earliest signs of deteriorating cognition.

W.'s confused syntax and non-sequitur comments can create discomfort in a reader accustomed to clarity and coherence in a person's speech. Such discomfort can also be experienced by a clinician or caregiver when attempting to communicate with a patient who babbles, speaks in fantastic partial truths, repeats what is said to them, or voices seemingly meaningless disordered speech. This discomfort can come from a romanticization of end of life patients, the deathbed scene in which a person expresses peace with death and dies without pain or agitation surrounded by family members. The discomfort can also disclose an underlying expectation of reciprocity in the caregiving relationship, an expectation that exceeds the patient's capabilities. Ultimately, it is not the patient's responsibility to put the clinician or caregiver at ease. To expect that the relational dynamic with a demented patient will be based on mutual recognition and response is to unfairly burden the patient, who may be able to intuit that they are not meeting the expectations of their caregivers but not understand why or what to do to remedy to problem.

Language and Loss of Relationality for Alzheimer's Patients

A person with dementia experiences multiple losses that accompany cognitive decline: the loss of short term memory, of basic social awareness and skills, and the loss of communicating with others in a coherent way, both in terms of expression and in reception. These individual losses also contribute to the loss of relationships as visitors may not know how to engage with a person when they no longer have a shared world of meaning. These losses do not necessarily lead to grief for the patient—in many cases, the person easily adapts to the changes in ability and relationality and has limited awareness of how he or she used to be. As with W., you may not have access to

the interiority of a person with dementia, or may feel as though there is no interiority there at all—some say of those with Alzheimer's that you can see the light go in and out of their eyes. Characters such as W. demonstrate that a person can confused, disoriented to person and place, and, in terms of demeanor, be unrecognizable from who they were before, yet still have a desire for company and engagement. Family or friends may say that their family member may not know or care whether or not they visit; *Rockabye* shows that for some there remains a longing for the company of another person, even if one's memory is compromised. Visiting those who do not demonstrate recognition, gratitude, or meaningful responses to questions or comments can be experienced as frustrating or distressing for family and friends, making them less likely to visit regularly. However, clinicians working with patients in this population can educate family members about the value of their visits even if the visits are not immediately rewarding for the visitors.

<center>Clinical Interactions with Verbally or Cognitively Challenged Patients</center>

Working with verbally and cognitively challenged patients can prove challenging for those who are trained to speak with clinical authority. Professional competence, and even an intuitive comprehension of what a patient is attempting to communicate, reaches a limit-point with patients who do not have complete ability to think and speak coherently. Conversations, on both sides, can lack understanding and recognition of what is being communicated. The comprehension-gap that exists in the encounter can have problematic consequences. When conversations are replete with misunderstanding and confusion, the caregiver may shorten an encounter with a patient or avoid verbal interactions with the person altogether. Additionally, there may be a move to fill in the gaps of what a patient is attempting to express. I suggest that this move to translate for a patient what a patient is attempting to communicate can be a form of

professional overreach. In medical ethics language, this over-extension of translation on behalf of the patient is a form of soft paternalism. The clinician, in effect, knows *for* the patient what the patient desires or believes. The patient is not fully autonomous; however, the patient has not lost his or her autonomy entirely. Instead, the patient has a type of partial autonomy that can be honored in the clinical encounter.

Though patients with dementia can be described as incoherent or speaking in a confused, meaningless way, they may be communicating a memory, or a desire, fear, or other emotional state--only what the person is communicating does not correspond with the listener's understanding or perception of the past or current context. In some cases, the caregiver, because he or she spends more time with the patient, knows the events or figures that the patient is referring to, even if the patient is fuzzy on the details. Day to day interactions create a scenario in which the caregiver is able to accurately reconfigure what the patient mistakenly remembers. For instance, a woman may speak to her caregiver about the kind man that she spent time with the day before, not realizing that in fact her caregiver is the man she was with, and that he is her husband. She is communicating her sense of pleasure in his company, despite being unable to be precise about his identity. However, a clinician is less likely to be able to comprehend the spirit of what the patient is communicating due to the short-term nature of their interactions.

### How Beckett Can Be Used in Narrative Medicine

Addressing the limits of narrative medicine through the use of modern literature in clinical pedagogy can lead to a dialogical context in which patients do not have to speak with high-level awareness or verbal ability in the clinical encounter. Through the practice of reading strange texts such as Beckett's dramatic works, or watching performances of his work, clinician's can become more at ease with patients exhibiting fragmented or incoherent speech. Additionally,

clinicians can become aware of their impulse to speak over or for a patient when they practice

enduring the discomfort that comes from not being able to understand what a patient is trying to

communicate.

The value of narrative medicine extends beyond developing clinical skills to the expansion

of a non-professional caregiver's ability to attend to a family member with dementia. Caring for

a person with dementia can create such discomfort for the caregiver that the person may receive

inadequate physical care or needed socialization. Embarrassment, discomfort, irritation, and an

overwhelming sense of frustration are some of the responses one may have when interacting with

a dementia patient. These responses may not cease to be unpleasant for the caregiver; however,

when they are expected, the caregiver may be less likely to avoid interacting with the patient or

rush their encounters.

Methods of narrative medicine do not have to rely solely on Aristotelian models of drama.

In fact, dramatic works that do not have distinct characters, a linear plot, or identifiable context

may prove more valuable for those working with patients in the clinical encounter due to the

reality that clinicians only meet patients for a brief amount of time and they usually interact with

them in a depersonalized institutional context. Modern literature though it appears to radicalize

the human experience of isolation and disjointed or impossible communication, in many ways

comes closer to lived human experience than classic models of narrativity. Whereas current

narrative methods strive to teach clinicians to demonstrate a close attention to detail by reading

literature with nuanced characters and plotlines, narrative methods that look to modern literature

can teach clinicians how to attend to patients with confused speech or cognition. Not expecting

a patient to perform as a character and not expecting the dialogue to demonstrate mutual

understanding and recognition can collapse the expectations for the discourse in a positive way, reducing pressure for the patient to meet the clinician's needs.

Individuals with dementia may be able to offer a narrative account of their lives, though in fragments and fleeting episodes of clarity. Despite their ability to recount their histories in a meaningful way, their ability to engage in coherent speech can be underestimated by their caregivers. While this is understandable, considering the majority of some patient's speech is incoherent, such low expectations can lead to social negligence and missed opportunities to relate to patients in a therapeutic way. Further, a patient may be indicating sites of pain--physical, emotional, and spiritual--as well as potential sources of comfort and support, in their lucid moments or through their confabulatory accounts.

Attending to patients with confusing speech or mentation requires patience on the part of the caregiver, as well as an ability to read between the lines and interpret what the patient may be communicating. There is a danger in clinical overreach here, particularly with the complicated history of paternalism in medicine. A caregiver may rush to interpret a patient's concerns or dismiss concerns that do not align with the clinician's interpretive framework. However, because individuals with dementia can be clinically and socially neglected, there is crucial need to intentionally engage in a relational manner with such patients, even when the encounter lacks mutuality or cognitive understanding. The patient may monologue, engage in repetitive speech, or respond to a clinician's questions in mismatched fashion; yet there can still be meaning in what the patient is communicating. The communication problem is compounded when the patient is aggressive, but, again, the patient may be presenting as hostile because of pain, hunger, loneliness, or a variety of concerns that can addressed by the caregiver. The ability to interpret a patient's behavior is enhanced by frequent encounters with patients; those who receive care at home, as

well as residents of home-like facilities in which caregivers are familiar with patients are examples

of those that can benefit from caregivers' ability to interpret their needs, even if this action is not

always successful.

I suggest that the skills required for narrative competency, developed or improved through

a study of literature in narrative medicine, are germane even for patients with cognitive or verbal

limitations such as those with Alzheimer's disease or dementia unspecified. Most approaches

to narrative medicine rely on patients who are able to verbally engage with the clinician in a

sophisticated way; in a sense, the patient then meets the clinicians where they are. Humanistic

medicine, in contrast, centers on meeting the patients where they are, and does not require a

high-level response to the clinician's dialogical approach.

In literature, the reader often has access to the interior world of a character. Training in

narrative medicine, and the character analysis involved in the process, can then lead a clinician to

assume that access to the inner landscape of another person is possible in a clinical relationship.

I assert that this approach to engaging with patients, while laudable, is ethically problematic in

a few ways. One, the clinician assumes an ability to understand a patient based on the limited

information provided by the patient. Patients, especially those with addiction concerns or a desire

to have the clinician view their healthcare choices in a positive manner, are not always reliable

narrators, compromising the clinician's ability to accurately interpret a patient's experience. The

clinician does not have the details about a person's desires, fears, motivations and so on, provided

by an omniscient narrator in a work of literature. Training in narrative medicine has the potential

to lead a clinician to believe that he or she has the perspective of an omniscient narrator; hence

Sayantani DasGupta calling for narrative humility that recognizes that the clinician does not

have access to the inner landscape of another person.[25] In *Rockabye*, W. herself does not fully know the details of her account—she continuously checks herself and revises her narrative. If she cannot articulate her own experience with precision and certainty, Beckett points to the improbability of another doing so on her behalf.

Two, when the clinician believes he or she can interpret a patient's narrative on the patient's behalf, the patient is then disempowered from interpreting his or her own story—in a sense, it is appropriated from them. For many patients in the clinical encounter, the patient's version of the account can be interpreted by the clinician and then this account can then be held up for verification by the clinician. Comments such as I hear you saying X, is that right? and questions such as am I understanding you correctly? Correct me if I am mistaken, etc., allow the possibility for reconfiguring a patient's account so that there is mutual understanding. However, for patients who are neurologically compromised, the patient's account cannot necessarily be affirmed or modified because of their disoriented mental state. In such cases, if the clinician attempts to interpret the patient's narrative, the asymmetry of power that exists between clinician and patient becomes even more exaggerated, compromising narrative medicine's goals of mutuality and reciprocity.[26]

Beckett's dramatizes scenarios in which the limits of language and understanding are brought into sharp relief. The realization that can occur from engaging his work is that there is no "right" response. There is no answer or solution to the predicament the characters are in; there is

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25. Sayantani DasGupta, "Narrative Humility," *The Lancet* 371, no. 9617 (2008): 980 – 981.

26. In some cases, particularly when a patient is aphasic, it is appropriate and medically necessary to interpret pain on the patient's behalf, especially for those who are unable to speak about their pain. In such cases it is better to err on the side of interpreting for the patient that pain is present when there are observable physical cues (wincing, furrowing the brow, holding one's breath, clenching extremities, and so on).

not necessarily anything to figure out. This does not mean a person is speaking nonsense, though. Also, it is important to note that those with confused mentation can speak in a way that can be meaningful to others even if the content of the person's claims is off the mark, so the work of attempting to understand a person who speaks in a seemingly incoherent way remains necessary. Someone that has a close history with a person who has dementia may be able to connect the person's account with historical events or persons, interpreting the feeling or meaning embedded in what the person is articulating (mimesis according to Anne Carson's understanding). This is a deep form of communication even if the language used is technically incorrect (calling a companion a loving son, when it is the person's husband, for instance—the designation is incorrect, but the devotion (word) is true). However, there is no way to have certainty that one is accurately interpreting the person's account because it cannot be reliably validated.

Finally, it is questionable whether or not one has the ability to fully inhabit another person's interior world. There is distance between one's self and another person; there is even opacity with regard to understanding one's own motives, as Ricoeur reminds us. Beckett's play radicalizes a situation in which the observer does not have full access to the interiority of another person—one cannot understand what is happening to or within W. Her life is set apart from the observer's world. The play begins in media res, so the audience doesn't know what was happening before she begins speaking, and the play ends ambiguously, with W. closing her eyes and the rocking motion stopping. She could be asleep, she could be medicated, she could be dead. The setting for the play is bare, just a rocking chair in an empty room; Beckett providing scarce details about her individual environment or her personal history. We know that her mother died and that she yearned for companionship and ultimately did not find it, but beyond that, W.'s interior world and her past experience is unavailable to the audience.

Beckett disrupts an observer's sense of comprehension and literary consummation, highlighting what the reader does not know and cannot know. There is no way to thoroughly master or understand his characters. One can only speculate and gesture toward an approximate understanding, without cathartic satisfaction. This is precisely why his work is valuable for those committed to narrative methods in medicine. By encountering modern literature such as Beckett's dramatic works, a clinician can practice sitting with confusion, uncertainty, and the limits of non-biological clinical knowledge, experiences that will no doubt be faced in a medical context. The clinical encounter, like Beckett's work, is marked by uncertainty, ambiguous truths, undisclosed desires, and competing goals—the experience is not one structured by objectivity, certainty, or clarity for the clinician or for the patient. Struggling to understand Beckett's work and accepting that there are limits to one's comprehension will help a clinician navigate the obscure space of the clinical encounter by increasing one's tolerance with confusion and disorientation.

## The Limits of an Objective Evidence-Based Medical Epistemology

The figure in *Rockabye* engages in disrupted, repetitive speech, speaking in a manner that is similar to patients with neurological impairments. Her thought process is unclear and fragmented; yet there are moments of lucidity in her narrative. Alzheimer's patients similarly speak in a confused or disoriented way, but have episodes of clarity and dialogical understanding. Similarly, the form of speech may be confused but the content of what the person is attempting to communicate may be quite clear. In the play, W's desire for social interaction is unambiguous. Similarly, a person with Alzheimer's disease may be speaking about an event that did not actually occur, but the significance of the story emerges despite the disjointed details. Interpreting their needs takes time with them, and I suggest that the time clinicians and visitors spend with such individuals is shortened due to the discomfort they experience encountering disorganized speech.

For instance, in the play, W. is housebound and alone. She repeatedly speaks of how she looks out the window, if one were visiting her and kept hearing her repeat this, there may be a tendency to dismiss her words, especially if you know that she is incapable of getting up out of her chair to look out of her window. However, the way she describes viewing out her windows for another person reflects her status as a shut-in—there is no one to acknowledge her existence. She sees no signs of human activity around her. She is alone, looking for someone to see her, "famished eyes/like hers/to see/be seen."

For patients like the woman in *Rockabye*, the skillset and medical epistemology of scientific, evidence-based medicine reaches its limits. There is nothing physically wrong with W.; however, her experience of extreme isolation is a source of pain for her and calls for clinical attention or referral to psychosocial support. She represents the many individuals, often women, who will age alone without social support. Furthermore, her social isolations could potentially lead to a medical crisis in which she needlessly suffers. Her concern is not a medical one. However, physicians will encounter patients like her in their appointments, and having knowledge of the lives patients live outside of their time in the office can develop a response of compassion and a greater appreciation for patient-centered care. If a patient's loneliness is leading them to make repeated medical visits for human interaction, the clinician can encourage the patient to develop a social support that can meet that need for engagement, thereby reducing unnecessary medical visits and costs.

Additionally, reading texts like *Rockabye* and working with patients with cognitive and verbal challenges can evoke a sense of humility in clinicians, a virtue acknowledged by scholars within narrative medicine. The language of virtues in medicine can be subsumed by the language of principles in medical ethics. Yet, Beauchamp and Childress said that medical ethics is

comprised of the interplay of principles, character, and virtues. Humility is not a classical virtue, but a religious one, added to the classical virtues by Augustine. The examination of humility as a virtue in medical ethics calls for more attention.

Finally, reading disjointed baffling dramatic works such as Beckett's plays can disrupt a clinician's sense of competence in a positive way, reminding them that they do not have full access to a patients inner world and that the impulse to interpret a patient's words or behaviors, or the move to treat patients as literary objects rather than subjects, perpetuate a subtle form of medical paternalism. The doctor becomes the omniscient observer—more than just doctor knows best, doctor knows *all*. The very critiques of narrative medicine can be addressed through the use of modern literature in developing a narrative-based clinical practice.

## Invisibility and Social Neglect

Beckett's play serves as a useful resource for ethical analysis under the aegis of narrative medicine because he draws attention to the mode of life experienced by elderly individuals who often go socially unrecognized. A situation like W.'s is unlikely to be addressed in a medical ethics case study. Cases in health care ethics can skew toward the rare but fascinating scenarios in which an immediate decision must be made. The value of using literature as a source of ethical analysis comes from the variety of mundane experienced by characters. Even though their experiences are inventions of fiction, the plight of characters in novels and dramatic works can be closer to the lived experience of actual people than the case studies used as a source of analysis in medical ethics. When read as a literary case study in medical ethics, *Rockabye*, rather than focusing on the spectacle of a dramatic case, Beckett instead draws attention to a large population of individuals--those aging and dying alone. In short, *Rockabye* addresses the social disregard of an already marginalized population, making neglect an ethical problem worthy of notice. *Rockabye* is a

play with a single character, set in a single room. W. looks out of her window to other windows across from her, establishing the possibility that she lives in an urban environment. She could be surrounded by other individuals, yet still be alone, Beckett choosing to this setting to bring the contrast between her solitude and her populated surroundings into sharp relief.

<div align="center">A Focus on the Ordinary, on the Ethics of Daily Life</div>

Further, the experience of those aging and dying alone like W. is an on-going concern rather than a discrete, decision-based problem. Beckett's play asks the reader to consider the daily, ordinary experience of a growing population of individuals that do not have dilemma-based concerns. The experience of those managing chronic illness or pain similarly aligns with the experience of the solitary elderly in that their day-to-day life presents multiple, unglamorous issues that go unattended in medical ethics. Medical ethics can center on dilemma-based moral issues, rather than closely examining the health consequences of patients experiencing the pain of loneliness or unchosen solitude. One of the greatest challenges when considering the experience of those with long-term concerns is that there is no sense of completion for the ethicist, caregiver, or the individual. There is no quick fix or immediate solution to chronic concerns, thereby creating a less satisfying or role-affirming state for a clinician who is used to completing achievable tasks like diagnosis and cure-based healing. Encountering literary works such as Beckett's plays allow a clinician to practice the experience of uncertainty, confusion, and helplessness that they may face when working with patients with incurable or unidentifiable health concerns.

<div align="center">The Challenge of Elevating Autonomy as an Ethical Ideal</div>

Beckett's play radicalizes the downsides of autonomy, a foundational tenet of western medical ethics. We know little about W.'s former life—in ways her identity is lost because of her solitude; there is no one available to supplement or reinforce her memories. Expanding beyond her

character, W. can represent those who prefer to live alone rather than in assisted living facilities because they prize their independence, wanting to maintain it as long as possible. Doing so, however, comes the danger of isolating oneself from all acquaintance and support later in life. *Krapp's Last Tape* presents a similar situation, one applicable to life review. He listens to recordings of himself made on every birthday, rewinding the recordings and reflecting on his accounts—like W., he is alone, and though he has his independence, this is not necessarily his social preference. The shadow side of autonomy is atomistic individualism that can lead to social isolation for those at the end of life.

## The Limits of a Caregiver's Ability

The sense of disconnection experienced by the reader of *Rockabye* can parallel the experience of frustration and dissatisfaction by caregivers of those with dementia. Indeed, Alzheimer's patients can present a terrifying reminder of the limits of language as source of meaning, the fundamental isolation of the individual, and the possibility that memory and selfhood can (and will) be lost. They are a reminder that ultimately that we will not be able to remember our own lives and that we may not be remembered by those to whom we are deeply connected, our parents, our spouses, our siblings. When one engages with a person who has dementia there can be times when there is no moment of recognition, connection, or mutual regard. You know them, they do not know you as you are. This can be a radically discomfiting experience for those who know the patient. They may have to provide care for someone who is more like a stranger than a family member.

