The Dissertation Committee for Andrew J. Taylor certifies that this is the approved version of the following dissertation:

Cultivating the Moral Imagination

Committee:

Michele Carter, Ph.D., Supervisor

Anne Hudson Jones, Ph.D.

William Winslade J.D., Ph.D.

Alok Dabi, M.D.

Soham Al Snih, M.D. Ph.D.

Monica Rasmus Ph.D., M.Ed.

Cultivating the Moral Imagination

by

Andrew J. Taylor, MS, BS

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To my wife, Dee,

for everything!

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Cultivating the Moral Imagination

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Supervisor: Michele Carter, Ph.D.

The moral imagination is a type of moral competence, moral disposition, or moral intelligence that can be cultivated and that leads to an expanded vision of whom the moral agent has a moral duty to. The moral imagination is essential in the lifework of the clinician and it is a type of moral excellence that the moral agent strives for but has not yet attained. The moral imagination leads us to consider what it might be like to be the Other, whether or not the Other is in any particular type of distress. In this way the moral imagination leads us to participate genuinely in deliberative democracies. From the moral imagination flows the individual identifiable virtues: empathy, compassion, witnessing, courage, and love. In medical terms, these virtues are the signs and symptoms that the moral imagination is alive in the moral agent and these virtues ought to be cultivated. Cultivating the moral imagination can be accomplished through the use of examples of moral exemplars and the use of stories of various kinds. Pathographies, the illness stories of persons, can be particularly valuable in the cultivation of the moral imagination of clinicians. I use several pathographies about patients with locked-in syndrome to argue for the use of pathographies in general, and in the moral education of clinicians. Interprofessional education, when students learn with, about, and from each other, is used to deliver ethics education. I argue that narratives can be used effectively to enhance current efforts in ethics-oriented interprofessional education and to develop the humanistic clinician.

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Preface

This project defines the moral imagination and then explores the ways in which the human being, the clinician particularly, can cultivate the growth of moral imagination. The moral imagination is a phrase that many scholars of different stripes have written about, and I use many of their thoughts and ideas to ultimately formulate my own explanation of what the moral imagination is. As I write about it here, the *moral imagination* is a type of moral excellence, moral competence, or moral disposition that can be cultivated throughout a human being's life span. Being in tune with one's moral imagination affects the moral agent's attitude toward the Other, ways of communicating with the Other, and the way in which she sees herself in the world. For clinicians, the development of the moral imagination is essential and should be seen on par with attempts at continuing clinical competence. In the same ways that clinicians strive to stay abreast of scientific and technical developments in their given fields of practice, there should be a concomitant striving for moral competence.

In many ways the ideas that I write about in this project are an amalgamation of several aspects of my life that include my clinical experience as a respiratory therapist, my twenty years of experience teaching undergraduate allied health students, my development as a thinker in the areas of morals and ethics, and the experiences in my private life as a husband and a father. As a clinician who has experienced existential crises at the bedside, certain lingering thoughts are pervasive. In the medical world it is easy to see the patient through medicalized eyes. Indeed, in a very real way, clinicians are trained to see patients this way, to understand the patient not as a person, but in medical terms (e.g., diagnosis, treatment, prognosis, etc.). Eventually though, this way of seeing, whether it is acknowledged or not, becomes insufficient, and the clinician, who is

a moral agent, must search for a more excellent way of understanding the clinician-patient relationship. Clinicians, those who take moral development seriously, must search for deeper and richer ways of understanding their moral duty toward the persons they care for. Those persons include the ill, their colleagues, and themselves. This project is an attempt to help those serious-minded clinicians in their search.

After about two years of full-time teaching in the Respiratory Therapy program at Texas Southern University, I was asked to take on the responsibility of teaching an interdisciplinary bioethics course. Not only were there respiratory therapy students who registered for the course, but there were also (and still are) students from clinical laboratory science, health administration, environmental health, health information management, and dietetics who took part in the course. At the time I knew nothing about teaching bioethics didactically, although I had some clinical experience with ethical dilemmas. In an attempt to do the best job that I could with the course, I set out to find resources that would inform my teaching. Over the years I discovered and used books like Tom Beauchamp and James Childress' *The Principles of Biomedical Ethics*, George Pozgar's *Legal and Ethical Issues for Health Professionals*, and Gregory Pence's *Medical Ethics: Accounts of Groundbreaking Cases*. These resources were helpful, but I left them with a sense of wanting a deeper and richer way of engaging with moral and ethical issues in the biomedical context.

Eventually and thankfully I learned about the medical humanities graduate program at the University of Texas Medical Branch, Galveston. The real strength of the graduate program is its interdisciplinary approach. Being exposed to the different epistemologies, the various ways of seeing and knowing the human being and the moral and ethical challenges that human beings

face, has been essential in my own self-development and my development as a thinker. I have found those deeper and richer ways of seeing that I was in search of.

My private life, like the lives of the others of us who live in this country, helps to shape the ways in which I think about morality too. We are living in very strange times. We are confronted daily with both challenges and opportunities to think about who we are, and what we genuinely believe. Our sociopolitical discourse has turned into something that is at best argumentative and unproductive, and at its worst, hateful and mean-spirited. This dissertation about the moral imagination has been inspired by this sociopolitical reality as well and by the sense that we can do better as individuals and as a nation.

In his famous treatise on love, the Apostle Paul, before he begins to tell his reader what love is and what love does, makes sure that the reader understands that love is a more excellent way. That is what I am arguing for in this dissertation. Whether the moral agent is in the clinic as a clinician or as a patient, in the classroom as a teacher or student, or in the polis as a citizen or a leader, we must strive for more excellent ways to understand each other and to communicate with one another.

Introduction

It is hard to live in Houston, Texas, and escape the ubiquitous mantra of one of the leading cancer hospitals in all the world, M. D. Anderson "Making Cancer History." Before I get too far into my introduction, I will admit quickly that if I were diagnosed with cancer today or tomorrow, I would hurriedly make my way to this renowned hospital. However, the slogan of the well-known hospital can be interpreted at least two ways. First, the hospital claims that it is "Making Cancer History" because of the gifted and talented researchers and health professionals that work for the hospital, M. D. Anderson is progressively marching toward new discoveries in cancer treatment and these discoveries are historic, groundbreaking. But there is another way that we might interpret the saying, M. D. Anderson "Making Cancer History" because of the prowess of the research enterprise at M. D. Anderson, eventually, if given enough time, cancer will be a reality of the past. Cancer will eventually be history. Whenever I see commercials or billboards that use this slogan I think about the subliminal messages that the slogan sends. How might this message and messages like it influence the ways in which we think about science, medicine, our lives, and our future?

I see M. D. Anderson's motto as just one more attempt to convince us that science has all the answers to the questions that we have about our common human condition. One of those important questions has to do with meaning. Where does the moral agent find meaning in life, particularly when life is hard and does not make sense? The narrative of science and by extension medicine's narrative, is a story of triumph, of victory, and of conquest. But is the story true? In 2003 at the age of fifty-three my mother was admitted to a small hospital on the

periphery of the Texas Medical Center in Houston to have a hysterectomy.[1] Her normal Obstetrician-Gynecologist performed the surgery and my mother seemed to be doing well one day after the procedure. On the second day of her recovery while still in the hospital, her physician came to see her. I was in the room when he showed up. Her doctor told her that the pathology report had come back on her ovaries and the ovaries had tested positive for cancer. We would find out later that she had stage IV ovarian cancer. She would need an additional surgery early the next morning and subsequent courses of chemotherapy. This physician told us that he would not be performing the second surgery, but a specialist from M.D. Anderson was being consulted on my mother's case and she would be performing the second procedure. The specialist from M. D. Anderson did come in to speak with my mother that evening. She was a soft spoken and compassionate physician with an unforgettable name, and she explained the procedure to us thoroughly. She performed the surgery, managed my mother's post-operative chemotherapy as an outpatient, and now seventeen years later, my mother is alive and well. This was a victory for medicine.

About two years before my mother's bout with cancer, my maternal grandmother died of end-stage renal disease. This is a woman that I love immeasurably. She had been diagnosed with kidney failure about seven years earlier and had been successfully dialyzed three days per week since that time. She started out driving herself to the dialysis clinic at 5:00 a.m. each morning that she was scheduled for treatment. She did this for several years. Eventually though, because of her vision problems and lassitude after the treatment, she needed a ride to and from the dialysis clinic. Slowly but surely, her body began to wear down. She got an infection on one of her feet, gangrene set in, and she required an amputation. She continued to decline to the

[1] I have allowed my mother to read this narrative and obtained her consent to tell her story.

point where she could not do anything for herself, including toileting. She would not eat and required a percutaneous gastrostomy (PEG) tube for feedings and hydration, but still we kept up the dialysis and performed all of her care at home. She no longer recognized us and when she was awake, she would scream continuously. Soon we were faced with a decision. Should we continue to use medical technology to keep her alive, when it was obvious that the treatment was only prolonging her misery? As a family we decided against further treatment (dialysis), we decided in favor of hospice, and she expired about five days later. This was a loss for medicine.

And this is our reality in the common human condition. Yes, medicine does win many victories, but more often than we like to admit, scientific medicine loses. As a result of these losses we may become disillusioned with medicine and realize that medicine does not have the ultimate answers to our deepest questions, questions about meaning. Medicine cannot solve all of humanity's problems. So where do we look for answers when medicine has come up short, when we have been disappointed by medicine? In a sense this is the overarching question of this dissertation. If medicine is not the answer, where might we find a solution to our human questions about meaning? In scientific medicine we look for answers that are objective, certain, and predictable. But when we are disappointed by scientific medicine, we are left with the realities of life, those things that are subjective, uncertain, and unpredictable. We are left with life as it really is.

I suggest in this project that real meaning is found in human relationships, in the ways in which we relate to one another, and I suggest that the development of a moral imagination can help us in our human interactions. This is the subject of chapter one. The *moral imagination,* as I define it here, is a type of moral competence or moral disposition that the moral agent begins to acquire very early in life and that can flourish throughout a lifetime, if it is nurtured intentionally.

It begins with the idea of imagining what it must be like to be in the Other's situation, but does not stop there. There is much more that is required of the moral agent. In chapter one I review some of the things that have been written by other scholars about the moral imagination before settling on what I think is a slightly broader and somewhat different conception of the moral imagination. Although I talk about and sincerely believe that the concepts that I explore in this dissertation can be applied to the general public, my real focus in this project is on the work and wellbeing of the clinician. I am interested here primarily in the cultivation of the moral imagination of the clinician and how that cultivation affects the clinician's life, her patients, the patient's family, and the clinician's colleagues.

If the moral imagination is a type of competence, then that competence can be assessed by the presence (or absence) of essential virtues displayed by the moral agent. In medical terms the virtues are the signs and symptoms that the moral imagination is alive and well. The virtues that I choose to highlight are empathy, compassion, witnessing, courage, and love. This of course is not an exhaustive list, but these are the virtues that I see as essential for the clinician to do his best work.

In chapter two, the question that I attempt to answer has to do with how the moral imagination is actually cultivated. I begin my research in that chapter with an exploration of theories in educational psychology. I take a close look at the theories of Lawrence Kohlberg and Carol Gilligan. Kohlberg challenges us to think about moral theory and moral behavior in ways that demand some universals. Carol Gilligan reminds us that it is important to hear all of the voices in a given society if our theories about education and morality are going to be accurate. In this dissertation it is evident that I am very much influenced by the thinking and writing of Robert Coles, and ultimately I think Coles' ideas about moral development are most useful. I

believe that all of these thinkers have something to offer in the discussion about how the moral agent develops over time, and I suggest that none of these theories should be dismissed out of hand.

Chapter three explores how narratives might be used to fertilize the moral imagination. Novels have long been recognized as having moral importance. The novelist, many believe, can use her skill to craft stories of moral importance. Novels, and the characters within them, can stay with readers, become their moral companions, and have a lasting influence on the reader's life. In chapter three I explore the possibility that other books, *pathographies*, might be able to do this same type of work. *Pathographies* are stories that are written about an illness experience. Using the theories of Anne Hunsaker Hawkins and Arthur W. Frank, I explore some of the benefits and limitations of using these types of stories. Ultimately I believe that this type of literature can have a lasting effect on clinicians. As a specific example of these types of books and the moral work that they can do, I review five pathographies written by or about persons with locked-in syndrome. Locked-in syndrome, in its classic form, leaves the patient with "total immobility except for vertical eye movements or blinking."[2] I believe that locked-in syndrome and the pathographies written about the illness experiences of these patients are excellent tools for the fertilization of the moral imagination.

Chapter four focuses on stimulating the moral imagination in interprofessional education. Interprofessional education occurs when "students from two or more professions learn about, from, and with each other to enable effective collaboration and improve health outcomes."[3] One of the domains for learning in interprofessional education is the area of virtues and ethics. In this

[2] Steven Laureys, "The Locked-in Syndrome: What Is It Like to Be Conscious but Paralyzed and Voiceless?," *Progress in Brain Research* 150 (2005): 497.

[3] World Health Organization, "Framework for Action on Interprofessional Education and Collaboration," accessed October 8, 2020, https://www.chicagomanualofstyle.org/tools_citationguide/citation-guide-1.html.

chapter I review the scant literature that is available about what I call ethics-oriented interprofessional education and then recommend the use of certain narratives to stimulate growth of the moral imagination. Ultimately I believe that the approach to ethics-oriented interprofessional education is not sufficient and that there are more excellent ways to prepare clinicians for interprofessional collaboration.

In this project I posit that the development of the moral agent's moral imagination is at least a part of the answer to the lingering questions that human beings have about where to find meaning in our lives. Scientific medicine, we have discovered, does not have all the answers. We are challenged then to look elsewhere. This dissertation does not point the moral agent toward the abstract, certain, and predictable world of science, but it points us toward the particular, uncertain, unpredictable real lives of human beings.

Chapter 1

Defining the Moral Imagination

And now these three remain: faith, hope and love. But the greatest of these is love.

The Apostle Paul

I Cor. 13:13

"My heart is filled with love for this country."

Barack Obama, *The Audacity of Hope*

In January 2013, I was working the night shift as a respiratory therapist in a small 250 - bed hospital in Houston, just north of the Texas Medical Center. My shift started at 11:00 p.m., and after getting shift report from the respiratory therapist who was leaving to go home, I reached my assigned area for the night, the long-term acute-care intensive care unit, at about 11:30 p.m. This area of the hospital was designed to care for patients who, among other things, were difficult to wean from mechanical ventilation. These patients were usually in this ICU for months at a time.

Normally when I would arrive to my assigned area, I would greet all of the visible nursing staff with a general salutation, and then throughout the night have more intimate conversations with each nurse as we met at the patient's bedside or as we discussed issues that would arise with our shared patients. But something was different on this particular night. Sharan (pseudonym), was one of the regular nurses on this unit, was preparing to give her patient a bath, but she was noticeably distressed. When I asked her what was the matter, she expressed

anger and frustration about her patient's medical condition and his family's perceived lack of understanding about his prognosis.

The patient of concern was a seventy-eight-year-old man with multiple medical problems who had been ventilator dependent for several months. Despite repeated attempts by the medical staff and the respiratory therapists, the patient had failed to show progress in weaning from the ventilator. The patient had had a tracheostomy tube inserted, which was intended to help facilitate weaning from mechanical ventilation, but the patient was still ventilator dependent. Additionally, the patient had a Foley catheter (for urine collection), a rectal tube (for stool collection), a percutaneous endoscopic gastrostomy or PEG tube (for feedings), had multiple intravenous lines, was bed-ridden, and had skin breakdown in several places on his body. The patient was minimally conscious, but not well orientated to person, place, and time.

The clinical picture of Sharon's patient was not uncommon for this particular unit in this long-term care facility. Most of the nurses on this unit had at least one patient with similar comorbidities, and caring for these patients was both physically and emotionally taxing. But Sharon was frustrated because as a nurse she was doing all she knew how to do for her patient, she was delivering the best care she knew how, yet it seemed that her efforts were fruitless. Sharon was experiencing what might be described as *moral distress*.

First coined by Andrew Jameton in 1984, *moral distress* is said to occur when a health professional encounters circumstances in which she "knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action."[4] In addition, *moral distress* may be experienced by health professionals when medical technology is used in

[4] Andrew Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, NJ: Prentice Hall, 1984), 6.

situations that the professional believes "are futile at the end of life."[5] The healthcare practitioner in these situations knows what is medically appropriate to do but is unsure about the benefit that medical care is providing, and therefore she questions whether the care is morally appropriate.

All the science and technology available were being used to help Sharon's patient, yet the patient was not getting better, and seemed to get progressively worse. Sharon's question that night to me was, "What are we doing?" By asking that question, Sharon was sharing her frustrations with me concerning the lack of progress of her patient, the patient's seemingly bleak prognosis, and the lack of understanding that the patient's family had about either of these issues.

I could certainly identify with the sense of frustration that Sharon was feeling. As a respiratory therapist I too had these same feelings of inadequacy, the feeling that the care that I provided for patients, more often than I wanted to admit, care that was directed by physicians and medically appropriate, provided little if any real benefit for the patient. Memories of various conversations with my respiratory therapy colleagues about these same issues came to mind. For Sharon and me, in that shared space, the question was, what to do right now.

As one human being in communication with another who is in obvious moral distress, I felt the need to say something encouraging to Sharon. I wanted to assure her that I understood what she was feeling and that I had dealt with similar questions about our work with these patients. I also wanted us both to see this situation from the patient's perspective, to ask ourselves how we would feel if we were the patient. So, in an effort to encourage her and to

[5] Elizabeth Dzeng, "Navigating the Liminal State between Life and Death: Clinician Moral Distress and Uncertainty Regarding New Life-Sustaining Technologies," *American Journal of Bioethics* 17, no. 2 (February 2017): 22.

help us both get through our shift, I asked her this question: "If we don't care for this patient, who will? Certainly, we do not have all the answers and we cannot fix all of the problems that we encounter as we do our jobs, but what we can do is care for the patient; do the very best that we can. Perhaps a cure is not possible, but caring is not optional."

Later, as I thought about this encounter with Sharon, I imagined how often issues like these arise for clinicians and the various ways these issues might be resolved or perhaps be left unresolved. I thought about whether or not clinicians are equipped to handle these issues or if these feelings of inadequacy are simply ignored. If moments of *moral distress*, moments like Sharon experiences above, are not dealt with adequately, what type of *moral residue*, "lingering feelings after a morally problematic experience has passed," might occur. I wondered if these unresolved moral issues might lead to burn out or apathy within the health professions, or something worse?[6] I also wondered if there were ways to prepare clinicians for these inevitable moments of existential anxiety and turmoil, moments when the lived experience of patients, their families, and of clinicians themselves require more than science and technology can offer, moments that require an expanded and cultivated *moral imagination.*

My argument in this chapter is an attempt to address these questions. As a clinician what are the moral duties that we have to our patients, to one another, and to ourselves, and how does the cultivation of the *moral imagination* assist the moral agent in fulfilling those duties? As seen in the conversation between Sharon and me above, the moral imagination is at work when the moral agent attempts to see a conversation or moral dilemma from the perspective of the Other, and he asks himself, what must it be like to be in the Other's situation. In addition to this way of

[6] Vicky Lachman, "Moral Resilience: Managing Moral Distress and Moral Residue," *MedSurg Nursing* 25, no. 2 (March-April 2016): 121.

seeing that is relevant to the healthcare context, I think it is important to demonstrate, particularly because of the sociopolitical context in which we live, that the moral imagination is also alive and at work in our larger society as well. Virtues are character traits that are displayed by the moral agent, and they are signs of an active moral imagination. This chapter will include a list of virtues that are essential in the clinician's development. I will begin this chapter with an explanation of what the moral imagination is.

Defining the Moral Imagination

The *Stanford Encyclopedia of Philosophy* says that to use the *imagination* is to "represent without aiming at things as they actually, presently, and subjectively are."[7] One can use *imagination* to represent "possibilities other than the actual, to represent times other than the present, and to represent perspectives other than one's own."[8] The imagination is a powerful tool for the moral agent, but it can of course be put to use for both good and evil purposes.

The imagination, according to Michel Eyquem de Montaigne points to "some human potentiality of the mind to affect the physical body or the body's environment."[9] In his essay, "Of the Power of the Imagination," Montaigne discusses a wide array of examples of both the positive and negative effects of the imagination. His overarching point regarding the imagination is that it is a powerful resource, and the breadth of this resource is still ill defined. When the moral agent uses this powerful resource that is the human imagination to aim at the

[7] Shen-yi Liao and Tamar Gendler, "Imagination," *The Stanford Encyclopedia of Philosophy*, (Summer 2020 Edition), edited by Edward N. Zalta, accessed October 3, 2020, https://plato.stanford.edu/archives/sum2020/entries/imagination.

[8] Ibid.

[9] Michel de Montaigne, "Of the Power of the Imagination," *The Complete Essays of Montaigne*, trans. Donald M. Frame (Stanford, CA: Stanford University Press, 1958), 75.

good and to choose what is right, to broaden her moral competence and deepen her moral intelligence, she is cultivating her moral imagination.

Many scholars of different stripes have attempted to define and explain what the *moral imagination* is and why it is significant in the lives of moral agents. My attempt to see things from Sharon's perspective and to encourage us both to imagine what we would want if we were the patient, "what it might be like to be in such a situation," points to the *moral imagination*.[10] Ronald A. Carson, in his article "Educating the Moral Imagination," suggests that the *moral imagination* may best be understood as a "capacity that can be cultivated, a capacity to imagine something of what it must be like to be in the predicament of the patient sitting opposite you in the examining room or lying in the hospital bed before you."[11] When talking about this type of moral competence, Carson is careful to explain what the moral imagination is not; it is not to fully identify with the Others experience, or to feel what the Other feels. This is not truly possible. But what is possible is for the moral agent to take a moment to really listen, to reflect, and to imagine, "to come to some sense of what it must be like to be in another person's shoes."[12] Carson says in another place, that "it is by attentive listening and imaginative responding to the polyphony of voices in a culture that one learns what others believe and how they think, how they see the world and make sense of their experience in it. "This practice," says Carson, "is at once liberating (from narrow vision) and engaging (of other lifeways)."[13] As a medical humanist, Carson is concerned with the ways in which our cultivated moral imagination

[10] Ronald A. Carson, "Educating the Moral Imagination," in *Practicing the Medical Humanities: Engaging Physicians and Patients*, ed. Ron A. Carson, Chester R. Burns, and Thomas R. Cole (Hagerstown, MD: University Publishing Group, 2003), 36.

[11] Ibid, 28.

[12] Ibid.

[13] Ronald A. Carson, "Engaged Humanities: Moral Work in the Precincts of Medicine," *Perspectives in Biology and Medicine* 50, no. 3 (2007): 327.

will affect patient care, but his focus on how the moral agent listens and how she responds to others has great implications for the larger culture as well. I will return to this thought later.

Nicole M. Piemonte in her book *Afflicted: How Vulnerability Can Heal Medical Education and Practice* shares a similar view as Carson's regarding the moral imagination and its import for the medical professions. In *Afflicted* Piemonte explores what she believes are the shortcomings of medical education and the practice of medicine. She links these deficiencies in medicine, and in science in a broader sense, to the unique epistemic view of science, a way of seeing that privileges scientific, objective, verifiable truth. Piemonte argues that while this epistemic view has led to great scientific and technological discovery and progress, it has also caused a neglect of other just as important ways of understanding the clinical professional-patient relationship. As she discusses ways of understanding the patient that cannot be accounted for in simple biological notions of the human being, Piemonte suggests that the cultivation of the moral imagination "can open students up to new horizons of understanding," which she believes can lead to deeper understanding of "what it might be like to live with a serious illness or injury."[14]

These newly developed "horizons of understanding" that Piemonte points to in medical students is a sign of the cultivated moral imagination. When students began to see beyond the common scientific medical model of disease (assessment, physical findings, diagnosis, treatment, prognosis, etc.) and begin to imagine what the illness experience is like for the patient, how the patient's life has changed because of the disease diagnosis, the student's moral imagination is being cultivated.

[14] Nicole M. Piemonte, *Afflicted: How Vulnerability Can Heal Medical Education and Practice* (Cambridge: The MIT Press, 2016), 142.

Both Carson and Piemonte describe the moral imagination as an invaluable asset for the clinician, an asset that can expand the way in which clinical professionals understand the patient's illness experience. The cultivation of the moral imagination, which is a broadened way of seeing, a deeper level of moral competence, is also important for the relationships that the clinical professional forms with others on the interprofessional team. Ultimately, the moral imagination will also affect the way she sees herself as a moral agent.

The moral imagination as described by these two authors sounds a lot like the indispensable moral virtue, empathy. A short but profound definition of *empathy* is offered by philosopher Judith Andre who says that we display empathy when we are "distressed at the distress of others."[15] Educational psychologist Michele Borba in her book, *Building Moral Intelligence,* contributes to our understanding of empathy when she says that "empathy is the ability to understand and feel for another person's concerns."[16] Borba goes on to say that empathy "is the foundation of moral intelligence" and the cultivation of empathy is critical because it increases the moral agent's "awareness of other's ideas and opinions."[17] Carson warns his reader about the limits of empathy when he says that "to empathize is to simultaneously feel one's way into another person's situation while holding to the awareness that the other person's experience exists independently of us."[18] Carson's explication helps to guard against the notion that empathy is "feeling what the other feels" or "walking in the other's shoes."

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[15] Judith Andre, "The Medical Humanities as Contributing to Moral Growth and Development," In *Practicing the Medical Humanities: Engaging Physicians and Patients*, ed. Ronald A. Carson, Chester R. Burns, and Thomas R. Cole (Hagerstown, MD: University Publishing Group, 2003), 36.

[16] Michele Borba, *Building Moral Intelligence: The Seven Essential Virtues That Teach Kids to Do the Right Thing* (San Francisco, CA: Jossey-Bass, 2001), 14.

[17] Ibid. 8.

[18] Carson, "Educating the Moral Imagination," 35.

Empathy is an invaluable virtue for the moral agent in general, and for clinicians specifically. This virtue is necessary for the provision of quality patient care and it makes sense that these medical humanists focus on the development of this virtue and that their explanations of the moral imagination would reflect this understanding. But who do we normally empathize with? Usually when we summon the virtue of empathy, when we call it up, we are focusing on a situation or a person who needs our help, who, in our mind, deserves some help. These individuals are vulnerable in one way or another, and we may want to rescue them from their trials and tribulations. This is good, and as human moral agents, and certainly as clinicians, these are appropriate moral reactions.

However, the conception of the moral imagination that I envision is broader than the ones described above. My understanding of what is required of the moral agent goes beyond what these articulations of the moral imagination above call for. In addition to asking ourselves "what it might be like to live with a serious illness or injury" or imagining how we might feel if we were going through some other difficult situation, the moral imagination should also address how we respond to the other that is not in distress at all, but simply sees a particular situation or issue from a different perspective than our own.[19] How do we as moral agents respond to others when they have considered opinions that differ from the ones we have formed? Answering this question will have important implications for both the medical context, and our larger public lives. In order to expand our definition of the moral imagination I will have to look at conceptions of this term that originate outside the medical context.

[19] Piemonte, *Afflicted*, xxiv.

A Public Moral Imagination

According to historian Gertrude Himmelfarb, it was Edmond Burke who first "introduced the term *moral imagination* into political discourse."[20] Burke, who has been described as the most influential political thinker of the eighteenth century in England, uses the term *moral imagination* to describe an aspect of sociopolitical life that he sees as crucial to the long term success of a nation.[21] In his now widely read *Reflections on the Revolution in France*, first published on November 1, 1790, Burke is cautioning his readers in France and England against what he sees as a growing affinity for the types of sentiments that led to the French Revolution.[22] In a larger sense, Burke is pushing back against the French Enlightenment and its potential influence across the continent of Europe.[23] Burke sees the newly granted liberty of the French people as potentially disastrous:

> I must be tolerably sure, before I venture publicly to congratulate men upon a blessing, that they have really received one. . . I should therefore suspend my congratulations on the new liberty of France, until I was informed how it had been combined with government; with a public force; with the discipline and obedience of armies; with the collection of an effective and well-distributed revenue; with morality and religion; with the solidity of property; with peace and order; with civil and social manners. All these (in their way) are good things too; and, without them, liberty is not a benefit whilst it lasts, and is not likely to continue long. The effect of liberty to individuals is, that they may do what they please: We ought to see what it will please them to do, before we risqué congratulations, which may be soon turned into complaints.[24]

For Burke, liberty was best secured when there was a balance between personal autonomy, the authority of a monarch, and constitutional parliamentary government. The

[20] Gertrude Himmelfarb, *The Moral Imagination: From Adam Smith to Lionel Trilling*, 2nd ed. (Lanham: Rowman & Littlefield, 2012), ix.

[21] Edmond Burke, *Reflections on the Revolution* in France, ed. L. G. Mitchell (New York: Oxford University Press, 1993), 77.

[22] Ibid., vii.

[23] Gertrude Himmelfarb, "Reflections on Burke's Reflections," *New Criterion* 27, no. 6 (February 2009): 4.

[24] Burke, *Reflections*, 8.

English considered the "legal hereditary succession of their crown as among their rights, not as among their wrongs; as a benefit, not as a grievance, as a security for their liberty, not as a badge of servitude."[25] The French, on the other hand, had only disdain for their old way of government and saw revolution as the only means to liberty. But the French Revolution was not just political, it was "a total revolution – a social, religious, and economic revolution as well as a political revolution."[26] It was a tearing down and tearing away from all things familiar with no regard for the history and culture of the French people, a history and culture that held a certain reverence for the monarchy.

Whether or not we agree with Burke's assessment of the French Revolution or with his political theory, what is helpful in this current project is Burke's understanding of what the *moral imagination* is and how it works in the polis. The State for Burke is upheld by a contract or partnership between leaders and the citizens of a country. Leaders and citizens exist in "a great chain of being, an overarching contract, that gives legitimacy not only to politics but to all aspects of life."[27]

The polis is "a partnership in all science, a partnership in all art; a partnership in every virtue, and in all perfection."[28] Burke goes on to say that "society is indeed a contract . . . not only between those that are living but between those who are dead, and those who are to be born."[29] As such there should not be an attempt to hastily dissolve this contract, as in the French Revolution, but every effort should be made to uphold this civic partnership.

[25] Ibid.
[26] Ibid., 6.
[27] Himmelfarb, "Reflections on Burke's Reflections," 6.
[28] Burke, *Reflections,* 41.
[29] Ibid., 41.

Also in view for Burke was the loss of what he refers to as chivalry. In addition to turning the French people away from their religious, political, and economic history, the French Revolution and the Enlightenment ideals that brought it to pass, had succeeded in destroying the sense of chivalry, "honor, reverence, sentiments, and manners" that was shared in the French public.[30] The virtues of chivalry are "the product of the moral imagination."[31] The results of this loss are described by Burke when he says, "The nurse of manly sentiment and heroic enterprise is gone. It is done, that sensibility of principle, that chastity of honor, which felt a stain like a wound, which inspired courage whilst it mitigated ferocity, which ennobled whatever it touched, and under which vice itself lost half its evil, by losing all its grossness."[32]

This loss of chivalry has widespread implications from Burke's point of view, and this loss is felt not just individually, but collectively. Burke continues to lament this loss of chivalry and the effect of this loss on society in this often quoted text below:

> But now all is to be changed. All the pleasing illusions which made power gentle, and obedience liberal, which harmonized the different shades of life, and which, by a bland assimilation, incorporated into politics the sentiments which beautify and soften private society, are to be dissolved by this new conquering empire of light and reason. All the decent drapery of life is to be rudely torn off. All the superadded ideas, furnished from the wardrobe of a *moral imagination*, which the heart owns, and the understanding ratifies, as necessary to cover the defects of our naked shivering nature, and to raise it to dignity in our own estimation, are to be exploded as a ridiculous, absurd, and antiquated fashion.[33]

The *moral imagination* then for Burke, is a source from which virtue flows, the individual virtues that are shared in common by the public. The moral imagination also helps to

[30] Himmelfarb, "Reflections," 7.
[31] Ibid.
[32] Burke, *Reflections*, 7.
[33] Ibid., 77. This is Burke's only use of the phrase, the moral imagination, in the entire letter.

bring harmony to a society and does so despite the socioeconomic and power differences between people. It binds the public together collectively and lifts a people above what they could be individually. It makes the collective public, which is tied to the past, present, and future, worthy of respect.

Aristotle and a Public Moral Imagination

Burke's idea of society as a contract or partnership between citizens resonates with much of what Aristotle has to say about the polis in the *Nicomachean Ethics*. Aristotle's goal in this project is to explain what *eudaimonia* (the good life) consists of. *Eudaimonia* may also be understood as happiness, well-being, or human flourishing. It is suggested by Stephen Watt that Aristotle's motivation for this work is to direct statesmen in forming societies that will allow individual citizens to flourish.[34] It is the goal of political science and by extension, statesmen or politicians, to "produce a certain character in the citizens, namely to make them virtuous, and capable of performing noble actions."[35]

In *the Ethics* Aristotle points toward a public moral imagination, to the importance of the people around the developing moral agent who contribute to her moral growth. In Book One Aristotle discusses what he calls the "self-sufficiency of happiness," which is not a focus exclusively on the individual self, but rather includes "one's parents and children and wife, and one's friends and fellow citizens in general, since man," Aristotle says, "is by nature a social

[34] Stephan Watt, introduction to *The Nicomachean Ethics*, trans. Harris Rackham (Ware, Hertfordshire: Wordsworth Editions, 1996), xiii.

[35] Aristotle, *The Nicomachean Ethics*, trans. Harris Rackham (WareHertfordshire: Wordsworth Editions, 1996), 17.

being."[36] In order for moral agents to flourish they must be in contact with their family, friends, and other citizens. They cannot develop morally in isolation.

Friendship is especially significant to Aristotle and he devotes Books Eight and Nine to defining the types of friendships that exist; he discusses their distinctive characteristics. As an essential part of the community of the moral agent, "friendship is one of the most indispensable requirements of life," and "perfect friendship," one of the three types of friendship that Aristotle discusses, "occurs between the good and those who resemble each other in virtue."[37]

Ultimately in Book Ten, Aristotle settles on "the activity of contemplation" as the means to a happy life or a life of human flourishing.[38] But admittedly, it is the duty of the statesmen or politician to provide the socioeconomic conditions that allow moral agents to flourish. This is achieved if "men's lives are regulated by a certain intelligence, and by a right system, invested with adequate sanctions."[39] Philosophers that live the contemplative life are the happiest men, but politicians are also essential for producing the right types of societies for this contemplation to take place in.

Following Burke's prescription above for a contract or partnership of the citizens in a society, a partnership that includes leaders, I see the necessity of merging these ideas with Aristotle's. The moral imagination, particularly in democratic societies, requires contemplation, or what Aristotle refers to as *deliberation* when he describes the duties of politicians, by all citizens.[40] It is not sufficient for philosophers and politicians to engage in reflective, contemplative thought, but each citizen ought to participate in the act of deliberation. We

[36] Ibid., 11.
[37] Ibid.
[38] Ibid.
[39] Ibid. 280.
[40] Ibid. 59.

deliberate about things, according to Aristotle, "that can be effected by our agency."[41] *Deliberation* can be defined as "reasoning on the merits of public policy" and is an essential component of a democratic society.[42]

On a Deliberative Democracy

The term *deliberative democracy* was coined by professor and political theorist Joseph Bessette. In his book, *The Mild Voice of Reason*, Bessette explains the deliberative nature of American national government, particularly the United States Congress, and he sets out to prove that creating a society where deliberation was central was the intention of the Founding Fathers of our nation and the framers of the United States Constitution. While Bessette allows for a minimum amount of deliberation between common citizens, he suggests that deliberation happens most and best in the confines of Congress. According to Bessette:

> There are two general reasons why representatives could be expected to do a better job of deliberating about public policy than their constituents. First, they are typically more knowledgeable and experienced in public affairs. Second, they function in an institutional setting that fosters collective reasoning about common concerns, while their constituents usually lack the time, inclination, or environment to engage in a similar enterprise.[43]

While I agree with Bessette's assessment that the conditions for deliberation are more ideal for politicians, I believe that the common citizens within a democratic society should deliberate about the important issues that affect their lives. This deliberation among common citizens will then have influence on the deliberation that takes place among the representatives of citizens.

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[41] Ibid. 59.

[42] Joseph Bessette, *The Mild Voice of Reason: Deliberative Democracy and American National Government* (Chicago: University of Chicago Press, 1994), xi.

[43] Ibid., 2.

Political theorists Amy Guttmann and Dennis Thompson would agree that the deliberative duty of common citizens is essential in a democracy. In their book, *Democracy and Disagreement*, Gutmann and Thompson argue for *a public* that is more fully engaged in the deliberative process. They point to what they call a "deliberative deficit" when this type of political activity is not fostered:

> If democratic citizens are to value political liberty not merely as a means of pursuing their self-interest or group interest, if they are to weigh the interests of others and to guide their actions by a sense of justice, then democratic societies must encourage the give-and-take of moral argument about the substance of controversial political issues, of which there are bound to be many. Forums for deliberation should abound. Citizens and their accountable representatives should continually confront their moral conflicts together, in collective efforts to find justifiable ways of resolving their political disagreements.[44]

Guttmann and Thompson have a more expansive understanding of the need for deliberation among the citizens of a nation. The type of deliberative democracy that they call for is an essential ingredient in fostering a public moral imagination. This type of deliberation cultivates conversations among citizens, but it also encourages a dialogue that is not self-centered, but focuses on what is good for society more broadly. As Guttmann and Thompson suggest, political and moral disagreements are unavoidable in a democracy, but the ways we attempt to resolve these disagreements are important.

An Expanded Definition of the Moral Imagination

[44] Amy Gutman and Dennis Thompson, *Democracy and Disagreement: Why Moral Conflict Cannot be Avoided in Politics, and What Should Be Done About It* (Cambridge, MA: Harvard University Press, 1996), 37.

So far we have considered the work of the medical humanists Carson and Piemonte who suggest that the moral imagination is best understood as a capacity of the moral agent to image what it might be like to be in a particularly difficult situation. Their formulations of the moral imagination sound a lot like empathy, which is a needed virtue for the clinical professional and the broader public in general, but I do not believe their constructions go far enough. Empathy is usually expressed toward those who are in distress of some type and we feel a need to rescue the person who is in distress. But how does the moral imagination guide us when we interact with persons who are not in distress, but with whom we morally disagree?

The moral imagination must also include the ideas that Edmond Burke posits about society more broadly and the inherent contract or partnerships that exists between citizens. This partnership is best understood as a deliberative partnership where citizens, along with their leaders, engage in honest, fair, reflective dialogue about the things that they will inevitably disagree about.

This way of thinking about moral and political disagreement and reflection about how we should attempt to resolve these disagreements, brings to mind the thoughts laid out by then Senator Barak Obama in his book *The Audacity of Hope: Thoughts on Reclaiming the American Dream.* In this project, Obama offers his readers a pleasant alternative to twenty-first century "politics as usual." He explores the ways in which the American people historically have had a collective moral imagination. Although Obama never uses the phrase moral imagination in the book, his thoughts about the American body politic are clearly consonant with the idea of a public moral imagination, that as a group of people, a polis, we have made an investment in one another, we have a stake in one another, there is such a thing as the common good, and within our body politic there are shared understandings that pull us together, rather than drive us apart.

In the United States we have a common set of values, one of which is an unquenchable hope, that remains alive in the hearts and minds of most Americans, and these values can inspire us to pride, duty, and sacrifice. Instead of focusing on and stirring the negative tensions within the body politic, Obama is calling his readers to authentic ways of seeing politics and therefore government. He pushes back against the contemporary ways of "winner take all" and "by any means necessary" politics, and ushers the American people toward a political dialogue that is not nasty and subverting, but a dialogue that acknowledges the others' right to have an opinion that is different, a dialogue that tries to understand how a person has arrived at a particular way of seeing the world.[45]

Obama, like Carson and Piemonte, use empathy as a starting point for what he calls his "moral code" (*AOH*, 66). This moral code is based on how he says he understands the "Golden Rule – not simply as a call to sympathy or charity, but as something more demanding, a call to stand in someone else's shoes and see through their eyes"[46] (*AOH*, 66). But Obama does not stop his explanation of what his moral code spurs him to do here. He goes on to discuss the demands of the moral code more fully, and this part of his discussion is consonant with what we have heard from the political theorists and philosopher above. Obama says that "I am obligated to try to see the world through George Bush's eyes, no matter how much I may disagree with him" (*AOH*, 66). A better understanding of our moral duty should "calls us all to task, the conservative and the liberal, the powerful and the powerless, the oppressed and the oppressor.

[45] Barak Obama, *The Audacity of Hope: Thoughts on Reclaiming the American Dream* (New York: Broadway Paperbacks , 2006), 146. All subsequent references to *The Audacity of Hope* in this chapter will be cited parenthetically in the text, with the abbreviation *AOH*, followed by the page number.

[46] Charity. Obama's use of the word *charity* here is more consistent with the way in which the word is used in American common vernacular.

We are all shaken out of our complacency. We are all forced beyond our limited vision" (*AOH*, 68).

Here we see the moral imagination at work. The moral imagination does include empathy, as well as many other essential virtues that are necessary to live a flourishing life, but the moral imagination goes beyond our usual ways of thinking about to whom to show empathy, who needs our empathy. The *moral imagination* is a sort of moral competence or moral disposition that can be cultivated and that leads to an expanded vision of whom the moral agent has a moral duty towards. It is a type of "moral excellence," or what Coles would call "moral intelligence," that the moral agent strives for, but has not yet attained.[47][48] The *moral imagination* leads us to consider what it might be like to be in the Other's shoes, whether or not that person is experiencing a particular type of distress. From the moral imagination flows the individual identifiable virtues: empathy, compassion, witnessing, courage, and love. In medical terms, these virtues are the signs and symptoms that the moral imagination is alive in the moral agent and these virtues ought to be cultivated.

Signs of a Cultivated Moral Imagination: The Essential Virtues

The list of virtues that I choose to focus on here is certainly not an exhaustive one, and a good argument could be made that this narrow list (empathy, compassion, courage, patience, and love) is far too short. I agree that there are other worthwhile virtues that could have been explored: wisdom, self-control, kindness, prudence, respect, conscience, tolerance, justice,

[47] Robert Coles, *The Moral Intelligence of Children: How to Raise a Moral Child (*New York: Plume Publishing, *1998),* 4.

[48] Andre, "The Medical Humanities," 53.

benevolence, or fortitude. There are several good reasons why I have chosen to delimit the list. Because this is a medical humanities dissertation and much of the work of the medical humanities is done in the classroom, I have chosen to focus on virtues that I believe can be, at least in part, cultivated in a didactic setting. Second, later in this chapter my goal is to associate these virtues with some moral heroes or exemplars of moral strength, so this list also serves as a prelude of things to come in this project. Third and practically, because a dissertation is not an eternal project, the list must be restricted. The list is not in any particular order of significance; however, I do approach the virtue of love last, because I believe that of all the virtues that one might discuss, love is most important.

Virtues are dispositions of character. Aristotle in *The Nicomachean Ethics* says that virtues are "settled dispositions of the mind determining the choice of actions and emotions."[49] Virtues are the mean between two extremes.[50] The moral agent is not born with these pleasant dispositions but they are formed by habit.[51] "Nature," according to Aristotle, "gives us the capacity to receive them, and this capacity is brought to maturity by habit."[52] The virtues are the life signs of the moral imagination.

Empathy

On April 9, 1967, Martin Luther King, Jr. preached a sermon at the New Covenant Baptist Church in Chicago entitled, "Three Dimensions of a Complete Life."[53] In this sermon

[49] Aristotle, *The Nicomachean Ethics*, 41.
[50] Ibid.
[51] Ibid., 33.
[52] Ibid.
[53] Martin King, *Letter from Birmingham Jail* (London: Penguin Books, 2018), 32.

King expounds on the Apostle John's biblical writings in the Book of the Revelation 21:16 that focuses on the new city of God; this city, according to John, is perfect. The dimensions of the new city are of equal length, breath, and height. King uses this imagery of the perfect city as the point on which to launch his sermon, using these dimensions as a three-fold formula for the perfect life. Like the perfect world that John describes in the Revelation, the perfect life or complete life is one that is three dimensional. This is a life that is complete on all sides.

The first dimension of life, length, is used to represent the inward concern for one's own welfare, the moral agent's personal goals and ambitions. This, according to King, is "rational and healthy self-interest."[54] It involves loving one's self, discovering what one is called to do, and seeing the dignity in all labor. But as King turns his attention to the second dimension of a complete life, the breadth of life, he points his hearers and us toward empathy. King cautions us not to get stuck focusing on the length of life, on the self, but to add to length of life breadth, "for a man has not begun to live until he can rise above the narrow confines of his own individual concerns to the broader concerns of all humanity."[55] Unfortunately, there are some people who consider life to be all about the self; about me, myself, and I. For these people life is lived completely with a focus on personal accomplishment and pleasure, and they use people only as mere means. Aristotle reminds us that there are friendships that share these characteristics.[56] Friendships that are really about utility, what the individual person can gain from the relationship. The breadth of life, however, for King moves the moral agent beyond self-concern to concern for the welfare of others.

[54] King, *Birmingham Jail*, 33.
[55] King, *Birmingham Jail*, 37.
[56] Friendships. Aristotle argues in the *Nicomachean Ethics* that these types of friendships, which he calls friendships of utility, are relationships that are about the benefits that one accrues from the other person. If that benefit is no longer available, the friendship dissolves.

Borba agrees that this *concern for others* is a crucial element in the development and expression of empathy. Borba, who is a child psychologist and offers parents advice on helping their children develop morally, calls empathy "the first essential virtue of moral intelligence."[57] She defines *empathy* as "the ability to understand and feel for another person's concern."[58] Empathy is critically important to "halt violent and cruel behavior," and it "urges us to treat others kindly."[59]

Empathy in medicine, according to physician and philosopher Reidar Pedersen, is "the appropriate understanding of the patient."[60] Relying on Hans-Georg Gadamer's hermeneutical perspective, Pedersen says that our appropriate understanding "always involves interpretation which is influenced by the subject's horizon, where the subject's 'prejudices' and 'situatedness' are important constituents."[61] Pederson reminds us that even in our best attempt, we cannot fully feel what the Other feels or walk in the Other's shoes.

I like Andre's definition of empathy best; it is short, but it captures the essence of what empathy is about. Andre says that *empathy* is "distress at the distress of others."[62] She goes on to say that this virtue can be detected in very young infants but "this infant response needs to grow."[63] The indispensable elements of time, experience, and formal and informal education are necessary for empathic growth. In chapter two I will describe in detail how the medical humanities can assist with the cultivation of virtues like empathy.

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[57] Borba, *Building Moral Intelligence*, 14.

[58] Ordering the Virtues. Although Borba argues that there are seven essential virtues, three of seven make up what she calls a "moral core." Empathy, conscience, and self-control form the foundation of the child's moral life. The other virtues are built on this foundation.

[59] Borba, *Building Moral Intelligence*, 14.

[60] Reidar Pedersen, "Empathy Development in Medical Education," *Medical Teacher 32, no. 7 (*2010): 594.

[61] Pedersen, "Empathy Development in Medical Education," 594.

[62] Andre, "The Medical Humanities," 48.

[63] Ibid.

Psychologist Paul Bloom defines *empathy* as "the act of coming to experience the world as you think someone else does," and he links this virtue as it is commonly conceptualized with the feelings and emotions of the empathizer.[64] In his book *Against Empathy: The Case for Rational Compassion,* Bloom suggests that the world would be a better place if empathy in the common way we understand it did not exist. Bloom, who is greatly influenced by the Eighteen century economist and philosopher Adam Smith, is against this common way of understanding empathy, but does allow for what he and his colleagues call *cognitive empathy,* which occurs when the moral agent thinks about or understands what the Other is experiencing.[65] This thought process does not involve feelings but will allow the moral agent in a utilitarian sense to consider the best mode of action and how to best proceed. Bloom in general argues against being directed by emotion and instead attempts to convince his reader of a more just and fair (a better) way of making moral decisions, that is, to act with rational compassion using deliberative reasoning. In a larger sense Bloom is arguing for the value of conscious deliberative reasoning in everyday life. Bloom suggests that reason, the act of justification and explanation in a way that is convincing to a neutral third party, can lead to moral insight.[66] While Bloom points out much of the psychological research that has been done to prove how irrational and unreasonable human beings are, he posits that our capacity for thoughtful reflection is still present and prevalent in the areas of our lives that matter most.

Although I cannot agree wholeheartedly with Bloom's take on empathy, there is a part of his argument that resonates with my larger project here. His call for thoughtful deliberative reasoning is consonant with the way in which I define the moral imagination above, and his

[64] Paul Bloom, *Against Empathy: The Case for Rational Compassion* (New York: HarperCollins Books, 2016), 16.
[65] Ibid., 17.
[66] Ibid., 51.

application of these ideas to the process of being empathetic in thought provoking. Despite my excitement about this part of Bloom's work there is the need for caution. Bloom's conception of empathy as best expressed as "a thinking process" and not "a feeling" is a reminder of the remnants of Cartesian dualism, and although Bloom attempts to argue that he is aware of the limitations of this way of seeing the world, I think his argument points to a proposed mind-body distinction.

When human beings experience distress in their lives these experiences involve more than their minds, they involve their emotions as well. When I hear that my close friend's mother has been diagnosed with cancer or my colleague's wife has died, I do process this information cognitively, but my human response does not stop there. In order for me to empathize with these individuals my feelings must be involved. I imagine what it must be like to be in that other person's place and this leads to an emotional response.

Empathy then is an indispensable virtue for health professionals to develop. Unfortunately, it has been suggested that there is a loss of empathy during the training of clinical professionals.[67] The acquisition of "biomedical knowledge and paradigms" has been implicated as the reason for this loss of empathy.[68] The work of the medical humanities has been suggested as a large part of the solution.[69]

Compassion

Martha Nussbaum in her book *Upheavals of Thought: The Intelligence of Emotions* says that *compassion* is "a painful emotion occasioned by the awareness of another person's

[67] Pedersen, "Empathy Development in Medical Education," 593.
[68] Ibid., 595.
[69] Piemonte, *Afflicted*, 126.

undeserved misfortune."[70] Nussbaum's definition of compassion is derived from Aristotle's use of the Greek word for *pity* (*eleos*) in *Rhetoric*.[71] In *Rhetoric* Aristotle defines *pity* as "a feeling of pain caused by the sight of some evil, destructive or painful, which befalls one who does not deserve it, and which we might expect to befall ourselves or some friend of ours, and moreover to befall us soon."[72] Nussbaum points out that there has been "more than the usual degree of verbal confusion in the English language concerning what to call the experience" she defines as compassion above.[73] She goes on to say that "the terms pity, sympathy, and empathy all appear in texts and in common usage, usually without clear distinction either from one another or from what I am calling compassion."[74] I prefer using compassion rather than pity because, as Nussbaum points out, "the term pity has recently come to have nuances of condescension and superiority to the sufferer that it did not have" earlier in history.[75]

Although Nussbaum is highly influenced by Aristotle and her thinking about compassion builds on Aristotle's work, Nussbaum's argument diverges from Aristotle's in one important way. For Aristotle showing compassion has three "cognitive requirements" of the onlooker.[76] First, there must be "an appraisal that the suffering is serious rather than trivial."[77] Second, there is also a belief that the person does not deserve the suffering.[78] Finally, the moral agent believes that there is a realistic possibility that his future could hold similar possibilities; this same misfortune could happen to them or someone they care for.[79] This third requirement is explained

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[70] Martha Nussbaum, *Upheavals of Thought: The Intelligence of Emotions* (Cambridge: Cambridge University Press, 2003), 301.
[71] Ibid., 306.
[72] Aristotle, *Rhetoric*, trans. W. Rhys Roberts (New York: Barnes & Noble Books, 2005), 291.
[73] Nussbaum, *Upheavals of Thought*, 301.
[74] Ibid.
[75] Ibid.
[76] Ibid., 306.
[77] Ibid.
[78] Ibid.
[79] Ibid.

by Aristotle: "we pity those who are like us in age, character, disposition, social standing, or birth; for in all these cases it appears more likely that the same misfortune may befall us also. Here too we have to remember the general principle that what we fear for ourselves excites our pity when it happens to others."[80] For Nussbaum, this last point will be a point of departure away from Aristotle's thinking and toward a broader way of thinking about compassion. Aristotle's focus on those who are similar to us narrows the sphere of our compassion too much for Nussbaum.