The minimalism of Beckett's plays gives the reader or viewer little to work with when it comes to interpretation. Similarly, when a clinician meets a patient in the clinical context, especially when the patient is alone, there may be little information to draw from to establish a person's history or identity. They present in many ways the way Beckets' characters do—with

disrupted speech, confused mentation, sudden bursts of hostility or inappropriate laughter..

Working with challenging texts in which characters are erratic, speak in an incoherent or

inaccessible way, and offer no clues as to their larger identity or inner world can create a sense of

disequilibrium in the reader that can serve as useful practice for clinicians who will encounter

similar patients in their practice of medicine.

When a caregiver becomes aware of the limits of understanding a patient's words, there

can then be a turn toward other forms of therapeutic interaction that do not rely on such a high-

level of awareness or participation on the part of the patient. For instance, when modes beyond

speech are considered as valid forms of communication with patients, music, dance, touch, and

visual media can then serve as legitimate vehicles of connectivity for caregivers, especially non-

professional caregivers.

In the next chapter, I speak to the value of hospitality as it relates to engaging with

patients who have cognitive or verbal limitations. The value of hospitality is that it does not

require anything on the patient's part—there is no expectation of reward or recognition. When

one provides care for another as a stranger, it ultimately does not matter whether or not you have

access to a patient's thoughts or memories or if they are familiar as the person you knew before.

Instead, you care for them in the alien, sometimes radically alien, way they present themselves.

An approach informed by religious hospitality is one in which there is no expectation

of acknowledgement or reward. Concern is given freely and without conditions. A caregiver

approaching a patient in a posture of hospitality makes no demands on the patient, releasing

the expectation that the caregiver will experience the satisfaction or stimulation of dialogical

reciprocity. Expecting the patient to meet the needs of the caregiver can be a form of

objectification. Even with limited dialogical abilities, the patient may be able to intuit that the

caregiver is expecting a response from the patient, leading to a state of distress. When a caregiver approaches a patient with no expectation of recognition or reward, the patient is then valued not for his or her ability to perform or satisfy another, but for his or her intrinsic value.

Interacting with a patient with fragmented speech can create discomfort on the part of the visitor. I suggest that in addition to showing the patient hospitality, the experience of internal discomfort is also shown hospitality--one then welcomes the sense of the stranger within. By learning to be open to feelings of discomfort, a caregiver then will continue to interact with a patient even if the experience is not immediately rewarding. True beneficence then, means that a caregiver attends to a patient with no expectation of response on the part of the patient. The patient may not be able to express gratitude, smile, or even make eye contact. Because the grammar of human interaction can involve deeply imbedded, but unspoken expectations, such as a the expectation of a response to a question, there can be a high level of discomfort when these expectations go unmet.

## Conclusion

To conclude, though the practice of narrative medicine reaches a limit-point when applied to patients with compromised verbal or cognitive abilities, the goals of the method of clinical practice remain tenable. Indeed, by carefully attending to literature featuring characters that offer little access to their interior worlds or speak in a fragmented manner, clinicians can practice the self-awareness and skill-set necessary to attend to patients who dot no offer mutuality, reciprocity, or recognition of the caregiver. Narrative medicine then becomes truly patient-centered as there is no move to perform in a way that requires validation from the patient. If there is an expectation that a patient will be responsive to the clinician's method of practice, this expectation can put pressure on an already vulnerable individual to meet the needs of the clinician. Encountering

the work of Samuel Beckett allows one to practice dwelling with discomfort and recognizing the

impulse to try to interpret behaviors and words that may prove impenetrable to understanding,

moving to infuse them with meaning when there is none or the meaning is not fully available

because it cannot be validated by the patient.

Beckett's characters, in the end, are strangers. In some cases, they are strangers even to

themselves; i.e., Krapp listening to his younger self with scant recognition, as if he were hearing

an account from an different, unknown person rather then himself. Yet, with both Krapp and

W., their words indicate that their solitary state of being is a source of pain for them. Reading

Beckett's work in the context of narrative medicine provides opportunities for the clinician

to identify pain in its manifold forms beyond the physical. In the next chapter, I suggest that

Saunders' view of total pain offers a comprehensive approach to understanding a patient's state of

being, in that her view of pain takes into account personal, social, spiritual and existential distress.

Using a framework of Christian ethics focused on the Matthean call to care for the least

of these, to approach others and oneself in a posture of humility, and to give without expecting

reward, can deepen one's ability to be present with patients who do not satisfy a caregivers

expectations of reciprocity. While there are valid feminist critiques of the charge to give selflessly,

there is nevertheless value in releasing one's expectations that the patient will satisfy the needs and

desires of the clinician in a medical context. The concept of the wounded healer is particularly

valuable as it focuses on the limits, rather than on the merits, of the caregiver. With regard to

how language functions in Christian writings, Christian sacred texts, much like Beckett's work,

can create more confusion than understanding. The language used in Christian sacred texts

involves parables, paradox, and repetitive language. Turning to Christian theology offers modes

of being present with patients that may be challenging to communicate with or patients that are

unremarkable medically (i.e., such as patients with chronic illness). I maintain that the Christian practice of hospitality in the form of welcoming the stranger, over and above just welcoming the friend or relative, holds particular value for clinicians engaging with patients who have limited neurological or verbal capacity. In the next and final chapter, I examine the contributions of Cicely Saunders' religious lens and the theologically-informed practice of hospitality as they relate to working with this population of patients.

CHAPTER FIVE

RELIGIOUS APPROACHES TO PAIN AND CLINICAL PRACTICE

In this chapter, I address the role of religion in hospice and palliative care, tracing the trajectory of

religion in the early history of the hospice movement to the status of religion and spiritual care in

Western hospices today. Because the place of religion has been formally recognized through the

use of spiritual assessment measures in the clinical context, I examine their role in religious and

spiritual care, approaching them as a modality of narrative medicine and as a vehicle for making

an assessment about a patient's pain or distress that may go neglected, if unintentionally. Spiritual

assessments specifically address the existential, emotional, and spiritual pain of a patient, thereby

recognizing dimensions of pain that may go unaddressed in assessments oriented to physical

pain.

To conclude, I suggest a retrieval of religious modes of being and practices for both

hospice patients and caregivers, looking to how the theological concept of hospitality can

accommodate those in pain and those experiencing discomfort, uncertainty, or grief. I examine

a selection of practices that I suggest are portrayals of hospitality. The selection of practices is not

meant to be comprehensive, but to show how multiple approaches to pain can be interpreted as

demonstrating hospitality. For caregivers, the religious practice of bearing witness, as articulated

here by Dorothee Soelle, serves as an example of how one can be present for patients regardless

of their cognitive or verbal abilities. The practice of accompaniment described by Paul Ricoeur

in *Living Up to Death* reflects a similar approach to being with patients, particularly those at the

end of life. Another option, "companioning the dying" described by grief counselor Greg Yoder,

offers a way of being with patients, similar to Ricoeur's, that can be practiced by those who

identify as spiritual or religious as well as those who are non-religious. Hospitality does not have

to be interpreted or practiced from a theological point of view. Yet Cicely Saunders' motivation

for establishing the hospice model of care was explicitly religious in intention and practice, even

down to the structure of the first residential hospice, designed with the chapel at its center. In the

following section, I examine the religious roots of hospitality, connecting the history of hospice

care, specifically how pain is understood, to practices of being with the dying that do not rely on

cognitive or verbal abilities or reciprocity. To do so, I turn to Saunders' theological construal of

personhood, pain, and clinical practices.

## An Introduction to the Religious Background of Hospice Care

The religious foundation of hospice preceded the advocacy of Cicely Saunders. The term hospice

had been used in the medieval era, to describe a place of lodging for those on pilgrimage, a

place to receive nourishment, both physical and spiritual, on a person's sacred journey. During

the period of the crusades from 1095 to 1291, hospices were rest stops for soldiers making their

way to the Holy Lands and also served as locations of care for travelers and the poor who were

incurably ill. Hospices emerged as specialized locations of terminal care in the 19th century,

founded primarily by Roman Catholic and Protestant religious groups (Methodist and Anglican).

Women in religious orders were instrumental in the development of residential care for dying

patients. One of the earliest Western hospices that identified as spiritually-informed place of care

for terminal patients was established by Jeanne Garnier in Lyon, France in 1842, L'Association

des Dames de Calaire.[1] The Irish Sisters of Charity, founded by Mary Aikenhead, served those

who poor, in prison, sick, or dying; their Christian identity, like Cicely Saunders', informed by the

charge in Matthew 25 in the New Testament text to care for the least of these, the ill and destitute.[2]

The Irish Sisters of Charity provided care for terminal patients and used the name hospice to

refer specifically to end of life care, as death was a form of pilgrimage in that it is a stop along

the way to communion with God.[3] Our Lady's Hospice, founded by the Sisters, opened in 1879

to provide spiritual and physical care for those who were terminal; pharmacological methods of

pain management were limited, but presence, touch, and attention served as methods of comfort

care.[4] Comfort care for the dying was not a new concept, as care had been practiced largely in

homes before the medicalization of death occurred in the mid-1800's; however, the development

of locations of care for strangers, including the indigent and the dying, was furthered by those in

religious orders.[5]

The mission of the Irish Sisters of Charity, also known as the Religious Sisters of Charity,

profoundly shaped Cicely Saunders' theology of care and medical epistemology.[6] Trained as

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1. James Lewis Milton, *Medicine and Care of the Dying: A Modern History* (Oxford; New York: Oxford University Press, 2007), 20.

2. D. Kerr , "Mother Mary Aikenhead, the Irish Sisters of Charity and our Lady's Hospice for the Dying," *The American Journal of Hospice & Palliative Care* 10, no. 3 (1993).

3. Cicely M. Saunders, *Cicely Saunders: Selected Writings 1958-2004* (Oxford; New York: Oxford University Press, 2006), 147.

4. Lewis, *Medicine and Care of the Dying: A Modern History*, 20

5. Ibid.

6. Though established and currently headquartered in Ireland, the work of the Religious Sisters of Charity extends to Africa and South America. When hospices were being developed by the sisters in the 19th century, there were orders in Australia as well; these orders now constitute a separate entity, but share the history being pioneers in the hospice movement.

a nurse, medical social worker, and physician, Saunders worked or volunteered in both Roman Catholic and Protestant institutions oriented to comfort care for the terminally ill; in these contexts her philosophy of pain management and patient identity began to coalesce. In the course of her medical training, in 1958, Saunders worked at St. Joseph's home for the dying in London, established by the Sisters of Charity, there attending to and documenting her observations and the words of over 900 patients, becoming even more committed to the mutual goals of religion and medicine.[7] In 1967, Saunders and a team of physicians opened St. Christopher's Hospice in London, the flagship model of modern hospice.

Though Saunders did not establish the religious foundation of hospice, she was uniquely vocal about the role of religion in medicine, particularly for her time. Mainstream Christianity was on the decline in the post-war United States, and had already been declining in Europe, when Saunders was speaking openly about her Christian identity and how it related to her medical epistemology and interpretation of patient identity.[8] While Saunders was a London physician, her vision of end-of-life medical treatment extended to the development of hospice programs in the United States. Florence Wald, Dean of the Yale School of Nursing, invited her to be a visiting professor in the spring of 1965. Saunders work, and the direct inspiration her work caused in others like Wald, who took a sabbatical from Yale to study the practices of care at St. Christopher's in London, led to the establishment of the first hospice center in the United States,

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7. Jenny Buckley, *Palliative Care: An Integrated Approach* (Chichester, U.K.: Wiley-Blackwell, 2008), 176. See also Saunders' "Hospice—a Meeting Place for Religion and Science," first published in *Science and Faith*: 263-76.

8. Mark A. Noll, *A History of Christianity in the United States and Canada* (Grand Rapids, Mich.: W.B. Eerdmans, 1992), 465. Mainline church membership declined precipitously from 1965 to 1988 in the United States, from 31 million to 25 million, during the time Saunders was openly discussing the religious basis of hospice treatment.

the Connecticut Hospice in 1974. Wald shared Saunders' vision of hospice treatment as one that

addresses patients' spiritual and religious concerns.[9] The need for attention to spiritual and

religious care was formally recognized by Congress when the Medicare benefit for the program

was made permanent in 1986.[10]

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**The Theological Vision of Cicely Saunders**

**and the Concept of Total Pain**

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Two events occurred which moved Saunders to view her work with the dying as more than just

medical treatment. In1945, Saunders had an experience that led to her conversion to Christianity,

a commitment that would distinctly shape her approach to patient care in hospice.[11] "It was as

though I suddenly felt the wind behind me rather than in my face," she said of her experience.

"I thought to myself: 'Please let this be real'. I prayed to know how best to serve God."[12] Closely

following this experience, Saunders met David Tasma, a meeting that would prove to be

instrumental in the establishment of the first modern hospice as a physical location of care. In the

summer of 1947, when working as a medical social worker, she met Tasma, a 40 year old Polish

man from the Warsaw ghetto.[13] He was receiving palliative surgery for cancer at the time, and

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9. Florence S. Wald and Judith L. Lief, "In Quest of the Spiritual Component of Care for the Terminally Ill : Proceedings of a Colloquium (May 3-4, 1986), Yale University School of Nursing" [publisher not identified].

10. "Hospice: A Historical Perspective: National Hospice and Palliative Care Organization, http://www.nhpco.org/history-hospice-care.

11. Sioned Evans and Andrew Davison, *Care for the Dying: A Practical and Pastoral Guide* (Eugene, OR: Cascade Books, 2014), 5.

12. From her obituary, "Dame Cicely Saunders, OM," in the *Telegraph*, July 15, 2005. http://www.telegraph.co.uk/news/obituaries/1494039/Dame-Cicely-Saunders-OM.html

13. Barbara Monroe and David Oliviere, *Patient Participation in Palliative Care: A Voice for the Voiceless* (New York: Oxford University Press, 2003), 3-4.

Saunders would visit him during his follow-up treatments at a different hospital, noting that he was receiving care in a large surgical ward and that she was possibly his only visitor.[14] Her encounter with Tasma moved her deeply; she spoke of him often and with profound affection. On one of her visits with him he asked her for something to comfort him and she recited some psalms and then offered to read to him. He declined, saying, "No. I only want what is in your mind and in your heart."[15] Her experience with Tasma led to her recognition of the need for a physical place of care for patients, one specialized in treating the terminally ill.[16] When Tasma died, he left Saunders €500, saying to her, "I will become a window in your home." Tasma's words imprinted Saunders' vision, not only of what terminal care could be, but also of a stand-alone hospice.

Saunders credits Tasma with being the founder of St. Christopher's. Additionally, her relationship with him, as his only visitor in a place that was foreign to him, led to her awareness that patient's require more than just medical treatment of physical symptoms. They long for recognition and meaningful connections with other people. Following her conversion, Saunders framed her personal work with patients and the institutional mission of hospice theologically. Consistent elements of her theology emerge in her writings, including her medical research, and I address these thematic categories below.

<div align="center">Saunders' Theological Anthropology of Patients and Caregivers</div>

**Imago Dei**

Theologically, Saunders uses the language of *imago dei* to describe her approach to

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14. Ibid.

15. Ibid.

16. Cicely M. Saunders, "St Christopher's Hospice," *St Thomas' Hospital Gazette* (1991): 10.

patients, one in which she views them individually as sacred and worthy of respect regardless of their condition or instrumental value. Deeply informed by her Christian faith, and candid about it, she saw every patient as having the face of Christ. In her understanding, care of patients was not merely care of a person in front of her, a person separate and in need of only physical care. Rather, the patient in front of her is the embodiment of the sacred. For Saunders, caring for the stranger is caring for Christ.[17] In her approach to patient care, she both generalizes patients, viewing them all as manifestations of the divine, and addresses them individually. She specifically notes in one text that she titled it "Care of the Dying Person, " rather than "Care of the Dying," emphasizing that she views each individual patient as distinct and of sacred worth. Cohering with her medical epistemology, her research methods did not address a generic category of patients, common in contemporary evidence-based medicine. Instead, she spoke to individual patients to hear their specific accounts of pain and their preferences for terminal care, recording their conversations and drawing on their words as legitimate sources of medical information.

Stemming from her understanding of the *imago dei*, Saunders rejects the idea of the model patient, as the sacred can be presented to us in any form, not merely that which makes us comfortable. Such an approach is particularly valuable for end of life care because patients are often socially isolated due to others' discomfort their state, even friends and family members. Saunders resists any sentimentalization of hospice patients, a form of reductive objectification. An image of a perfect patient can be cause caregivers to avoid patients that may not present in a way they find pleasing. For Saunders, the sacred does not present itself in a way the individual expects or prefers, but arrives on its own terms.

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17. Wald, *In Quest of the Spiritual Component of Care*, 41.

**Priesthood of All Believers**

Saunders unambiguously viewed the work at St. Christopher's as religious work. The

mission statement of the hospice demonstrates the theological grounding of her medical

epistemology:

> St. Christopher's Hospice is a religious foundation, based on the full Christian faith in
> God, through Christ. Its aim is to express the love of God to all who come, in every
> possible way; in skilled nursing and medical care, in the use of every scientific means of
> relieving suffering and distress, in understanding personal sympathy, with respect for the
> dignity of each patient as a human being, precious to God and man.[18]

Additionally, she maintained that those working at St. Christopher's were engaging in a

form of pastoral care through their medical treatment of dying patients. Included in the Articles

of Association are the following principles:

1. That each person who serves in this hospice must give his or her own special contribution
   in their own way.

2. That dying people must find peace and be found by God, quietly, in their own way,
   without being in any way subjected to pressure from others, however well-meant.

3. That 'love is the way through,' given in care, skill, thoughtfulness, prayer and silence.

4. That this service must be *group work*, open to further light and expansion, as the Holy
   Spirit may lead.

5. That to be of any real use such a foundation must give the patients—whether they have
   faith or not—a sense of *security*: through faith in God, through Christ's victory over pain
   and death, through mutual fellowship and the spirit of prayer, radiating out from the
   Chapel into every part of the corporate life.[19]

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18. Ibid.

19. Ibid. Underlining in the original.

For Saunders, providing spiritual care was not limited to those who were professionally trained to specialize in the work. Theologically, she asserted a "priesthood of all believers" approach to care, rather than limiting care of the spirit to priests or ministers, though she did recognize their value on the hospice team and the contribution of their training and experience in specialized ministry. Her model of hospice care did not categorize treatment into rigid professional roles, but recognized that personal connections will occur in the patient/caregiver relationship that extend beyond one's professional duties and expectations. She identified hospice work as vocational rather than merely professional.

**Religion as Central to Identity, Rather than Supplemental**

In biomedical approaches to patient care, attending to patient's religious identity is a goal of care recognized as a dimension of patient-centered medical treatment. Yet, this recognition can be secondary to the primary goal of treating a patient's physical being. Saunders' concept of patient care at St. Christopher's is distinct in that care is both medical and religious. The layout of St. Christopher's hospice reflects her epistemology of care. Structurally, the chapel stands foremost in the hospice and takes up over half of the building's space. Her vision for the building stemmed from her connection with David Tasma who said he wanted to be a window in her home. The centrality of religion in her concept of patient identity corresponds with her theological-informed view that hospice patients are not mere bodies and that the core of their identities does not come from their illness or their status as terminal, but from their intrinsic value as individuals with particular and irreplaceable histories.

**Existential Nature of Being**

Saunders' theological anthropology was shaped by her Anglican faith and by her attraction to existential understandings of what it means to be human. She was particularly

drawn to the work of Teilhard de Chardin, a French Jesuit priest, and Viktor Frankl, an Austrian psychiatrist and Holocaust survivor who developed a model of existential therapy based on his experience as a prisoner.[20] She draws on Chardin to speak to the seeming-conflict between hope and acceptance for those who are terminal with regard to medical treatment.[21] For Chardin, human experience involves a form of acceptance of one's conditions (what he describes as "diminishment") as well as resistance against these conditions.[22] Saunders draws on Chardin's work to emphasize that we live in the face of death, choosing to live in honesty about the structure of human experience—that it will end—while not submitting to bitter resignation or despair. She expands on his thought to emphasize that medical treatment and comfort care can be used for those who are dying, without promoting false hope about a patient's prognosis. Additionally, she finds value in his concept that we live in a paradoxical context of resistance and acceptance, and that reflecting on this human predicament is part of the spiritual work that can be done when pain is adequately managed.[23]

Viktor Frankl developed logotherapy, a meaning-based form of therapeutic reflection, following his experience in Auschwitz where he was imprisoned. He observed that some individuals were able to survive and find meaning in a context fundamentally hostile to life. Using the language of freedom, he maintained that humans were free to choose how they interpreted

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20. Viktor E. Frankl, *Man's Search for Meaning: An Introduction to Logotherapy* (New York: Simon & Schuster, 1984).

21. Cicely Saunders, "Facing Death," in *The Way* (1984), 298.

22. Pierre Teilhard de Chardin, *The Divine Milieu: An Essay on the Interior Life.* (New York: Harper, 1960).

23. Saunders, "Facing Death," 300.

any context in which they found themselves, regardless of one's external conditions.[24] Saunders connected Frankl's words to what she observed in her hospice work, specifically with regard to patients whose deaths were imminent. She quotes one family member who said, "We lived a lifetime in three weeks," to describe the reality that one can live fully in the face of impending death in a form of *kairos* time despite the restrictions of *chronos* time. The activity of striving for meaning described by Frankl is one that she frequently observed among patients and those who were bereaved. Honesty about the reality of death often prompted this activity in her experience.[25]

Saunders' approach to religion in hospice has been critiqued for veering toward a form of generic spirituality, due to her esteem for Frankl's work and the broadness with which religion and spirituality is approached in hospice.[26] However, Saunders' existentialism was fundamentally Christian in nature. Whereas she did value Frankl's claim that it is meaning in life rather than the conditions in which one finds oneself that gives a person the will to live, she maintained her view that we are beings that live in the face of death as Christ did. Christ partook in the fullness of human experience, including birth and death, and he serves as a reminder that God is with us even as we leave this life. For Saunders, an existentialist view of life was not generic, but a central aspect of her view of Christianity.

### Concept of Spiritual Pain as an Element of Total Pain

Saunders recognized that a dying patient could not focus on his or her experience, relationships, or sense of the sacred, if the patient was in physical pain. Her medical views were deepened by her

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24. Frankl, *Man's Search for Meaning*, 132.

25. Saunders, "Facing Death," 299.

26. As Tony Walter notes in "Spirituality in Palliative Care: Opportunity or Burden? Palliative Medicine 16: 99-104, "Frankl himself argues that it is the loss of religion and of tradition that leaves many modern people with an existential vacuum which they must fill up with individually sought meanings," 137.

experience listening to the accounts of patients, and, even toward the end of her life, she would

recount the stories her patients told her about how pain dramatically narrowed their worlds.[27]

One of the patients, Mrs. T, when invited to talk about her pain said, "Well doctor, the pain

began in my back, but now it seems that all of me is wrong."[28] The phrase "all of me is wrong"

is the linchpin of Saunders' view of "total pain," a term she devised to signify that pain extends

beyond the bodily experience of physical distress.[29] Mrs. T continued, "My husband and son

were marvelous but they were at work and they would have had to stay off and lose their money.

I could have cried for the pills and injections although I knew I shouldn't. Everything seemed

to be against me and nobody seemed to understand." Saunders, taking the words of Mrs. T and

her other patients seriously as a source of medical information, recognized that having to ask for

pain medication, instead of having medication routinely given, was also a source of preventable

distress in patients. During her time volunteering as a nurse at St. Luke's Hospital she encountered

the practice of continual pain control for patients through the use of oral opiates.[30] Due to her

conversations with patients and her observations of pain management at St. Luke's, Saunders

furthered the practice of comprehensive pain management for terminal patients by advocating for

continuous treatment of pain. She learned from her patients that when their pain was managed,

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27. Barbara Monroe and David Oliviere, *Patient Participation in Palliative Care: A Voice for the Voiceless*, 5.

28. Cicely Saunders, "Care of Patients Suffering from Terminal Illness at St Joseph's Hospice," *Nursing Mirror* (Hackney, London: February 14, 1964): vii-x.

29. Saunders, *Living with Dying*.

30. Saunders, *St Christopher's Hospice*, 10.

they could then attend to personal, social, and spiritual concerns, that they could be themselves again.[31]

Saunders, in her consistent advocacy for pain management, did not aim to reduce a patient's total pain to zero. In naming the physical and social dimensions of pain experienced by terminal patients (including agitation, nausea, and isolation), she indeed emphasizes that all measures should be taken to address a patient's distress.[32] However, with regard to spiritual pain, her approach centers on attention and presence rather than on alleviation of symptoms. She suggests a companionship model, in which a caregiver stays with a patient, providing support through presence rather than through medical or psychosocial measures. The intention is to remain with a patient as they transition, an approach based on "being with" rather than "doing for." For Saunders, spiritual distress can lead to a form of reconciliation with and acceptance of one's life—both its content and its culmination. If a patient's predicament is managed for them or is addressed solely through pharmacological means or psychosocial protocol, an opportunity for spiritual agency can be lost. Additionally, a clinician's sense of impotence concerning a patient's spiritual distress may lead them to avoid addressing the patient's concerns. Speaking to this, Saunders notes: "Dying is not a psychiatric illness and does not usually call for specialized skills in counseling in depth. Those who distance themselves, feeling that they can bring nothing but a lack of comprehension, do not realize that it is often their attempt to understand and not success

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31. Rather than perpetuating a binary between body and mind in the medical context, Saunders included somatic pain in her understanding of medical pain that could be treated pharmacologically, calling for the use of psychotropic drugs in pain management to treat depression and anxiety. See her 1981 speech for being awarded the Templeton Prize in religion in *Cicely Saunders: Selected Writings 1958-2004* (Oxford: Oxford University Press, 2006), 147-162, 149.

32. Cicely Saunders, Mary Baines, and R.J. Dunlop, *Living with Dying : A Guide to Palliative Care* (Oxford; New York: Oxford University Press, 1995), 46.

in doing so that eases the patient's loneliness."[33] Saunders recognizes the radical loneliness of

the terminally ill and is deeply aware of, and troubled by, the reality that many will experience

isolation and abandonment as they die, an unchosen solitude that can compound a person's fear

of dying. She believed that God experienced this form of death through Christ; that God was and

is present with humankind because God freely chose to experience human death. Her theology

of presence informs of her vision of hospice care. The companionship model she describes can

be offered by those who are non-religious; however the basis for the approach, for Saunders, is

distinctly Christian in nature. She uses the language, "Watch with me. . ." a reference to the New

Testament account of the night before Jesus of Nazareth died. In the narrative, he addressed his

disciples, saying to them "My soul is overwhelmed with sorrow to the point of death. Stay here

and keep watch with me."[34] He experienced the human need for the presence of others as he

faced his death. The fear of dying alone is a common one for end of life patients, and Saunders

recognized that this fear can be a source of deep pain for a person, even when physical pain is

treated.

Largely due to Saunders' advocacy about spiritual pain as a dimension of total pain, and

Wald's shared appreciation of this view in the United States, spiritual and religious care came to be

recognized as a fundamental aspect of health care for those at the end of life.[35] Though the value

of spiritual care extends beyond serving the needs and preferences of those at the end of life, a

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33. Ibid.

34. Matt 26:38.

35. Arthur W. Frank, "Narratives of Spirituality and Religion in End-of-Life Care," in *Narrative Research in Health and Illness* (Blackwell Publishing Ltd, 2004; 2008), 141.

patient's turn toward death creates a particular opportunity for spiritual and religious reflection.[36] There are connections between religious reflection and life review for terminal patients. Primarily, both modes of reflection address existential concerns, including concerns about the value of one's life, the appropriateness of one's choices, the reality of loss, and consciousness of both the presence or the absence of gratitude and regret. Saunders uses the language of spiritual pain, cohering with her mission to comprehensively manage a patient's pain in all its dimensions. However, she also speaks positively of the ways in which a religious framework offers support and comfort for patients, providing a mode of interpreting their lives that is not based on their instrumental value but on their intrinsic worth.[37]

Again, Saunders cannot be described as being interested in eliminating spiritual pain, though reduction of physical pain is certainly a goal in her view. Using the language of freedom, she maintains that relief from physical pain then allows one to address spiritual, social, and personal concerns. This is significant because spiritual assessments and methods of reflection such as life review can unearth sources of pain for patients that extend beyond the physical, thereby creating more pain for the patient than was present before the process. Saunders' theological framework maintains that God is with us in our suffering; however, physical pain can dominate one's awareness to such a degree that an individual's ability to reflect on spiritual, religious, social, and personal concerns is nearly impossible. Thus, with physical pain controlled, the potential for engaging in person reflection increases.

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36. Daniel Sulmasy, "Ethos, Mythos, and Thanatos: Spirituality and Ethics at the End of Life," *Journal of Pain and Symptom Management* 46, no. 3 (2013): 448.; Christina Puchalski, "Spiritual Issues as an Essential Element of Quality Palliative Care: A Commentary," *The Journal of Clinical Ethics* 19, no. 2 (2008): 161.

37. Saunders, *Cicely Saunders: Selected Writings 1958-2004*, 227

The goal of care with regard to spiritual pain is not necessarily to resolve it, but rather to have the freedom to attend to its presence. Saunders repeatedly uses the language of freedom, both medically (freedom from pain) and spiritually (freedom to focus on one's relationship with God or what gives life meaning). While some patients experience spiritual growth and a encounter a new understanding of time, relationality, and sense of intrinsic value, this is not the case for all patients. Saunders believes God's activity in the world and in a person's inner being is a mystery and that a clinician reaches the limits of his or her power when it comes to spiritual and religious matters. She upholds the Christian paradox that strength can be found in weakness and that in dying one can find new life. This is not to say that she glorifies suffering or a passive response to clinical treatment; on the contrary, she is unrelenting in her advocacy for comprehensive pain control. When she uses the language of acceptance, she does so to emphasize the reality that we are born into a life structured by death, loss, and grief, and that honest awareness of this fact and acceptance of our brief sojourn allows us to engage in the fullness of life intentionally. Hence her use of the phrase, "living with dying," a phrase that discloses her recognition of the limitlessness of *kairos* time even as it exists within the limits of chronological time.

Whereas physical pain is located in the body and can often be treated pharmacologically, spiritual pain has various sources and calls for specialized attention. Professional chaplains serve on hospice interdisciplinary teams to address these needs which can become acute as death nears. Because a chaplain is not usually at an admission or present in an initial clinical encounter, it is crucial that the admitting clinician is familiar with how to take a spiritual assessment and feels comfortable making a chaplain referral. While the work of a hospice chaplain can include engaging in the process of life review, and the themes that I identified in chapter 2, including

regret, grief, and desire for forgiveness, have a spiritual or religious valence, there is a distinction between spiritual assessments and the process of life review. I address the differences between them later in this chapter.

## Religion in Hospice and Palliative Medicine Today

Though hospices today are unlikely to have an overtly religious mission or vision statement like St. Christopher's, there continues to be recognition of the role religion and spirituality have in the provision of care.[38] The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) requires that hospitals attend to the spiritual and religious needs of patients. JCAHO does not specify or mandate how this attention should manifest, but nevertheless there is institutional recognition of the place of religion in a medical context.[39] Abiding by a patient-centered mission involves approaching patient care as a multi-dimensional task, rather than limiting patient care to the biological. Recognition of the role of religion and spirituality in medical care continues to grow, due in large part to the advocacy and scholarship of physicians interested in the subject, particularly Christina Puchalski and Daniel Sulmasy. Co-developer of FICA, a commonly used spiritual assessment tool, Puchalski advocates for routine spiritual assessments when physicians take patient histories; she strives to normalize conversations that take into account the religious and spiritual dimensions of patients. Though JCAHO maintains in their diversity statement that physicians have an obligation to respect a patient's religion, Puchalski takes this obligation further to include the recognition and assessment of a patient's

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38. Paul Bramadat, Harold G. Coward, and Kelli I. Stajduhar, *Spirituality in Hospice Palliative Care*, (New York: SUNY Press, 2013), 25.

39. From the Joint Commision's Standards "Frequently Asked Questions" page: http://www.jointcommission.org/mobile/standards_information/jcfaqdetails. aspx?StandardsFAQId=290&StandardsFAQChapterId=29

individual needs as an aspect of clinical care.[40] In addition to expanding the scope of what should be included in the clinical encounter, Puchalski's vision has a pedagogical focus. She maintains that all medical students should have education available that addresses the religious and spiritual component of patient care, and that that comprehensive, patient-centered care for all patients includes recognition of the patient's world of meaning; as it is now, palliative care is the only domain of medicine that specifically includes attention to religion and spirituality in the goals of care.[41] Her advocacy has been instrumental in the expansion of medical school curricula that includes religion and spirituality, not merely as a domain of the medical humanities, but as central to clinical care for patients.[42] Her concept of health extends beyond physical wellness, instead cohering with the World Health Organization's definition of health as the "dynamic state of complete physical, mental, spiritual, and social well-being and not just the absence of disease or infirmity."[43] She maintains that comprehensive care for patients includes recognition of the spiritual and religious dimensions of their lives. Physicians often hesitate to inquire about a patient's religiosity because they do not feel adequately trained in the study of religion, hence her promotion of curricula on religion in clinical training.

Scholarship by Daniel Sulmasy similarly addresses the need to attend to a patient's

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40. From "Introduction to Credentialing," Preceding Standard MS.4.10, Joint Commission on the Accreditation of Health Care Organization, *Comprehensive Accreditation Manual for Hospitals,* 2008.

41. Michael J. Balboni, Christiana M. Puchalski, and John R. Peteet, "The Relationship between Medicine, Spirituality and Religion: Three Models for Integration," *Journal of Religion and Health* 53, no. 5 (2014): 1586.

42. Christina M. Puchalski and David B. Larson, "Developing Curricula in Spirituality and Medicine," *Academic Medicine* 73, no. 9 (1998): 970.

43. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946.

spiritual and religious identity, particularly for patients at the end of life. Sulmasy, a physician and Franciscan friar, notes that patients prefer that their physicians inquire about the subject in the clinical encounter, regardless of the physician's identification as religious.[44] There is no need to abide by a strict secularism in the medical context, as "the artificial neutrality of enforced secularism inevitably leads to a discussion that is conceptually impoverished, lacking the language to address the existential questions of suffering in ways that are meaningful to the patient."[45] In fact, Sulmasy maintains that physicians have a moral obligation to actively inquire about a patient's spiritual and religious identity, both because potential sources of support and meaning can go untapped.[46] To the question of whether or not it is the role of the clinician to inquire about a patient's spiritual concerns, he responds, "[I]f physicians and other healthcare professionals have sworn to treat patients to the best of their ability and judgment, and the best care treats patients as whole persons, then to treat patients in a way that ignores the fundamental meaning that the patient sees in suffering, healing, life, and death is to treat patients superficially and to fall short of the best ability and judgment."[47] For Sulmasy, a clinical posture based on respect for patients as persons includes recognition of the spiritual and religious dimensions of their identity.

Sulmasy worries that a patient's spiritual distress may be neglected by physicians allergic to conversations about religion and spirituality in the clinical encounter. However, he recognizes

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44. Also addressed in this article by Farr Curlin and Peter Moschovis, "Is Religious Devotion Relevant to the Doctor-Patient Relationship?" *Journal of Family Practice* 53, no. 8 (2004).

45. Ibid.

46. Daniel P. Sulmasy, *The Rebirth of the Clinic: An Introduction to Spirituality in Health Care* (Washington, D.C.: Georgetown University Press, 2006).

47. Daniel Sulmasy, "Spirituality, Religion, and Clinical Care," *Chest* 135, no. 6 (2009): 1635.

that while religiosity can provide comfort for some patients, this does not hold true for all.[48]

Manifestations of religious coping in response to illness can be both negative and positive, making the need for clinical assessment of how the patient understands the function of religion and spirituality in his or her life all the more crucial. On the negative side, patients may feel guilt, anxiety, fear, and denial as a result of their religious or theological framework.[49] Positively, religious coping can provide a sense of meaning, value, and connection for patients, in addition to linking a patient to a supportive community.[50] Though Sulmasy does note the medical benefits of belief and a sense of the transcendent, his reason for promoting conversations about spirituality and religion in the clinical encounter do not spring from an interest in medical efficacy. He does not believe the sacred should, or can, be limited or instrumentalized to the medical benefits one may experience as a result of belief. Like Puchalski, Sulmasy does not believe a lack of religiosity of the part of the physician should preclude conversations about a patient's beliefs. Both Puchalski and Sulmasy recognize that the professional capacity of physicians does not include pastoral care; consequently, they maintain that physicians make referrals to chaplains or the spiritual care department for specialized attention to religious and spiritual needs.[51]

## Religion in Clinical Medical Education

Curricula designed to train clinicians in taking a spiritual history are becoming more common

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48. KM Trevino, M Balboni, A Zollfrank, T Balboni, and HG Prigerson, "Negative Religious Coping as a Correlate of Suicidal Ideation in Patients with Advanced Cancer" *Psycho-Oncology* 23, no. 8 (2014): 936.

49. Daniel Sulmasy, "Spiritual Issues in the Care of Dying Patients: '. . . It's Okay between Me and God,'" *JAMA* 296, no. 11 (2006): 1389.

50. Ibid.

51. Sulmasy, *Spirituality, Religion, and Clinical Care*, 1640.

in medical education. In residency programs, clinicians may encounter more sustained exposure to spiritual care if there is an active spiritual care program in their internship environment. In addition to the patient-centered aspects of recognizing a patient's religious and spiritual identity, there is medical value in training a clinician to inquire about a patient's spiritual and religious history and identity. Patients often make medical decisions based on their religious framework, so the relationship between medicine and religion calls for clinical attention. Decisions regarding end of life care, resuscitation, reproductive decisions, autopsies, organ donation, pain management, and blood transfusions are just a few examples of when a patient's religious identity informs their decision-making. Even if a patient defies the medical guidelines of their tradition, a Roman Catholic woman receiving in vitro fertilization, for instance, the patient may have some spiritual conflict that warrants further conversation about her spiritual well-being. Also, patients indicate that they want their clinicians to inquire about their spiritual or religious lives.[52] Cicely Saunders' recognition that the spiritual dimension of human identity relates to clinical care is not one that is limited to end of life care, by any means. However, the end of life is a unique time of religious reflection for many individuals and attention to this reflective activity is valuable in a medical context.

### Religion's Precarious Place in Hospice and Palliative Care

Hospice care, as stated in the first section of the chapter, originally was a form of physical and spiritual care for travelers in need, often individuals who were indigent or terminally ill. Saunders continued the legacy of spiritual care in hospice through her vocal support of the role of religion in medical care for terminal patients. Today, however, spiritual and religious care in hospice is

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52. Christina Puchalski, "The Role of Spirituality in Health Care." *Proceedings (Baylor University. Medical Center)* 14, no. 4 (2001): 352.

less central to care, and in some instances such attention has become peripheral in a way that Saunders did not envision. As Ann Bradshaw notes in "The Spiritual Dimension of Hospice: The Secularization of an Ideal" the original concept of a religious call to engage in hospice work has been supplanted by a secular professionalism on the part of the caregiver and a personal empowerment model of patient identity.[53] There has been a shift in the Western context from hospice as a religious model of care toward hospice as a medical model of care detached from any religious foundation.