Instead of a focus on similarities between onlooker and sufferer, Nussbaum prefers to broaden the reach of compassion with a focus on what she calls the "eudaimonistic character of the emotions."[81] For Nussbaum, the *eudaimonistic judgement* is the idea that when I view the suffering of the Other, I become vulnerable to that suffering and understand that for the Other, the suffering affects her possibilities of human flourishing. This judgement invites the Other into the onlooker's circle of concern. How similar the Other is to me is not as important as is the recognition of how her current pain might affect her ability for future flourishing.

Compassion is also clearly distinguishable from empathy. Empathy, as noted above, is best defined as "distress at the distress of others," but the distress that is experienced by the onlooker by itself, does nothing to relieve the suffering of the person in distress.[82] This is why compassion is different. In addition to attempting to place oneself in the position of the one who is experiencing a particular trial or tribulation, the onlooker is moved with compassion, that is, they are inclined to do something about the distress of the sufferer. So, compassion is distress at the distress of the other that leads to beneficent action. Nussbaum agrees that compassion carries

[80] Aristotle, *Rhetoric,* 295.
[81] Nussbaum, *Upheavals of Thought,* 318.
[82] Andre, "The Medical Humanities," 55.

with it the need for subsequent action.[83] The motivation for action is the result of the pain the onlooker feels in response to the pain of the sufferer.[84]

I think the best example of this distinction between compassion and empathy can be seen in the familiar story of the Good Samaritan. This parable is recorded in the Bible in Luke 10:30-35. Although the story is a very familiar one, it is worth recounting it here in its entirety:

> A certain man went down from Jerusalem to Jericho and fell among thieves, which stripped him of his raiment, and wounded him, and departed, leaving him half dead. And by chance there came down a certain priest that way: and when he saw him, he passed by on the other side. And likewise, a Levite, when he was at the place, came and looked on him, and passed by on the other side. But a certain Samaritan, as he journeyed, came where he was: and when he saw him, he had *compassion* on him, and went to him, and bound up his wounds, pouring in oil and wine, and set him on his own beast, and brought him to an inn, and took care of him. And on the morrow when he departed, he took out two pence, and gave them to the host, and said unto him, Take care of him; and whatsoever thou spendest more, when I come again, I will repay thee.

The context of this parable is that Jesus, who tells the parable, is involved in a debate with a lawyer (an expert in Jewish law) and the central question of the debate concerns how to define the word *neighbor*. Indeed, the question that Jesus puts to the lawyer at the end of the parable is, "Which of these three, thinkest thou, was neighbor unto him that fell among the thieves?" The question of being a neighbor to the injured man in the parable was important to the Jewish people of Jesus' day, and it is important to us here because it offers us insight into the mind and emotions of the one who is moved with compassion. Again, compassion is essentially distinguished from empathy because of the action-oriented nature of the emotion. The one who feels compassion is moved to assist the sufferer with "beneficent action."[85] The moral agent that

[83] Nussbaum, *Upheavals of Thought*, 302.
[84] Ibid., 325.
[85] Ibid., 33.

is moved by compassion will do more than empathize with the sufferer, he will be moved to take action.

If I were teaching this parable I would point out to my students that this "certain man" is unnamed, suggesting that he could be any man, he could be any of us, man or woman. Any of us could find ourselves in a situation, through no fault of our own, in which we might need the compassion of another person, the compassion of a stranger. Another notable observation from the parable is the fact that the man travels down from Jerusalem to Jericho. It has been suggested that this fact, his origin and his destination, help us identify the likelihood that this man is Jewish himself. [86] This bit of information makes the response of the first two passersby, both Jewish leaders in the temple, even more interesting.

The first person to encounter the injured man was one of the priests, the highest ranking spiritual leaders in the temple. The priest sees the injured man but does not take time to find out if the man is alive or dead. Next the Levite, another temple official although of lower rank than the priests, encounters the wounded traveler. His response is similar to the priests, but at least he takes a closer look at the person who is injured. It might be argued that the Levite has empathy for the wounded man as exhibited by his attempt to see how bad the man was injured. But for whatever reason, neither of these first two passersby attend to the man's needs. The response of both of these religious leaders brings to mind the pain of the one who is in need of compassion. What types of things cause this pain? Aristotle says, among other things, "friendlessness" and "evil coming from a source from which good ought to have come."[87] This Jewish man would certainly expect that his fellow Jewish neighbors would help him in his time of need, but this was

[86] John Walvoord and Roy Zuck, *The Bible Knowledge Commentary* (Colorado Springs: Cook Publishing, 1983), 234.

[87] Aristotle, *Rhetoric*, 293

not the case. Instead, it was a Samaritan, the unlikeliest of heroes, who came to the man's rescue.[88]

Now there are reasons that have been offered in support of the religious leaders not offering assistance to the wounded man. Perhaps the priest and Levite thought the man was dead, and for both of these temple officials, handling dead bodies was forbidden; the experience would make them unable to perform their duties in the temple. Or, some have suggested, the priest and Levite were themselves fearful, not knowing if the bandits who wounded this man that had been left for dead, were still around.[89] Perhaps these two religious officials lacked the courage to help the wounded man.

The Samaritan, however, shows us the essence of compassion. He took the time to investigate the seriousness of the man's condition and he empathizes with the man.[90] And then the text says that "he had compassion" on the man: the Samaritan tended to the man's wounds, placed the man on his own beast, took him to an inn, and took care of him. The action that the Samaritan traveler takes costs him both time and treasure; this again is what distinguishes empathy from compassion. There is an associated cost, a sacrifice when we display compassion. In fact, when the Samaritan traveler has to leave the wounded man the next day in the care of the inn keeper, he puts a down payment on any further care that the man will need, and then promises to repay the host of the establishment for any further cost incurred.

There are those of course who argue that all of this discussion of virtue is nonsense. They would claim that human beings are too selfish and self-centered to genuinely care about the plight of others, and even when we perform acts of so called kindness and benevolence, these

[88] Warren Wiersbe, *The Wiersbe Bible Commentary* (Colorado Springs, CO: Cook Publishing, 2007), 171.
[89] Ibid.

acts are done selfishly. When we rescue the one who is suffering, we don't do it to help them, but we do it to ease our own conscience and to rid our minds of the thoughts of the other's pain.

Why does compassion need to be cultivated in clinical professionals? Students are graded on their performance and professionals are paid for their services. Shouldn't this be enough to compel students and professionals alike to be compassionate in the care of their patients? Unfortunately, there are some clinicians who have been motivated towards the helping professions for the wrong reasons. When I talk to students about why they have chosen these professions, it is common for them to speak altruistically about their desire to help the hurting. It is also very common for their list of motivations to include the robust job markets and high salaries that these professions offer. As a practicing clinician myself, it appears that some individuals have chosen these professions for the wrong reasons.

Secondly, we need to focus on compassion because as human beings we need to be reminded. We need to be reminded that our patients are people, that they have lives that they are living that are broader than diseases, diagnoses, treatments, prescriptions, and therapies. A focus on compassion can help both students and professionals go beyond what they are graded on or what they are paid to do. The absence of these rewards can easily turn into excuses not to take action. Compassion inspires us to go beyond even what we are rewarded to do.

Witnessing as a Moral Virtue

Witnessing requires "really hearing" the story of the other. Often we listen but we do not "really hear" because we are too busy. This is true in both our professional and personal lives. Psychologist Clark Moustakas hints at this problem in the opening lines of chapter four of his

book *Being-In, Being-For, Being-With*, when he says "communication is often inauthentic and manipulative. Daily I witness the failure of people to pause and allow silent moments to open space that invites thoughtfulness."[91] As human beings I don't think we mean to have counterfeit communication with those around us, but life is just so busy. We have good intentions and we want to communicate thoughtfully and respectfully, we want to give each individual our undivided attention, but the pressures of life crowd these earnest desires out before 10:00 a.m.

So I agree with sociologist Arthur Frank who suggests that "perhaps the simplest but most powerful, even threatening message" that medical humanists should communicate to clinical professionals is to "slow down."[92] Frank acknowledges all of the forces that cause clinicians to be in such a hurry and he summarized them as "institutional demands for productivity."[93] Yet he still insists that the advice to slow down is the right exhortation. Honestly, being a witness many times may not require any additional time at all.[94] It may just entail a new way of seeing our relationships with those around us.

Whether in a court of law, on the scene of an automobile accident, or even as Frank suggests, after (or during) an illness experience, a witness tells a story. This story is a testimony about the facts that the witness has first person knowledge of. The testimony about the illness experience "is valuable for a variety of purposes: for the teller's reordering of her life story, as guidance to others who will follow," and particularly for clinical professionals, "to provide caregivers with an understanding of what the ill experience."[95] While Frank believes that there is moral significance in this act of witnessing he also believes that the body of the storyteller becomes the

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[91] Clark Moustakas, *Being-In, Being-For, Being-With* (Northvale, NJ: Jason Aronson Inc., 1995), 61.

[92] Arthur W. Frank, "The Voices that Accompany Me," *The Journal of Medical Humanities* 41, (2020): 177.

[93] Ibid.

[94] Ibid.

[95] Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: The University of Chicago Press, 1995), 140.

proof that the testimony is authentic. Frank explains that "those of us that love to use stories of the ill to teach and to illustrate may *have* these stories, but only the ill person can *be* the story."[96] What is also significant for the clinical professional is Frank's postulation of "reciprocity of witnessing," what I refer to simply as witnessing above.[97] The storyteller has a moral responsibility to testify, to tell her story, but the hearer, according to Frank, has a moral responsibility to "receive that testimony."[98] For Frank "witnessing always implies relationship."[99] This relationship might be between two or more friends, between colleagues, between a husband and his wife, or the relationship could be between a patient and a clinical professional. My use of the word *witness* includes both the telling of the story by the ill person and the hearing of the story by the one who is in relationship with the ill person. So, the way in which I use the term witness in this project is slightly different from Frank's use of the term.

Frank's witnessing resonates well with Moustakas' advice on how to make relationships meaningful. For Moustakas the key elements of meaningful communication in relationships are "receptivity," "attunement," and what he calls "bodying forth."[100] *Receptivity,* according the Moustakas, means "to be present, to be open, to listen with love, and to hear and receive whatever manifests itself, whatever appears in the consciousness of the other, to let what is be and in its being disclose its nature."[101] Receptivity also involves allowing "the other person [to] tell a story in his or her own way, in its own process and unfolding."[102] Being receptive does not involve being judgmental about the information that is received, offering a critique, or an

[96] Ibid., 141.
[97] Ibid., 143.
[98] Ibid.
[99] Ibid.
[100] Moustakas, *Being-In, Being-For, Being-With*, 79.
[101] Ibid.
[102] Ibid.

analysis.[103] The receptive listener simply receives information and remains "fully present in being."[104]

Attunement is a further move towards synchrony or oneness with the speaker. In *attunement* the moral agent takes into account the other person's emotions, physical space, and experience. The moral agent is attuned to the other's "moods, situation, conditions, and ways."[105] The moral agent "experiences the worry, guilt, fear, anger, hurt, loneliness, boredom, and emptiness in such a way that this other person feels my presence, knows the impact of my face, posture, and being."[106]

Bodying forth, Moustakas says, "is an advanced presence, an ahead-of-itself, that creates rhythms to support and encourage life and relations with others."[107] The moral agent projects herself into the future to anticipate the movements and needs of the other. The goal of *bodying forth* is to create a safe environment for communication and the relationship to flourish. These three dispositions of communication, receptivity, attunement, and bodying forth, are further enabled by the next three ways of Being that Moustakas discusses.

Being-in, Being-For, and Being-with are the three processes that "contribute to the development of relationships and enable receptivity, attunement, and bodying forth."[108] *Being-in* requires the moral agent to "totally focus on the other, her thoughts, and feelings; every scene or portrait, seeing it exactly as it is depicted."[109] The moral agent does not "select, interpret, advise,

[103] Ibid.
[104] Ibid., 80.
[105] Moustakas, *Being-In, Being-For, Being-With*, 80. The moral agent attempts to experience the emotion of the other: worry, guilt, fear, anger, hurt, loneliness, boredom, emptiness. The point is for the other person to feel the presence of the moral agent.
[106] Ibid.
[107] Ibid.
[108] Ibid.
[109] Ibid., 82.

or direct."[110] At this point Frank's witnessing diverges slightly from Moustakas' argument. It is Frank's contention, and I agree, that as human beings we are "constitutionally unable to just listen. When we hear something, we irresistibly start thinking about it, interpreting it, evaluating it"[111] It is important, I suggest, to understand this limitation on being a "pure witness" of the other's story so that we might attempt to retard the interpretive process.

Being-For, the second element of facilitating a relationship, is a position of advocacy. As the moral agent I take a stand for the other. Together we stand "against all others who would minimize, deprecate, or deny this person's right to be and grow."[112] As a moral agent "I directly and actively promote activities and events that will benefit the other by providing opportunities, resources, and plans aimed at positive resolution of problems, in the direction of the person's own interests, preferences, and predispositions."[113]

Being-with also contributes to the development of relationships, but is distinguishable from *Being-In* and *Being-For*. *Being-With* goes further than the previous two elements and takes into consideration that "I am always present as an individual self, with my own knowledge and experiences. What another person communicates enters into my own awareness and perception and through a process of indwelling, leads me to form my own understandings, beliefs, and judgments."[114] Frank uses the term *being with* in his work as well, but his use of the term is different in a significant way from the way in which Moustakas uses it.[115] *Being-with* for Frank stops short of considering the listeners point of view. For Moustakas this is a key consideration and may even lead to disagreements in relationships. *Being with* for Moustakas involves

[110] Ibid.
[111] Frank, "The Voices that Accompany Me," 174.
[112] Moustakas, *Being-In, Being-For, Being-With*, 83.
[113] Ibid., 84.
[114] Ibid.
[115] Frank, "The Voices that Accompany Me," 174.

"listening and hearing the other's feelings, thoughts, and objectives, but it also means offering my own perceptions and views."[116] The listener should be careful not to rush to this aspect of the communication, but this facet of relationships should not be excluded. I appreciate this part of Moustakas' argument because this seems to be the way authentic relationships work. It is quite conceivable that "two persons, though fully committed and participating in a fundamental relationship, may at any point be on separate paths of understanding, in terms of what is essential to move life forward."[117] As their conversation continues "they remain with each other, listening, respecting, and differing in their views and feelings," but they still have a singular goal, the health of the relationship.[118] In the process, hopefully, "a new vision emerges of what is essential, and both persons shift in some ways their perception and judgment."[119] Even when this ideal cannot be accomplished, both parties remain respectful of the other person's position and open to further deliberation.

For the clinical professional witnessing is a reminder to engage in authentic communication with patients, colleagues, and even with friends and family members. It is a reminder to slow down, not to take more time, but to use the time that we have more authentically, more thoughtfully. And when it is necessary, we must be willing to spend more time than is convenient in order to really hear what the other says.

[116] Moustakas, *Being-In, Being-For, Being-With*, 84.
[117] Ibid.
[118] Ibid., 85.
[119] Ibid.

Courage

The following illustration is one example of when clinical professionals must display courage:

> It takes courage to continue to do this work. This house stinks. Mr. Smith has chronic obstructive pulmonary disease and because of his disease process, the low level of oxygen in his blood, and his difficulty breathing when he moves around, it is hard for him to perform his routine personal care. It is difficult for him to bathe regularly, to shave and brush his teeth, and to attempt to clean his home. Despite being on oxygen, after a routine trip to the bathroom, he is out of breath. The kitchen is a mess. There are dirty dishes everywhere, dishes that have been here for weeks, with old food on them. I can't even see the countertop. And the worst part of it, in every one of these houses, are the animals. Mr. Smith only has two dogs, but I've been in houses where the patient had four dogs, some big dogs, and three cats, and because of the health condition of the patient, there is no way the patient can care for these animals. The animals have not been bathed either, and sometimes, in the most dire circumstances, there is animal refuse to step over. The house stinks and I need courage to continue to come here and care for this patient.

In addition to examples like the one above, students need courage to gain clinical experience and complete their licensure exams. Surgeons need courage to attempt surgeries that carry with them higher than normal risk. Nurses need courage to perform wound care for patients that have unspeakably horrible wounds.

Courage is the necessary virtue that enables the clinical professional to display the other virtues that I have discussed above. In order to show empathy, compassion, or to be a witness, clinicians must have courage. Aristotle postulated that "courage is the observance of the mean between respect of fear and confidence."[120] This of course is Aristotle's common formula for all of the virtues; they are means between two extremes. The definition helps us first understand what courage is not. Courage is not the absence of fear. In fact, Aristotle says later that the

[120] Aristotle, *Nicomachean Ethics*, 65.

person "who exceeds in fearlessness," or "who exceeds in confidence," is either "mad" or "rash."[121] These extremes for Aristotle are not normal psychological states. Fear, we are assured, is a normal human emotion. Courage, therefore, is acting in spite of fear, and not in the absence of fear.

Another aspect of courage in Aristotle's formulation is what Aristotle might call "true courage" or "greater courage."[122] This is evident when the moral agent has to face "sudden alarms."[123] As Aristotle says, "bravery in unforeseen danger springs more from character, as there is less time for preparation; one might resolve to face a danger one can foresee, from calculation and on principle, but only a fixed disposition of courage will enable one to face sudden peril."[124]

In *After Virtue* philosopher Alasdair MacIntyre defines courage as "the capacity to risk harm or danger to oneself."[125] Courage is a virtue, according MacIntyre, because of its connection to care and concern. Our willingness to risk harm for individuals, our community, or a particular cause demonstrates how genuine our care is for those entities. The moral agent might profess her care or concern for someone or something, but unless she is willing to risk harm or put herself in danger for that person or thing, her avowed level of care is suspect.[126] MacIntyre's point is important for clinical professionals because our business is foundationally to care for and show concern for our patients. As mentioned above, sometimes threats of fear may arise from the patient's home environment, but at other times fearful situations may develop with another member of the interprofessional team or they can arise from institutional forces.

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[121] Ibid., 67.
[122] Ibid., 70.
[123] Ibid.
[124] Ibid., 71.
[125] Alasdair MacIntyre, *After Virtue* 2nd Edition (Notre Dame: University of Notre Dame Press, 1984), 192.
[126] MacIntyre, *After Virtue*, 192.

Sometimes the patient himself may present challenges that require courage. In his article, "Taking Care of the Hateful Patient," physician James E. Groves admits that there are some patients that kindle "aversion, fear, despair, or even downright malice.[127] Physician Michael Hawking and his colleagues suggest that "caring for difficult patients is an inescapable part" of the work of clinicians.[128] While physicians may have the option of transferring these difficult patients to other colleagues, most clinicians do not have this option.[129] Ultimately Hawkins suggests that these patients must be treated with courage and compassion, and that these virtues should be cultivated in medical training. These "habits of character" say the authors, can equip clinicians to act in ways that facilitate their patient's healing, even when the patient's behavior makes the clinician's task more difficult.[130]

Love

I saved love for last because love is the most important virtue to discuss. I base this claim chiefly on my own experience and from statements from the Apostle Paul in the Scriptures, statements like "Charity never faileth" and "And now abideth faith, hope, charity, these three; but the greatest of these is charity." These two statements about love (charity) are both found in I Corinthians chapter thirteen, the Apostle's great treatise on love. Even people who do not read the Bible regularly are familiar with at least a portion of this discourse. The

[127] James E. Groves, "Taking Care of the Hateful Patient," *The New England Journal of Medicine* 298, no. 16 (April 1978): 883.

[128] Michael Hawking, "Courage and Compassion: Virtues in Caring for the So-Called 'Difficult' Patients," *Medical Education* 19, no. 4 (April 2017): 359.

[129] Groves, "Taking Care of the Hateful Patient," 884.

[130] Ibid.

Greek word translated here as charity is the word agape.[131] I will say quite a bit about this type of love later, but for now, I will simply say that *agape* is the type of love that God has for the world he created and that Christians ought to have for others.

Early on I must admit that this sounds like a strange exhortation, telling clinical professionals that they should love their patients. Clinicians are trained to deliver competent care to their patients, and I understand that many would argue that this should be enough. An expectation of love as the normative disposition seems, even to me, at first glance, a stretch. But perhaps a better understanding of what is meant when the word love is used will shed light on what I am actually calling for here.

In the English language we are somewhat confused by the use of the word love because we may use the term, the same word, but mean very different things when using it. In fact, the term may be used without truly having a particular meaning in mind. Clive Staples Lewis's project, "The Four Loves," is helpful as a guide to a better understanding of how we might use this term with clarity. C. S. Lewis writes from an unabashedly Christian perspective, and while this can be a stumbling block for some, the book's practicality will be a reward for those who read the book in spite of their reservations.

Lewis's basic thesis is that "God is Love" therefore love is a person. Lewis, a lay theologian, explains that the Greeks had four words that they used to covey the meanings that we attempt to convey when we use the word love. He also posits several times in the narrative that there are many instances in which there is a necessary overlapping of the four loves. Lewis begins his explication of love with the Greek word *storge*, which means affection. This love is

[131] James Strong, *Strong's Exhaustive Concordance of the Bible* (Peabody, MA: Hendrickson Publishers, 2007), 181.

an affection felt especially for parents or for the children of parents.[132] Lewis describes it as the least discriminating of the loves (*TFL*, 47). Affection is the kind of love that one does not have to necessarily do anything to earn. Affection, says Lewis, makes appreciation of individuals possible and therefore leads to "the broadening of our taste for humanity" (*TFL*, 48). So, while this love is typical of those familial relationships at home, it can be shared as well with others whom we find ourselves in close proximity to, those in "the college, the ship, or the religious house." (*TFL*, 48). Affection has the added value of being able to "enter into the other loves" adding color to them and becoming "the very medium in which from day to day they operate" (*TFL*, 49). It is easy to see how the love of eros, being in love with the other, can benefit from this aspect of affection.

The next type of love on Lewis's list is friendship, translated from the Greek word *philia.* Lewis points out that most people in the modern world do not consider friendship a type of love, but "to the Ancients, friendship was the happiest and most fully human of all loves" (*TFL*, 73). Lewis describes it as the least natural of all loves and the least necessary, and he posits that "few moderns value it because few experience it" (*TFL*, 74). This assessment by Lewis sounds harsh, but Aristotle in *The Nicomachean Ethics* agrees with Lewis. Aristotle devotes two books, books eight and nine, to the subject of friendship. This fact alone is noteworthy; no other topic in Aristotle's *Ethics* is afforded this much attention. His approach though is slightly different from Lewis's, and instead of purporting that many people do not have friends, he chooses to talk about different types of friendships.

[132] C. S. Lewis, *The Four Loves* (New York: HarperCollings Books, 1960), 41. All subsequent references to The Four Loves in this chapter will be cited parenthetically in the text, with the abbreviation *TFL*, followed by the page number.

Aristotle defines friendship as "mutual goodwill" and he suggests that there are three kinds of friendships.[133] There are friendships "of utility."[134] These are friends that "do not love each other in themselves" but the friendship is based on the benefits that accrue to each individual from the relationship.[135] This use of the word friendship would be too careless for Lewis, and he would prefer to call this arrangement by some other name. Aristotle also talks about friendships based on pleasure; these are people who are fun to be around and that make us feel good while we are in their company.[136] The problem with these so called types of friendships, friendships of utility and of pleasure, is that they only last as long as the benefit lasts. But "perfect friendship," according to Aristotle, is that type of friendship that occurs between two people who are "good in themselves" and they each ""wish the good of their friends for their friends' sake.[137] These friends are friends in the "fullest sense."[138]

It does not seem inappropriate to me for clinical professionals to think of their relationships with their patients as friendships in the "fullest sense." Although these are professional relationships there is still space for both the patient and the clinician to "wish the good" of the other. If I am a patient it seems permissible for me to want to see my clinician flourish in every way possible. And as a clinician, it also makes sense for me to want my patient to prosper not only in the professional-patient relationship, but in every aspect of her life.

Eros love or "being in love" with someone is the third type of love that Lewis discusses (*TFL,* 117). Commonly in many circles when people think of e*ros,* they think of sexual

[133] Ibid., 207.
[134] Ibid.
[135] Ibid.
[136] Ibid.
[137] Ibid., 208.
[138] Ibid.

relationships or love that is distinguished by its sexual nature. While this type of love is clearly off limits for the clinician-patient relationship, Lewis's explication of the depth and motivation of eros love may still be helpful even for this project. Eros, according to Lewis, "makes a man desire a woman, but one particular woman. In some mysterious but quite indisputable fashion the lover desires the Beloved herself, not the pleasure she can give" (*TFL*, 121). Lewis's conception of eros love is one that separates sexual gratification from the love that the lover feels for her beloved. Eros, for Lewis, is deeper and wider than sexual gratification and he goes to great lengths in this section of the project to make this distinction. I suggest that what is of value about this type of love for the clinician-patient relationship is the focus on the particular person. It is important for both clinicians and patients to see beyond their particular needs and to engage authentically with the other particular person in the therapeutic relationship.