There are a few reasons for this attenuation. One is how funding is structured in the Medicare hospice benefit in the U.S. In 1982, Congress assured funding for hospice care; however, the funding was limited to a daily reimbursement rate for care. Due to this compensation cap, reimbursement would be set at one rate for the entirety of the team-based care, including medical and skilled nursing care. The funding structure then can create a situation in which a patient's needs are triaged according to what is perceived as most critical, often the patient's medical needs, especially for late referrals to hospice. At the same time, Congress recognized the need to address a patient's spiritual and religious needs by affirming the definition of patient care as stated by the National Hospice Organization that "Symptom control includes assessing and responding to the physical, emotional, social, and spiritual needs of the patient/family."[54] Though there is no specific funding set apart to reimburse spiritual care staff, there is nevertheless explicit recognition of the need for spiritual and religious care in the suite of hospice services.

Other reasons for the decreased role of religion in end of life care include the expansion

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53. A. Bradshaw, "The Spiritual Dimension of Hospice: The Secularization of an Ideal," *Social Science & Medicine (1982)* 43, no. 3 (1996): 409.

54. Cathy Siebold, *The Hospice Movement: Easing Death's Pains* (New York; Toronto; New York: Twayne ; Maxwell Macmillan Canada ; Maxwell Macmillan International, 1992), 122.

of religious pluralism and the growth of secularism in western society. When Cicely Saunders established St. Christopher's Hospice, she could safely assume that spiritual care for patients would, by and large, be motivated by Christian beliefs and practices. Chaplains today, however, are trained to provide care to patients and family members from a variety of global religious backgrounds. While such an approach has been critiqued as a form of spiritual "Esperanto" it commendably recognizes that a patient's religious identity cannot be presumed to be the culture's majority religion. The increase in language of "spirituality" has also worked to erode the religious foundation of hospice care. Karen Garces-Flory in "The Politics of Spirituality" asserts that contemporary hospices needlessly create a binary between religion and spirituality, and affirm a vague spirituality and mélange of spiritual practices such as meditation over a patient's religion and religious practices, particularly when the patient is Christian. Garces-Flory suggests that by privileging spirituality over religion, hospices in the U.S. have frayed the historical connection between religion and hospice care to the detriment of patient care.

Another reason religion has become peripheral in hospice care is because of the widespread transition to evidence-based medicine. This transition has led to the need to concretize religious experience in a way that can be labeled, quantified, and repeated. With the turn toward evidence-based medicine, pastoral care programs in hospitals worked to legitimate their professional contribution to medicine by utilizing standardized methods of assessment in care. Hence, the development of spiritual care screening tools and assessments used to identify the need for pastoral services and to document a specialized form of care in the clinical encounter. While useful for prompting conversations that may otherwise not occur, the assessments have the potential to reduce spiritual and religious care to the use of the assessment tools. Spiritual and religious care then becomes narrowed and plugged into an efficiency-based model that may

not fully address a patient's desires or needs in the clinical encounter. Fortunately, there are other modes of offering religious and spiritual care to patients and family members that extend beyond dialogical assessment tools; I address a few of them in following sections. Concerns about funding and the other reasons for the reduced role of religion in medicine remain, however, and call for further attention that cannot be provided within the limits of this project.

### The Particular Value of Attending to Religious and Spiritual Care for
### End of Life Patients and the Ethical Implications of Not Doing So

Patients commonly structure their end of life treatment decisions on their religious views.[55] The end of life brings questions of meaning, identity, and moral behavior into sharp relief, as I noted in the chapter on life review as a form of ethical analysis. Therefore, the need for clinicians to be comfortable with religiosity and spirituality when demonstrated by their patients is even higher for those receiving hospice and palliative care than it is for those receiving non-terminal care. As religion is linked closely to conceptions of the moral self on the part of the patient, to overlook the role of religiosity in a patient's life is to neglect an important source of medical information. Assuming that a patient is secular because the clinician is secular can be a form of soft paternalism on the part of the clinician. When a physician correlates religiosity with irrational desire (for a miracle cure or divine intervention, for a choice to endure treatable pain), a subtle, but problematic strain of paternalism manifests. Patients are highly sensitive to the judgment of their clinicians, especially their doctors. If a doctor demonstrates negative response to a patient's religiosity, the patient may then hesitate to discuss a significant source of structure and meaning for his or her life. Training in religion can teach a clinician to be sensitive to and withhold judgment about a patient's religiosity.

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55. Sulmasy, "Ethos, Mythos, Thanatos."

Recently scholarship has described palliative care as "totalizing" care, an attempt to manage all aspects of a patient's dying process.[56] Such claims are overstated—Bishop describes the bereavement care offered by hospice and palliative care programs as "reaching beyond the grave" to continue to be involved in managing care.[57] Far from controlling or managing a patient's dying process, the multi-dimensional model of care offered by hospice and palliative care programs offers treatment options for the patient so that the patient can individually tailor care. Offering an array of care options is far from "totalizing" the experience. Rather, patient preference for care is maximized in a situation where there are multiple modalities of care available (spiritual, psychosocial, etc.) Being unable to choose among different options of care poses more of a problem than having too many options presented by a team of caregivers. Though there is no active system of management involved, like a hospice or palliative care program, does not mean that the patient has the freedom to choose his or her care plan for end of life treatment. For instance, if a patient is shuttled into an ICU unit, the patient's death there is also "managed" but often without patient choice in determining the type of care received.

Not including religion and spirituality in patient care is to demonstrate a neglect of the patient as person.[58] As noted by Therese Lysaught, the history of medical ethics shows a turn toward respect for autonomy over a respect for persons.[59] By including religion and spirituality

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56. Jeffrey Paul Bishop, *The Anticipatory Corpse : Medicine, Power, and the Care of the Dying* (Notre Dame, Ind.: University of Notre Dame Press, 2011).

57. Ibid.

58. Paul Ramsey, *The Patient as Person: Explorations in Medical Ethics* (New Haven: Yale University Press, 1970).

59. M. Therese Lysaught, "Respect: Or, how Respect for Persons Became Respect for Autonomy," *The Journal of Medicine and Philosophy* 29, no. 6 (2004), 665.

in conversations about religion, there is recognition that a patient may live in a world of meaning that influences his or her manner of living and manner of understanding death and dying. There is thus an expansion of understanding patient identity supplementing a principlist framework that prioritizes autonomy, choice, and freedom as ethical guideposts rather than relationality, dependency, and limits.

When a patient is experiencing loneliness at the end of life, religious and spiritual resources offer a source of presence for the patient, thereby increasing the patient's quality of life. Not all elderly patients have friends and family to visit them, and some turn to clinicians for a form of social interaction that can be provided through religious organizations. While this approach to religion could be considered instrumental, the value of a social support network for lonely patients exceeds any issues that may come with approaching religious organizations instrumentally. Offering the option of spiritual care during a patient's admission or when given indicators by the patient is best considered a standard practice. Axial forms of care may serve a therapeutic social need for patients who are often isolated and experiencing loneliness or depression. There are few downsides to offering as much care as possible to a patient who may have limited social resources. As stated previously, there is no cause for the physician to feel responsible for providing spiritual and religious care, only that the physician knows when to appropriately make referrals for professional care the patient agrees to receive.

### Narrative Methods and Religion in Hospice and Palliative Care

Because patients indicate that they would like their physicians to address their spiritual life, educational material regarding the subject is becoming more prominent in medical education. Christina Puchalski advocates for medical training that includes material on religion and spirituality, but mere exposure to models of spiritual care such as those taught in an introductory

course does not ensure that a clinician has had adequate training in discerning when it is appropriate or inappropriate for the clinician to prompt a conversation about religion or make religious statements.[60] Various assessment tools exist that are designed to address a patient's spiritual and religious needs. The most commonly used assessment tools are FICA,[61] SPIRIT,[62] HOPE,[63] and the 7x7 model.[64] In general, the tools inquire about a patient's religious and spiritual identity, their connection to a religious social group, how their religion connects with how they understand why they are in the hospital, and how they would like their spiritual and religious needs to be addressed. The dialogical tools also assess whether or not religion is used as a positive or negative means of coping with illness and how they expect their religion to serve them in the future.

I suggested in Chapter two that life review as it manifests in hospice care demonstrates a process of moral self-analysis. A person, when faced with the end of his or her life and when equipped with the cognitive ability, makes a retrospective turn and evaluates how he or she lived. One of the dimensions or moral self-evaluation concerns religion and spirituality. A patient may

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60. The requirements for board-certified chaplaincy move beyond introductory or continuing education medical school courses, and the certification process creates a system of accountability, one important in clinical contexts in which patients are often vulnerable and may have limited mobility to leave a scenario that makes them uncomfortable. Ideally, a medical school course on spirituality will emphasize when it is appropriate to offer or request a chaplain referral, rather than promoting the idea that the physician is adequately trained to identify and meet the patient's spiritual or religious needs.

61. C. Puchalski and A. Romer, "Taking a spiritual history allows clinicians to understand patients more fully," *Journal of Palliative Medicine* 3, no. 1. (2000):129-137.

62. T. Maugans, "The SPIRITual History," *ArchFam Med* 5, no. 1 (1996): 11-16.

63. G. Anandarajah and E. Hight, "Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment," *Am Fam Physician* 63, no. 1 (2001): 81-89.

64. George Fitchett, *Assessing Spiritual Needs: A Guide for Caregivers* (Ohio: Academic Renewal Press, 2002).

consider whether or not he or she lived in a way that honored God; additionally, a patient may

feel abandoned or judged by God. Limiting life review to a mere recounting of biographical events

impoverishes a process that is intended to be a mode of reflection about what mattered most for

patients. For many, there are religious or spiritual aspects of their identity that call for attention,

such aspects of selfhood can go unrecognized by secular models of care. Frequently talk about

the role of religion in medicine approaches religious and spiritual care as ad hoc, a supplemental

form of add-on care that enhances a patient's experience in and beyond the clinical encounter. A

person's religious identity is rarely just an accent to who they are, however. Instead, religiosity can

deeply inform how a person views his or her identity and experience of illness and suffering. It

also offers a frame for interpreting the totality of a person's life, body, mind, and spirit.

Gordon Allport, Harvard psychologist and, along with William James, one of the earliest

social scientists to critically examine religiosity as a legitimate and non-pathological subject,

offered a distinction with regard to approaches to religion that can be used to clarify how its role

is understood in medicine. In his text, *The Individual and his Religion*, he distinguishes between

intrinsic and extrinsic religiosity; intrinsic religiosity is how Allport describes religion as an end

in and of itself in which a person internalizes religious values and extrinsic religiosity is more

performative, a mode of religiosity that is used as a means to an end.[65] Allport in collaboration

with Michael Ross, developed one of the first assessments of religiosity, the Religious Orientation

Scale, a precursor to the spiritual assessments that exist today.[66] The spiritual assessments used

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65. Gordon W. Allport, *The Individual and His Religion, a Psychological Interpretation* (New York: Macmillan, 1950).

66. Gordon Allport and Michael J. Ross, "Personal Religious Orientation and Prejudice," *Journal of Personality and Social Psychology* 5, no. 4 (Apr 1967): 432-443.

today specifically address the intrinsic and extrinsic religiosity of patients.[67] Additionally, much of the scholarship on religion and medicine concerns the religiosity of the patient, with some recognition of the ways attending to the religious and spiritual needs of patients can meet forms of extrinsic religiosity for clinicians (such as prayer in the clinical encounter). I submit that there is value in attending to the intrinsic religiosity of caregivers as well, a subject I address in the concluding section of this chapter.

There are two distinct benefits that result from addressing the religiosity of patients. First, a person can be reminded of how his or her religion understands human value. For instance, in the Christian tradition, a person's value does not come from extrinsic categories of worth (one's job, familial status, gender, social position, etc.). Rather, a person's value is fundamentally intrinsic coming from being made in the image of God.[68] The second benefit concerns how life and death are framed. If the goal of life is not achievement or longevity but communion with God, the prospect of death can be less terrifying. Research shows that those who ascribe to religious belief are less likely to consider ending their lives prematurely through the means of physician assisted suicide.[69] If death is considered to be a time of presence with the sacred, or a point on the journey toward presence with the sacred, a person may feel less alone and afraid to transition from life.

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67. One could say that the language of "spirituality" comports with Allport's concept of intrinsic religiosity. However, the very language of religion is anathema to some individuals; many patients identify specifically as spiritual and *not* religious.

68. John Swinton and Richard Payne, *Living Well and Dying Faithfully: Christian Practices for End-of-Life Care* (William B. Eerdmans Pub. Co., 2009).

69. C. Hains and N.J Hulbert-Williams, "Attitudes Toward Euthanasia and Physician-Assisted Suicide: A Study of the Multivariate Effects of Healthcare Training, Patient Characteristics, Religion and Locus of Control," *Journal of Medical Ethics*. 39, no. 11 (2013): 713.

In addition to the theological support that can result from recognizing a patient's religiosity and prompting reminders of how the patient's religion understands human value and the event of death, there are medical reasons for inviting conversation about a patient's religiosity or spiritual identity. Patients can be connected with their communities of support and receive social stimulation through such religious networks; this is particularly valuable for patients who may not receive support from their families of origin. Additionally, there are religious and spiritual methods of pain management that can comfort patients when other means are insufficient. As religion focuses on healing rather than treatment or cure, religion can be especially valuable for those who are dying from a terminal disease where cure is not possible.

## Critiques of Spiritual Assessments

Some scholars critique spiritual assessment tools for perpetuating a "check-list mentality" in care, one in which the patient is asked about their history in a cursory way just to meet the institution's assessment requirements. The underlying idea is that spiritual care is passively conforming to a medical model based on quantitative standards of care.[70] A similar critique is made of principlism in medical ethics, that the four principles of autonomy, beneficence, non-maleficence, and justice become four categories that can be briefly considered, a cursory approach that can result in overlooking or ignoring other ethical issues that may arise in clinical care. As with principlism in medical ethics, spiritual assessments may appear to be simple heuristics used to document that a patient's concerns have been addressed; however, the communication tools often serve as prompts to deepen conversations about a patient's fears, concerns, or care preferences. Though in some cases they can be limited communication devices, based on the person using them or the context of their use, they are intended to be springboards to further dialogue or

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70. Bishop, *The Anticipatory Corpse*, 242.

to serve as vehicles for making pastoral care referrals. The alternative to not using spiritual assessment tools, even when used in check-list fashion, is to risk neglecting a patient's spiritual and religious identity, one that often provides solace and social support during times of illness or medical need.

Those critical of spiritual assessment tools can overstate their case when they address their concerns exclusively to admission questionnaires or to quantitative standards. As described previously, not all tools are quantitative measures of spiritual needs; instead many of them are qualitative guides to open-ended discussion. It is worth noting, however, that the very questions asked in the standards do structure and in ways limit the conversation. When the conversation is primarily directed by the clinician based on set questions, the patient then becomes a passive recipient of attention rather than the agent in the conversation. The efficacy of the tool depends on the person inviting the conversation. When referrals to other spiritual caregivers are made, this allows greater opportunity for a patient to connect with someone he or she feels comfortable with. Ultimately, spiritual assessments are useful for identifying spiritual distress and the ways in which a patient's spiritual and religious identity can possibly shape their medical decisions. They also serve as methods of engaging in patient-centered care and provide an object of conversation for patients who may be radically socially isolated; this is especially true for those at the end of life. Critiques that the assessments are designed to quantify, control, or measure a patient's spiritual or religious identity fail to recognize that the value for the patient may differ from the institutional value of the assessments. Additionally, it is better for a patient's religious or spiritual identity to be recognized via a portable, generic tool such as one of the pneumonically-named prompts, rather than the patient's religious and spiritual identity be neglected out of an overzealous fear of constricting the conversation. Furthermore, the religious and spiritual assessments are valuable

in that they can keep the conversation focused on the patient's identity. The potential exists for a professional caregiver, especially for clinicians and chaplains in training, to speak about his or her own beliefs, thereby inappropriately controlling or influencing a patient due to the asymmetry of power involved in the relationship. Rather than being a flaw, the structured nature of established spiritual assessments such as HOPE, FICA, and SPIRIT then beneficially limit and direct the conversation to the patient's spiritual or religious identity.

<div align="center">Distinction between Spiritual Assessments and Life Review</div>

Life review in hospice relates to spiritual assessments in the following ways. One, both are structured on a narrative presentation of the patient's experience that emerge in dialogical fashion. Additionally, both modalities of narration can elicit positive and negative responses in patients, reports of satisfaction and gratitude as well as reports of anger, sorrow, regret, and a sense of injustice. Both call on the patient to reflect on his or her individual life, taking into account the ways one has been formed by significant roles and relationships. In this sense, both models move beyond scientistic medicine into the domain of humanistic care, highly oriented to the patient as person.

Spiritual assessments and life review are distinct in that spiritual assessments, though structured on open-ended questions, are goal-based and formalized though the use of specific questions, hence the frequent use of acronyms for spiritual assessments. The goal is to locate sources of spiritual and religious support for the patient and to identify any spiritual or religious distress the patient may have. Referrals to chaplains can then be made, and the chaplain can connect the patient with sources of support in the community or offer pastoral care and counseling for distress the patient or family may have. Whereas life review is supplemental to

patient care, spiritual assessments are part of admission protocol in many hospitals, due to the

JCAHO standards of spiritual assessment (cut and past those standards here).

Questions of meaning, identity, and moral behavior can emerge in both forms of

assessment. Even if the individual does not identify as religious, chances are high that religion

shaped his or her formation, through schooling, political life, aesthetics, gender expectations and

so on. As Daniel Sulmasy notes, even those who are atheist or hostile to religion still demonstrate

a relationship with religion and cannot claim that it plays no role in their lives. Comments

related to forgiveness, regret, accomplishment, all can be interpreted from a religious framework.

Additionally, a sense of fear that one did not live in a way that honored God is explicitly religious.

Comments that concern being punished in death for what a person did or did not do in life are

saturated in religiosity. In cases where individuals disclose their fear or terror being judged after

they die, it is crucial to heed Margaret Mohrmann's admonition to be acutely aware of the impulse

to try to "heal" or "fix" the person, to force a sense of closure on someone.[71] While a sense of

peace and healing can occur, recognizing the source of this desire is necessary in the encounter

with a dying patient. Is the patient the one interested in healing or is it the person facilitating

dialogue? Mohrmann notes the danger of imposing one's own sense of justice or healing onto

another person in an "imperialism of empathy."[72]

Life review has a retrospective focus more so than spiritual assessments, which are

designed to identify immediate needs or resources of support. In life review, a patient considers

the content of his or her life, turning toward how one lived rather than how one will live. In

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71.  Margaret E. Mohrmann, "Ethical Grounding for a Profession of Hospital Chaplaincy," *The Hastings Center Report* 38, no. 6 (2008): 22.

72.  Ibid.

spiritual assessments, because they are done on patients who are not terminal, there can be more of a focus on the patient's present experience and on the patient's hopes for the future.