In his article entitled "The Role of Prudent Love in the Practice of Clinical Medicine," James Marcum makes a similar claim about the importance of love and the therapeutic relationship. Marcum posits a novel "compound virtue" that he calls *prudent-love* and suggests that these two virtues are separately essential for clinical practice, but he says that they are also "synergistic."[139] This synergism leads to a greater benefit for the therapeutic relationship than either virtue would yield alone. Prudent-love allows the relationship to be both "therapeutic for patients and fulfilling for clinicians."[140]

While eros for Lewis does not focus exclusively on the sexual nature of that type of love, Walt Whitman's conception of eros is primarily of a sexual nature. In several of Whitman's poems in his collection, *Leaves of Grass*, Whitman shares his ideas about the democracy of the

[139] James A. Marcum, "The Role of Prudent Love in the Practice of Clinical Medicine," *Journal of Evaluation in Clinical Practice* 17, no. 5 (October 2011): 879.

[140] Marcum, "The Role of Prudent Love in the Practice of Clinical Medicine, 880.

United States, and Whitman's new democratic vision is a vision of love, erotic love.[141] The new conception of democratic love as eros, according to Whitman, must include a new attitude toward the physical "body and its sexuality."[142] Writing around the time of the American Civil War, Whitman's poetry focuses on, among other things, the overthrow of slavery, love for the preserved union, and racial and gender discrimination.[143] Whitman sets out to create a "democratic counter-cosmos" which he refers to as "the greatest poem."[144] Whitman contrasts this new cosmology with the old philosophical and religious ways of understanding the American democracy in his socio-political context. In the new cosmos the body is the basis for human equality because of the similarity of the human body in all nations and at all times over all the earth.[145] Therefore all human bodies are equally worthy of respect. In addition, all bodies are "equally needy and finite and mortal," and also "equally noble and beautiful."[146] It is irrational then to "treat some bodies with dignity and others as mere meat."[147] Not only are the general bodies dignified, but dignity is also ascribed to the sexual organs of both men and women in Whitman's poetry.[148] Misogyny is the result of "our misplaced disgust with our sexual organs and acts," and the need to blame someone, women, for those acts.[149] Erotic love is the essential love because it is used to "reach into the inside of a thing beneath its perceived surface, an insertion of oneself into the thing to explore its hidden recesses."[150] Eros love allows

[141] Nussbaum, *Upheavals of Thought*, 645.
[142] Ibid., 646.
[143] Ibid., 647.
[144] Ibid., 656.
[145] Ibid., 661.
[146] Ibid., 662.
[147] Ibid.
[148] Ibid.
[149] Ibid.
[150] Ibid., 665.

the lover to reach beyond the superficial stereotyped notions of who the other is, and to explore more deeply the value of each individual.

The final love that Lewis explores is charity, *agape* in the Greek. Truly the best has been saved for last. Most often when people use the word love, this is not what they mean. Charity is a "Divine-Gift love" that Lewis contrasts with the natural loves, affection, friendship, and being in love (*TFL,* 149). Charity, as Lewis defines it, is a gift love that "seeks simply the good of the loved object for the object's own sake" (*TFL*, 164). Our natural loves are always directed toward persons that we in some way find "intrinsically lovable" (*TFL,* 164). But charity "enables the lover to love what is not naturally lovable: lepers, criminals, enemies, morons, the sulky, the superior, and the sneering" (*TFL,* 164).

In the Church, charity is what makes some congregations "fishers of men" while others are simply "keepers of the aquarium." In an aquarium the owner-keeper chooses the type and number of fish she wants based on their several characteristics. But fisherman throw out their nets or fishing lines and they reel in whatever fish happens to bite on a given day. The Church is then called to love these different people with their problems and issues despite the fact that they bring both good and bad characteristics to the Church. Charity loves the object of its love not because of the faults of the one loved, but in spite of those faults.

Very near the end of Senator Barak Obama's book, *The Audacity of Hope*, he exclaims "My heart is filled with love for this country" (*AOH,* 362). There will be no doubt for the close reader of Obama's book that the love that he is talking about in reference to America is charity. It requires charity to love America; not *eros*, not *storge*, not *philia*, but *agape*. Certainly, America has many past and present faults. These types of faults however are not unique to

America. Lewis alludes to this fact when he talks about the kinds of histories countries tell about themselves:

> The actual history of every country is full of shabby and even shameful doings. The heroic stories, if taken to be typical, give a false impression of it and are often themselves open to serious historical criticism. Hence patriotism based on our glorious past is fair game for the debunker. As knowledge increases it may snap and be converted into disillusioned cynicism, or may be maintained by a voluntary shutting of the eyes (*TFL*, 32).

Obama's love for America has to be charity, because he is fully aware of the country's past, but he is still filled with audacious hope. He does not tell a story of America and her politics that ignores the serious and sinful faults of her past and present, but he chooses to point his reader toward our common moral imagination. Obama focuses on the fact that as a group of people, a polis, we have made an investment in one another. As an American body politic, according to Obama, we have a stake in one another, there is such a thing as a common good, and there are among us shared understandings that pull us together, rather than drive us apart.

For the clinical professional then, charity has to be the love that I call for here. Charity, again according to the Apostle, "beareth all things, believeth all things, hopes all things, endureth all things. When all of the aforementioned virtues are stretched thin and tested beyond imagination, charity will extend grace. Even when the clinician has to deal with the "hateful patient" or the difficulty family, the unreasonable institutional constraints, or the problematic colleague, charity is present and will extend grace.

The virtues that I have explored above are the essential components of the moral imagination. They are the spokes in a wheel that begin to turn in childhood, but they must be maintained and strengthened throughout our lives. In chapter two I will discuss in detail how the

moral imagination can be developed and cultivated and, particularly, how the medical humanities should take part in this project.

Chapter 2

Cultivating the Moral Imagination

The function of education, therefore, is to teach one to think intensively and to think critically . . . intelligence plus character, that is the goal of true education.

The Maroon Tiger, 1947

Martin Luther King Jr.

"Can you tell me, Socrates, whether virtue is something teachable? Or is it not teachable, but something that comes from practice? Or is it something neither from practice nor from learning, but something that comes to human beings by nature, or some other way?"

Plato's Meno

What makes a good person? This is a question that is asked by child psychiatrist Robert Coles in the first chapter of his book *The Moral Intelligence of Children.* For Coles, the answer to this question is pretty straightforward. The adults in a child's life (parents and teachers primarily) give shape to the virtues of children, and these virtues are expressed in a child's behavior. In the project mentioned above Coles is focused on how character develops in children from the earliest months of life through adolescence, and how children become either "good persons," "not so good persons," or "bad persons."[151]

Coles, whose investigational method brings him in close proximity to children, their parents and teachers, recounts a discussion that he had on this topic of "what makes a good person" with a group of classroom teachers. Coles writes about a portion of the conversation:

[151] Robert Coles, *The Moral Intelligence of Children* (New York: Penguin Books,1998), 3. All subsequent references to The Moral Intelligence of Children in this chapter will be cited parenthetically in the text, with the abbreviation *MIC*, followed by the page number.

> There are the good of heart: a teacher observed, and she continued, "there are also the ones with hearts of stone." A group of classroom teachers and I were chilled by the latter thought, of the child who develops into a not very good person. And of course, we wondered together what might be done in the classroom (or at home) to make for more good-hearted souls and fewer stony-hearted ones. I had no magic wand to wave, nor did any of them. They asked me what I do (or would do) in the face of some of the dilemmas or troubled moments they described to me – that is, how to make the Golden Rule, the matter of empathy, so crucial to any discussion of morality and of being a "good person," come alive for students in such a way that their lives (their behavior), and not only their minds (their thoughts), are affected (*MIC*, 10).

After some deliberation about this question, Coles reads Leo Tolstoy's story to the group, "The Old Grandfather and the Grandson."

> The grandfather had become very old. His legs wouldn't go, his eyes didn't see, his ears didn't hear, he had no teeth. And when he ate, the food dripped from his mouth.
>
> The son and daughter-in-law stopped setting a place for him at the table and gave him supper in back of the stove. Once they brought dinner down to him in a cup. The old man wanted to move the cup and dropped and broke it. The daughter-in-law began to grumble at the old man for spoiling everything in the house and breaking the cups and said that she would now give him dinner in a dishpan. The old man only sighed and said nothing.
>
> Once the husband and wife were staying at home and watching their small son playing on the floor with some wooden planks: he was building something. The father asked: "What is that you are doing, Misha?" And Misha said: "Dear Father, I am making a dishpan. So that when you and dear Mother become old, you may be fed from this dishpan."
>
> The husband and wife looked at one another and began to weep. They became ashamed of so offending the old man, and from then on seated him at the table and waited on him.

In Tolstoy's story Misha's parents are ashamed, and rightfully so. To their credit, they are also repentant. Like many parents and teachers these adults failed to realize just how much they teach their children (or their students) morally without the use of words. For Coles this is the most important and powerful way that parents and teachers teach moral lessons; they teach by their example. Even before the child is born, parents, both mother and father, make decisions, decisions to eat healthier, not to smoke and not to

drink alcohol excessively, and these decisions will affect the unborn child. This moral action continues throughout the life of the child. The day-in-day-out, minute-by-minute, unconscious examples that adults show children. In this way adults make children witnesses to their own moral behavior; children learn how to be with others in large part by observation, and these experiences help to shape the child's moral imagination (*MIC*, 5). Unfortunately, it is easy for parents and teachers to forget "that prior to a particular time or crisis or concern we have all along been making certain moral points to our children, sending them messages directly or by implication: in their sum, our notion of how one ought to behave under a variety of circumstances. Much of all that – the day-by-day encounters with children, during which we say yes or no, smile or frown, advocate one or another line of thought, course of action – is done quite naturally, by 'instinct,' that is, with no great amount of deliberative energy expended" (*MIC*, 170).

With the use of Tolstoy's story Coles also points us toward the importance of the use of literature in the shaping of the moral agent's imagination. But stories do not have to be of this well-crafted variety to be useful for moral teaching. All sorts of narratives can be used for moral purposes, and the autobiographical stories of parents and teachers can be employed with great utility. Other types of stories, like those written by ill persons or persons that have recovered from illnesses, I believe are of particular usefulness, especially for clinicians, in cultivating the moral imagination. The explicit use of these types of narratives to develop the moral imagination will be my focus in chapter three of this project.

"The Old Grandfather and the Grandson" also points the reader toward two of the cornerstones of any discussion of virtues and the moral imagination: empathy and the

Golden Rule. It is easy for us to villainize the son and daughter-in-law in this story and to perhaps miss the larger point, the point at which the reader might also be implicated for his own moral callousness, or at least reminded of the necessity of placing herself in the position of the other. This is the work of the moral imagination.

In chapter one I defined the moral imagination as a type of moral competence, moral excellence, or a moral disposition that can be cultivated and that leads to an expanded vision of who the moral agent has a moral duty towards. The moral imagination leads us to consider what it might be like to be in the other's shoes, whether or not that person is experiencing a particular type of distress. From the moral imagination flows the individual identifiable virtues: empathy, compassion, patience, courage, and love. The demonstration of these virtues are the signs and symptoms of the moral imagination. This concept of the moral imagination has far reaching implications in the clinic, the classroom, and the polis.

In this chapter I need to answer two important questions. First, if the moral imagination is as important as I claim, how do we help it grow; how do we cultivate it? The second question for this chapter is a related one. If the moral imagination is being cultivated and is growing, how do we know? Stated a slightly different way: how can we assess the growth of the moral imagination? The moral imagination exists on a continuum and each moral agent is on a personal journey towards moral perfection, a journey that never ends. For those who take moral development and moral behavior seriously, there is an earnest striving toward perfection, a perfection that the moral agent never reaches.

I will begin this chapter with a discussion of the ways in which the moral imagination can be cultivated. Parents and teachers are key moral exemplars for their children, but other exemplars, some who are known personally and others who are not, are also critical guideposts

for moral development. Medical humanists with their focus on the moral development of medical students and other clinicians will be an important part of this discussion. Next, I will address the ways in which the growth of the moral imagination can be assessed. This process of moral growth begins very early in life and undoubtedly there are periods in our lives when we seem stagnant morally, even seem to regress. Moral development though, if taken seriously, can continue throughout out one's lifetime.

The Quality of a Lived Life

The question that is asked of Socrates by Meno in the Platonic dialogue is a good place to begin: "Can you tell me, Socrates, whether virtue is something teachable? Or is it not teachable, but something that comes from practice? Or is it something neither from practice nor from learning, but something that comes to human beings by nature, or some other way?"[152] Unfortunately, we never get a solid answer to these question that Meno raises from Socrates in this dialogue. But this is still the appropriate place to start. This very old question gives us a panoramic view of our task. There are indeed some thinkers like Robert Coles, who suggest that virtue, morality, is teachable. Others, like Aristotle, would be inclined to agree with Coles, but would suggest that virtues are solidified by habit or practice. And most intriguing, there are thinkers like Lawrence Kohlberg, who believe that nature instills within each of us, dimly, a sense of morality, and this dim light is brightened through experience and the right type of guidance.

[152] Plato, *Meno*, trans. George Anastaplo and Laurence Berns (Newburyport, MA: Focus Publishing, 2004), 1.

Morality, according to philosophers Louis Pojman and James Fieser, "makes reference to write/wrong/permissible behavior with regard to basic values."[153] Morality is related to law in some important ways, but in the final analysis, morality is a much higher standard of right and wrong than is the law. Morality can be closely tied to religion and most organized religions teach moral lessons, but morality need not be understood through the lens of religion. Morality, again according to Pojman, is "grounded in reason and human experience."[154]

For Coles morality is not something that should be demonstrated in one's personal life only, but it should define who a person is both at work and in leisure, with one's colleagues and with one's family. In his article, "Medical Ethics and Living a Life," Coles is bothered by this question of the range or breadth of our moral experience. He attempts to answer an age old question: "How does one live a decent and honorable life, and is it right to separate a person's 'private life' from his or her working life?"[155] Coles highlights the importance of connecting the kind of life one wants to live as a professional with the lived experience of one's every day existence. He challenges his reader to avoid dichotomizing one's life into separate compartments and to realize that these two aspects of one's life, the professional and the private, *should be* consistently lived, from a moral point of view. Coles is pushing us toward an understanding of morality in everyday life, all of life. He wants his readers to know that "a person's work is part of a person's life, and the two combined as *lifework* must be seen as constantly responsive to the moral decisions that we never stop making, day in and day out."[156] It is in our everyday experiences and through our everyday choices, moral choices, that we will

[153] Louis P. Pojman, and James Fieser, *Ethical Theory: Classical and Contemporary Readings* (Boston: Wadsworth, 2011), 2.

[154] Pojman, *Ethical Theory*, 3.

[155] Robert Coles, "Medical Ethics and Living a Life," *New England Journal of Medicine* 301, no. 8 (1979): 444.

[156] Ibid., 445.

create a life for ourselves that we can or cannot live with. Our moral choices can gradually, almost unnoticeably, lead us either toward the person we want to become or toward a person that is unrecognizable. Coles is writing to adults. Clinicians, and physicians most particularly, are the audience for Coles' article, those that either have completed their graduate medical training, and perhaps those that are still in training. But where does one begin to learn how to make these daily decisions, decisions that are so critical to the kind of person one will become?

In another of Coles' writings, his book *Lives of Moral Leadership*, he gives us a clue as to when and how moral training begins. Coles takes us back to the period in his own life when he was challenged to remember the people who had made a difference for him morally. He was twenty-eight years old and had recently been drafted into the United States military. As a new officer, a captain in the Air Force, Coles was being asked, along with other new officers, this question by an older officer: "Who have been the leaders in your life – the people you really respected, the folks who stood for something?"[157] This older officer, a colonel, a surgeon in the Air Force, was challenging Coles and his peers to think of specific examples of people who had inspired them morally. The older officer's overarching point to the young officers that day was that they were now leaders, moral leaders, and they should keep this in mind constantly. So, he continued to challenge the group to "Think of an example, an instance" (*LML*, 166). Finally, after much deliberation, a response came from one of Coles' peers in the group. Coles tells us the story as recounted by the young officer:

> He had gone with his mother to the library in the Tennessee town where they lived so comfortably, only to become a witness to a brief but tense incident. His mother was holding his hand, preparing to take him into the children's room of the library, when she abruptly stopped in her tracks, and tightened her grip on

[157] Robert Coles, *Lives of Moral Leadership: Men and Women Who Have Made a Difference* (New York: Random House, 2000), 166. All subsequent references to *Lives of Moral Leadership* in this chapter will be cited parenthetically in the text, with the abbreviation *LML*, followed by the page number.

> him. She listened as the librarian was telling a dark-skinned mother, also there with her son, that there was no admission for them that day of the week. His mother had intervened, objected to the librarian's refusal of this mother and son who suddenly had become, by virtue of their skin, unwelcome inhabitants from a foreign land, even though they lived in the same town, and occupied the servants quarters in one of its estates. The result was a dramatic step taken: "My mom asked the colored lady if she could go get some books for her, and take them out on her card. She asked the colored lady if she'd trust us to be of help, and she squeezed my hand, as if she was reminding me that I was part of the 'us' she'd just mentioned (*LML*, 174).

The story that Coles shares with us demonstrates how a parent, a mother, was a moral example for her young son. Distressed by the treatment of another person, another mother who also had her son with her, this moral agent, at the crossroads of an opportunity to do good, made her son a witness to her actions. This young officer's mother's moral imagination was indeed at work as she considered what it must be like to be this other mother, a mother who was trying like she was, to obtain books for her child, but was denied unfairly. This experience obviously made an impression on the young officer who was at the time a child, because years later he is able to recount the story as "an example, an instance" of moral leadership. Later in the same chapter Coles tell us plainly that the older officer, the colonel, knew all along that "home is where we first get 'hit' morally, first learn from others about the much approved and the outright renounced" (*LML*, 174). Coles would say that we first begin to learn morals at home and our parents are our first teachers.

Parents and Teachers

In the fall of 2019, I began to teach my three sixteen-year-old adolescents to drive a car. My wife and I decided rather than send the kids to a driving school, for the home driving school

option. In Texas this means that all of the instruction for the driver's license is online and the driving hours behind the wheel are supervised by the child's parent or guardian. Teaching my children to drive is exciting and stressful, but also challenging in a way that I had not anticipated. The home driving course contains six hours of online classes that the students have to complete before they can get their driving permits. Once the permits are in hand the student-driver, with the parent in the front seat, can begin to accumulate practice hours. There are many more online hours that must be done over the six-month period after the permit to drive is received, while the student-driver is accumulating their hours behind the wheel.

Now I have three distinctly different learners in my class: an over confident learner who thinks he knows everything, an overly cautious learner who seems to have to learn the same lessons every time she gets behind the wheel of the car, and a disinterested learner who has to be motivated all the way. This is funny! What has surprised me though about the entire process is the moral nature of the experience. For their entire lives my children have been watching their mother and me drive, and they have picked up on certain tendencies that we have behind the wheel. I hope that we have, for the most part, communicated through our actions that driving should be done safely, courteously, attentively, and skillfully. Now as we teach them to drive and give them instructions on how driving *ought* to be done, I am challenged when I am behind the wheel myself, to practice what I am preaching. I pay special attention to the same rules that I am teaching them, and I want to demonstrate that the rules for driving apply to all of us the same. I want to show them for instance, that a rolling stop at a stop sign is not appropriate, and that when you make a right turn at a red light you should come to a complete stop.

This is the way we teach our children moral behavior as well. Parents are the first moral teachers for their children, but primary and secondary school teachers are instrumental too. They

are taught in word and in deed, but most powerfully, they are taught by example, every day, consciously and unconsciously. In *Moral Intelligence* Coles makes this point very plain. Coles says unequivocally that "the most persuasive moral teaching we adults do is by example: the witness of our lives, our ways of being with others and speaking to them and getting on with them – all of that taken in slowly, cumulatively, by our sons and daughters, our students" (*MIC*, 31). The witness, the one who observes moral behavior and can testify to what they have seen and heard, is taught moral behavior in a most profound way.

Coles is not against other forms of moral teaching and acknowledges that every avenue, every resource at the disposal of adults should be used. "To be sure," he adds, "other sources can count a great deal: formal lectures or explicit talks, reading and more reading and discussions of what has been read, reprimands and reminders with punishment of various kinds, churchgoing or synagogue attendance, the experience of hearing sermons and being told about biblical messages, and the moral lessons and wisdom of our secular novelists, poets, and play-writes – all of that can count a great deal" (*MIC,* 31). But in the final analysis Coles assigns first place to "teaching by example," to "the unself-conscious moments that are what we think of simply as the unfolding events of the day and the week turn out to be the really powerful and persuasive times, morally" (*MIC*, 31).

This point about the power of parental influence on morality may have been made best by Samuel and Pearl Oliner in their book, *The Altruistic Personality: Rescuers of Jews in Nazi Europe.* In this project the Oliner's document, analyze, and evaluate good acts and good people; people (Gentiles) who risked their lives to save Jews during World War II. They report that "there were between 50,000 to 500,000 non-Jews who helped Jews, an outsider minority

group, survive during the precarious years of Nazi occupation in Europe."[158] The Oliners interviewed nearly 700 persons (406 rescuers, 126 nonrescuers, and 150 survivors) living in several countries in Nazi-occupied Europe to attempt to determine whether rescue was primarily of opportunity, or if it was a matter of character (personal attributes) – particularly learned values and personality characteristics.[159] This extremely small number of rescuers, when compared to the total number of people who lived in occupied European countries, proves that individuals are not entirely powerless to resist the forces of evil. But there were many more people, people that the Oliner's classified as *bystanders* – "nonrescuers that said they had done nothing out of the ordinary during the war either to help other people or resist the Nazis" – who did nothing.[160] What separated the *rescuer* from the *bystander*? *Rescuers* acted altruistically despite perceived risks to themselves and their families and whether or not they had economic security and a perceived adequate living space for those who they rescued. The authors document that it was the values learned from parents which "prompted and sustained their involvement" in rescuing Jews.[161]

The Oliners document that "how one perceives the victims is an important element in making a decision to help, and that parents play a major role in shaping such perceptions."[162] One of the most important themes uncovered by the Oliners, a value that rescuers had learned from their parents, was the theme that all people are equal and have equal rights. The parents of rescuers had taught them "egalitarianism and the basic universal similarity of all people."[163] An

[158] Samuel P. Oliner and Pearl M. Oliner, *The Altruistic Personality: Rescuers of Jew in Nazi Europe* (New York: Free Press, 1992), 1.
[159] Ibid., 2.
[160] Ibid., 4.
[161] Ibid., 142.
[162] Ibid., 149.
[163] Ibid., 143.

often repeated phrase by those that were interviewed was "people are people."[164] Although "Nazi propaganda portrayed all Jews as genetically flawed in both character and physical appearance," rescuers testified that their parents had taught them countervailing notions during their formative years.[165] Rescuers also reported that parents had taught them to focus less on the self and more on others. "Rescuers," the Oliner's inform us, "brought to the war a greater receptivity to other's needs because they had learned from their parents that others were very important. They had learned the importance not only of human relationships but also of relating to others in specific ways."[166]

This work makes an important contribution to this dialogue about the nature of moral education. Their work lends credence to the fact that the moral lessons that children and adolescents learn from their parents certainly make a difference in the kinds of moral action that these young moral witnesses will take in the future. In addition, according to Harold M. Schulweis who wrote the forward to the Oliner's project, the book offers "a beacon for moral education and morale for post-Holocaust generations," and it "challenges the hopelessness about the future."[167] The message from the Oliner's work is a welcome respite for our souls in times like these.

Psychologist Michele Borba agrees that parents and teachers play an invaluable role in helping their children get off to a solid start morally. In her book *Building Moral Intelligence,* Borba offers parents and teachers ways in which they can help children develop what she calls the seven essential virtues (empathy, conscience, self-control, respect, kindness, tolerance, and

[164] Ibid.
[165] Ibid.
[166] Ibid., 162.
[167] Ibid., xiii.

fairness).[168] These virtues will help children both think and act morally. The qualities are learned as both parents and teachers "emphasize the importance of the virtues over and over and the child repeatedly practices these moral behaviors."[169] There are reasons, according to Borba, that moral development is particularly challenging today: "many of the social factors that nurture moral development are disintegrating and kids are constantly bombarded with outside messages that go against the very values that parents attempt to instill."[170] Because there is no way for parents to totally protect their children from these toxic influences, parents should "morally vaccinate" their kids by building their moral intelligence and helping them develop moral strength of character.[171] Borba reassures us that morality is learned and therefore parents are their children's first and most important moral instructors. Borba, like Coles, suggests that it is never too early to begin teaching moral lessons. She suggests that the *moral core* or foundational virtues are empathy, conscience, and self-control.[172] Although instruction and moral growth should begin very early in life, the process is one that continues throughout the lifespan.

This collection of the seven essential virtues that Borba thinks are so critical for moral development is what educational psychologist Lawrence Kohlberg calls a "bag of virtues" approach, and Kohlberg argues that this method to teaching morality while common, is inappropriate. Kohlberg defines the *bag of virtues* - as "a set of personality traits generally considered to be positive."[173] Kohlberg, who is widely known for his theory of moral development (I cover Kohlberg's stages in detail later in this chapter), purports that the "bag of

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[168] Borba, *Building Moral Intelligence*, 6.
[169] Ibid., 11.
[170] Ibid., 4.
[171] Ibid., 5.
[172] Ibid., 9.
[173] Lawrence Kohlberg, *The Philosophy of Moral Development: Moral Stages and the Idea of Justice* (New York: Harper & Row, 1981), 9.

virtues" method has two primary flaws. First, the particular virtues in one person's bag will seldom match exactly, the virtues in another person's bag.[174] When I compare my "bag" from chapter one (empathy, compassion, witnessing, courage, and love) to Borba's bag mentioned above, Kohlberg's point is made very plainly, but this does not seem to be a fatal flaw with this method. After all, scholars don't typically suggest that their list of virtues is an exhaustive list, and usually they are highlighting a group of virtues that they feel are important or foundational for one reason or another. Most thinkers make room for the addition of other important virtues. The second reason that Kohlberg resists the teaching of morality with a list of virtues is that he thinks that it is difficult to gain consensus on the definition of the virtues themselves. As Kohlberg says: "What is one person's integrity is another person's stubbornness, what is one person's honesty in expressing your true feelings is another person's insensitivity to the feelings of others."[175] This argument too of Kohlberg's is less than convincing. While definitional clarity may indeed be a problem in certain instances of defining virtues, this seems to be rare and not the norm.