Both models allow a patient an opportunity to discuss types of pain that are non-medical in nature. Elaine Scarry notes that pain limits communication and the understanding of others when is comes to another person's pain.[73] However, as Anne Jurecic suggests in *Illness as Narrative*, this radical inability to articulate one's pain can be overstated.[74] Jurecic maintains that there can be a shared experience of pain, and that the shared reality of pain can be experienced in vicarious ways, such as through literature and other modalities of narrative medicine. When a patient is allowed an opportunity to discuss pain with his or her caregiver, this allows for the possibility that the patient will be connected to resources that serve to address this pain, such as the possibility of a pastoral care referral.

The role of the patient's interlocutor provides another distinction between the two methods of discourse. Due largely to the advocacy of Christine Puchalski, spiritual assessments are typically done by the physician as a feature of the patient's medical history. Research shows that patients would like their physicians to inquire about the religious and spiritual dimensions of their identities. Life review, on the other hand, is often engaged in with a volunteer companion or a family member, a dynamic less influenced by a hierarchical role structure. Clinicians may be constrained by organizational factors and have less time to listen patients reflect on concerns that are not immediately medical.

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73. Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985).

74. Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012).

**How Religion Can Address the Limits of Narrative**

**Methods in Medicine with Non-verbal Patients**

Spiritual assessments serve as useful prompts for conversations about religion that otherwise may not occur in the clinical encounter. However, such tools suffer from the same limits of narrative medicine addressed in Chapter three. While maintaining the value of life review and spiritual assessments for patients who are verbal and cognitively able to engage in such activities, I recognize that not all are able to offer a coherent narrative of selfhood or spiritual or religious identity due to limitations often related to their decline. For instance, they require a degree of self-reflection that may not be available to patients in pain. Narrative methods, by design, rely on a high level of awareness and ability for patients, a level that may not be possible for patients at the end of life. Additionally, spiritual assessments assume that the patient is able to speak about his or her history, community, and beliefs. I suggest that there are non-verbal forms of religious and spiritual presence that can enhance care for end of life patients, particularly with regard to a patient's social needs, including the need for personal interaction and the need for touch. The modes of presence that I speak to are options for the caregiver of an end of life patient, both clinical caregivers and non-clinical caregivers.

Religious and spiritual modes of presence for end of life patients are not intended to displace pharmacological forms of pain management. Instead, such options for patient care are intended to supplement elements of pain and discomfort that can continue to be present for patients even while receiving pharmacological care or to serve as options for soothing patients whose agitated state does not necessarily warrant sedation or medication for anxiety. For instance, a patient with Alzheimer's Disease may be distressed over a misplaced personal item and engage in behaviors such as repetitive speech, yelling, or self-harm. Religious techniques such

as providing rosary beads to Roman Catholic patients can redirect the patient's attention to an activity that is familiar and soothing.

Terminal restlessness is a form of agitation that many patients experience as they make the transition toward dying. Terminal restlessness can manifest as physical distress, moaning, picking, clenching one's jaw and limbs, and other forms of physical agitation. Such states are not always assuaged medically; however, a patient may be calmed through the use of touch, soothing words, low lighting, or familiar music. In these instances, the value of a person comfortable with using religious or spiritual modes of soothing cannot be overstated. Currently, doulas for the dying are trained in offering such modes of presence for patients.[75] Social Isolation and the damaging effects such experience has on quality of life for patients can also be addressed through recognition of the value of religious and spiritual forms of behavior. For instance, when patients receive visits by chaplains or volunteers, even if the patient is non-verbal or non-responsive, the company of another person can still be calming for the patient. Often, it is the caregiver who is uncomfortable with visiting a non-responsive or agitated patient. This may be because there is an expectation of response or recognition from the patient that the patient is unable to give. I turn to the value of religion and spirituality as it relates to the role of the caregiver in the next section.

In addition to vocally supporting comprehensive pain management, Cicely Saunders advocated for a form of non-verbal presence with patients who are facing death. She maintained that patients benefit from having someone "be with" them rather than "do for" them, and that patients can be comforted through means that extend beyond the medical. She upheld the intrinsic value of both patients and caregivers in her concept of care: patients do not have to

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75.  H. Elliot, "Death Doulas Complement Nursing Care at the End of Life," *Nursing Times : NT.* 110, no. 34/35 (2014): 7.

perform what it means to be a model patient and caregivers can serve them by their intentional presence rather than by striving to cure, heal, or fix the patient. Her concept of presence with those who are dying is informed by her Christian faith; however, her model of patient care can be engaged in by those who are secular as the mode of presence does not require any verbal declaration of faith or professional standing as a minister or chaplain. Forms of patient care at the Zen Hospice Project, for instance, recommend similar modes of being with patients.[76] Paul Ricoeur uses the language of accompaniment to describe intentional presence with others, a mode of presence that can be offered by secular caregivers.[77]

The value of physical presence has been established by multiple studies that measure patient distress at the end of life. Regrettably, many patients continue to die alone and away from the populated domains of institutions where they receive care. Increasing the amount of chaplain referrals can lead to more comfortable, even peaceful, deaths for patients. Sometimes all it takes is having another person speak to a patient and hold their hand for a patient in terminal distress to be soothed. In the next section, I examine hospitality as a theological frame for understanding Saunders' concept of presence with patients.

### Hospitality as a Practice for Hospice Patients and Caregivers

The word hospital and the word hospice share the same etymological source: the root word *hoste*, a word that means both guest and host.[78] From this source, the word "hospitality" is derived, a word that connotes positive reception of guests. All three of these terms, hospital, hospice, and hospitality concern relationships with the stranger, in some cases the unbidden, unwelcome

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76. Merrill Collett, *At Home with Dying : A Zen Hospice Approach* (Boston: Shambhala, 1999).

77. Paul Ricoeur, *Living Up to Death* (University of Chicago Press, 2009).

78. Etymological root is Old French; the Latin is *hospitem*, the nominative Latin is *hospes*.

stranger. The concept of hospitality connects with medical care by offering an alternative medical epistemology, particularly for dying patients. In this section, I attend to the ways a theological concept of hospitality can function for both hospice patients and caregivers.

### Hospitality as an Option for How a Patient Can Respond to Pain

In addition to the recognition of spiritual pain fundamental to the hospice model of care, there is also a recognition of the grotesque body, or the body as stranger. In hospice, honesty about what to expect in the dying process shapes conversations in the clinical encounter. Without softening content, patients and caregivers are informed about potential social and physical changes the patient may experience. Contrary to the image of the deathbed gathering—the sentimentalized notion of the "good death"—socially, a patient may turn inward and become uninterested in life events like anniversaries, birthdays, and graduations. As the person moves closer to death there are also marked physical changes; skin may become cold and feel moist, toes and lips may turn blue or purple, breathing may appear labored and sound like gasping or a rattle. A beloved person can become unfamiliar or may not recognize friends and family members; they may become like strangers to each other.

Turning to a theological analysis, it is hospice's hospitality to the body as stranger that demonstrates the model's contribution to medical epistemology. In the New Testament, the Greek word *philoxenia* is used in reference to hospitality in the early Christian tradition. The roots of this word are *philieo*, a love of those who are known to us and for whom we have friendly affection, and *xenos*, the word for stranger.[79] Hospitality, thus, is not about providing sustenance for beloved family and friends; rather it is about providing the type of care that we

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79. Christine Pohl, *Making Room: Recovering Hospitality As a Christian Tradition* (Grand Rapids, MI: W.B. Eerdmans, 1999), 31.

would show to family or close friends to then meet the needs of those who are foreign to us. To make the distinction it may help to understand hospitality as serving as host to the alien rather than as offering welcome to the wanted and expected guest.[80] Because the language of hospitality connotes delight at the visitor's presence, using the term "hosting" instead allows for the recognition that the experience of encountering the stranger is not necessarily a positive one in which one greets the stranger with kindness and offers a gift of welcome. With regard to the role of the caregiver, a theological understanding of hospitality as hosting means that the focus is on the guest and not on the host as the gracious bestower of gift. The concept of hosting suggests creating space for another with no expectation of reciprocation or recognition.

In his text *Anatheism*, Richard Kearney claims that one can respond to the call of the stranger in two ways, with hospitality or with hostility.[81] However, because the stranger possibly bears the presence of the divine, he urges one to risk responding to the stranger's call with hospitality rather than hostility, opening oneself up to encountering the sacred in the form of the stranger. Kearney's work can deepen an understanding of how to live with pain, particularly pain that extends over time and cannot be managed pharmacologically. Building on his work, pain can be interpreted as the uninvited, even unwelcome, stranger that demands a response. The "stranger" is not necessarily separate from us; rather, when one experiences bodily pain one can perceive one's own body as a site of alienation, even invasion. Rather than responding with hostility, which I interpret as aggressive medical care, one can respond with hospitality, serving as a host to an unwelcome guest. Hosting is a particularly valuable concept with regard to how

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80. Distinction in the Latin *hospes*, which connotes hosting rather than hospitality.

81. Richard Kearney, *Anatheism: Returning to God After God* (New York: Columbia University Press, 2010).

terminal patients respond to pain, particularly pain that cannot be fully managed medically, such as the "total pain" Saunders describes. Hosting presents a way for patients to maintain agency during a time when much is out of their control and the possibility of the complete erasure of pain is minimal or, for some, undesired. The concept of hosting pain does not involve militaristic approaches to clinical care or sacrificially enduring pain; instead, hosting pain can be interpreted as allowing a strange presence to exist within you without having to strenuously fight this presence or having to warmly greet it.

Before speaking to what it means to host pain as the stranger, let me to briefly outline what hostility looks like in the medical model of care. In the biomedical model of care in the United States, war-based language is often used to frame a plan of care or conversation about symptom management. There is a "battle to be won," a patient chooses to "fight," a tumor will be "destroyed," disease is the "enemy," and ultimately death is a "foe" to be fought as well.[82] The Dylan Thomas line "Rage against the dying of the light" is used as a rallying cry. This approach to pain management—hostility—values agency, power, and resistance. While there is merit in this approach, it can be employed needlessly for patients for whom it is more costly, physically, emotionally, and socially, than it is beneficial. For instance if a patient has to leave one's family to receive specialized medical care in another city, and this patient has a terminal prognosis and limited energy, the personal cost of treatment in terms of separation from a support network and the energy it takes to participate in medical treatment, can dramatically outweigh the benefits. What is the value of fighting the "battle" against disease when one is alone, exhausted, and exiled from home?

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82. Susan Sontag speaks to the use of this language in her text *Illness As Metaphor* (New York: Vintage Books, 1979).

Denial of illness is another form of hostility. Hostility is not limited to aggressive forms of treatment; it can also include neglect of self and others. Rather than neglect being an absence of agency, neglect, is an intentional choice not to act in the interest of wellness. In medicine, this would manifest in the form of not following through with the clinical plan of care, or not heeding the call of the body to receive medical attention. There is one asterisk here that calls for attention and that is that social minorities, including, but not limited to those who are marginalized due to size, gender, class, race, or ability, often are shaped to believe that their bodies are not valuable and therefore do not warrant care. Finally, a third form of hostility toward pain is to hide the broken body in a cocoon of technology. When one is hidden in what is thought to be the necessary and protective barrier of medical equipment, there is distance created between the body as-it-is, and the body as shielded from the reality of pain, disease, and death. Concealing the compromised body can be perceived as a form of hostility toward the body.

The option of hospitality, in which one sees oneself as a host to the stranger, does not require an aggressive posture, or a charitable one. By hosting the pain residing within you, there is no expectation that one has to cheerfully greet this presence or that one has to fight it. Instead, one recognizes its presence and makes accommodations for it. By making accommodations, one engages in all forms of pain management available, including pharmacologic treatments. Hosting pain does not mean passively accepting its presence; it instead means recognizing the limits of one's ability to remove it. With chronic pain related to terminal disease, daily treatment for pain may limit one's ability to be aware to such a degree that the burdens outweigh the benefits of medical treatment. Furthermore, not all pain can be treated pharmacologically. Though hospice and palliative care physician Ira Byock maintains that all physical pain can be treated, not all pain is located in the body; spiritual and emotional pain can remain even when one's physical

pain is managed.[83] Additionally, a person may not want to turn to pharmacologic treatments due to medical side effects such as fatigue or nausea or because they are unable to access the financial or medical resources to fully manage their pain. Because not all forms of pain can be or are ameliorated medically, in addition to responding to the stranger with hostility or hospitality, hosting offers another type of response, one that stands as a mediating point between welcome and rejection.

One may not be able to make the pain leave; however, one can maintain agency through how the presence of pain is interpreted. When one is unable to exercise power over the presence of pain in the body, one can still, assuming cognitive ability remains, have agency in how one responds to pain. Though pain can involve a disruption of self that causes one to feel dispossessed, through communicating one's pain to others, one can hold to a sense of self through the witness of another who recognizes the pain one is hosting. Dorothee Soelle in her text *Suffering* describes the agency involved in identifying, naming, and articulating to another the conditions of one's suffering.[84] According to Soelle, suffering is compounded when experienced alone and suffering is reduced when its reality is communicated to and recognized by another.

**Dorothee Soelle on Suffering, Language, and Bearing Witness**

In Soelle's text, she offers a resource for how to interpret and respond to physical, mental, social, and spiritual pain from a Christian standpoint, though her claims are not limited to this tradition. Rather than looking at suffering in a monochromatic way, she looks at different types of suffering with particular attention given to suffering that is caused by human agents. She presents two

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83. Ira Byock, *Dying Well: Peace and Possibilities at the End of Life* (New York: Riverhead Books, 1998).

84. Dorothee Sölle, *Suffering* (Philadelphia: Fortress Press, 1975).

primary questions: "What are the causes of my suffering?" and "What meaning can be found in my suffering?" She examines Christian responses to these questions, particularly responses that she sees as limited or even dangerous. For instance, the idea that God intentionally sacrificed God's child out of love is a concept of God that has consequences for human behavior, one that can increase suffering rather than freeing Christians from it.[85] Even the idea of a suffering God can be problematic, particularly if it leads one to passive resignation to suffering, both suffering in one's own life as well as in the lives of others.[86] Any spiritualization of suffering that limits human agency is one she will unapologetically critique. For Soelle, suffering that is caused by political or economic social conditions does not call for passive acceptance, denial, or resting in "meaning." Rather, it calls for intentional effort oriented toward social transformation in a way that honors God.

In terms of a model for how to respond to suffering, the theologically-informed process of articulation Soelle describes can lead one from passivity to transformative agency in response to suffering. The first response is being rendered mute by suffering and being utterly paralyzed in the face of one's experience. The second response is moving to a place of lament. One way of engaging in lament is through using psalmic language. Psalms can also serve as a source for participating in communal responses to suffering, supplementing one's individual response to both the experience of pain and the relationship one has with sacred texts. Finally, Soelle's third step is to engage in acts of social transformation in which one works to eliminate the conditions that cause suffering.

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85. Ibid., 172.

86. Though he has an eschatological vision informed by hope rather than passive resignation and despair, Jürgen Moltmann speaks to the idea of divine suffering to which Soelle refers in his text *The Crucified God: The Cross of Christ As the Foundation and Criticism of Christian Theology* (New York: Harper & Row, 1974).

While the third movement in Soelle's process is less germane to hospice patients, it nonetheless can be understood as a way to respond to pain management, with the focus on reducing or eliminating pain through medical, psychosocial, and spiritual modes of care.

Soelle's theological orientation emerges in her mystical understanding of suffering and selfhood—that there is a type of union with God that occurs in which one's self becomes incorporated in the mystery of God's self. Though as a Christian realist, Soelle could be seen as being suspicious of how the language of "mystery" is used and how this language functions as another form of passivity, she does use language of the void in a way that is similar to the poetic language of mystery. Drawing on the work of Simone Weil, Soelle notes that suffering can be a time when one can touch the limits of the void of human experience.[87] It is through the act of loving even in the void that one can have agency within suffering. In hospice, there is awareness that death is a limit of life, similar to the limit of the void, and it is through recognition of and preparation for this limit that patients and family members can have agency and can experience death in its fullness, not necessarily as a positive event, but as a natural one in the course of human life.

In addition to offering the model of naming and articulating one's pain through lament, Soelle offers another mode of response: one can bear witness to pain. Bearing witness is something one can do particularly in response to the suffering of another. However, one can bear witness to the pain that dwells within oneself as well, a theological variation of hosting. One can recognize the pain or grief that inhabits one's being, without having to work to obliterate this presence through aggressively curative medical care such as that provided in the biomedical

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87. Simone Weil uses the language of loving in the void in her text *Gravity and Grace* (New York: Putnam, 1952).

model or having to amiably endure it in a posture of welcome or benign passivity. Both the model of bearing witness and Soelle's three-phase response to pain demonstrate Kearney's vision of how one can be host to the "unwelcome guest" of pain, particularly the physical, emotional, and spiritual pain experienced by terminal patients in hospice.

## A Theology of Hospitality for Hospice Caregivers

In discourse about medicine and religion, attention often centers on the religious or spiritual identity of the patient as the recipient of care. Respect for patient's rights and a mission of patient-centered humanistic care motivate a clinician's attention to take into account the patient's identity in its fullness; such an approach includes recognition of dimensions of patient identity that incorporate spiritual and the religious, aspects of selfhood that prove significant for a sizable majority of patients. In this section, I reframe the conversation. Rather than turning toward the patient's religious or spiritual identity as is so often done in research on religion and medicine, I turn toward the religious and spiritual identity of the caregiver. Rather than addressing the spiritual or religious identity of the caregiver, previous research has centered on the spiritual and religious role of the caregiver; however, that research continues to be patient-oriented in that it focuses on how to best provide care for patients, usually through an initial spiritual assessment prompted by the clinician. Instead of a role-orientation, in which a clinician attunes to the needs of the patient, I consider the ways in which a clinician's spiritual or religious identity can provide a way of interpreting and engaging in the practice of care. I propose that a theology of hospitality can be a resource for how a caregiver approaches care for a person at the end of life. In the following section, I speak to how theology offers both a frame for understanding how a caregiver approaches patient care as well as a modality of care for those who are dying.

As stated in section 1 of this chapter, the theological concept of hospitality connects with

the early history of the hospice movement in the West. Hospices provided a place of respite for soldiers, the indigent, or those on pilgrimage, the work perceived as a way to assist those on their journey to the sacred. Next, Cicely Saunders interpreted end of life care as a form of spiritual practice based on Matthew 25. She intentionally chose the name hospice because of its history as a theological concept of care. For Saunders, developing the modern hospice inseparable from her self-identity as a Christian. Her work with hospice as a physician was a religious vocation in her understanding. My attention to the religious and spiritual identity of the hospice caregiver aligns closely with Saunders view of vocation. I expand on her view of vocation by describing how a theology of hospitality can offer a mode of presence for those in hospice care. In the following section I turn to the ways a caregiver can apply the theological concept of hospitality to patient encounters as a model that does not require narrative abilities on the part of the patient. Hospitality can be both an internal state of being that informs how one views interactions with others, especially those who have nothing to offer us in return. Additionally, hospitality can inform modes of being present with those who are dying as a form of spiritual and religious practice. In the following, I address theological expressions that can be valuable for understanding how hospitality can relate to patient care.

## Hospitality as Bearing Witness to Those who are Dying

The language of witnessing is used to describe intentional, compassionate presence for those at the end of life. Though language of "bearing witness" has a religious history, clinicians also use the term in a medical context to refer to patient-centeredness in the clinical encounter. Arthur Kleinman uses the term "empathic witnessing" when suggesting modes of being present with

those who are suffering.[88] Additionally, Rita Charon uses the language of witnessing when discussing what it means to attend closely to patients, listening to them with what Henry James calls "the great empty cup of attention" in a posture of deep listening.[89] Witnessing, or bearing witness, involves continuous presence with a person, offering mindful attention and intentional presence. There is no goal or task involved other than being with the person during their experience.

Cicely Saunders similarly draws on the concept of witnessing when she uses the language "watch with me" as a response to what a patient may desire when the patient faces death.[90] "Watch with me" is what Jesus of Nazareth says the night before his death, knowing that his death is imminent. Even though his death is undertaken freely, he does not want to be alone as he waits for the moment to come. This sense of expectant waiting can also be found with hospice patients who know their time is limited. Not all patients are aware of their environment, many turn inward as they transition to death; yet, the witness can still be present for the individual providing physical comfort through touch as well as providing support for the loved ones of the patient who may need presence and support through their experience of the death.

A value of bearing witness for those transitioning from life is that it does not involve any response from the patient. This is particularly valuable for those patients who may be non-verbal or non-responsive at the end of life. It is not uncommon for patients to turn inward as they transition, and if those bearing witness understands this, they will not expect any kind of

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88. Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988), 154.

89. Rita Charon, "Narrative Medicine: Attention, Representation, Affiliation," *Narrative* 13, no. 3 (2005), 261.

90. Cicely Saunders, "'Watch with Me,'" *Nursing Times* 61, no. 48 (1965), 1615.

affirmation or acknowledgement of their presence. The dynamic is not one based on mutual

recognition or one that is expected to be interactive. There are no expectations that the patient die

well or according to the witness's vision or preference. By having no expectations of the patient,

one can then honor their intrinsic value as a person of sacred worth, one that does not have to do

anything or perform in any way to earn recognition, care, and the presence of another. Cultivating

a presence based on hospitality allows a caregiver to continue to be there for patients who may

be non-responsive, agitated, or even combative. There is thus a return to how hospice originally

functioned, as a way-station of care for those in need on their way to encounter God, regardless of

the condition of the traveler.

<div align="center">

**Accompaniment as a Model of Presence Possible**

**Regardless of Narrative Ability**

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In the works addressed in previous chapters, Ricoeur speaks to the self as constitutively narrative

and social; in a collection of his last writings before his death in 2005, he offers a way of being

present with another person that is centered on receptivity, but not necessarily on the offering

or reception of a person's verbal narrative. In *Living Up to Death: Mourning and Cheerfulness*,

Ricoeur reflects on meaning, care and presence at the end of life, when one is facing the end of

their life, as he was when he wrote most of the book. He notes that those who are terminal tend

to be life-oriented more than death-oriented—that is, they see themselves as living, not dying.[91]

Though they are terminal, they are nevertheless *alive*, and call for being treated accordingly.

Using language of "the Essential" to describe transcultural religious awareness, Ricoeur defines

compassionate presence as including "the gaze that sees the dying person as still living, as calling

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91. Paul Ricoeur and David Pellauer. *Living Up to Death* (Chicago: University of Chicago Press, 2009), 13-14. The title draws from the first section of the book, the section on which I focus.

on the deepest resources of life, as borne by the emergence of the Essential in [the] experience of still-living . . . It is the gaze of compassion and not that of the spectator anticipating the already-dead."[92] The gaze of compassion is what defines the act of accompanying for Ricoeur, and it is his language of accompanying that holds value for clinicians and non-professional caregivers. Accompanying is a mode of being present for one who is dying— a mode of being that includes an embrace of compassion that holds a person in the present moment rather than being oriented toward the event of the person's death. Accompaniment is informed by narrativity in that it is centered on empathic presence with one who is facing the end of one's narrative. Accompaniment, in this sense, holds great value for caregiver in hospice, in particular.

Through accompanying another, one can be present for and attentive to a patient as a living person and not as merely a dying being or the bearer of diagnosis. Unlike the verbal encounter between caregiver and patient, the act of accompanying can be done with persons who have a cognitive deficit, aphasia or who are unconscious. In these cases it is not the patient's verbal narrative that is interpreted; rather it is their time-narrative that is being interpreted. More clearly, it is the reality that the person is *not dead yet*, but is living and worthy of compassionate presence that is interpreted. Regarding the physical component of accompanying, in "Prudential Judgment," Ricoeur speaks to the need to maintain the dignity of the patient, noting that "the dignity of the patient is not menaced solely on the level of language, but by all the concessions to familiarity, triviality, [and] vulgarity in the everyday relations between the members of the medical personnel and the hospitalized persons."[93] Similarly, Laurie Zoloth, though she recognizes the place of reflection on one's narrative and the stories present in sacred texts, resists

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92. Ricoeur, *Living Up to Death*, 17.

93. Ricoeur, "Prudential Judgment," 18.

any form of rarefied abstract intellectualism in bioethics that neglects the creatureliness of humans.[94] Dr. Zoloth notes that bioethics does involve rigorous attention to theoretical problems and dilemma/decision centered consultations, but she says, "Bioethics is also about and perhaps centrally about the tasks of daily living in a fragile body with foreknowledge of our own death."

In *Living Up to Death*, Ricoeur, like narrative bioethicists, maintains the not only the value of physical presence, but also the value of the imagination, linking the imagination to the possibility of compassion and to the ethical domain in medical care. Speaking of the nature of compassion, he writes that, in addition to it having a professional dimension, "there is also a properly ethical dimension, concerning the capacity to accompany in imagination and in sympathy the still living dying person's struggle, still living until dead."[95] He says that act of accompanying and the gaze of compassion are fundamentally relational and more than medical. In other words, non-professional caregivers can also be present in an act of accompaniment for the other. The use of narrative method in ethics and in care such as the act of accompanying, centers on belief that empathic presence and understanding *is* possible, that the alterity of the other can be overstated. Though there is epistemic distance, there is also empathic connection. Ronald Carson looks to the hyphen as representing the relationship between clinician and patient. He writes, "The hyphenated space in the doctor-patient relationship is a luminal place of ethical

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94.  Zoloth, "Faith and Reasoning(s)," 270. In a footnote to this claim, she points out that much of the literature in bioethics speaks to the "white, middle-class, university-trained reader," and, because of this, the literature rarely includes accounts from those providing daily care such as nurse's aides or licensed nurses. See footnote 33.

95.  Ricoeur, *Living Up to Death*, 18.

encounter, alternating voices and actions—back and forth, address and response . . . The hyphen points to the prospect of overcoming silence with meaningful conversation."[96]

Relationality between oneself and another is possible even if certainty about the quality of the other's mode of being is not possible to attain. This relationality occurs when the clinician asks for and listens to the narrative offered by the patient. For Ricoeur, the listening involved in accompanying another cannot be considered a merely passive act; rather it is one that can be folded within his understanding of passive activity or active passivity. He uses the language of detachment to describe the act of becoming a vessel for another, service being that which "conjoins the negative detachment (renouncing oneself) and the positive force of detachment, of availability for and openness to the essential."[97] Rita Charon considers the role of detachment as it relates to the empathic imagination when she reflects on the following question: "How does one empty the self or at least suspend the self so as to become a receptive vessel for the language and experience of another? This imaginative, active, receptive, aesthetic experience of donating the self toward the meaning-making of the other is a dramatic, daring, transformative move."[98] This act, the act of listening, appears to be a passive one, but, in fact, it is marked by activity and intentional engagement. Charon lifts up a phrase Henry James uses to describe listening; he calls the act one in which the listener becomes "the great empty cup of attention."[99] One can offer this

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96. Ronald Carson, "The Hyphenated Space: Liminality in the Doctor-Patient Relationship" in *Stories Matter*, 180.

97. Ricoeur, *Living Up to Death*, 51. In this section, Ricoeur is speaking specifically to, in his words, the kenosis/necrosis of Christ, though his words about service parallel his words about accompaniment as receptivity.

98. Charon, "Narrative Medicine," 263.

99. Charon, "Narrative Medicine," 263 from Henry James' *The Wings of a Dove* (London: Mandarin, 1998).

presence to another through Ricoeur's understanding of the practice of accompanying, regardless of narrative ability on the part of the patient or religious status of the clinician.

Companioning the dying, as described by counselor Greg Yoder, reimagines clinical approaches to patient care for end of life caregivers.[100] The companioning model, building on Alan Wofelt's research on grief and mourning and the practices of companioning the bereaved, corresponds with the previous models mentioned, bearing witness and accompaniment, models that demonstrate hospitality to the stranger. Yoder identifies eight aspects of companioning, listed below. Each applies to care for those who might be perceived by clinicians and caregivers as challenging patients, due to cognitive or verbal limits or due to the nature of their pain.

1. Companioning is about honoring all parts of the spirit; it is not about focusing only on intellect.

2. Companioning is more about curiosity; it is less about our expertise.

3. Companioning is about walking alongside; it is less about leading or being led.

4. Companioning the dying is often more about being still; it is not always about urgent movements forward.

5. Companioning the dying means discovering the gifts of sacred silence; it does not mean filling up every moment with talk.

6. Companioning is about being present to another's spiritual and emotional pain; it is not about taking away or fixing it.

7. Companioning is about respecting disorder and confusion; it is not about imposing order and logic.

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100. Greg Yoder, *Companioning the Dying: A Soulful Guide for Caregivers* (Fort Collins, CO: Companion Press, 2005).

8.      Companioning is about going into the wilderness of the soul with another human being; it is not about thinking you are responsible for finding a way out.

Yoder urges clinicians and caregivers to relax their expectations, often romanticized and frequently self-gratifying, of a rewarding clinical encounter, particularly as such expectations can put pressure on vulnerable patients or family members to labor to please the clinician. Yoder asks that caregivers meet patients where they are, as they are, and critiques scholarship that idealizes the dying experience:

> In much of the literature on dying, there is a glaring lack of reference to spiritually or emotionally distressful deaths that perhaps represent less pleasant examples to teach from. And when they are explored, I get a strong impression that those deaths are viewed as less-than or tragic because the one dying was not able to respond to traditional help or in ways offered by the authors . . . The implication is that less poignant, distressful death outcomes, which are many in my experience, are regrettably relegated to the wasn't-that-too-bad category.

Yoder's approach demonstrates hospitality to the stranger by reminding the caregiver that the actual experience of being with patients, unlike the sentimentalized ideal of this experience, can be frustrating, uncomfortable, and shocking rather than peaceful or compelling. To care for a patient expecting that the encounter will be intimate and heartwarming, or even that they will be or comforted by your presence, is unfair to the patient. Such an approach is clinician-centered rather than patient-centered, evincing a reversal of hospitality to the stranger. The practice of companioning the dying, as described by Yoder, addresses the ethical implications of expecting reciprocity or reward from the clinical encounter. Such an approach can lead to the social isolation and potential neglect of patients who challenge the clinician or caregiver.

## Conclusion

Patients with cognitive or verbal limits do not fit the paradigm of clinician-patient relationality offered by narrative medicine if the encounter depends on conversational reciprocity and

understanding. Samuel Beckett provides an opportunity to practice encountering the stranger, the person both familiar, yet alien, whose language cannot be deciphered and whose physical embodiment and context evoke disorientation and perplexity, confounding expectations of culmination or even comprehension. Through the use of literature like Beckett's that defies understanding, provoking discomfort in clinicians trained to be competent, I suggest that clinicians can practice what it means to relax the impulse to understand, to undo the habits that come with a science-based model of clinical training. Approached from an expanded perspective, the clinical encounter can be framed as a mode of being with patients without the expectation of narrative satisfaction or dialogical reciprocity, an approach based on the practice of hospitality through bearing witness, accompaniment, and companioning. By increasing one's ability to assess and remain present with those who may be experiencing existential distress resulting from life review or the pain of social isolation that can come with aging and cognitive decline, clinicians can give attention to patients' pain in its many dimensions beyond the physical. Clinicians will undoubtedly meet patients that are challenging to work with due to their disease progression or because they are ill-tempered and unpleasant to be around. Nevertheless, the call in Matthew is to care for the least of these, to visit those who are sick, in prison, or dying; the stranger.

# BIBLIOGRAPHY

Alzheimer's Association, "Caregivers Support Groups," http://www.alz.org/care/alzheimers-dementia-support-groups.asp

"Alzheimer Deaths Increased during the Previous Decade," *JAMA* 309, no. 17 (May 1, 2013): 1767–1767.

"Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia* 10, no. 2 (2014).

Adams, Carolyn, Julia Bader, and Kathryn Horn. "Timing of Hospice Referral." *Home Health Care Management and Practice* 21, no. 2 (2009): 109-16.

Addis, D.R. and LJ Tippett. "Memory of Myself: Autobiographical Memory and Identity in Alzheimer's Disease." *Memory (Hove, England)* 12, no. 1 (2004): 56-74.

Allport, Gordon W. *The Individual and His Religion, a Psychological Interpretation.* New York: Macmillan, 1950.

Allport, Gordon and Michael J. Ross. "Personal Religious Orientation and Prejudice." *Journal of Personality and Social Psychology* 5, no. 4 (Apr 1967): 432-443.

Anandarajah, G. and E. Hight. "Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment." *Am Fam Physician* 63, no. 1 (2001): 81-89.

Andiman, Ronald. "A Physician's Response to the Midrashic Inivitation." William Cutter, *Midrash & Medicine : Healing Body and Soul in the Jewish Interpretive Tradition*. Woodstock, Vt.: Jewish Lights Pub., 2011.

Ando, M., T. Morita and S. O'Connor. "Primary Concerns of Advanced Cancer Patients Identified through the Structured Life Review Process: A Qualitative Study using a Text Mining Technique." *Palliative & Supportive Care* 5, no. 3 (2007): 265.

Ando, Michiyo, Tatsuya Morita, Tatsuo Akechi, and Takuya Okamoto. "Efficacy of Short-Term Life-Review Interviews on the Spiritual Well-being of Terminally Ill Cancer Patients." *Journal of Pain and Symptom Management* 39, no. 6 (6, 2010): 993-1002.

Angus, Derek and the Robert Wood Johnson Foundation ICU End-Of-Life Peer Group. "Use of Intensive Care at the End of Life in the United States: An epidemiologic study." *Critical care medicine* 32, no. 3 (2004): 638-643.

Asquith, Glenn. "Anton T. Boisen and the Study of "Living Human Documents."" *Journal of Presbyterian History* (1962-1985) 60, no. 3 (1982): 244-65.

Augustine, Gibb, John Montgomery. *The Confessions of Augustine*. New York: Garland Pub., 1980.

Baddeley, et al. "Dementia and Working Memory." *Quarterly Journal of Experimental Psychology* 38A (1986): 603-618.

Balboni, Michael J., Christina M. Puchalski , and John R. Peteet. "The Relationship between Medicine, Spirituality and Religion: Three Models for Integration." *J Relig Health Journal of Religion and Health* 53, no. 5 (2014): 1586-98.

Barlow, David H. "Unraveling the Mysteries of Anxiety and its Disorders from the Perspective of Emotion Theory." *American Psychologist American Psychologist* 55, no. 11 (2000): 1247-63.

Beauchamp, Tom and James F. Childress. *Principles of Biomedical Ethics*. New York: Oxford University Press, 1979.

Ben-Zvi, L. (ed.) *Women in Beckett: Performance and Critical Perspectives*. Urbana and Chicago: University of Illinois Press, 1992.

Billroth, Theodor, Leon Banov, and Kellogg Speed. *The Medical Sciences in the German Universities : A Study in the History of Civilization*. New York: The Macmillan Company, 1924.

Birren, James E. and Kathryn N. Cochran. *Telling the Stories of Life through Guided Autobiography Groups*. Baltimore: Johns Hopkins University Press, 2001.

Birren, James E. and Donna E. Deutchman. *Guiding Autobiography Groups for Older Adults : Exploring the Fabric of Life*. Baltimore: Johns Hopkins University Press, 1991.

Birren, James E. *Encyclopedia of Gerontology*. Amsterdam; Boston: Academic Press, 2007.

Bishop, Jeffrey Paul. *The Anticipatory Corpse : Medicine, Power, and the Care of the Dying*. Notre Dame, Ind.: University of Notre Dame Press, 2011.

Booth, Wayne. "The Ethics of Medicine, as Revealed in Literature." In *Stories Matter: The Role of Narrative in Medical Ethics*, edited by Rita Charon and Martha Montello. New York: Routledge, 2002.

Bradshaw, A. "The Spiritual Dimension of Hospice: The Secularization of an Ideal." *Social Science & Medicine (1982)* 43, no. 3 (1996): 409-19.

Bramadat, Paul, Harold G. Coward, and Kelli I. Stajduhar. *Spirituality in Hospice Palliative Care,* 2013.

Bruner, Jerome S. *Making Stories : Law, Literature, Life*. New York: Farrar, Straus, and Giroux, 2002.

———. *Actual Minds, Possible Worlds*. Cambridge, Mass.: Harvard University Press, 1986.

Buckley, Jenny. *Palliative Care : An Integrated Approach*. Chichester, U.K.: Wiley-Blackwell, 2008.

Burkman, Katharine. *Myth and Ritual in the Plays of Samuel Beckett*. Rutherford, N.J.: Fairleigh Dickinson University Press, 1987.

Burns, Nancy. *Closure: The Rush to End Grief and What it Costs Us*. Philadelphia, PA: Temple University Press, 2011.

Butler, Robert. "The Life Review: An Interpretation of Reminiscence in the Aged." *Psychiatry* 26 (1963): 65-76.

Byock, Ira. *Dying Well: Peace and Possibilities at the End of Life*. New York: Riverhead Books, 1998.

Cacioppo, J.T, and M. E. Hughes, L.J. Waite, L. C. Hawkley, and R. A. Thisted, "Loneliness as a Specific Risk Factor for Depressive Symptoms: Cross-sectional and Longitudinal Analyses," *Psychology and Aging* 21, no.1 (2006), 140-151.

Cacioppo, John and William Patrick. *Loneliness: Human Nature and the Need for Social Connection*. New York: W.W. Norton & Co, 2008.

Cadge, Wendy. *Paging God: Religion in the Halls of Medicine*. Chicago, IL: University of Chicago Press, 2012.

Callahan, Daniel. *False Hopes : Why America's Quest for Perfect Health is a Recipe for Failure*. New York: Simon & Schuster, 1998.

Calman, Kenneth. "Quality of life in Cancer Patients--An Hypothesis." *Journal of Medical Ethics* 10.3 (1984): 124-127.

Campbell, Julie. "The Semantic Krapp in *Krapp's Last Tape*." *Samuel Beckett Today/Aujourd'hui: An Annual Bilingual Review/Revue Annuelle Bilingue* 6 (1997): 63-72.

Cassell, Eric J. *The Nature of Healing : The Modern Practice of Medicine*. Oxford; New York: Oxford University Press, 2013.

———. *The Nature of Suffering: And the Goals of Medicine*. New York: Oxford University Press, 1991.

Chambers, Tod. *The Fiction of Bioethics: Cases as Literary Texts*. New York: Routledge, 1999.

Chambers, Tod. "Misreading Montgomery." *Atrium* 11 (2003).

Chancellor B., A. Duncan, and A. Chatterjee. "Art Therapy for Alzheimer's Disease and Other Dementias." *Journal of Alzheimer's Disease : JAD* 39, no. 1 (2014): 1-11.

Charon, Rita and Martha Montello. *Stories Matter: The Role of Narrative in Medical Ethics*. New York: Routledge, 2002.

Charon, Rita. "The Great Empty Cup of Attention: The Doctor and the Illness in the Wings of the Dove." *Literature and Medicine* 9, no. 1 (1990): 105-24.