Kohlberg's overarching complaint though has to do with what he tags as *indoctrination*. Teaching morality as a "bag of virtues," a preconceived list, leads to *indoctrination* – teaching a person or group to accept a set of beliefs uncritically.[176] Kohlberg's theory of moral development, he says, is constitutionally opposed to any method that looks like indoctrination. When teachers or parents indoctrinate children they inculcate them with "their own or their society's arbitrary values"[177] Although some have posited that this type of "moralization" serves

[174] Ibid., 9.
[175] Ibid., 8.
[176] Ibid.
[177] Ibid., xxviii.

the interests of the classroom and of society, Kohlberg rejects this argument.[178] Ultimately, this type of moral teaching is "incompatible with the conceptions of civil liberties that are central not only to American democracy but to any just social system."[179] Teaching morality for Kohlberg is not a process of instilling virtues that children do not have, but a "drawing out of them that which is already within."[180] This "Socratic view" of moral teaching, at least Kohlberg's interpretation of it, is ideal because it allows the student to develop morally without the undue influence of teacher or society.

I think Kohlberg is wrong here. No matter how bright or genetically gifted a child is, children do not come equipped with the necessary academic or moral skills that they need to navigate successfully in the world. Children are given parents and teachers to assist them in their development. The moral examples that adults demonstrate to children are essential and the verbal reinforcement of those examples are critical. This is the way, primarily, that morality is taught. Once a child has some sense of morality, some foundation from which to grow in this area, then other methods of teaching are very useful. But at the beginning, children need examples and instruction and unfortunately many young people lack proper amounts of both. Parents and teachers are invaluable as they set examples for children and show them the way morally. High school students need moral instruction, undergraduate college students need good moral examples and moral development, and even those adults in graduate school and professional training need moral exemplars.

[178] Ibid., 6.
[179] Ibid., 8.
[180] Ibid., 46.

Medical Humanists: Encouragers of Moral Development

One special group of educators sees moral education and moral development, even their own moral development, as their primary and unifying objective. These are the practitioners of the medical humanities. In 1947 while an undergraduate student at Morehouse College, Martin Luther King Jr. wrote a paper for *The Maroon Tiger*, the school's student paper, entitled "The Purpose of Education." The contents of the short essay explicate both King's view of the misconception of the purpose of education by many of his contemporaries, and his assessment of what education *ought* to do for the one that undergoes the educational process. The former group, those who have missed education's purpose, think that education "should equip them with the proper instruments of exploitation so that they can forever trample over the masses," or they think that education should "furnish them with noble ends rather than means."[181] But King's idea of what education should do for the individual is much more meaningful, and even before he is twenty years old, he unveils his keen intellectual insight. According to King, education must enable men and women to become more efficient and effective in their thinking, to "think incisively" and to "think critically," to think "with 0moral ends in mind.[182] King concludes that "intelligence plus character, that is the goal of true education . . . to save man from the morass of propaganda."[183]

What King had in mind primarily was the purpose of higher education, as the audience for the *Maroon Tiger* was certainly the students, and possibly the faculty and staff of Morehouse

[181] Martin King, "The Purpose of Education," *The Marron Tiger* 1947, 123.
[182] Ibid.
[183] Ibid., 124.

College. Whether or not he had a broader view of education and its application in mind we cannot be sure, but certainly a more expansive application of his ideas would not be out of place. To "think incisively," "to think critically," and to think with "a moral end in mind" are certainly lofty goals for graduates of any institution of higher learning, and they are goals that the American public would do well to aim for also. This kind of uncommon thinking and the type of discourse it leads to is one of the distinguishing characteristics of human beings. Sadly, and regrettably, all too often the kind of verbal regurgitation that is encountered in the public sphere leaves much to be desired. Many people in American society do not think critically about the information they encounter in their media cocoons, and the public is told what to think and when to think it; they are sheep being led to the slaughter.

Rafael Campo points to this same issue, a wide-spread cultural issue that he called "anti-intellectualism."[184] In his article, "The Medical Humanities: For Lack of a Better Term," Campo has a view of the medical profession as being caught up in a larger cultural deterioration. A weakening of moral strength in society in general makes it more difficult to practice medicine in the modern era. The signs of this failing moral fortitude for the physician are things like "economic constraints" and "technological hubris" that are ever present.[185] Campo's solution to these problems is a return to the humanities for "renewal, reconnection, and meaning."[186] Campo reminds his readers that the medical humanities project was started because of a growing concern about the dehumanization of medical care, it was started to address the same kinds of concerns that he points to in his paper and that King is also calling our attention to.

[184] Rafael Campo, "'The Medical Humanities,' for Lack of a Better Term," *Journal of the American Medical Association* 294, no. 9 (September 2005): 1009.
[185] Ibid.
[186] Ibid.

The medical humanities is a multidisciplinary project that emerged in the late 1960s as an essential addition to professional medical training to address perceived issues in medical education, issues of "depersonalization, the centrality of molecular biology, and the teaching of mechanistic medicine."[187] Thomas Cole and his colleagues describe medical humanities as a "field" that is both "multidisciplinary" and "interdisciplinary." But they settle on the opinion that the various distinctions that can be made when attempting to define the medical humanities, whether medical humanities is a "field" or a "discipline," is not what is most important, but the most salient "point is that medical humanities draws from many disciplines to examine issues related to the development and practice of medicine and health care."[188] Ronald Carson tells us that from the beginning "humanities teaching programs encompassing ethics, history, literature, and religious studies, as well as law and, on occasion, visual studies and cultural anthropology, were established in medical schools with start-up funding from the National Endowment of the Humanities and private philanthropies."[189] Medical humanist Nicole Piemonte adds philosophy and disability studies to her list of humanities disciplines and suggests that all of the above mentioned disciplines are used to "foster a richer understanding of the human experience of illness, health, dis/ability, identity, gender, embodiment, and healthcare."[190] When it comes to the exact disciplines that are included in any single medical humanities program, while some disciplines may be seen as more critical than others, there is no "one size fits all" approach that should be taken. Each university or college that trains clinicians and biomedical scientists must determine the most expedient group of humanities disciplines for their particular academic

[187] Daniel M. Fox, "Who We Are: The Political Origins of the Medical Humanities," *Theoretical Medicine* 6, (October 1985):329.
[188] Ibid., 327.
[189] Carson, "Engaged Humanities," 324.
[190] Piemonte, *Afflicted*, 129.

project. The birth of first generation, graduate-level, interdisciplinary medical humanists may help to make these decisions easier for these educational programs. At the start, the addition of humanities teaching to the medical school curriculum was seen as a critical step to address "the shared concerns of the hospital chaplains, academic clinicians, and moral theologians and philosophers about the growing power of a technological imperative and a perceived trend toward depersonalization in medicine."[191]

When attempting to define the breadth and depth of the work of the medical humanities today it is essential to connect this multidisciplinary group of scholars to the history of Renaissance humanism, or the *studia humanitatis*. Julie Kutac and her colleagues describe succinctly the significance of the *studia humanitatis*:

> The *studia humanitatis*, which directly translates to 'the study of man or humanity,' was a curriculum that focused upon classical literature, grammar, logic, and rhetoric. The early humanists emphasized finding meaning through engaged reading and writing about the classics and envisioned an intellectual who left the ivory tower to be engaged in society. The goal of study was to gain wisdom and virtue that would be useful in an uncertain, contingent world. Renaissance proponents of the *studia humanitatis* distinguished it from the Scholastic tradition of their contemporary universities which, in its emphasis on technical minutiae, failed to give its learners guidance in their daily lives.[192]

The "Father of Humanism," Petrarch (Francesco Petrarca, 1304-1374), who lived in fourteenth-century Italy during a period of both social and personal volatility, is an example of the power of the *studia humanitatis*.[193] Living during the time of the Black Death, Petrarch suffered significant personal losses, witnessing the death of many close friends, family members,

[191] Carson, "Engaged Humanities," 321

[192] Julie Kutac, Rimma Osipov, and Andrew Childress, "Innovation Through Tradition: Rediscovering the 'Humanist' in the Medical Humanities," *Journal of Medical Humanities* 37, no.4 (2016): 374.

[193] Howard Brody, "Defining the Medical Humanities: Three Conceptions and Three Narratives," *Journal of Medical Humanities* 32, (2011): 4.

and the death of his beloved.[194] The grief for Petrarch was almost unbearable and he could not find solace in the prescribed methods of his day.[195] Petrarch instead "turned his attention inward, using writing as a way of exploring his inner self."[196] Petrarch found comfort as he tuned to the writings of the Roman orator and philosopher Cicero who had suffered through his own personal tragedies and written about those losses.[197] It was through the acts of reading and writing that Petrarch was able to "make meaning of his sense of loss and feelings of vulnerability in the face of *Fortuna*."[198]

Contrary to the "Scholasticism of the medieval university" the new curriculum of the *studia humanitatis* was intended to equip students with the ability to deal with life's contingency and unpredictability.[199] The curriculum included the study of "classical literature, grammar, logic, and rhetoric."[200] The curriculum was "introspective, dialogical, and inherently ethical."[201]

Practitioners of medical humanities today connect their work to Renaissance humanists like Petrarch in their attempt to help those they teach deal with lives that are "bewilderingly complex."[202] Writing in "Engaged Humanities" Carson makes the connection between the *studia humanitatis* and the work of the medical humanities in the twenty-first century:

> As in the cities of early modern Europe, we are in need of new literacies of imagination and intellect. Many experiences of illness and injury seem devoid of meaning, and suffering sometimes seems senseless. We abhor death and often mindlessly abet medicine's efforts to fend it off long after the flame is reduced to a flicker. Doctors and patients talk past each other, not knowing what questions to ask or anticipate. The goods of health care are unevenly distributed and beyond the reach of many.[203]

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[194] Kutac, "Innovation Through Tradition," 374.
[195] Ibid., 375.
[196] Ibid.
[197] Brody, "Defining the Medical Humanities," 4.
[198] Kutac, "Innovation Through Tradition," 375
[199] Ibid., 374.
[200] Ibid.
[201] Ibid.
[202] Carson, Engaged Humanities, 326.
[203] Ibid.

Added to this list of issues that Carson points to is the ubiquitous nature of technology during the clinician-patient encounter, even the electronic medical record (EMR). Touted as a tool to make the work of clinicians easier and the business of institutions more efficient, the EMR is itself a distraction from genuine communication. Just as Petrarch, Erasmus, Vesalius and other Renaissance humanists dealt with the real life issues of contingency and uncertainty during their time, the audiences of the medical humanities are faced with like challenges today. The practitioners of the medical humanities seek to engage clinicians, biomedical scientists, our colleagues, and the public in a dialogue about both science and human values.[204]

This multidisciplinary group of scholars are variously trained in the techniques of their own disciplines, but what unites medical humanities scholars is their unified focus on the development of the moral imagination. They are encouragers of moral development. Medical humanists do not make their audiences human or make them "more human," but their goal is to facilitate the more effective use of human qualities or skills (e.g., reading, listening, speaking, etc.).[205] The work of the medical humanities is not done through coercion, neither is it achieved through "indoctrination or manipulation."[206] Judith Andre exhorts medical humanists when she says that "there is nothing radical or dramatic in the idea that our work centrally concerns supporting moral development," but she reminds practitioners of medical humanities that "as teachers, speakers, writers, and organizers we offer tools for moral development that may be rejected."[207]

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[204] Carson, Engaged Humanities, 326.

[205] Anne Hudson Jones and Ronald Carson, "Medical Humanities at the University of Texas Medical Branch at Galveston," *Academic Medicine* 78, no. 1 (October 2010): 1009.

[206] Andre, "The Medical Humanities as Contributing to Moral Growth and Development," 60.

[207] Ibid., 61.

The audiences with whom practitioners of medical humanities engage are primarily adult audiences who have had, we hope, some decent foundational training in the moral realm. As I point out above, the role of parents and teachers here is invaluable. By the time students encounter medical humanities scholars at the collegiate level, they may have adopted certain moral exemplars that they look up to and model their behavior after. These may be exemplars that the student has had some personal experience with, or they may be historical figures. But by the time students first engage with the medical humanities project, even at the undergraduate level in their early twenties, they have certainly had some foundational moral experiences, good or bad. The medical humanists' responsibility is to "take our students where we find them, with their own mother tongues of morality, and – with the help of texts and ways of thinking drawn from our disciplines – to help them clarify their moral outlooks, become aware and respectful of other intelligences and sensibilities, and become fluent in their moral thinking."[208]

The method of teaching used by medical humanists is not ideally the traditional didactic, lecture style of teaching. But "teaching by indirection," which may seem uncomfortable to students who are used to the continuous noise of other styles of teaching.[209] Even the one teaching must remind herself that moments of silence are not necessarily bad, but that this type of guided instruction requires time for students to think. The kinds of lessons that medical humanists seek to impart "are teachable by means of tutored exposure to stories of suffering and persevering, interlaced with supervised rehearsal of lessons learned and insights gained, now transposed into the arena of patient care."[210]

[208] Carson, "Educating the Moral Imagination," 26.
[209] Piemonte, *Afflicted,* 135.
[210] Carson, "Educating the Moral Imagination," 28.

Of course, there are some thinkers that are not as convinced that the methods of the medical humanities serve altruistic purposes. In his essay, "Rejecting Medical Humanism: Medical Humanities and Metaphysics of Medicine," philosopher Jeffrey Bishop rejects humanism and medical humanism "as the cure-all for an increasingly mechanical medicine."[211] His critique of medical humanism, and narrative medicine specifically, is couched in a broader criticism of what he calls the "Western metaphysics of efficiency."[212] Being heavily influenced by Michel Foucault, Bishop uses words like *discipline, control*, and *governmentality*. His basic argument is that Western medicine has a metaphysics or identity of efficient control of its subjects. In the article he refers to an existing divide between *subject-object* and *theoria-praxis*. Bishop is pointing us to the manipulation of objects (patients) by subjects (clinicians) in the Western model of medicine. His major complaint then about Rita Charon and her narrative medicine techniques is that by making clinicians more effective in the areas of reading, writing, and empathic listening, narrative medicine only perpetuates the Western metaphysics of efficiency. Narrative medicine pushes Western medicine further in the wrong direction making it easier for patients to be controlled by clinicians.

Bishop's criticism of medical humanities seems to be misplaced. First, the origin narrative and contemporary conceptions of the medical humanities do not support Bishop's claims. Work in the medical humanities supports and encourages a dialogue between interlocutors that is respectful and not hierarchical. The use of narrative medicine techniques would promote a clinician-patient relationship where both persons see themselves as equals and not as being controlled by one or the other party.

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[211] Jeffrey P. Bishop, "Rejecting Medical Humanism: Medical Humanities and the Metaphysics of Medicine," *Journal of Medical Humanities* 29, (2008) 15.

[212] Ibid.

In the next section I want to shine the light on certain moral heroes, men and women, who have proven that living a virtuous life is possible and whose example *ought* to be motivation for us to do the same. Pointing to these moral exemplars helps answer the question of how moral growth takes place.

Exemplars of Moral Leadership

In chapter one I defined five essential virtues that are critical to the development of the moral imagination: empathy, compassion, witnessing, courage, and love. In this section I want to point to some flesh and blood examples of these virtues. Judith Andre suggests that a moral exemplar is "someone whose life would be admirable even to those who did not share his or her political and religious beliefs, who showed a sustained and deep commitment to certain ends throughout life, and who used tools and strategies that fit these fundamental commitments."[213] The lives of the three moral exemplars that I highlight here, Dorothy Day, Mitch Albom, and Martin Luther King Jr., fit this definition well and prove to us that these virtues can be lived out in the life of a moral leader. I agree with Robert Coles when he says that "we need heroes, people who inspire us, help shape us morally" (*LML*, xviii). Certainly the short list of moral exemplars that I put forward here could have included many other names, and hopefully when the reader attempts to put together a short list of her own, individuals that have inspired her to "purposeful action," her list will be different. This is actually the point. Moral exemplars inspire us on a personal level, for one reason or another, and they are people, some very well-known and others much less so, who point us in the "right" direction. Now this will be a troubling

[213] Andre, "The Medical Humanities as Contributing to Moral Growth and Development," 56.

normative position for some, that there is a so called "right" and "wrong" direction, but I am confident that there are some absolutes in this case.

Day, Albom, and King are names that many will recognize and rightfully so, but I have made another list as well. This list was motivated by a question that Coles asks the reader of his book *Lives of Moral Leadership: Men and Women Who Have Made a Difference*. In chapter eight of the book, "Handing Each Other Along: Moral Leaders in Everyday Life," Coles asks this question: "Who have been the leaders in your life – the people you really respected, the folks who stood for something" (*LML*, 166)? In response to his question, I took time to reflect on my growing up years and to give serious consideration to who these people were. Of course, my mother and maternal grandmother were on the list, but this was low-hanging fruit. Who else should be included on this list? As I reflected I realized that there were a group of men, football coaches and leaders in my church, who have help me to become the man that I am today. These are men who I think of often and who I truly appreciate. As a young boy without a father figure in the home for many years, these men helped me understand what a man of character looks like, but they were not perfect men; they all had their own flaws. This is another really important point about moral leaders. None of them was perfect or sinless. In fact, if perfection were the requirement to be a moral leader, none of us would qualify and we would have no moral heroes. This is the point that Coles makes in the title of his book mentioned above. Perfection is not the requirement, all that is needed is the desire "to make a difference."

Dorothy Day, an Exemplar of Empathy and Compassion

Dorothy Day was such a remarkable women that she could have legitimately been the only exemplar that I used in this part of the project. She was a woman who practiced "taking a stand."[214] She was "a moral leader whose leadership was based on prayer and faith leading to action – and on a felt reliance upon the leadership given to her by her colleague Peter Maurin" (*ARD*, 122). In 1933, Day and Maurin started The Catholic Worker movement, but they were in many ways quite different people. Coles summarizes their relationship this way: "she was a young, cosmopolitan woman, well-read and a friend of writers and artists and intellectuals; he was of French peasant background, considerably her elder, a working man and a wanderer who talked of Christ's life and teachings" (*ARD*, 123). Today, their work that started during the Great Depression in New York City has blossomed into work being done in 204 communities worldwide.

What makes Dorothy Day a great moral exemplar, like the men on my short list above, is the transparent nature with which she talked about her moral failures. Day was born in Brooklyn on November 8, 1897, "the third of five children in a lower-middle class family of tenuous security."[215] Day, who converted to Catholicism in 1927 at the age of thirty, lived a young adult life that I would describe as volatile. She earned a scholarship to attend the University of Illinois in 1914, but she would leave school after only two years.[216] At the age of nineteen she moved to New York City and worked as a reporter for *The Call*, a socialist paper,

[214] Robert Coles, *Dorothy Day: A Radical Devotion* (New York: DA CAPO Press, 1987), xix. All subsequent references to *Dorothy Day: A Radical Devotion* in this chapter will be cited parenthetically in the text, with the abbreviation *ARD*, followed by the page number.

[215] Dorothy Day, "Introduction," in *Dorothy Day: Selected Writings*, ed. Robert Ellsberg (Maryknoll: Orbis Books, 1983) xvii.

[216] Michael Kress, "Dorothy Day," in Spiritual Leaders Who Changed the World, ed. Ira Rifkin (Woodstock: Skylight Paths, 2008), 174.

the first of several different newspapers that she would write for (*ARD*, 3). At twenty years old she was in a Washington D.C. jail after having been arrested for marching with suffragettes. (*ARD*, 3). She tried nursing school for a while, but ultimately that profession did not appeal to her. She entered a common-law marriage with Forster Batterham, a man she described as "an anarchist, an Englishman by descent, and a biologist."[217] In December 1932 she was back in Washington D.C. participating in a hunger march, and while there, she prayed for a chance to be able to use her talents to help the poor. When she returned to New York City, she met Peter Maurin (*ARD*, 12). It is impossible to write about who Dorothy Day was and about the success of The Catholic Worker movement without giving significant attention to Peter Maurin's influence on Day; this is the way she would have wanted it. After Maurin's death in 1949 when writers interviewed Day, she was careful to include the essential contributions from Maurin. In her own words Day says: "I tell them about Peter, and what he did for us - to us. I tell them that they should stop all the time putting me first, forgetting Peter. He was the one who got us all going, kept us going here, when we started as a community" (*ARD*, 124). For Day, "life really did begin" when she met Peter Maurin (*ARD*, 4). Maurin's talk or "preaching," Day would have called it, was the persistent verbal encouragement or "needling" that motivated those around him, including Day, to get things done. Another of their colleagues, Robert Ellsberg, who served as editor for *The Catholic Worker* for three years, summarizes Maurin's outlook:

> The main problem with society was that sociology, economics, and politics had all been separated from the Gospel. In the process, society had lost any sense of the ultimate, transcendent purpose of human activity. Social life had come to be organized around the drive for production and the search for profits, rather than the full development of persons. Human beings, intended by God to be co-creators by virtue of their labor, had instead become alienated and atomized, bereft of any spirit of community, and reduced generally to the status of cogs in a machine.[218]

[217] Day, "Introduction," xxiii.
[218] Ibid., xxvi.

When Day and Maurin first met in 1932 "they both were searching for a way to relate their faith to the urgent social issues of the day."[219] Maurin, according to Day, was the visionary in their dyad and had a three-fold plan that they both agreed should be implemented. The plan included the establishment of a newspaper for "clarification of thought."[220] This idea developed into *The Catholic Worker* newspaper which is still published today seven times per year. The plan also included starting *houses of hospitality,* where the poor and homeless could be provided food and shelter. Maurin also suggested that they start "agronomic universities" or farming communes where people could learn to grow their own food and take care of themselves. The main emphasis of Maurin's plan might be summarized as what were called "works of mercy: feeding the hungry, clothing the naked, and sheltering the homeless."[221]

Empathy as I have defined it above, "distress at the distress of others," can be seen in Dorothy Day's life after her conversion to Catholicism, but it was also clearly present throughout her adult life. Coles in his book, *Dorothy Day: A Radical Devotion*, gives us some indication of Day's proclivity towards empathy: "Whether she was in jail, simply walking in the street, buying groceries, asking directions, browsing in a bookstore, or waiting in line to enter a theater or a museum, Dorothy Day was constantly noticing people, constantly ready to engage with them and let them become, even for a few moments, part of her life" (*ARD*, 112). She had worked for and gone to jail several times for the cause of the disenfranchised, and in a strange way she felt that she had betrayed the disenfranchised by converting to Catholicism. Day says in her book,

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[219] Day, "Introduction," xxvi.

[220] Dorothy Day, *Loaves and Fishes: The Inspiring Story of the Catholic Worker Movement* (Maryknoll, NY: Orbis Books, 1963), 7. All subsequent references to *Loaves and Fishes* in this chapter will be cited parenthetically in the text, with the abbreviation *LAF*, followed by the page number.

[221] Day, "Introduction," xxix.

Loaves and Fishes, that "I felt keenly that God was more on the side of the hungry, the ragged, the unemployed, than on the side of the comfortable churchgoers who gave so little heed to the misery of the needy and the groaning of the poor. I had prayed that some way would open up for me to do something, to line myself up on their side, to work for them, so that I would no longer feel that I had been false to them in embracing my new-found faith" (*LAF*, 13).

Her empathic concerns can be seen in the topics of the very first publication of *The Catholic Worker*, topics that included, "The Exploitation of the Negroes in the South, "The Plight of the Sharecroppers," "Child Labor in our Own Neighborhoods," "Some Recent Evictions," "A Local Strike Over Wages and Hours," and "Pleas for Better Home Relief" (*LAF*, 13). Day believed that real change would not take place until the plight of the poor was felt by each individual. She says in one place that

> The greatest challenge of the day: how to bring about a revolution of the heart, a revolution which has to start with each one of us? When we begin to take the lowest place, to wash the feet of others, to love our brothers with that burning love, that passion, which led Jesus to the Cross, then we can truly say, "Now I have begun" (*LAF*, 215).

The compassion of Dorothy Day is exemplified first by her choice to live in what has been called *voluntary poverty* (*LAF*, 215). For Day and for Maurin *voluntary poverty* led to a freedom from dependence on material possessions and led to an availability to serve others. The poor seemed to "always have room for one more at the table; everyone would just take a little less" (*LAF*, 216). This is just one of things that helped to define Day as an iconoclast.

Day's compassion is also seen in her choice to live in the houses of hospitality that she organized and managed, because for Day "the test of a life was its everyday moral texture – what one does, finally, with all the hours of each day" (*ARD*, 111). These were houses where the hungry could be fed and the homeless could sleep. For forty-seven years she made a conscious

choice to live among the urban poor, and for many of those years, she raised her only daughter, Tamar, in these houses of hospitality. Day was not unique in this regard though, this was the common mode of operation for those who worked in houses of hospitality, and because of this compassionate action, there was a merging of those who were serving and those who served. In a sense this was Day's vision for the family in America:

> It seems to me that in the future the family – the ideal family – will always try to care for one more. If every family that professed to follow Scriptural teaching whether Jew, Protestant, or Catholic, were to do this, there would be no need for huge institutions, houses of dead storage where human beings waste away in loneliness and despair. Responsibility must return to the parish with a hospice and a center for mutual aid to the group, to the family, to the individual (*ARD*, 198).