———. "Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation, and Validation in the Practice of the Ethicist." In *A Matter of Principles?: Ferment in U.S. Bioethics*, ed. Edwin DuBose, Ronald P. Hamel, and Laurence J. O'Connell. Valley Forge, Pa: Trinity Press International, 1994.

———. "Narrative Medicine: Form, Function, and Ethics." *Annals of Internal Medicine* 134, no. 1 (2001):83-87.

———. "Narrative Medicine: a Model for Empathy, Reflection, Profession, and Trust." *Journal of the American Medical Association* 286, no. 15 (2001): 1897-902.

———. "Narrative Reciprocity." *HAST Hastings Center Report* 44, no. s1 (2014): S21-4.

———. "Narrative Medicine: Attention, Representation, Affiliation." *Narrative* 13, no. 3 (2005): 261-70.

———. "A Momentary Watcher, or the Imperiled Reader of 'A Round of Visits.'" *Henry*

*James Review* 29 (2008): 275-86.

———. *Narrative Medicine: Honoring the Stories of Illness*. Oxford [u.a.]: Oxford Univ. Press, 2008.

Chochinov H.M., T. Hack, T. Hassard, L.J. Kristjanson, S. McClement, and M. Harlos. "Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life." *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology* 23, no. 24 (2005): 5520-5.

Chochinov, Harvey Max. *Dignity Therapy: Final Words for Final Days*. Oxford; New York: Oxford University Press, 2012.

Cloyes, Kristin and Susan J. Rosenkranz, Dawn Wold, Patricia H. Berry, and Katherine P. Supiano. "To be Truly Alive Motivation Among Prison Inmate Hospice Volunteers and the Transformative Process of End-of-Life Peer Care Service." *American Journal of Hospice and Palliative Medicine* (2013).

Collett, Merrill. *At Home with Dying: A Zen Hospice Approach*. Boston: Shambhala, 1999.

Conway, Kathlyn. *Beyond Words: Illness and the Limits of Expression*. Albuquerque: University of New Mexico Press, 2013.

Coulehan, Jack. et al. "The Best Lack All Conviction: Biomedical Ethics, Professionalism, and Social Responsibility." *Cambridge Quarterly of Healthcare Ethics* 12, no. 1 (2003): 24.

Coulehan, Jack. ""They Wouldn't Pay Attention": Death without Dignity." *American Journal of Hospice and Palliative Medicine* 22, no. 5 (2005): 339-43.

———. "From Virtue to Narrative: The Art of Healing." In *Toward Healing: Virtuous Practice, Spiritual Care and Narrative Medicine*. Akron, OH: Institute for Professionalism Inquiry, 2005.

Crisp, Jane. "Making Sense of the Stories that People with Alzheimer's Tell: A Journey with My Mother." *Nursing Inquiry* 2, no. 3 (1995): 133-40.

Curlin, Farr A. and Peter P. Moschovis. "Is Religious Devotion Relevant to the Doctor-Patient Relationship?" *Journal of Family Practice* 53, no. 8 (2004).

Cutter, William. *Midrash & Medicine: Healing Body and Soul in the Jewish Interpretive Tradition*. Woodstock, Vt.: Jewish Lights Pub., 2011.

DasGupta, Sayantani, Marsha Hurst. *Stories of Illness and Healing: Women Write their Bodies*. Kent, Ohio: Kent State University Press, 2007.

DasGupta, Sayantani. "Narrative Humility." *The Lancet* 371, no. 9617 (2008): 980 – 981.

DasGupta, Sayantani and Rita Charon. "Personal Illness Narratives: Using Reflective Writing to Teach Empathy." *Academic Medicine* 79 (2004): 351-56.

Dees, M.K., M.J. Vernooij-Dassen, W.J. Dekkers, K.C. Vissers, and C. van Weel. "'Unbearable Suffering': A Qualitative Study on the Perspectives of Patients Who Request Assistance in Dying." *Journal of Medical Ethics* 37, no. 12 (2011): 727-34.

Dewing, Jan. "Personhood and Dementia: Revisiting Tom Kitwood's Ideas." *OPN International Journal of Older People Nursing* 3, no. 1 (2008): 3-13.

Duffy, T.P. "The Flexner Report--100 Years Later." *The Yale Journal of Biology and Medicine* 84, no. 3 (2011): 269-76.

Duignan, D., L. Hedley, and R. Milverton. "Exploring Dance as a Therapy for Symptoms and Social Interaction in a Dementia Care Unit." *Nursing Times* 105, no. 30 (2009): 4-17.

Eagly, Alice Hendrickson. *Sex Differences in Social Behavior: A Social-Role Interpretation*. Hillsdale, N.J.: L. Erlbaum Associates, 1987.

Eddy, David. "Practice Policies: Guidelines for Methods." *JAMA* 263, no. 13 (1990): 1839–41.

Edson, Margaret. *W;t*. New York: Faber & Faber, 1999.

Effiong, Andem and Stephanie Harman. "Patients Who Lack Capacity and Lack Surrogates: Can They Enroll in Hospice?" *Journal of pain and symptom management* (2014).

Engel, John. *Narrative in Health Care : Healing Patients, Practitioners, Profession, and Community*. Oxford; New York: Radcliffe Publishing, 2008.

El Haj, Mohamad, Virginie Postal, and Philippe Allaine. "Music Enhances Autobiographical Memory in Mild Alzheimer's Disease." *Educational Gerontology* 38, no. 1 (2012): 30-41.

Elliot, H. "Death Doulas Complement Nursing Care at the End of Life." *Nursing Times : NT.* 110, no. 34/35 (2014): 7.

Engel, G.L. "The Need for a New Medical Model: A Challenge for Biomedicine." *Science (New York, N.Y.)* 196, no. 4286 (1977): 129-36.

Engel, John D. *Narrative in Health Care: Healing Patients, Practitioners, Profession, and Community*. Oxford; New York: Radcliffe Publishing, 2008.

Epner, D. E. and W. F. Baile. "Patient-Centered Care: The Key to Cultural Competence." *Annals of Oncology* 23, no. suppl 3 (April 01, 2012): 33-42.

Erikson, Erik H. *The Life Cycle Completed : Extended Version with New Chapters on the Ninth Stage of Development by Joan M. Erikson*. New York: W.W. Norton, 1998.

Esslin, Martin. "The Theatre of the Absurd." *The Tulane Drama Review* 4, no. 4 (1960): 3-15.

Evans, Sioned, and Andrew Davison. *Care for the Dying: A Practical and Pastoral Guide* (2014).

Exline, J., et al. "Forgiveness, Depressive Symptoms, and Communication at the End of Life: A Study with Family Members of Hospice Patients." *J Palliat Med* 15, no. 10 (2012). doi: 10.1089/jpm.2012.0138. Epub 2012 Jul 31

Fayers, Peter and David Machin. *Quality of Life: The Assessment, Analysis and Interpretation of Patient-reported Outcomes.* John Wiley & Sons, 2013.

Ferrell, Betty, Shirley Otis-Green, Reverend Pamela Baird, and Andrea Garcia. "Nurses' Responses to Requests for Forgiveness at the End of Life." *Journal of Pain and Symptom Management*, Vol. 47, no. 3 (2014): 631-641.

Fischer, Stacy, Sung-Joon Min, Lilia Cervantes, and Jean Kutner. "Where Do You Want to Spend Your Last Days of Life? Low Concordance between Preferred and Actual Site of Death among Hospitalized Adults." *Journal of Hospital Medicine* 8, no. 4 (2013).

Fishbein, Morris. *Medical Follies: An Analysis of the Foibles of Some Healing Cults, including Osteopathy, Homeopathy, Chiropractic, and the Electronic Reactions of Abrams, with Essays on the Anti-Vivisectionists, Health Legislation, Physical Culture, Birth Control, and Rejuvination.* New York: Boni & Liveright, 1925.

Fishbein, Morris. *The New Medical Follies: An Encyclopedia of Cultism and Quackery in these United States, with Essays on the Cult of Beauty, the Craze for Reduction, Rejuvenation, Eclecticism, Bread and Dietary Fads, Physical Therapy, and a Forecast as to the Physician of the Future.* New York: Boni & Liveright, 1927, New York: AMS Press 1977.

Figley, C. *Compassion Fatigue: Coping with Secondary Traumatic Stress Disorder in those who Treat the Traumatized.* New York, NY: Brunner Mazel, 1995.

Fitchett, George. *Assessing Spiritual Needs: A Guide for Caregivers.* Lima (Ohio): Academic Renewal Press, 2002.

Fitchett, George, et al. "Evidence-Based Chaplaincy Care: Attitudes and Practices in Diverse Healthcare Chaplain Samples." *Journal Of Health Care Chaplaincy* 20, no. 4 (2014).

Flaherty, Ellen. "How to Try this: Using Pain-Rating Scales with Older Adults - this Article Examines Three Pain-Rating Scales -the Numeric Rating Scale, the Verbal Descriptor Scale, and the Faces Pain Scale-Revised- that are Widely used with Older Patients." *The American Journal of Nursing.* (2008): 40.

Flanagan, John. "Measure of Quality of Life: Current State of the Art." *Archives of Physical and Medical Rehabilitation* 63 (1982): 56-59,

Flexner, Abraham and Daniel Updike, Berkeley, Carnegie Foundation for the Advancement of Teaching. Merrymount Press. *Medical Education in the United States and Canada : A Report to the Carnegie Foundation for the Advancement of Teaching*. 576 Fifth Avenue, New York City: [s.n.], 1910.

Frank, Arthur W. *The Wounded Storyteller : Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.

———. "Narratives of Spirituality and Religion in End-of-Life Care" in *Narrative Research in Health and Illness*. Blackwell Publishing Ltd, 2004; 2008.

Frankl, Viktor E. *Man's Search for Meaning : An Introduction to Logotherapy*. New York: Simon & Schuster, 1984.

Friedrich, M.J. "Therapeutic Environmental Design Aims to Help Patients with Alzheimer Disease." *JAMA* 301, no. 23 (June 17, 2009): 2430-.

Ganguli, M. and E. Rodriguez. "Reporting of Dementia on Death Certificates: A Community Study." *J Am Geriatr Soc* 47 (1999): 842–9.

Gardiner, P. "A Virtue Ethics Approach to Moral Dilemmas in Medicine." *Journal of Medical Ethics* 29, no. 5 (2003): 297-302.

Geertz, Clifford. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 1973.

Gontarski, S.E. *Crapp's First Tapes: Beckett's Manuscript Revisions of Krapp's Last Tape*. Philadelphia: Temple University, 1977.

Good, Byron. *Medicine, Rationality, and Experience : An Anthropological Perspective*. Cambridge; New York: Cambridge University Press, 1994.

Good, Mary-Jo DelVecchio. *Pain as Human Experience : An Anthropological Perspective*. Berkeley: University of California Press, 1992.

"Grief, Bereavement, and Loss" PDQ of the Supportive and Palliative Care Editorial Board. Bethesda, MD: National Cancer Institute, October 8, 2014. https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-hp-pdq.

Groninger, Hunter and Marcia Day Childress. "Samuel Beckett's *Rockaby*: Dramatizing the Plight of the Solitary Elderly at Life's End." *Perspectives in Biology and Medicine* 50, no. 2 (2007): 260-275.

Grossoehme, Daniel. "Chaplaincy and Narrative Theory, A Response to Fisk's Case Study." *The Journal of Health Care Chaplaincy* 19, no. 3 (2013): 99-111

Guéguen, N., S. Meineri, and V. Charles-Sire. "Improving Medication Adherence by using Practitioner Nonverbal Techniques: A Field Experiment on the Effect of Touch." *Journal of Behavioral Medicine* 33, no. 6 (2010): 466-73.

Haber, David. "Life Review: Implementation, Theory, Research, and Therapy." *International Journal of Aging and Human Development* 63, no. 2 (2006): 153-71.

Hahn, S.R., Kroenke, K., Spitzer, R.L. et al. "The Difficult Patient: Prevalence, Psychopathology, and Functional Impairment." *J Gen Intern Med* (1996).

Kellehear, Allan. "Spirituality and Palliative care: A Model of Needs." *Palliative Medicine* 14, no. 2 (2000): 149-155.

Haight, B.K. "The Therapeutic Role of a Structured Life Review Process in Homebound Elderly Subjects." *Journal of Gerontology* 43, no. 2 (1988): 40-4.

Haight, Barbara K. and Barrett S. Haight. *The Handbook of Structured Life Review*. Baltimore: Health Professions Press, 2007.

Hains, C.A.M. and N.J. Hulbert-Williams. "Attitudes Toward Euthanasia and Physician-Assisted Suicide: A Study of the Multivariate Effects of Healthcare Training, Patient Characteristics, Religion and Locus of Control." *Journal of Medical Ethics.* 39, no. 11 (2013): 713-6.

Haker, Hile. "Narrative Ethics in Health Care Chaplaincy." In *Medical Ethics in Health Care Chaplaincy: Essays* ed. Walter Moczynski, Hille Haker, and Katrin Bentele. Berlin: Lit, 2009.

Handzo, George and Kevin Flannelly, et al. "What Do Chaplains Really Do? II. Visitation in the New York Chaplaincy Study." *Journal of Health Care Chaplaincy* 14, no. 1 (2008): 53.

Hall, David. *Ricoeur and the Poetic Imperative: The Creative Tension Between Love and Justice*. New York: SUNY Press, 2007.

Hawkins, Anne Hunsaker. *Reconstructing Illness: Studies in Pathography*. West Lafayette, Ind.: Purdue University Press, 1993.

Heilferty, C. "Toward a Theory of Online Communication in Illness: Concept Analysis of Illness Blogs." *Journal of Advanced Nursing* 65: (2009):1539–1547.

Hendricks, Jon. *The Meaning of Reminiscence and Life Review*. Amityville, N.Y.: Baywood Pub. Co., 1995.

Hill, Heather. "Journey without a Map: Dance Therapy with Dementia Patients." *How the Arts make a Difference in Therapy.* (1993): 89-105.

Hooyman, N. and B. Kramer. *Living Through Loss; Interventions Across theLife Span*. New York Chichester, West Sussex: Columbia University Press, 2006.

Hospice Foundation of America. "Guide for Recalling and Telling your Life Story." Washington, D.C.: Hospice Foundation of America (2001).

"Hospice: A Historical Perspective." National Hospice and Palliative Care Organization, http://www.nhpco.org/history-hospice-care. Accessed December 10, 2014.

Hospice of Cincinnati, http://www.hospiceofcincinnati.org/life_review_info.shtml. Accessed 10/10/13.

"Hospice Policy Compendium: The Medicare Benefit, Regulations, Quality Reporting, and Public Policy." National Organization of Hospice and Palliative Care (2016).

Howarth, G. "Whatever Happened to Social Class? An Examination of the Neglect of Working Class Cultures in the Sociology of Death." *Health Sociology Review: The Journal of the Health Section of the Australian Sociological Association* 16, no. 5 (2007): 425-35.

Hyden, L.C. and L. Orulv. "Narrative and Identity in Alzheimer's Disease: A Case Study." *Journal of Aging Studies* 23, no. 4 (2009): 205-14.

Institute of Medicine (US) Committee on Palliative and End-of-Life Care for Children and Their Families; Field MJ, Behrman RE, editors. "When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families." Washington (DC): National Academies Press (US); 2003.

Institute for Professionalism Inquiry Conference Proceedings, Rita Charon, Jack Coulehan, and Christina Puchalski. *Toward Healing : Virtuous Practice, Spiritual Care and Narrative Medicine*. [Akron, OH ]: Institute for Professionalism Inquiry, 2005.

James, B., D. Bennett, P. Boyle, S. Leurgans, and J. Schneider. "Dementia From Alzheimer Disease and Mixed Pathologies in the Oldest Old." *JAMA* 307, no. 17 (2012):1798.

James B., S. Leurgans, L. Hebert LE, et al. "Contribution of Alzheimer Disease to Mortality in the United States" *Neurology* 82 (2014):1-6.

James, Henry. *The Portrait of a Lady. The Novels and Tales of Henry James*. New York: Kelley, [1881]1970.

———. *The Wings of a Dove*. London: Mandarin, [1902]1998.

Johnson, Mark. *Moral Imagination: Implications of Cognitive Science for Ethics*. Chicago:University of Chicago Press, 1993.

Jonsen, Albert. *The Birth of Bioethics*. New York: Oxford University Press, 1998.

Joinson, Carla. "Coping with Compassion Fatigue." *Nursing,* 22(4),118-120 1992.

Jurecic, Ann. *Illness as Narrative*. Pittsburgh: University of Pittsburgh Press, 2012.

Kearney, Richard. "Narrating Pain: The Power of Catharsis." *Paragraph* 30, no. 1 (2007).

———. *Anatheism : Returning to God After God*. New York: Columbia University Press, 2010.

Kerr, D. "Mother Mary Aikenhead, the Irish Sisters of Charity and our Lady's Hospice for the Dying." *The American Journal of Hospice & Palliative Care* 10, no. 3 (1993).

Kim, H., M. Chang, K. Rose, and S. Kim. "Predictors of Caregiver Burden in Caregivers of Individuals with Dementia." *Journal of Advanced Nursing* 68, no. 4 (2012): 846-55.

Kindell, Jacqueline, Karen Sage, John Keady, and Ray Wilkinson. "Adapting to Conversation with Semantic Dementia: Using Enactment as a Compensatory Strategy in Everyday Social Interaction." *JLCD International Journal of Language & Communication Disorders* 48, no. 5 (2013): 497-507.

Kitwood, T. M. *Coping with Dementia: The Person Comes First.* Leicester: British Psychological Society, 1996.

Kitwood, Tom. "The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease." *Ageing & Society* 10, no. 02 (1990): 177-96.

Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, 1988.

Knowlson, James. "Krapp's Last Tape: The Evolution of a Play: 1958-1975." *Journal of Beckett Studies* 1 (Winter, 1976).

———. *Damned to Fame: The Life of Samuel Beckett.* New York, NY: Touchstone Press, 1997.

Kontos, Pia and Gary Naglie. "Expressions of Personhood in Alzheimer's Disease: An Evaluation of Research-Based Theatre as a Pedagogical Tool." *Qualitative Health Research* 17, no. 6 (2007): 799-811.

Kübler-Ross, Elisabeth. *On Death and Dying what the Dying have to Teach Doctors, Nurses, Clergy, and their Own Families*. New York: Macmillan, 1969.

———. *On Death and Dying*. New York: Macmillan, 1974.

Lawton, M., et al. "A Two-factor Model of Caregiving Appraisal and Psychological Well-being" *Journals of Gerontology* 46, no. 4 (1991): 181–189.

Lepp, Margret, Karin C. Ringsberg, Ann-Kristin Holm, and Gunilla Sellersjö. "Dementia - Involving Patients and their Caregivers in a Drama Programme: The Caregivers' Experiences." *JOCN Journal of Clinical Nursing* 12, no. 6 (2003): 873-81.

Levin, S, D. Larson, and C. Puchalski. "Religion and spirituality in medicine: Research and education." *JAMA : The Journal of the American Medical Association* 278, no. 9 (1997): 792-793.

Lewis, M.I. and R.N. Butler. "Life-Review Therapy. Putting Memories to Work in Individual and Group Psychotherapy." *Geriatrics* 29, no. 11 (1974): 165-73.

Lewis, Milton James. *Medicine and Care of the Dying: A Modern History*. Oxford; New York: Oxford University Press, 2007.

*Living with Grief: Loss in Later Life*. ed. Doka, Kenneth J., John Breaux, and Jack D. Gordon Washington, DC: Hospice Foundation of America, 2002.