For Day "hospitality meant more than serving a meal, offering a bed, or opening a door; it meant opening one's heart to the needs of others."[222]

Mitch Albom: Exemplar of Witnessing

Mitch Albom, the author of *Tuesdays with Morrie*, is my exemplar of *witnessing*, specifically what Frank calls the "reciprocity of witnessing."[223] *Witnessing* requires that the one who listens to the testimony of the ill person slow down and really hear the story of the other, and for Frank, "witnessing always implies relationship."[224] Albom demonstrates this virtue when he takes time out of his very busy schedule to visit his former professor, Morrie Schwartz, who has been diagnosed with amyotrophic lateral sclerosis (ALS). These visits take place weekly, on Tuesdays.

[222] Day, "Introduction," xviii.
[223] Frank, *The Wounded Story Teller,* 143.
[224] Ibid.

I was acquainted with Albom years before I read his "final thesis" about his and Morrie's Tuesday conversations, and I had observed that he was a bright and thoughtful sports writer. I had enjoyed for some time his contributions to the Sunday morning cable television program, "The Sports Reporters." When I did finally read *Tuesdays with Morrie*, I read the book because it was one of the required readings for a course that I was enrolled in the spring of 2004. As I read the final lines of the last chapter of the book, I could not stop the tears from flowing. The book simply moved me. Perhaps it was because it was written so well; professional writers, especially sports writers, have a way of painting pictures for the reader. Or maybe the story resonated with me because of where Albom was in his life and career. I could identify with this young, unmarried, childless man who was busy making a life for himself, but who was not completely living up to his human potential; he was flourishing as a professional but not in his other human relationships. In *Tuesdays with Morrie* I saw a glimpse of what real friendship looks like, real sacrifice, and what Albom refers to as the real "meaning of life."[225]

I read the book in one day; it is only one-hundred and ninety-two pages long. Even in my haste to finish the reading and the twelve-page, double spaced paper, also part of the assignment for the course, the book left a permanent impression on me. Certainly, Morrie's exhortations and advice about how to live a meaningful life are invaluable for the reader, but Albom's role as witness to Morrie's illness experience is powerful as well.

As Albom reunites with his former professor, he reflects on Morrie's exhortations to him during his undergraduate years to be "fully human," and he also recalls how much he enjoyed just being with Morrie. It was normally on Tuesdays when Mitch and Morrie would have class

[225] Mitch Albom, *Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson* (New York: Broadway Books, 1997), 1. All subsequent references to *Tuesdays with Morrie* in this chapter will be cited parenthetically in the text, with the abbreviation *TWM*, followed by the page number.

together, or meet in Morrie's office, or even meet for lunch. These moments of togetherness were the foundation for their later reconnection.

One moment in the book is particularly poignant as an example of Albom's witnessing. On the second Tuesday of their meetings Morrie needed to be moved from the bed to the chair, and Mitch offers to help. Mitch, following the instructions of the more experienced professional caregiver, lifts Morrie from the bed to the chair and in so doing, a lasting impression is made on Mitch. As he reflects verbally about his actions he says: "Holding him like that moved me in a way I cannot describe, except to say I felt the seeds of death inside his shriveling frame, and as I laid him in his chair, adjusting his head on the pillows, I had the coldest realization that our time was running out. And I had to do something" (*TWM*, 58). Indeed, Albom does "do something." He makes himself consistently available for the meetings with Morrie on Tuesdays, and he is willing to be fully present, to show up both physically and emotionally. Albom along with Morrie decide at some point during these meetings to tell Morrie's story and because of that decision, they produce a masterful project that is full of helpful advice and is a powerful example of friendship.

Another part of the book that helps to testify to Albom's authentic witnessing is his creation of a list of topics that he wants to discuss with Morrie. In creating this list, Albom admits that there are certain aspects of life that he needs clarity about, and he dare not allow Morrie to leave this world without getting his input. Albom's list included the following topics: death, fear, aging, greed, marriage, family, society, forgiveness, and a meaningful life (*TWM*, 66). Certainly, these are important topics for Morrie to discuss with Albom, but because Albom produces this list, it ensures that both parties are fully committed to the dialogue.

Rev. Dr. Martin Luther King: An Exemplar of Courage and Love

You could not grow up in America as an African American boy during the 1970s and 1980s, as I did, and not hear the name Martin Luther King Jr., almost ad nauseam. Violence is done to Dr. King's name and his legacy because of the overuse of his name; familiarity breeds contempt I think. I don't have an answer for this problem, because without a doubt, King's name should be the most often mentioned name when the subject of the propagation of civil rights for minorities (including women) is mentioned in America. But the narrative needs to be more thoughtful and richer, so that the real significance of who King was is understood. By reading King's sermon's and other published works, the reader can begin to get a true idea of King's real brilliance.

At this point it is important to remind ourselves, especially in light of what we have learned about Dr. King since his death, that perfection is not the standard for our moral exemplars. The standard again is the desire to "make a difference," and no successful argument can be made against the fact that King did exactly that.

King, first of all, is an exemplar of courage. Beginning officially in 1954 with the Montgomery bus boycott, until his death in 1968, King was an example of thoughtful and courageous leadership. The seeds of this brave disposition, however, can be traced to his youth. The summer of 1963 and the direct-action nonviolent campaign in Birmingham, Alabama, has been described as a critical time and place in the civil rights movement. Birmingham, labeled as the most segregated city in the South, was controlled in many ways by one of the city

commissioners, Eugene "Bull" Connor.[226] Connor was Commissioner of Public Safety and in "Connor's Birmingham," says King, "the silent password was fear. It was fear not only on the part of the black oppressed, but also in the hearts of the white oppressors" (*WWW*, 48). In the larger state-wide sociopolitical context, the Governor of Alabama, George Wallace, had promised during his inauguration "'segregation now, segregation tomorrow, and segregation forever'" (*WWW*, 49). If you had visited the city in the years leading up to the summer of 1963 King tells us what we would have seen for ourselves:

> You would have found a general atmosphere of violence and brutality in Birmingham. Local racists have intimidated, mobbed, and even killed Negroes with impunity. One of the more vivid and recent examples of the terror of Birmingham was the castration of a Negro man, whose mutilated body had then been abandoned on a lonely road. No Negro home was protected from bombings and burnings. From the year 1957 through January of 1963, while Birmingham was still claiming that its Negroes were "satisfied," seventeen unsolved bombings of Negro churches and homes of civil-rights leaders had occurred (*WWW*, 49).

It is against this backdrop that King led a city-wide civil rights campaign. In his book, *Why We Can't Wait*, King explains why the summer of 1963 was the ideal time for what he calls the "Negro Revolution" (*WWW*, 141). Like the American Revolution and the Civil War, the Negro Revolution would change both its participants and the deeply rooted establishments of the country. The Negro, according to King, was deeply disappointed over several events in the recent history of America (*WWW*, 142). First, it had been nine years since the *Brown v. Board of Education* decision, but the progress towards true integration of public schools was almost nonexistent. There was dissatisfaction as well with both political parties. During the presidential campaigns leading up to the election in 1960, politicians on both sides of the aisle had promised

[226] Martin King, *Why We Can't Wait* (New York: Berkley Publishing, 1963), 47. All subsequent references to *Why We Can't Wait* in this chapter will be cited parenthetically in the text, with the abbreviation *WWW*, followed by the page number.

that racial equality and social justice would be a significant part of their agendas. But progress in these areas after the elections was too slow. Most disturbingly, it had been more than one hundred years since the signing of the Emancipation Proclamation, yet the Negro was still striving for real freedom. Ultimately King's courageous leadership would lead to tangible civil rights victories in Birmingham.

Certainly, King's gallantry in the face of opposition helped to galvanize his followers toward the same end. Even in situations when the movement felt the sting of defeat, there were says King, "intangible elements of victory" (*WWW*, 141). When describing specific setbacks in other cities in the South, King said that "despite the worst these communities could inflict, they could not drive the Negroes apart. Their blows only served to unite our ranks, stiffen our resistance and tap our deepest resources of courage" (*WWW*, 141). King goes on to say, "In this Revolution no plans have been written for retreat. Those who will not get into step will find that the parade has passed them by" (*WWW*, 165). King, other civil rights leaders around the country, and those whom they led were determined to persist in their efforts for change despite the real dangers they had to face.

In one of King's most brilliant sermons, "A Tough Mind and a Tender Heart," King directly addresses the type of person that is not ready to deal with racial oppression courageously. He characterizes this type of person as being "softminded."[227] The softminded, King says, "feels that the only way to deal with oppression is by adjusting to it. They acquiesce and resign themselves to segregation. They prefer to remain oppressed" (*STL*,18). The biblical text that he explores for the sermon, Matthew 10:16, uses a strange and enigmatic combination

[227] Martin Luther King, Jr., *Strength to Love* (Philadelphia: First Fortress Press, 1981), 18. All subsequent references to Strength to Love in this chapter will be cited parenthetically in the text, with the abbreviation *STL*, followed by the page number.

of virtues: "Be ye therefore wise as serpents, and harmless as doves" (*STL*, 17). It is certainly strange to think of these two animals as sharing like characteristics. However, the wisdom of the serpent, according to King, will be seen in the person that has a "tough mind," but toughmindedness is not enough. If a person is only toughminded, they will become "cold and detached, leaving one's life in a perpetual winter devoid of the warmth of spring and the gentle heat of summer" (*STL*, 18). A tough mind alone leads to the violence of hardheartedness, and violence never leads to lasting victories. One must add to toughmindedness the essential virtue of tenderheartedness. King sees the combination of these virtues as the essence of the direct-action nonviolent movement. This movement "combines toughmindedness and tenderheartedness and avoids the complacency and do-nothingness of the softminded and the violence and bitterness of the hardhearted" (*STL*, 19). King firmly believed that these two characteristics were the bedrock principles that would lead the Negro to victory in his fight for socio-political freedom. These two virtues kept in delicate balance would lead to freedom for both the Negro and for those who oppressed him.

We also see in King a great example of Love. In this section I rely heavily on three of King's sermons that he wrote while in Georgia jails. The first of these sermons is entitled, "Love Your Enemies." King does not want his audience to mistake his use of the word love for a fleeting sentiment that waxes and wanes based on external conditions, but the word for love that King uses here is *agape*. King says in this sermon that "the meaning of love is not to be confused with some sentimental outpouring. Love is something much deeper than emotional bosh" (*STL*, 52). He goes on to define agape as "understanding and creative, redemptive goodwill for all men" (*STL*, 52). Agape is "an overflowing love which seeks nothing in return, agape is the love of God operating in the human heart. At this level, we love men not because

we like them, nor because their ways appeal to us, nor even because they possess some type of divine spark; we love every man because God loves him" (*STL,* 52). It is one thing to muse about man's duty to love this way from a comfortable position in an ivory tower, but it is something altogether different to talk about loving your enemies while in jail. The experiential testing of King's love allows us to see the depth of this virtue in King.

The biblical exhortation to "Love Your Enemies" has been used by some to suggest that the Christian religion is a religion for the weak, but to truly love one's enemies proves rather the strength of the moral agent, and not her weakness. We are also sure that this is no easy task. Loving one's enemies, King says, requires the ability to forgive, the ability to see our "enemy-neighbor" with a broader purview than the offense alone, and it requires a motivation to win the enemie's friendship and understanding (*STL,* 51). We should love our enemies because it is a more excellent way and "hate returned for hate only multiplies hate" (*STL,* 53). Hate, according to King, "cannot drive out hate, only love can do that" (*STL*,53).

The last point from this sermon is especially important and focuses on the one who loves, rather than the object of her love. Hate, if left unchecked, can have harmful effects on the one who hates. Hate "scars the soul" of the one who hates, and it causes a schism in the hater's personality (*STL*, 53). Love, not hate, is the only force that is capable of transforming an enemy into a friend. The solution to race relations in King's America is this: "We must in strength and humility meet hate with love" (*STL*, 55).

King also deals with this matter of love in his sermon, "Love in Action." Here King uses for his sermon text, Luke 23:24: "Then said Jesus, 'Father, forgive them; for they know not what they do.'" These words of Christ are uttered during his crucifixion and are words of forgiveness for those who carry out this Roman form of capital punishment. King comments about these

words spoken in this context by saying that, "This is love at its best" (*STL*, 39). This is a great example of love because, as the title of the sermon suggests, love is about action. Too often the life of the believer and/or the moral agent is filled with inconsistencies, differences between the lofty altruistic words that are spoken, and the actions that are taken. King points out that this is the constant problem with many Christians, the inability to have our speech line up with our action. There is, King suggests, too often "a strange dichotomy, this agonizing gulf between the *ought* and the *is*" (*STL*, 42). Jesus is for King and for us, a perfect example of love. The real test of this love is a willingness to forgive, even our enemies. This love and forgiveness are opposed to our nature, a nature that would rather strike back or seek revenge. But King reminds us that "only goodness can drive out evil and only love can conquer hate" (*STL*, 42). The real brilliance of King is seen as he elucidates the second part of the text, "they know not what they do." People who use hate rather than love, according to King, are blind both intellectually and spiritually, and until they are enlightened they will never see things God's way; they will never be able to demonstrate this kind of love. The call though is wider than a spiritual call to be redeemed, it is also a "moral responsibility to be intelligent" (*STL*, 42). The Christian is called to love God with all our heart, soul and mind and "our heart can never be totally right if the head is totally wrong" (*STL*, 47).

The final sermon of King's that I want to explore for this section is "Shattered Dreams." King's text for the sermon is taken from the words of the Apostle Paul in Romans 15:24: "Whensoever I take my journey into Spain, I will come to you." In this sermon King is dealing with the fact that many times the things we want most in life, never come to fruition. Our deepest desires and our greatest dreams are often never realized. How should the moral agent respond under these circumstances? In the biblical text the Apostle Paul wanted desperately to

travel to Spain and to share the gospel in that country. In addition, he hoped to visit the church at Rome after leaving Spain, but he never got the opportunity to do either. Paul experienced "Shattered Dreams," and King's message to his listener is a word that ushers us toward a common reality. Those of us who share this mortal condition will also experience some "Shattered Dreams." When this happens, the moral agent has a choice to make, she can choose bitterness, detachment, and/or a fatalistic philosophy (*STL*, 91). But the better way, according to King, is to choose to honestly embrace the reality of your "shattered dream" and yet hold on to "a radiant hope," to have what Barak Obama calls, *The Audacity of Hope* (*STL*, 91).

It is this "radiant hope" that allows King to demonstrate what is to me, a surprisingly deep love for America. During King's struggle to lead the Negro toward sociopolitical justice, there were innumerable barriers and obstacles that could have led him into the state of bitterness that he describes above. And so, to avoid that bitterness King suggests to his followers that they need to develop a certain kind of vision, a "vision to see in this generation's ordeals the opportunity to transfigure both ourselves and American society" (*STL*, 93). He goes on to say, "our present suffering and our nonviolent struggle to be free may well offer to Western civilization the kind of spiritual dynamic so desperately needed for survival (*STL*, 93). To be sure, the trials and struggles that King talks about are endured by him personally. King summarizes his personal struggles this way:

> Due to my involvement in the struggle for the freedom of my people, I have known very few quiet days in the last few years. I have been imprisoned in Alabama and Georgia jails twelve times. My home has been bombed twice. A day seldom passes that my family and I are not the recipients of threats of death. I have been the victim of a near-fatal stabbing. So, in a real sense I have been battered by the storms of persecution. I must admit that at times I have been tempted to retreat to a more quiet and serene life. But every time such a temptation appeared, something came to strengthen and sustain my determination.

> I have learned now that the Master's burden is light precisely when we take his yoke upon us (*STL*, 152).

Despite the risks of harm and loss of life for himself and those close to him, King consistently spoke of his dreams of freedom, not for the Negro alone, but for all of America. The fight that the Negro was engaged in was a fight for a "finer America," and the goal of this army whose most powerful weapon was love, was to "banish the ugly blemish of racism scarring the image of America" (*STL*, 158).

Examples of a Clinician Moral Exemplar

Exploring the lives of Dorothy Day, Mitch Albom, and Martin Luther King has been an inspiring task. I have learned a lot about the kind of people they were, the ways in which they inspired others morally, and I am convinced that they are worthy to serve as moral exemplars for us today, to take their place in the great *cloud of witnesses* that is filled with our moral heroes of the past. But I think it is appropriate to end this section by writing about a contemporary clinician I have encountered, a woman that has "made a difference" for me personally.

Ashley Elizondo, D.D.S.

I have had every dental procedure known to man. Like most people, I have had simple things done to my teeth, cleanings and fillings, but I have also had extractions, root canals, bridges put in, and even implants. And I know that I am not close to being done with my dental escapades. Dental work is expensive, which is a significant barrier for many people, but it is also

emotionally taxing. Even for the experienced dental patient like myself, it requires courage on the part of the patient to stay with it. There were times I must admit, throughout the process of going back and forth to the dentist, of figuring out how I would pay for all of the procedures that I needed to have done, that I thought about giving up on having a functional set of teeth; I may have given up, if it were not for this clinician, Dr. Ashley Elizondo.

I had known of Dr. Elizondo for at least a couple of years before I became her patient. Her office is about two miles from my house, and I had been taking my kids to her dental office for all of their routine dental work, but I was seeing another dentist in the area. Over time I became disappointed and disillusioned with the dentist that I was seeing, and I decided to change dentists. Now there are several dentists that a new patient might be seen by in Dr. Elizondo's office, but thankfully I was assigned to her.

Before I ever sat in Dr. Elizondo's treatment room I knew that I would have a complex dental treatment plan. I had not had much dental attention during my childhood, I could only remember going to the dentist as a child once or twice. Unfortunately, when you are reared by a single parent with four other siblings, dental visits are not the top priority. The next time I remember having an encounter with a dentist was when I was an undergraduate, my first or second year in college. I had a very painful bottom molar that was preventing me from sleeping, eating, or concentrating, and I was taking a dangerous amount of Tylenol to mitigate the pain. I went to see an older dentist, a very kind grey-haired gentlemen that my mother knew, and after considering the cost of all of the proposed interventions, I chose the cheapest way of fixing the problem, a temporary fix, an extraction. This would be the first of several extractions that I would have over the years.

By the time I met Dr. Elizondo as a patient, I had been in and out of relationships with dentists, some relatively long, others quite short, but the trajectory of my dental health was certainly in a downward direction. I was very anxious about seeing her for the first time, partly because of what might be called the "stigma of poor dental hygiene." I felt ashamed that I had allowed my teeth to get this way, to be so bad. I prepared myself to endure the disgrace, whether overt or covert. But with Dr. Elizondo, I did not get the sense that she or her staff was judging me. Instead she took the time to listen to my concerns, and together, we put a long-term plan in place to ensure that I would have the best dental outcomes possible. The virtues of empathy, compassion, witnessing, courage, and love have all been demonstrated over the years by Dr. Elizondo, and here I rely on two of my experiences in her office to illustrate this point.

After my initial visit and evaluation, Dr. Elizondo and I set out on a journey together toward better dental health for me. One of the significant goals of my treatment plan was to enhance my ability to chew; I had missing molars at the bottom of my mouth, two on the left side, and one on the right side. In order to meet this goal, Dr. Elizondo suggested a great plan, to use my existing wisdom teeth as anchors for bridges that she would put in. With the execution of this plan I would have no missing spaces at the bottom of my mouth, and I would have the most functional bite of my adult life. I was pleased with the plan and we decided to proceed.

The bridge on the left was done first, and then the one on the right. Unfortunately though, the bridge on the right never really worked. It looked fantastic, but every time Dr. Elizondo would attach the bridge, it would work its way loose. She tried everything she knew to get the uncooperative bridge to work and even attempted to research why this might be happening. This went on for months, and I could tell that this complication really bothered her. She wanted me to be whole, to have the best possible outcome, but eventually we had to face the

reality that the original plan that we had would have to be altered. We were both disappointed, but I was encouraged by her sense of empathy and compassion for me. She also displayed courage during this period, because at some point she had to be brave enough to tell me that in spite of our best efforts, this part of the plan was not working, probably would never work. I appreciated her candid counsel.

The second story about Dr. Elizondo is a testament to her witnessing and love. I had been trying to figure out how to pay for all of the dental work that I needed and had decided to use my flexible spending account to set aside money specifically for my dental work. If you have every dealt with these bureaucracies you may know the pains of actually using these benefits. In short, dealing with these companies is more painful than going to the dentist. On the date in question I had some major procedures planned. I was beginning the process of having two upper-right implants put in, and I knew that I had more than enough money in my flexible spending account to have the work done. But when I attempted to use the card, the transaction was not approved. After speaking with someone over the phone, I found out that because of some technical issues, the funds would not be available to me until the next week. I was very upset, nearly in tears, actually in tears, and all of this was playing out in the dentist's chair. But I will never forget Dr. Elizondo's response to me that day. First, she took the time to listen to my concerns, she was a witness to my distress. Then she said "I don't care about the money right now; you can pay me later. You need to have this procedure done and we are going to start today."[228]

There are a lot of reasons why the onlooker might suggest that Dr. Elizondo continued with my treatment despite the fact that I could not pay my portion that day. That onlooker might

[228] I have allowed Dr. Ashley Elizondo to read this narrative about our experiences, to make suggestions and corrections where needed, and she has given her consent for me to use our story.

suggest that the fact that I did have dental insurance, I was gainfully employed, or had been faithful to pay my bills up to that point in our relationship, were the real reasons for her "altruistic behavior." But to know Dr. Elizondo, to be in her presence, to observe the way she interacts, not only with me but with all of her patients, is to really appreciate who she is. She really cares, and for her, it really is "not all about the money." She is a "good person," as well as a good dentist.

In this section of the chapter I have discussed the ways in which the moral imagination can be cultivated. I have discussed the role of parents and teachers in the process of moral growth and I have exhorted the reader to find for themselves some moral exemplars. In the next section I want to explore the second question for this chapter that deals with the assessment of the growth of the moral imagination. If the moral imagination is being cultivated and is growing, how do we know?

Assessing the Growth of the Moral Imagination

In the article, "The Medical Humanities as Contributing to Moral Growth and Development," Judith Andre tells us that thinking and research on the subject of moral development in "the twentieth-century European and American tradition begins with Jean Piaget."[229] Piaget's best known work "concerns cognitive development in children, but he also addressed moral development."[230] The "Piagetian stream," as Andre calls it, includes psychologists like Lawrence Kohlberg, James Rest, and Carol Gilligan.[231]

[229] Andre, "The Medical Humanities as Contributing to Moral Growth and Development," 42.
[230] Ibid.
[231] Ibid.

Lawrence Kohlberg is widely known for his *Philosophy of Moral Development* in which he lays out six stages of moral development. Kohlberg admits that his original intention for his dissertation was to "replicate Piaget's (1948) description of moral judgment stages, to extend them to adolescence, and to examine the relation of stage growth to opportunities to take the role to others in the social environment."[232] During the process of working on his dissertation Kohlberg expanded Piaget's two stages of moral development to six stages. He identified three levels of moral growth: preconventional, conventional, and postconventional.[233] Each of these levels contain two invariant stages. For Kohlberg moral development begins very early in life (stage one) and proceeds as the moral agent interacts with her environment and matures, hopefully to the highest level of moral judgement, stage six. All moral agents however, will not reach stages five or six. Kohlberg identifies some moral exemplars for us who were top level moral thinkers. This list includes men like Socrates, Abraham Lincoln, Henry David Thoreau, and Martin Luther King.[234] King, according to Kohlberg, is a stage-six moral thinker because, he like the other exemplars above, reached "autonomous morality." An example of King's stage six orientation can be seen in an excerpt from his *Letter from Birmingham Jail*:

> I have earnestly opposed violent tension, but there is a type of constructive, nonviolent tension which is necessary for growth. Just as Socrates felt that it was necessary to create a tension in the mind so that individuals could rise from the bondage of myths and half-truths to the unfettered realm of creative analysis and objective appraisal, so must we see the need for nonviolent gadflies to create the kind of tension in society that will help men rise from the dark depths of prejudice and racism to the majestic heights of understanding and brotherhood. The purpose of our direct action program is to create a situation so crises-packed that it will inevitably open the door to negotiation.

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[232] Kohlberg, *The Philosophy of Moral Development,* xvii.

[233] Kohlberg's Three Levels of Moral Development include the Preconventional (Stages One and Two), Conventional (Stages Three and Four), and Postconventional levels (Stages Five and Six). While some authors like Andre call Kohlberg's stages of moral development levels, Kohlberg clearly posited three levels, each level containing two distinct stages.

[234] Kohlberg, *The Philosophy of Moral Development,* 27.

> One may well ask: 'How can you advocate breaking some laws and obeying others?' The answer lies in the fact that there are two types of laws: just and unjust. I would be the first to advocate obeying just laws. One has not only a legal but a moral responsibility to obey just laws. Conversely, one has a moral responsibility to disobey unjust laws. . . Now what is the difference between the two? How does one determine whether a law is just or unjust? A just law is a man-made code that squares with the moral law or the law of God. An unjust law is a code that is out of harmony with moral law.
>
> In no sense do I advocate evading or defying the law, as would the rabid segregationist. That would lead to anarchy. One who breaks an unjust law must do so openly, lovingly, and with a willingness to accept the penalty. I submit that an individual who breaks a law that conscience tells him in unjust, and who willingly accepts the penalty of imprisonment in order to arouse the conscience of the community over its injustice, is in reality expressing the highest respect for law.[235]

This letter, originally written on the edges of a newspaper while King was in the Birmingham jail, is King's response to several white clergyman who called the activities of King and the other members of the Southern Christian Leadership Conference (SCLC) "unwise and untimely."[236] King, who had been invited to Alabama by the local chapter of the SCLC, was leading a nonviolent action program against injustice. The demonstrations that were led by King were made necessary because of the failure of city officials of Birmingham to engage in good faith negotiations regarding Negro civil rights efforts. The goal of nonviolent direct action was to foster negotiation. King expresses his discontent with white moderates as well as the white Church for their failure to support the Negro civil rights efforts and he explains why it is necessary, even morally obligatory, to disobey morally unjust laws.