Lindemann, Hilde. *Damaged Identities, Narrative Repair*. Ithaca: Cornell University Press, 2001.

Lorde, Audre. *The Cancer Journals*. San Francisco: Aunt Lute Books, 1997.

Luo, Y., L. Hawkley, L. Waite, and J. Cacioppo. "Loneliness, Health, and Mortality in Old Age: A National Longitudinal Study." *Social science & medicine (1982)* 74, no. 6 (2012):907-914. doi:10.1016/j.socscimed.2011.11.028.

Lysaught, Therese. "Respect: Or, how Respect for Persons Became Respect for Autonomy." *The Journal of Medicine and Philosophy* 29, no. 6 (2004): 665-80.

———. *On Moral Medicine : Theological Perspectives in Medical Ethics*. Grand Rapids, Mich.: W.B. Eerdmans Pub. Co., 2012.

MacIntyre, Alasdair. "Epistemological Crises, Dramatic Narrative, and the Philosophy of Science." *The Monist* 60, no. 4 (October 1977): 453–472;

Mako, C., K. Galek, and S. Poppito. "Spiritual Pain among Patients with Advanced Cancer in Palliative Care." *Journal of Palliative Medicine* 9, (2006):1106–1113.

Maleske, M. "Hospice Care. Pet Therapy." *Hospitals & Health Networks / AHA* 78, no. 11 (2004).

Malkin, Jeanette. "Matters of Memory in *Krapp's Last Tape* and *Not I*." *Journal of Dramatic Theory and Criticism* 11.2 (Spring 1997): 25-39.

Mastel-Smith, B., B. Binder, A. Malecha, G. Hersch, L. Symes, and J. McFarlane. "Testing Therapeutic Life Review Offered by Home Care Workers to Decrease Depression among Home-Dwelling Older Women." *Issues in Mental Health Nursing* 27, no. 10 (2006): 1037-49.

Mattingly, Cheryl, and Maureen Hayes Fleming. *Clinical Reasoning*. Philadelphia: F.A. Davis, 1994.

Mattingly, Cheryl. *Stories In Clinical Time*. Cambridge, UK: Cambridge University Press, 1998.

———. *Narrative And The Cultural Construction Of Illness And Healing*. Berkeley, Calif. [u.a.]: Univ. of California Press, 2008.

———. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge, UK: Cambridge University Press, 2008.

Maugans, T. "The SPIRITual History." *ArchFam Med* 5, no. 1 (1996): 11-16.

"Medicare Conditions of Participation: Bereavement," NHPCO, https://www.nhpco.org/sites/default/files/public/regulatory/Bereavement_tip_sheet.pdf

"Medicare Hospice Conditions of Participation: Spiritual Caregiver," NHPCO, https://www.nhpco.org/sites/default/files/public/regulatory/Spiritual_tip_sheet.pdf

"Medicare Hospice Conditions of Participation Volunteer 5% Cost Savings Match Information Sheet: A Resource for Volunteer Managers" http://www.nhpco.org/sites/default/files/public/regulatory/Volunteer_Cost_Savings_Information.pdf Accessed 2/1/2014.

Meier, Diane E. "Palliative Care in Hospitals." *Journal of Hospital Medicine* 1, no. 1 (2006): 21-8.

Michiyo, Ando, et al., "Efficacy of Short-Term Life-Review Interviews on the Spiritual Well-being of Terminally Ill Cancer Patients," *Journal of Pain and Symptom Management* 39, no. 6 (2010): 993.

Miller, Susan C., Pedro Gozalo, and Vincent Mor. "Hospice Enrollment and Hospitalization of Dying Nursing Home Patients." *The American Journal of Medicine* 111, no. 1 (2001): 38.

Mitchell, S., S. Miller, and J. Teno, et al. "Prediction of 6-month Survival of Nursing Home Residents with Advanced Dementia using ADEPT vs Hospice Eligibility Guidelines." *JAMA* 304, no. 17 (2010): 1929-1935.

Mohrmann, Margaret E. "Ethical Grounding for a Profession of Hospital Chaplaincy." *The Hastings Center Report* 38, no. 6 (2008): 18-23.

Moltmann, Jürgen. *The Crucified God: The Cross of Christ As the Foundation and Criticism of Christian Theology*. New York: Harper & Row, 1974.

Monroe, Barbara and David Oliviere. *Patient Participation in Palliative Care: A Voice for the Voiceless*. New York: Oxford University Press, 2003.

Montgomery, Kathryn. *How Doctors Think: Clinical Judgment and the Practice of Medicine*. Oxford; New York: Oxford University Press, 2006.

———. *Doctors' Stories : The Narrative Structure of Medical Knowledge*. Princeton, N.J.: Princeton University Press, 1991.

Najjar, N., L.W. Davis, K. Beck-Coon, and C.C. Doebbeling. "Compassion Fatigue: A Review of the Research to Date and Relevance to Cancer-care Providers." *Journal of Health Psychology 14 (2009)*: 267-277.

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Department of Health, Education and Welfare. September 30, 1978. The Belmont Report. Washington, DC: United States Government Printing Office.

Neimeyer, Robert A. *Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved*. New York: Routledge, 2012.

Newman, Laura. "Elisabeth Kübler-Ross." *British Medical Journal* 329.7466 (2004).

Noll, Mark A. *A History of Christianity in the United States and Canada*. Grand Rapids, Mich.: W.B. Eerdmans, 1992.

Normann, H., K. Asplund, and A. Norberg "Confirmation and Lucidity During Conversations with a Woman with Severe Dementia." *Journal of Advanced Nursing* 39 (2002): 370–376.

Nussbaum, Martha. *Love's Knowledge: Essays on Philosophy and Literature*. New York: Oxford University Press, 1990.

———. *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and Philosophy*. Cambridge: Cambridge University Press, 2001.

O'Mahony, S. "Against Narrative Medicine." *Perspectives in Biology and Medicine* 56, no. 4 (2013): 611-9.

Ong, Chi-Keong and Duncan Forbes. "Embracing Cicely Saunders's Concept of Total Pain." *BMJ: British Medical Journal* 331, no. 7516 (2005): 576-7.

Örulv, Linda,Hydén and Lars-Christer. "Confabulation: Sense-Making, Self-Making and World-Making in Dementia." *Discourse Studies* 8, no. 5 (2006): 647-73.

Parsons, Talcott. "The Sick Role and the Role of the Physician Reconsidered." *The Milbank Memorial Fund Quarterly.Health and Society* 53, no. 3 (1975): 257-78.

Pesut, Barbara, Shane Sinclair, George Fitchett, Madeleine Greig, and Sarah E. Koss. "Health Care Chaplaincy: A Scoping Review of the Evidence 2009–2014." *Journal of Health Care Chaplaincy* 22, no. 2 (2016): 67-84.

Phelan, James. "Editor's Column: Who's here? Thoughts on Narrative Identity and Narrative Imperialism." *Narrative* 13, no. 3 (2005): 205-10.

Piette, Adam. "Ending the Mother's Ghost: *Beckett's Ill Seen Ill Said* and *Rockabye*." *Complutense Journal of English Studies* 83, no. 22 (2014): 81-90.

Pohl, Christine. *Making Room: Recovering Hospitality As a Christian Tradition*. GrandRapids, Mich: W.B. Eerdmans, 1999.

Polubinski, J.P. and L. West. "Implementation of a Massage Therapy Program in the Home Hospice Setting." *Journal of Pain and Symptom Management* 30, no. 1 (2005).

Puchalski, Christina M. and David B. Larson. "Developing Curricula in Spirituality and Medicine." *Academic Medicine* 73, no. 9 (1998): 970-74.

Puchalski, C. and A. Romer. "Taking a Spiritual History Allows Clinicians to Understand Patients more Fully." *Journal of Palliative Medicine* 3, no. 1. (2000):129-137.

Puchalski, Christina. "The Role of Spirituality in Health Care." *Proceedings (Baylor University. Medical Center)* 14, no. 4 (2001): 352-7.

———. *A time for listening and caring: Spirituality and the care of the chronically ill and dying* (New York, NY: Oxford University Press, 2006).

———. "Spirituality and Medicine: Curricula in Medical Education," *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 21, no.1 (2006).

———. "Spiritual Issues as an Essential Element of Quality Palliative Care: A Commentary." *The Journal of Clinical Ethics* 19, no. 2 (2008).

Pusey, E.B. *Confessions of Saint Augustine*. Masterpieces of American Literature. Collector's Edition. New York: Pocket Books, 1951.

Rahner, Karl. *Foundations of Christian Faith: An Introduction to the Idea of Christianity*. New York: Seabury Press, 1978.

Ramsey, Paul. *The Patient as Person: Explorations in Medical Ethics*. New Haven: Yale University Press, 1970.

Randall, William. "Storywork: Autobiographical Learning in Later Life." *ACE New Directions for Adult and Continuing Education* 2010, no. 126 (2010): 25-36.

Rando, T.A. "An Investigation of Grief and Adaptation in Parents Whose Children have Died from Cancer." *Journal of Pediatric Psychology* 8, no. 1 (1983): 3-20.

Ready, Rebecca and Brian R Ott. "Quality of Life Measures for Dementia. "*Health and Quality of Life Outcomes* 1 (2003): 11.

Reisberg, Barry, Steven H. Ferris, Mony J. de Leon, Elia Sinaiko Emile Franssen, Alan Kluger, Pervez Mir, Jeffrey Borenstein, Ajax E. George, Emma Shulman, Gertrude Steinberg, and Jacob Cohen. "Stage-Specific Behavioral, Cognitive, and in Vivo Changes in Community Residing Subjects with Age-Associated Memory Impairment and Primary Degenerative Dementia of the Alzheimer Type." *DDR Drug Development Research* 15, no. 2-3 (1988): 101-14.

Ressler, P., Y. Bradshaw, L. Gualtieri, and K. Chui. "Communicating the Experience of Chronic Pain and Illness Through Blogging." J Med Internet Res 14, no. 5 (2012):e143.

Reverby, Susan. *Examining Tuskegee : The Infamous Syphilis Study and its Legacy*. Chapel Hill: University of North Carolina Press, 2009.

Richmond, Caroline. "Dame Cicely Saunders." *British Medical Journal* 331, no. 7510 (2005): 238.

Ricoeur, Paul. *The Symbolism of Evil.* New York: Harper & Row, 1967.

———. *Time and Narrative*. Chicago: University of Chicago Press, 1984.

———. *Fallible Man*. New York: Fordham University Press, 1986.

———. *Oneself as Another*. Chicago: University of Chicago Press, 1992.

———. *Memory, History, Forgetting*. Chicago: University of Chicago Press, 2004.

———. "Living Up to Death." University of Chicago Press, 2009.

Rodriquez, J. "Narrating Dementia: Self and Community in an Online Forum." *Qualitative Health Research* 23, no. 9 (2013): 1215-27.

Rosignoli, Stefano. "Dreaming through the Confessions: On the Intertextuality of the Augustinian Excerpts in Samuel Beckett's 'Dream' Notebook." *Journal Of Beckett Studies* (Edinburgh University Press) 25, no. 1 (April 2016): 39-55.

Saunders, Cicely. "Care of Patients Suffering from Terminal Illness at St Joseph's Hospice." *Nursing Mirror* (Hackney, London: February 14, 1964): vii-x.

———. "'Watch with Me." *Nursing Times* 61, no. 48 (1965): 1615-7.

———. "Facing Death." *The Way* (1984).

———. *St. Christopher's in Celebration: Twenty-One Years at Britain's First Modern Hospice*. London: Hodder and Stoughton, 1988.

———. "St Christopher's Hospice." *St Thomas' Hospital Gazette* (1991).

———. *Cicely Saunders: Selected Writings 1958-2004*. Oxford; New York: Oxford University Press, 2006.

Saunders, Cicely M. and Mary Baines. *Living with Dying: The Management of Terminal Disease*. Oxford; New York: Oxford University Press, 1983.

Saunders, Cicely M., Mary Baines, and R.J. Dunlop. *Living with Dying: A Guide to Palliative Care*. Oxford; New York: Oxford University Press, 1995.

Scarry, Elaine. *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford University Press, 1985.

Shanafelt, T. "Enhancing Meaning in Work: A Prescription for Preventing Physician Burnout and Promoting Patient-centered Care." *JAMA* 302 (2009): 1338–40.

Shapiro, Johanna. "Current Controversy: Illness Narratives: Reliability, Authenticity and the Empathic Witness." *Medical Humanities* 37, no. 2 (2011): 68-72.

Sharf, B. and M. Vanderford. "Illness Narratives and the Social Construction of Reality." In *Handbook of Health Communication*, ed. T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott. Mahwah, NJ: Lawrence Erlbaum, 2003.

Siebold, Cathy. *The Hospice Movement : Easing Death's Pains*. New York; Toronto; New York: Twayne ; Maxwell Macmillan Canada ; Maxwell Macmillan International, 1992.

Smith, Glenn E. and Mark W. Bondi. *Mild Cognitive Impairment and Dementia: Definitions, Diagnosis, and Treatment*. New York: Oxford University Press, 2013.

Sölle, Dorothee. *Suffering*. Philadelphia: Fortress Press, 1975.

Sontag, Susan. *Illness As Metaphor*. New York: Vintage Books, 1979.

Spiro, Howard. "Empathy: An Introduction." in *Empathy and the Practice of Medicine*, ed. Howard Spiro, Mary Curnen, Enid Peschel, and Deborah St. James. New Haven: Yale University Press, 1993.

Stadnyk, Robin, Susan C. Jurczak, Vanessa Johnson, Haley Augustine, and Russell D. Sampson. "Effects of the Physical and Social Environment on Resident-Family Member Activities in Assisted Living Facilities for Persons with Dementia." *Seniors Housing & Care Journal* 21, no. 1 (2013).

Strawson, Galen. "Against Narrativity." *Ratio* 17, no. 4 (2004a): 428-52.

Sulmasy, D.P. "Ethos, Mythos, and Thanatos: Spirituality and Ethics at the End of Life." *Journal of Pain and Symptom Management* 46, no. 3 (2013a): 447-51.

———. "Spiritual Issues in the Care of Dying Patients: ". . . It's Okay between Me and God"." *JAMA* 296, no. 11 (2006): 1385-92.

———. *The Rebirth of the Clinic : An Introduction to Spirituality in Health Care*. Washington, D.C.: Georgetown University Press, 2006.

———. "Spirituality, Religion, and Clinical Care." *Chest* 135, no. 6 (2009): 1634-42.

Sweeting, Helen and Mary Gilhooly. "Dementia and the Phenomenon of Social Death." *SHIL Sociology of Health & Illness* 19, no. 1 (1997): 93-117.

Swinton, John and Richard Payne. "Living Well and Dying Faithfully: Christian Practices for End-of-Life Care."William B. Eerdmans Pub. Co., 2009.

Taylor, Janelle. "The Story Catches You and You Fall Down: Tragedy, Ethnography, and ''Cultural Competence." *Medical Anthropology Quarterly* 17 (2003): 159–181.

Tappen, R., C. Williams, S. Fishman, and T. Touhy. "Persistence of Self in Advanced Alzheimer's Disease." *Image: Journal of Nursing Scholarship* 31 (1999): 121–125.

Teilhard de Chardin, Pierre. *The Divine Milieu; an Essay on the Interior Life.* New York: Harper, 1960.

Thompson, Teresa. "The Applicability of Narrative Ethics." *Journal of Applied Communication Research* 37, no. 2. (May 2009): 190.

Tillich, Paul. *The Courage to Be*. New Haven, CT: Yale University Press, 1952.

Timmer, E., G.J. Westerhof, and F. Dittmann-Kohli. ""When Looking Back on My Past Life I Regret. . .": Retrospective Regret in the Second Half of Life." *Death Studies* 29, no. 7 (2005): 625-44.

Tippett, L. and D. Addis. "Memory of Myself: Autobiographical Memory and Identity in Alzheimer's Disease." *Memory (Hove, England)* 12, no. 1 (2004): 57.

Tolstoy, Leo, Lynn Solotaroff. *The Death of Ivan Illyich*. Toronto; New York: Bantam Books, 1985.

Trevino, K.M., M. Balboni, A. Zollfrank, T. Balboni, and H.G. Prigerson. "Negative Religious Coping as a Correlate of Suicidal Ideation in Patients with Advanced Cancer." *Psycho-Oncology* 23, no. 8 (2014): 936-45.

Turner, John C. *Rediscovering the Social Group: Self-Categorization Theory*. Oxford, UK; New York, NY, USA: B. Blackwell, 1987.

Tsushima, Michiko. "'Memory is the Belly of the Mind: Augustine's Concept of Memory in Beckett." *Samuel Beckett Today / Aujourd'Hui*, vol. 19 (2008): 123–132.

Valdes, Mario. *A Ricoeur Reader: Reflection and Imagination*. Toronto: University of Toronto Press, 1991.

Wald, Florence S. and Judith L. Lief. Yale University, School of Nursing. "In Quest of the Spiritual Component of Care for the Terminally Ill : Proceedings of a Colloquium may 3-4, 1986, Yale University School of Nursing."[publisher not identified], 1986.

Walter, Tony. "Spirituality in Palliative Care: Opportunity or Burden?" *Palliative Medicine* 16: 99-104,

Ware, Bonnie. *Top Five Regrets of the Dying*. Hay House: 2012.

Webster, Jeffrey Dean and Mary E. McCall. "Reminiscence Functions Across Adulthood: A Replication and Extension." *Journal of Adult Development* 6, no. 1 (1999): 73-85.

Weil, Simone. *Gravity and Grace*. New York: Putnam, 1952.

White, Michael and David Epston. *Narrative Means to Therapeutic Ends*. New York: Norton, 1990.

Wilson, Erica. "Dying Without a Home: Understanding and Responding to Palliative and End-of-Life Care Needs of Homeless Patients." *Journal of Pain and Symptom Management* 45, no. 2 (2013): 403-403.

Wray, Alison. "Formulaic Language as a Barrier to Effective Communication with People with Alzheimer's Disease." *CMLR Canadian Modern Language Review/ La Revue Canadienne Des Langues Vivantes* 67, no. 4 (2011): 429-58.

Yaffe, K. "Treatment of Alzheimer Disease and Prognosis of Dementia: Time to Translate Research to Results." *JAMA* 304, no. 17 (2010):1952-1953.

Yoder, Greg. *Companioning the Dying: A Soulful Guide for Caregivers*. Fort Collins, CO: Companion Press, 2005.

Zalaquett, Carlos P., Andrea N. Stens. "Psychosocial Treatments for Major Depression and Dysthymia in Older Adults: A Review of the Research Literature." *Journal of Counseling & Development* 84, no. 2 (2006): 192-201.

Zaner, R.M. "Medicine and Dialogue." *The Journal of Medicine and Philosophy* 15, no. 3 (1990): 303-25.

VITA

Tara Flanagan, Assistant Professor of Religious Studies at Maria College in Albany, New York, received her Ph.D. at Loyola University Chicago in the Department of Theology and Religious Studies with a specialization in ethics. She completed her chaplaincy training at Westchester Medical Center in New York with a residency in pediatric palliative care at the Maria Fareri Children's Hospital, then joined the clinical staff at New York-Presbyterian/Lawrence Community Health Services as their hospice chaplain. Her research and publications address the role of religion and ethics in hospice and palliative care, with special attention given to the place of chaplaincy in a healthcare context. She teaches courses on medical ethics, theology, and comparative religious ethics, often using literature as a source for critical analysis and ethical reflection.