Martin Luther King is a stage-six moral thinker, according to Kohlberg, because his moral reasoning is oriented toward "universal ethical principles."[237] The particular universal

[235] Martin Luther King, Jr., *Letter from Birmingham Jail*, (London, UK: Penguin Books, 1964), 12.
[236] Ibid., 6.
[237] Kohlberg, *The Philosophy of Moral Development,* 19.

principle that is of concern for Kohlberg, the principle that all of his research focuses on, is the principle of justice. *Justice* is a principle that guides the moral agent in "resolving competing claims."[238] It is a principle that guides the moral agent to "treat every person's claim impartially regardless of the person."[239] This principle is "not only a rule of action but a reason for action. As a reason for action, justice is called *respect for* people."[240] Like Plato, John Dewey, and Piaget before him, Kohlberg "recognized justice as a structure, a pattern of equilibrium or harmony in a group or society."[241] A stage six orientation in Kohlberg's theory of moral development is achieved when the moral agent's reasoning focuses on the universality of "the equality of human rights" and "the respect for the dignity of human beings as individuals."[242] King "was a moral leader, a moral educator of adults, not because he was a spokesperson for the welfare of blacks, not because he was against violence, not because he was a minister of religion, but because, as he himself said, he was a drum major for justice. His words and deeds were primarily designed to induce America to respond to racial problems in terms of a sense of justice, and any particular action he took had value for this reason, not just because of the concrete political end it might achieve."[243]

For various reasons Martin Luther King was a post conventional moral thinker in Kohlberg's scheme, the ultimate type of moral thinker. King along with other thinkers like Lincoln and Socrates reached this highest level of moral reasoning, but Kohlberg also suggests that most people in a given society will not reach this highest level. The following case study will allow for the exploration and explication of Kohlberg's entire theory.

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[238] Ibid., 40.
[239] Ibid.
[240] Ibid., 140.
[241] Ibid., 40.
[242] Ibid., 19.
[243] Ibid., 38.

The Heinz Dilemma

Kohlberg and his colleagues performed longitudinal research on seventy-five American boys beginning in early adolescence.[244] In addition, their work included cross-cultural studies of the same kind in Taiwan and Mexico. Their methods included the use of case studies that were presented to their subjects and the subject's responses were recorded and graded (classified as Stage 1-6). These cases, which were used because of their moral content, allowed the subjects to reason about the morally appropriate thing to do in a given situation. The Heinz Dilemma is a well-known case from Kohlberg's work:

> In Europe, a woman was near death from a very bad disease, a special kind of cancer. There was one drug that the doctors thought might save her. It was a form of radium that a druggist in the same town had recently discovered. The drug was expensive to make, but the druggist was charging ten times what the drug cost him to make. He paid $200 for the radium and charged $2000 for a small dose of the drug. The sick woman's husband, Heinz, went to everyone he knew to borrow the money, but he could get together only about $1000, which was half of what it cost. He told the druggist that his wife was dying and asked him to sell it cheaper or let him pay later. But the druggist said, "No, I discovered the drug and I'm going to make money from it." Heinz got desperate and broke into the man's store to steal the drug for his wife.[245]

After reading the Heinz case research subjects would be asked to evaluate the husband's actions. Was the husband right or wrong for stealing the drug for his wife and why? The responses of the research subjects helped Kohlberg and his colleagues determine what level of moral reasoning the subjects had achieved. The ultimate goal for all moral agents is that they reach stage-six moral reasoning which is demonstrated by an autonomous adherence to a universal ethical

[244] Ibid., 16.
[245] Ibid., 12.

principle. Autonomy for Kohlberg is essential because it demonstrates that moral decisions are "decisions of conscience in accord with self-chosen ethical principles appealing to logical comprehensiveness, universality, and consistency."[246]

The first level of moral reasoning in Kohlberg's theory is the *preconventional level*. This level contains the first two stages, *stages one and two*. At the *preconventional level* "the child is responsive to cultural rules and labels of good and bad, right or wrong, but interprets these labels in terms of either the physical or the hedonistic consequences of action."[247] The child that is at *stage-one* in Kohlberg's scheme, which is a "*punishment and obedience orientation*," will not think that Heinz is right to steal the drug for his wife. Because it is illegal to steal and Heinz risks being caught and sent to prison for stealing, the stage-one child reasons that this act is morally wrong. At *stage two*, "the *instrumental relativist orientation*, right action consists of that which instrumentally satisfies one's needs and occasionally the needs of others."[248] The *stage-two* thinker would support Heinz's stealing of the drug for his wife, because the wife is instrumentally valuable to the husband. Heinz needs his wife to cook and clean for him, so he should steal the drug to save her life, not because she has intrinsic value as a human being, but because of what might be instrumentally lost upon her death.

The second level of moral reasoning in Kohlberg's theory is the c*onventional level*. This level contains *stages three and four*. At the *conventional level* "maintaining the expectations of the individual's family, group, or nation is perceived as valuable in its own right, regardless of immediate and obvious consequences."[249] The moral agent that has reached *stage three*, the "*interpersonal concordance orientation*," will support Heinz's stealing of the drug because

[246] Ibid., 19.
[247] Ibid., 17.
[248] Ibid.
[249] Ibid., 18.

husbands are supposed to love their wives. Inherent in this idea of loving one's wife is the willingness to provide for her needs, even if it means stealing. At this stage of moral reasoning what is most important to Heinz's is his relationship to his wife, the fact that they are of the same family. It is morally permissible to steal the drug for his wife, but Heinz's action would be impermissible if she were not related to him. Once the moral agent reaches *stage four*, a "*society maintaining orientation,* there is an orientation toward authority, fixed rules, and the maintenance of the social order. Right behavior consists of doing one's duty, showing respect for authority, and maintaining the given social order for its own sake."[250] The *stage four* moral thinker steals the drug for his wife and justifies his actions based on influences other than the universal value of human life. For example, the moral agent may be influenced by religion (e.g., his wife is a child of God) and the sense that his religion requires a respect for God's authority. Heinz's respect for God's authority entails placing a higher value on human life over the value property or money.

The highest level of moral reasoning according to Kohlberg is *level three,* the *postconventional level*. This level contains *stages five and six*. At the *postconventional level* "there is a clear effort to define moral values and principles that have validity and application apart from the authority of the groups or people holding these principles and apart from the individual's own identification with these groups."[251] At *stage five*, the "*social contract orientation,* right action tends to be defined in terms of general individual rights and in terms of standards that have been critically examined and agreed on by the whole society."[252] Heinz would steal the drug for his wife and reason that this stealing is justified not because she is his

[250] Ibid., *18.*
[251] Ibid.
[252] Ibid.

wife, but because her life has "inherent value, whether or not it is valued by a particular individual."[253] At *stage five* Heinz is justified in stealing the drug whether it is for his wife, a distant relative, a coworker, or even a complete stranger. The focus at this level of moral reasoning is on the social contract. Moral agents recognize that they have certain individual and inalienable universal rights, but so do other moral agents in a society. Along with the rights of the individual, each person in a given society has a duty not to infringe upon the rights of others. *Stage six* is the final stage, the "*universal ethical principle orientation*." This is the stage that I mentioned above in relation to Martin Luther King. At *stage six* "right action is defined by the decision of conscience in accord with self-chosen ethical principles."[254] Once Heinz reaches *stage 6,* whether or not he should steal the drug to save a life is an easy choice. The value of human life, any person's life, is "absolute in representing a universal and equal respect for the human as an individual."[255] The moral agent is not concerned with obeying rules and avoiding punishment, but she makes decisions that help her avoid self-condemnation.

For Kohlberg's theory the *six stages* "represent an invariant developmental sequence."[256] These stages are experienced by the moral agent one at a time and occur sequentially. For instance, *stage five* cannot be reached before *stage four*. Stage movement is also never regressive, moral agents are always moving forward from stage to stage. Kohlberg does allow however for the possibility that a moral agent may hold place in more than one stage at a time, as the person moves from one stage to another. "Children," Kohlberg says, "may move through

[253] Ibid., 22.
[254] Ibid., 19.
[255] Ibid., 22.
[256] Ibid., *23.*

these stages at varying speeds and may be found half in and half out of a particular stage."[257] Individual development may stop at any given stage.

Kohlberg's theory of moral development is valuable as a comprehensive and systematic way of assessing the growth of the moral agent. Kohlberg's work offers those who are interested in the moral development of their children and students ways of thinking about a subject that needs intentional focus. Moral instructors focus on content, but how can they assess whether or not they are being effective? Kohlberg reminds us that advancement in chronological age does not equate to progress in moral development, but his theory and empirical research gives us insight into the kinds of moral development that can take place during childhood, adolescence, and even into the young adult years. If we take Kohlberg seriously we understand that moral development takes place in stages that are sequential and that there is a step-wise process for both learning and teaching. Children do not move from *stage one* to *stage four* for instance. Discussions with children and students should be tailored with this idea in mind so that the movement to the next stage in moral development is facilitated.

Floyd (George Floyd): A Real Person Whom I Remember

The death of George Floyd while in the custody of four Minneapolis police officers has brought America once again to a very sad day. Personally, I am melancholic and mournful. I met Floyd (people who knew him personally never called him by his first name) for the first time during the summer of 1989 when he, along with other in-coming freshmen football players, reported to camp at Jack Yates High School, in the Third Ward section of Houston, Texas. I

[257] Ibid.

would be a junior that year when school began in the fall. I do not pretend to have had a really close relationship with Floyd nor did I spend much time with him away from football. I can say though, that the following year in 1990, Floyd along with several other sophomores, would be a critical asset to our varsity football team and a key part of our success during my senior year. I remember thinking during that year just how special their group would be when they rose to be seniors themselves; that team eventually played for the state championship in the fall of 1992. I remember attending that game.

Floyd was a great athlete, always the tallest person on the field, and he had a great pair of hands. As one of the captains of the football team my senior year, I remember him as a good follower and an all-around good kid. He did not give us any trouble. He was thoroughly liked by all the players and coaches, and he smiled a lot. It had been nearly thirty years since I had even heard Floyd's name. Like so many of the people we know in high school, even people in our own graduation class, his name seemed to be buried in my personal history. His name was buried until Tuesday, May 26, 2020, when I somehow heard about an African American man who had died in the custody of four Minneapolis police officers, one of whom had his knee on the man's neck. The details that I heard were intriguing, and because I do not make a habit of watching news on television, I searched the internet for details and a possible video of the incident. What I saw shocked me and my immediate response about the officers was, "They all should go to jail for this crime." But no exclamation point. I shut the video off and dismissed the event as "another black man dead on the streets."

I admit that although Floyd's face looked somewhat familiar to me, I quickly dismissed the possibility of knowing him, probably because this event happened in Minnesota, and I was in Texas. I did not realize that I actually knew the man in the video until I was prompted by a close

friend, a friend who follows Texas high school football closely, to take a second look. He had seen the local news in Houston, highlights of Floyd's career at Yates, heard that he had graduated in 1993, and knew that I had to have known this man in the video. I got the call on Wednesday morning as my friend and I were both drinking coffee (this is our usual way of keeping up with each other), and this friend made me know that I had a personal connection with this incident in Minnesota. The George Floyd on television was "Floyd," my former teammate at Yates high school. Knowing that information, for me, made all the difference. I had an emotional response that lasted for days, a mournful brooding that I could not shake. Even now, more than two weeks after I made the connection, when I sit and think about all that has happened and is happening in this country, I remember and am sad.

But my sadness extends beyond the facts that surround Floyd's death, as tragic as it is and as traumatic as it is to watch on video. I am sad for several other reasons. First, I am sad because of my initial response to the incident when I thought that I did not know the man in the video personally. To me at that time he was just, merely, "another dead black man in the streets." I am disturbed at my sense of comfort with the idea that it is somehow "normal" or common to see this result over and over again. I'm disappointed in myself, the healthcare professional, the humanist.

I am also sad because of the unrest that the country is now experiencing, not the protests, because there should be protests and an upheaval of the kinds of injustice that allow deaths like Floyd's to occur. But I am disturbed with the burning of infrastructure, the looting of stores, and the lack of clear and cogent leadership from so called civil rights groups (e.g., Black Lives Matter).

And I am sad because of the conversation I had to have with my sixteen-year-old son; my son, who is learning to drive now and has his learners permit, who will soon be driving on his own, driving perhaps sometimes after dark. We sat down the other day and had a conversation that I have heard other black men talk about having with their sons, and knew that I would one day have to have with my own. The conversation might be entitled, "What to do if you are Stopped by the Police." We had our conversation and as is my custom when I speak to my kids, I try to ask them questions about what they know about a topic before the dialogue starts. I asked my son, "What would you do if you were stopped by the police?" His response, what he had to add to the conversation, "Keep my hands on the steering wheel." His response gave me pause, because my intentions were not to talk to him about the logistics of such an encounter, but to speak to him about his demeanor, his deportment with police officers. I wanted to remind him of the things that his mother and I have taught him his whole life: be respectful, say "yes sir" and "no ma'am," be compliant and follow directions. I wanted him to know that the time to argue, even when you think you are right, is not on the side of the road; arguments are for courtrooms. Above all, what I wanted to convey to him was, in the words of one of the black elders of my church, "survive the incident," or in my own words, "Get your black butt home safely."

Can Kohlberg help us in the twenty-first century, in times like these? I think so. Kohlberg claims that the highest level of moral judgment is *stage six,* which represents the point at which the moral agent appeals to universal ethical principles.[258] For Kohlberg, examples of these principles are well-known articulations like the Golden Rule or Kant's categorical imperative. Also, at stage six, right moral decisions are decisions of conscience and these

[258] Kohlberg, *The Philosophy of Moral Development,* 19.

decisions are made in light of the universality of justice, the reciprocity and equality of human rights, and respect for the dignity of human beings.

What Kohlberg is calling for is not for all human beings to love each other or even to like each other, but to, at minimum, respect each other as human beings. His work reminds us of the need to support our children's moral growth through adolescence and into young adulthood, the growth of their consciences. Our goals in moral instruction and moral living should be to reach the point at which we can embrace the fact that all human beings have basic human rights and that as moral agents we are obligated not to infringe upon those rights.

The moral imagination as I have articulated it in this project, a principle for living, is also very helpful here. If the moral agent is serious about developing moral competence then she has an ever-expanding vision of who she has a moral duty towards. This expanding horizon will allow her to consider what it might be like to be the other, whether or not that person is experiencing a particular type of distress. The moral imagination then has an effect on how we treat other human beings, but also effects the types of conversations that we have with the other. Our dialogues can be respectful and dignified even when we vehemently disagree. In times like these we need moral agents that are serious about their personal moral development, serious about development their moral imaginations.

In A Different Voice

For American feminist, ethicist, and psychologist Carol Gilligan the "essence of moral decision" and moral development is about moral choice, but in order to express a choice, a voice

must be heard, a voice must be included in a conversation.[259] This is Gilligan's major argument against Lawrence Kohlberg's *Philosophy of Moral Development*. In the similitude of Freud and Piaget, the voices of women in Kohlberg's work were marginalized to the periphery of conversations about moral development, or their voices were absent altogether. In developing his *Philosophy*, Kohlberg admits that he and his colleagues studied "seventy-five American boys from adolescence on" and they studied these male subjects into adulthood.[260] The male subjects were "continually presented with hypothetical moral dilemmas" to determine their level of moral stage development. So as Gilligan's work on moral development emerges, she is positing a novel or previously ignored way of seeing moral development, a way of seeing that includes women's voices; ultimately she calls this way of seeing moral development an e*thic of care*.

Because women's voices had been excluded from the critical or essential theory-building studies of psychological research up to this point, the experiences of men, white men, had been taken up as representative of all human experience.[261] Furthermore, in a more general way, in a male-voiced civilization, a patriarchal world, women have to struggle to find their voices and must resist the temptation to qualify or doubt their voices. "Listening to women," Gilligan says, "I heard a difference and discovered that bringing in women's lives changes both psychology and history. It literally changes the voice: how the human story is told, and who tells it."[262] An *ethic of care* as Gilligan conceives it is more in line with the way women make moral judgements because it points to a relational ethic. Much more prevalent when Gilligan first published this work, but still relevant today, women have been seen as "nurturer, caretaker, and

[259] Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Cambridge, MA: Harvard University Press, 1982), 67.
[260] Kohlberg, *The Philosophy of Moral Development*, 16.
[261] Gilligan, *In a Different Voice,* xiii.
[262] Ibid., xi.

helpmate, the weaver of those networks of relationships on which she relies."[263] Women have both defined themselves and judged themselves based on these relational connections. It is then not difficult to understand the significance that women place on relationships when they make moral judgements. Men however, based on Kohlberg's theory, reach higher levels of moral development as they get closer to independence or autonomy.[264] Indeed the highest level of moral development for Kohlberg is reached when the moral agent makes decisions that are "self-chosen."[265] Gilligan is not arguing that women or men make moral decisions in one particular way to the exclusion of all other ways, but that the inclusion of women's voices allows for a deeper and richer way of understanding how moral decisions can be settled on by either gender. Gilligan sees the 1973 Roe v. Wade decision and its subsequent thrusting upon women the right to choose and the responsibilities for the choices they make in the area of sexual reproduction, as a watershed moment not just in the area of women's rights, but in the area of psychological theory development. Roe v. Wade provided the twin opportunities of choice and voice for women. One of the studies that Gilligan relies on heavily to develop the *ethic of care*, is the *abortion decision study*, a study that she herself conducts, which allows her to see the emergence of "different modes of thinking about morality" and "different views of the self."[266]

Again, Gilligan is careful to posit a construct of moral developmental that is broader than a gender-based theory. The e*thics of care* that she envisions, she admits, was primarily based on research that was done with women subjects and the voices of women were used to document its development.[267] But Gilligan sees the implications of her work as being much broader than

[263] Ibid., 17.
[264] Kohlberg, *The Philosophy of Moral Development*, 18.
[265] Ibid., 19.
[266] Ibid., 3.
[267] Gilligan, *In a Different Voice, 2.*

explaining gender-based differences in moral judgement. In the opening pages of her book, *In a Different Voice*, Gilligan makes this point clear. "My interest," Gilligan says, "lies in the interaction of experience and thought, in different voices and the dialogues to which they give rise, in the way we listen to ourselves and to others, in the stories we tell about our lives."[268] So Gilligan is leading us not just to include the voices of women in psychological research about moral development, but to include the Other, to include all excluded voices. When we fail to hear the Other, whether the Other's voice is female, or poor, or disabled, we fail to consider the ways in which our constructions, be they psychological, educational, social, or economic, are limited.

"Come what may, I'll do what's right!"

Ethics is about action. Pojman and Fieser remind us that "ethics has a distinct action-guiding aspect, and, as such, it belongs to the group of practical institutions that includes religion, law, and etiquette."[269] In this section of the chapter I am attempting to address the issue of how we can know that a moral agent is growing, developing, making progress. Kohlberg answers this query by offering us stages of moral development that he developed philosophically, and then proved empirically. But Kohlberg's proofs are based on theoretical Socratic questions that are asked to a group of all male test subjects under ideal or controlled circumstances, and those responses may not tell us a lot about what these same subjects would actually do when presented with real life moral dilemmas. The advancement of research subjects through the various Kohlbergian stages also seems to be significantly contingent upon a person's

[268] Ibid.
[269] Pojman and Fieser, *Ethical Theory: Classical and Contemporary Readings*, 2.

socioeconomic status. During Kohlberg's cross-cultural research, "middle-class children were found to be more advanced in moral judgment than matched lower-class children."[270] Kohlberg posits that "middle-class children and working-class children move through the same sequences, but the middle-class children move farther and faster."[271] Kohlberg explains this difference by referring to the children's opportunities for *role taking*. Psychological *role taking* as Kohlberg defines it, is the "tendency to react to others as to the self, and to react to the self's behavior from the other's point of view. The centrality of role taking for moral judgement is recognized in the notion that moral judgment is based on sympathy for others, as well as in the notion that the moral judge must adopt the perspective of the 'impartial spectator' or the 'generalized other.'"[272] Opportunities for role taking are more plentiful in "certain types of middle-class families" as opposed to lower-class families or village cultures.[273]

The first chapter in Coles' book, *The Moral Life of Children*, is entitled "Psychoanalysis and Moral Development." In that chapter Coles admits that when he first began to follow children like Ruby Bridges and her white counterparts in the 1960s in the American South, he was determined to see their lived experiences through the same types of psychological "stages, and phases and periods" that we see in Piaget's and Kohlberg's work (*MLC*, 25). But eventually, after much exhortation from his wife, he begins to focus in on the "acts of these boys and girls, the deeds they manage" (*MLC*, 25). Many of the subjects that Coles followed were poor and had parents who were marginally educated, but these individuals, many of them, demonstrated remarkable moral stamina and moral leadership. Many of these same subjects, because of their

[270] Kohlberg, *The Philosophy of Moral Development*, 24.
[271] Ibid., 25.
[272] Ibid., 141.
[273] Robert Coles, *The Moral Life of Children* (New York: Atlantic Monthly Press, 1986), 27. All subsequent references to The *Moral Life of Children* in this chapter will be cited in the text parenthetically, with the abbreviation *MLC*, followed by the page number.

age, socioeconomic status, or "cognitive inadequacies" would not fare well in Kohlberg's scheme of things (*MLC,* 26). As Coles makes his point about the importance of moral action he is reminded of one particular youth, a white adolescent, who was the first white student to speak to and eventually defend a black student in one of Atlanta's desegregated high schools. Coles points out that this young man "had never been presented with all those moral situations freighted with twists and turns, alternatives and possibilities! He'd never been asked to say what he'd do if . . ." (*MLC*, 26). As Coles interviews the young man he notices a change in both thought and action as he experiences a real-life moral dilemma:

> The young man found himself, inexplicably and suddenly, without forethought (he later had to acknowledge this condition repeatedly, when asked by me and others), impelled to help out "a nigger" (the words of the helper!). He described the incident (and himself) in this way: "I didn't want any part of them here. They belong with their own, and we belong with our own – that's what we all said. Then those two kids came here, and they had a rough time. They were all by themselves. The school had to get police protection for them. I didn't hold back, no more than anyone else. I said, 'Go, nigger, go,' with all the others. I meant it. But after a few weeks, I began to see a kid, not a nigger – a guy who knew how to smile when it was rough going, and who walked straight and tall, and was polite. Then it happened. I saw a few people cuss at him. 'The dirty nigger,' they kept calling him, and soon they were pushing him in a corner, and it looked like trouble, bad trouble. I went over and broke it up. I said, 'Hey, cut it out.' They all look at me as if I was crazy, my white buddies and the nigger, too. . . Soon he was championing him personally, while still decrying "integration." Finally, he would become a friend of black youth's and advocate "an end to the whole lousy business of segregation" (*MLC*, 28).

For Coles, these are the types of experiences that determine whether or not the moral agent is growing. The actions of the moral agent when confronted with real life moral dilemmas are much more meaningful than responses to well-crafted research questions asked by an examiner. What seems to be especially important to Coles is the spontaneous or serendipitous nature with which these changes in thought and action

occur. The "suddenness" that Coles mentions above is emphasized in other places in Coles' work. In the *Afterword* of *Lives of Moral Leadership* for instance, Coles focuses on the importance of the "suddenness" of our moral actions. As we make moral decisions, decisions to do what is right, we often times do so "suddenly" and therefore surprise those around us and surprise ourselves. What Coles is trying to exhort all of us to become is a moral exemplar or moral hero, right where we are, to "take hold of our lives morally, give them shape – to become our own moral leaders as well as ones eager to take note of others" (*LML*, 245). In that same afterword Coles records this quote from one of his interviewees, "Come what may, I'll do what's right!" (*LML*, 245). The statement was quoted from a school-aged girl who had watched her African American mother lead her to a recently desegregated school in New Orleans. The mother was determined to get her child the best education possible despite the angry mobs that gathered daily outside the school and hurled insults at the African American parents and children. When asked by school officials if she planned to continue to bring her child to school the mother, in her child's hearing, had said, "Yes I will, I will because it's up to me to lead my child, so that she can lead others by showing she'll do the right, come what may" (*LML*, 245). The nameless school-aged girl takes her mother's "come what may," according to Coles, and turns it into her own statement of determination, "Come what may, I'll do what's right" (*LML*, 245).

For Coles, the assessment of moral growth has to do with the decisions that we make as moral agents and the actions that are tied to those decisions. This mother's decision to "stick with it" despite the difficulty she faced daily is an example to her child who is watching and following. Coles reminds us that our moral reflection about

hypothetical “what ifs” are not meaningful unless they lead us to moral action that others can take note of.

In this chapter I have dealt with two questions. First, I have talked about how the moral imagination can be cultivated. I have pointed to the role of parents as the moral agent’s first instructors in morality and I have included teachers as a part of the essential core of moral instruction. I also discussed the role of medical humanists and their unifying educational goal of cultivating the moral imagination. Moral learning and moral development begin very early in the life of the moral agent and can continue throughout the life span. Secondly, in this chapter I addressed the ways in which the growth of the moral imagination can be assessed. It is important for those who engage in moral instruction to have some sense of how they will know that the moral agent is growing.

In the next chapter I will focus more specifically on a particular way of cultivating the moral imagination. Chapter three will deal with the use of narratives, particularly narratives of illness, in moral growth.

Chapter 3
Using Narratives to Fertilize the Moral Imagination

Lord, let it alone this year also, till I shall dig about it, and dung it: And if it bear fruit, well: and if not, then after that thou shalt cut it down.

Luke 13:6–9, King James Version

We all remember in our own lives times when a book has become for us a signpost, a continuing presence in our lives.

Robert Coles, *The Call of Stories*, pg. 68

Jacob Wrestles with God

The story of the life of the biblical character Jacob is one of the most significant Old Testament stories in all of Scripture. Of course the whole Bible is a story, told in sixty-six separate books, the moral of which can be found in one verse, John 3:16. Jacob's story is significant for this current project because it is a model of what Arthur W. Frank means when he points us to the power of the *Wounded Storyteller*.

Jacob was the twin son of the Old Testament patriarch Isaac and his wife Rebekah. Jacob's name means "one who supplants" or "the heel-gripper," and early in his life Jacob is determined to live down to his name. When he and his older brother Esau are born, Esau comes our first, but Jacob is seen clutching his brother's heel. As the eldest son in the family Esau should have had the birthright – special privileges belonging to the firstborn male in the family, including a double portion of the estate as an inheritance - but Jacob takes advantage of his brother's weakness and grabs the birthright from him. The final straw for Esau would be Jacob's stealing of his father's blessing from him. As Isaac grows old in age, he calls Esau to his side, as Near Eastern custom would have it, to prepare to pass on to him the paternal family blessing.

The blessing that Esau looked forward to would be both social and economic, it would contain declarations of power and wealth. But before Isaac could bless Esau, Jacob along with his mother Rebekah, devise a plan to deceive Isaac and have him bless Jacob instead of Esau. The deceptive plan of Rebekah and Jacob works, Isaac unknowingly blesses Jacob rather than Esau, but when the trickery is discovered, Esau promises to kill Jacob. Fearing for Jacob's life, Rebekah sends Jacob away until Esau's wrath can be abated.

It would be twenty years before Esau and Jacob saw one another again face-to-face. Jacob is now on his way back to his home country, and Esau, who knows that Jacob is on his way home, sets out to meet him along with four hundred of his own men. Jacob by this time has two wives and eleven sons and fearing for his life and the lives of his family he separates from them and is left alone. Being alone Jacob has time to think about who he has been in the past, and the impending meeting between him and his brother. It is not until Jacob is left alone that he encounters the angel of the Lord and he wrestles with the angle all night long. This wrestling for Jacob is a spiritual matter because Jacob is wrestling with the type of person he has been in his past as much as he is struggling to become someone new. During the wrestling match Jacob is *wounded*, he is crippled, and as a result of his *wound*, he limps for the rest of his life. In addition to *the wound* that Jacob receives he also has his name changed from Jacob (the heel-gripper) to *Israel* (Prince with God). What a fantastic and remarkable event! The only problem that Jacob has is a problem of evidence. Because Jacob was left alone, he is the only living witness to this episode. How can he prove all these remarkable things that have taken place? In the future when people ask him about his limp and he tells his story, his *wound* will be "the evidence that

his story is true."[274] Jacob has become a *wounded storyteller* and the power of his testimony comes from his *wound*.

Beginning in the second half of the twentieth century many other storytellers began to share out of their own sense of *being wounded*. These storytellers were not wounded while wrestling with an omnipotent God, but their wounds were the result of struggling through illness experiences. Like Jacob many of these storytellers experienced a personal change during their struggle with illness and the evidence of that change is *the wound* that they carry.

In a similar way as Arthur Frank I want to argue in this chapter that stories about illness experiences, what I choose to call *pathographies*, have certain moral import. In short, they can be used to fertilize the moral imagination as I have defined it above. These stories can have a significant amount of moral value for all moral agents in *the public*, but for the clinician, they can have particular utility. Other stories like novels have long been recognized as having a certain moral weight. I claim here that pathographies can do a similar type of work.

The Moral Work That Novels Do

Robert Coles in his book, *The Call of Stories: Teaching and the Moral Imagination*, tells us how important all kinds of stories, both oral and written, can be. This is a common theme in Coles' work and Coles himself is a good storyteller. What kinds of stories call us? Coles begins the book in its introduction by telling his reader a story that is couched within a larger narrative. The first story is about how Coles and his brother, both of them children at the time, were influenced by their parents' reading of literature to one another, his father reading to his mother

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

and his mother reading to his father, out loud, in their home. Coles admits that this habit of his parents was at first somewhat irritating to both him and his brother, but he also acknowledges that the practice had great positive influence on them both. This first story is enveloped within a larger narrative that deals with the kinds of stories families tell one another. Many of these stories do not come from books, but are what I would call oral autobiographical stories. They are stories that are told primarily by parents to their children that help children develop a sense of what is right and wrong, a sense of what things in life are important and not so important, an understanding about how people *ought* to be treated, and stories about who counts in life and who does not. For Coles, these types of stories have great moral import.

As a trained pediatrician and psychiatrist Robert Coles is also concerned with another type of story, the stories of his patients, particularly his psychiatric patients. Early on in his psychiatric training Coles feels the tension of two ways of understanding the role of his profession. His two mentors, one who instructs Coles to dig deeper into the scientific theories of psychiatry, and the other who encourages him to listen to the biographical stories of his patients, bring Coles to a crossroads in his own development as a clinician. Eventually Coles recognizes for himself that the seeds of the problems of his most troubled patients lies in their own stories, stories that they must be allowed to articulate.

But the kind of stories that Coles is most taken with, at least in his project mentioned above, is the novel. By the time Coles begins to teach his course "Literature in Medicine" at Harvard Medical School in 1974, he is convinced that novels have a unique ability to shape the moral imagination.[275] Coles' conception of the moral imagination begins with the intentionality

[275] Robert Coles, *The Call of Stories: Teaching and the Moral Imagination* (Boston: Houghton Mifflin Company, 1989), 94. All subsequent references to *The Call of Stories* in this chapter will be cited parenthetically in the text, with the abbreviation *TCS*, followed by the page number.

of the authors of novels. Great writers of novels attempt to make certain moral points about their own "sense of life" or how one *ought* to live. The power of these well-crafted stories to influence the reader long after class discussions are over so that even when all the coursework is done, students reflect on the influence of these stories on their lives. Students, not all of them but a significant number of them, report that these stories have become tools for moral reasoning, that the characters in these stories have become their companions, and that these characters speak to them and are spoken to. This is the way in which stories call us. Coles has a great affinity for novels and the moral work that they do. I would characterize his feelings for novels with words like *reverence* and *affection*.

Martha Nussbaum on the other hand would agree with everything Coles has to say about the moral import of novels, but she would want him to say these things with more depth and more passion. If Coles has an affinity for novels, Nussbaum loves novels deeply. In the volume of her essays, *Love's Knowledge*, Nussbaum uses the introduction of the volume, "Form and Content, Philosophy and Literature," to express her deep love for the genre of novels and to explain why the novel is such a useful tool in moral instruction. Nussbaum's overarching argument has to do with the inclusion of the novel as one essential part of moral inquiry and she purports that the form and style of writing about the moral life is just as important as the content of such writing. Nussbaum contrasts the common form and style of Western moral philosophy with other forms, tragic poetry and the novel, that she considers more suitable to express the ethical dynamics of real life. The form and style of Western philosophy is significantly influenced by the natural sciences and this influence has led to moral theory that attempts to be scientific, abstract, general, and universalizable. For Nussbaum, the choice of form itself is a statement, a choice about what is and is not important to the author and for her intended

audience. Nussbaum is not arguing that the novel should replace moral philosophy, but that the novel must be included in any serious investigation of the ethical life. Novels are superior to other forms because they are works of literary art – the artist can intend certain responses from his audience - they touch the emotions, they focus on the development of the soul or they speak to the heart, and they give priority to the particular. For Nussbaum, the love in *Love's Knowledge*, is a *type* of emotion, it represents all of the other emotions, and is used to demonstrate how emotions can be intelligent. Love and the other human emotions are intelligent and essential to live the good human life and a focus on ethics without attention to the emotions is incomplete.

Novels are books that can be read and reread. They have characters that both speak to the one who reads, and these characters can be spoken to. Coles' students describe these stories as "becoming a part of you" or "staying with you" and the students describe a sense of "getting lost" in these books. The students also testify to trying to determine which characters in these books they most resemble. As the writer has certain moral intentions for her readers, the writer and reader enter a type of "moral communion" and are "in cahoots" with each other. (*LML*, 65).

The fact is that Nussbaum is significantly influenced by Aristotle and what she calls the "Aristotelian ethical view."[276] Nussbaum believes that Aristotle's *sense of life* can be found in many of the best novels. This Aristotelian view includes several characteristics: a non-commensurability of the valuable things, a priority for the particular, the ethical value of the emotions, and the ethical relevance of uncontrolled happenings.[277] First, what does Nussbaum mean by the "non-commensurability of the valuable things," how do novelist make this point?

[276] Martha C. Nussbaum, *Love's Knowledge: Essays on Philosophy and Literature* (New York: Oxford University Press, 1992), 35.

[277] Ibid., 43.

The novelist, according to Nussbaum, helps her reader see the complex nature of real life by avoiding the fallacy that life can be reduced to quantitative choices.[278] Often times in real life the moral agent is presented with "two qualitatively different actions or commitments" and because of the circumstances of life, the moral agent must choose one course of action over the other.[279] The novelist is an expert at presenting his reader with these types of moral dilemmas.

The literary artist in crafting novels also focuses on the particular – "the ability to discern, acutely and responsively, the salient features of one's particular situation."[280] The focus on the particular is in sharp contrast to a Western philosophical attempt at moral inquiry that is general and abstract. A focus on the particular prepares the moral agent to respond to "new and unanticipated features" of a given dilemma, pay attention to the "context embeddedness of relevant features" and to give attention to the "ethical relevance of particular persons and relationships."[281] A focus on traditional moral philosophy does not lead the reader into this type of deep moral inquiry as preparation for dealing with ethics in real life.

Another salient feature of the novel is the way in which the novelist activates the emotions. Nussbaum is thoroughly interested in the intelligence of the emotions and she is pushing back against the idea that the emotions are not trustworthy. This a part of her larger project of resisting the deeply entrenched remnants of Cartesian dualism. Nussbaum believes, as did Aristotle, "that practical reasoning unaccompanied by emotion is not sufficient for practical wisdom; that emotions are not only no more unreliable than intellectual calculations, but frequently are more reliable, and less deceptively seductive."[282] The novelist helps his reader

[278] Ibid., 36.
[279] Ibid., 37.
[280] Ibid.
[281] Ibid., 38.
[282] Ibid., 40.

understand the inescapable convergence of cognition and emotion and this is important preparation for dealing with ethics in real life.

Lastly, the novelist focuses on the "ethical relevance of uncontrolled happenings," or what might be called *contingency.* The moral agent learns by engaging with these books that life is filled with *contingency*, that the most well laid plans in life are subject to change, and many times, to drastic change. The way that these unplanned and uncontrollable events can shape a life, and the moral agent's response to these events, are morally significant.

For scholars like Coles and Nussbaum the novel is an invaluable resource of moral inquiry. Both of these thinkers were introduced to novels at a very early age, but Nussbaum describes her relationship to these books in the similitude that one would describe a very close friendship. Her "serious" and "solitary" childhood is filled with these books and she reads them with "love" and she thinks "about many questions."[283] The largest of these questions is what many would call a philosophical question, a question about how to live a good life. Of course, for Coles this same question is always looming, and Coles is convinced that one's work and one's "real life" cannot be separated but must be combined into what he refers to as life-work. But as much as I admire Coles' work, Nussbaum just seems to go further. This is not a criticism of Coles' approach as the level of accessibility of Coles' work is much more endearing to me. Nussbaum, however, does sum up the worth of novels well. Hear her explanation of the significance of novels in her own words: "Literature [by literature she means specifically novels here] is an extension of life not only horizontally, bringing the reader into contact with events or locations or persons or problems he or she has not otherwise met, but also, so to speak,

[283] Ibid., 11.

vertically, giving the reader experience that is deeper, sharper, and more precise than much of what takes place in life."[284] These authors are both convinced that the novel does invaluable work in the precincts of teaching about the moral life, and I am convinced as well.

But are there other types of books that might be used to do this same type of work? I believe so, especially if the genre of books has particular import for a group of readers and those readers are guided toward certain significant elements of those readings, elements that we see pointed to in novels. In the next section I want to examine the possibility of the pathography doing this kind of moral work for clinicians. To be sure, these books have their own moral utility as well.

The Moral Work that Pathographies *Can* Do

What are pathographies? If we follow literary scholar Anne Hunsaker Hawkins' definition, a *pathography* is "a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death."[285] While both Oliver Sacks and Freud had also used the term *pathography* in various ways, Hawkins uses pathography consistently to refer to stories about an illness experience that is written either by the ill person or a person who is in a close relationship with the ill person. These types of stories are called by other names also: *narratives of illness*, *first-person narratives of illness*, *illness narratives*, *memoirs of illness*, *autopathographies*, and *biopathographies*.

[284] Ibid., 48.

[285] Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette: Purdue University, 1999,), 228.

For the purposes of this project, I will use the word *pathography* for at least two reasons. First, my primary audience for the use of these stories is the clinician, and as such the blending of the two root words, *patho* (meaning disease) and *graphy* (meaning to record or to write), should be familiar to this audience. Other medical terms like *pathology* and *pathophysiology*, or *electrocardiography* and *radiography*, should be an easy association for clinicians, and somewhat intriguing to clinician-students. Secondly, the prefix *patho* seems to focus the use of these books on diseases, which is a topic that clinicians will readily appreciate. Frank prefers the term *first-person narrative of illness* or *illness stories,* and argues that the use of the word *pathography* places these stories under the "authority of the medical gaze" and is counterproductive.[286] The whole point of writing these illness stories, in Frank's opinion, is to break free of the power of the medical narrative, so the name that is chosen for these stories has inherent meaning.

In Hawkins' project, *Reconstructing Illness: Studies in Pathography*, she focuses on book-length writings about illness experiences, but she does use the term *pathography* several times in the book to refer to shorter works on illness (e.g., articles). Drawing on her dissertation work that centered on narratives of spiritual conversion, Hawkins focuses on the similarities between narratives of spiritual conversion and narratives about illness. She examines the ways in which writers of pathographies use myths and metaphors to explain the significance of their experiences, to help "make sense of it all."[287] *Myths*, according to Hawkins, are both "illusions or fictive" and they point toward "a deeper significance or a more profound truth."[288] They are "macro-level phenomena that represent the way a given culture or cultures have come to

[286] Frank, *The Wounded Storyteller*, 190.
[287] Hawkins, *Reconstructing Illness*, 18.
[288] Ibid., 19.

understand experience overtime. Thus, echoes of such universal myths as *the battle, the journey,* and *death and rebirth,* can be found everywhere in the human world and human reconfiguration of the natural world."[289] These universal myths are used by ill persons to describe their experience with disease and illness. A person may describe her diagnosis of breast cancer and the subsequent treatment as a battle with the disease, a journey through illness, or a death to the old person and a rebirth after her cancer has gone into remission. Hawkins makes a distinction between these very common transcultural myths, and other myths she calls *ideological myths* – myths that are specific to a particular culture and temporal context. The myth of healthy-mindedness is one such ideological myth.[290]

Illness experiences are traumatic for both the ill person and for those individuals who are in close relationship with the ill. Hawkins sees the work of psychiatrist Robert J. Lifton and his theory of *formulation* – "a psychological process whereby the individual suffering from trauma returns to the world of the living" - as central to the thesis of her project.[291] In the traumatic experience of illness, myths and metaphors serve a therapeutic end by aiding the one who is ill (or their loved one) in reconstructing a sense of normalcy, or "building a bridge" between the traumatic experience and the world that the traumatized person is attempting to reconnect with.[292] The act of writing the pathography helps the author to master the traumatic experience.

Pathographies also serve the important function of recording traumatic illness experiences for those of us who are not yet ill. This target audience would include both future sufferers of illness (which we all are) and clinicians who care for the ill. I believe that these

[289] Ibid., xv.
[290] Ibid., xiii.
[291] Ibid., 24.
[292] Ibid.

stories of illness are invaluable resources for clinicians, even those who are still in training and who have limited clinical experience.

In *The Wounded Storyteller* Frank also focuses on pathographies but his conception of the work that these books do is somewhat different from Hawkins'. In this project Frank posits his theory of *narrative ethics.* Frank's conception of *narrative ethics* focuses on the ways in which lives can be affected by stories that are told by ill persons; the life of the storyteller and the lives of those who listen to her story. These stories are told not by *patients* but by *persons*. The patient's story is told in a medical narrative that is controlled by medical professionals, but the *person's* story is told by the ill person herself. Like Hawkins, Frank sees the various audiences for these stories as including the ill person herself, those who hear the ill person's story, and the clinicians who care for the ill person.

The telling of these stories for Frank though, both orally and in written form, is a sign of our postmodern times. Ironically, it is the success of modern medicine that has led to the possibility of this postmodern storytelling. During the modern era science and the disease model of medicine (diagnosis, etiology, treatment, prognosis, etc.) had its own grand narrative about the patient, and the medical chart was the authoritative story of the patient.[293] The medical narrative was primary and the patient's story, if told at all, was secondary, took second place, and was less than authoritative. But now in the postmodern era ill persons have come to understand that medicine's narrative about their illness experience is insufficient. The modern grand narrative of medicine does not help the ill person understand how to reconstruct his life after a serious illness

[293] Frank, *The Wounded Storyteller*, 85.

experience. In postmodern times ill persons struggle to *find their voices* and tell their own stories.[294] These stories do not take second place but are primary in importance.

Frank is positing a narrative ethics that helps ill persons understand how to live a good life while being ill. This is what makes Frank's project a moral or ethical project. In this sense the work that Frank is doing is an attempt to answer Aristotle's age-old question about how one can live a good life, or experience *eudaimonia*. In a sense, it is the same project that Nussbaum and Coles are working on. Narrative ethics is about personal becoming, it is a commitment to shaping oneself as a human being and stories are the media of this shaping. The *remission society*, those who are chronically ill or who remain under the *gaze* of the medical community for an extended period (e.g., cancer patients), live up to their ethical responsibility to themselves and to others by telling *self-stories*.[295] When persons *witness*, or tell their stories, they assume responsibility for telling what happened, they turn illness into moral responsibility.

The telling of *self-stories* is both a verbal and bodily act performed by the *body-self*. The term *body-self* is Frank's way of placing emphasis on the significance of the physical body, especially during periods of illness. When we are well, we typically ignore our bodies, or the body is not an object of our immediate attention. But when diseases are diagnosed and illness occurs, the body that was abstract comes to center stage. Frank believes that the body informs the message of the ill person. "The body," Frank says, "is not mute, but it is inarticulate; it does not use speech, yet begets it."[296] Two illustrations may be helpful here.

[294] Ibid., 7.
[295] Ibid., 8.
[296] Ibid., 9.

When I was a younger man, pain was foreign to me. I could lift anything I wanted to lift, walk, or run, it did not matter, my body responded without complaint. But now at forty-seven years old, if I sit in a chair too long, when I try to stand, my knees speak to me. There is a discomfort that comes from the body and the message usually has something to do with lifestyle changes. This is what Frank means when he refers to the body speaking, although the body is "inarticulate" it does have a message.

Also, during the current COVID-19 pandemic, people all over the world are wearing surgical masks and other types of face-coverings when they leave home. These masks, although protective, make it difficult to recognize people who would otherwise be easily identifiable. But the other day as I left the store, I came to understand better what Frank means when he says the body speaks. When my daughter and I went through the exit doors of the store I noticed a lady about a hundred yards away from us who was coming in our direction. Right away I thought that I might know this person but, not to be embarrassed or embarrass her, I proceeded and tried to avoid eye contact with the lady. When we were about twenty-five feet apart, she called out to me, greeted me and asked me how my wife and other kids were doing. Our bodies had spoken to one another before we spoke verbally. We had a certain familiarity with one another because of the shape and movement of our bodies, even with our faces covered. For Frank, this type of body language takes on greater significance during illness, and if we are attentive, we can hear the bodies of ill persons speaking.

This testimony of the body-self has moral implications for both the ill person and the one who receives the ill person's testimony. For the person who is ill these stories are a way of shaping the body-self, because the illness experience for Frank is a moral experience that presents the ill person with an opportunity to shape himself morally, for the better. Not all ill

persons will take advantage of this opportunity, but for the ones who do, this is a powerful opportunity for change. As these stories are told and re-told, the ill person is shaped by perpetual self-reflection or what Frank calls *reflexive monitoring*. "*Reflexive monitoring,"* according to Frank, "is the perpetual readjustment of past and present to create and sustain a good story."[297] For the ill, storytelling becomes a way of working out and working through the changing identity that the illness experience brings, but the storytelling process is also for the other.

The telling of the ill person's story implies that there is someone to listen to this story. The storytelling act is also a moral act because the story is told for the other. Stories of illness are testimonies to the fact that lives can be rebuilt after illness, even in the presence of chronic disease. Ill persons "seek not to provide a map that can guide others - each person must create his own – but rather to witness the experience of reconstructing one's own map."[298] Storytelling is done for the other to fulfill the moral responsibility of the ill person.

The moral implications for the listener have to do with receiving the story of the ill person. Both of these acts, the telling of the story and hearing the story, are a form of *witnessing*. Frank uses this term in a legal sense. When one becomes a witness she assumes responsibility for telling what has happed.[299] The ill person does this by sharing her illness experience, but the listener also becomes a witness by hearing the ill person's testimony, because "witnessing always implies relationship."[300] Someone must tell a story, but someone else must hear this story. "Thus, the witness makes a witness of others; a particular quality of the word witness is its movement of outward concentric circles. When someone receives the testimony of another, that

[297] Ibid., 65.
[298] Ibid., 17.
[299] Ibid., 137.
[300] Ibid., 143.

person becomes a witness, and so on."[301] This is what Frank refers to as the *reciprocity of witnessing*.[302] The one who listens to the ill person's story enters into a dyadic relationship with the ill person. They both become, and are becoming, *communicative bodies*.

The *communicative body* is at the crux of Frank's argument for narrative ethics. This *communicative body-self* is one who "accepts its contingency as part of the fundamental contingency of life. The human body, for all its resilience, is fragile: breakdown is built into it."[303] The other key aspect of the communicative body is that it recognizes this same contingency in the other's body, and seeks to form a dyadic relationship with these other bodies. In this way the communicative body exists for the other and recognizes the moral obligations of existence. Frank believes that the communicative body should be the normative aspiration for the body-self; all persons should strive for this type of relational ethic.

Frank's conception of narrative ethics places an enormous amount of responsibility on the ill person, a responsibility that he designates as moral responsibility. This seems like a lot to ask of ill persons. Certainly, there are many ill persons who feel compelled to share their story; the proliferation of published book-length pathographies is proof of this fact. But making the sharing of one's story obligatory is perhaps too much to ask of some.

There is a wide array of pathographies that have been written covering disease experiences, from prostate and breast cancer to cardiovascular disease and multiple sclerosis. The type of pathography that I am interested in for this project though are those that tell the story of people who are in or have been in locked-in syndrome. Locked-in syndrome presents the

[301] Ibid., 142.
[302] Ibid., 143.
[303] Ibid., 49.

patient, their caregivers, and their family members with unique challenges that should prove beneficial to the clinician. The ethical dilemmas encountered during the care of these individuals are ripe for rich discussions and moral growth.

The challenge in using these pathographies, or any books aimed at moral development, is the time it takes to both read and discuss the material. Clinicians and clinician-students spend a great amount of time learning scientific facts and participating in clinical experiences. They often feel crunched for time as they try to balance their school life and real life. The pathographies that are used to meet the goal of moral development need to be written well enough to be effective, but short enough to be used efficiently. There are five pathographies about locked-in syndrome that I want to explore below, but before I do that, I will define locked-in syndrome.

What is Locked-in Syndrome?

For a simple definition of the disorder I like Jean-Dominque Bauby's description. While describing himself and his condition, Bauby offers the following: "Paralyzed from head to toe, the patient, his mind intact, is imprisoned inside his own body, unable to speak or move. In my case, blinking my left eye is my only means of communication."[304] No definition from a medical source will offer us a better explanation of the state of the patient in locked-in syndrome. The term *locked-in syndrome* was first used in the medical literature by Fred Plum and Jerome Posner in 1966 in their book, *Diagnosis of Stupor and Coma*.[305] Their description of locked-in patients

[304] Jean-Domonique Bauby, *The Diving Bell and the Butterfly* (New York: Random House, 1998), 4. All subsequent references to *The Diving Bell and the Butterfly* will be cited parenthetically in the text, with the abbreviation *DBB*, followed by the page number.

[305] Barbara A. Wilson, Paul Allen, Anita Rose, and Veronika Kubickova, *Locked-in Syndrome After Brain Damage: Living Within My Head* (New York: Routledge, 2019), 1.

is more technical but essentially the same as Bauby's. The patients that they describe has "quadriplegia, lower cranial nerve paralysis, mutism with preservation of consciousness, vertical gaze and upper eyelid movement."[306] But long before Plum, Posner, and Bauby, Alexandre Dumas in his novel, *The Count of Monte Cristo*, describes one of his characters as being locked-in. The novel, published in 1844, describes the paternal figure Noirtier de Villefort as having had a stroke and being locked in as a result:

> That poor Monsieur Noirtier, a paralyzed old man, a mute, frozen corpse awaiting its final decomposition . . . [He was] seated in his wheelchair, in which he was placed every morning and from which he was lifted at night. Sight and hearing were the only senses which, like two sparks, still animated that physical body already so close to the grave. He commanded with his eyes, he thanked with his eyes; and it was almost frightening to see them flashing with anger or sparkling with joy in that otherwise stony face.[307]

So, the novelist's description of locked-in syndrome predates that of science.

There are three types of locked-in syndrome, classic, incomplete, and total, that are distinguished based on the level of mobility that the patient maintains after they suffer a brainstem stroke. In the classic form, patients experience "total immobility except for vertical eye movements or blinking."[308] In incomplete locked-in syndrome the patient is left with "remnants of voluntary motion."[309] This is probably the type of locked-in syndrome that Jean-Dominique Bauby has as he describes his locked-in state in the book, *The Diving Bell and the Butterfly*. Along with the ability to move his left eye lid, he maintains enough control over his

[306] Wilson, *Locked-in Syndrome After Brain Damage*, 1.
[307] Alexandre Dumas, *The Count of Monte Cristo* (New York: Bantom Dell, 2003), 245.
[308] Steven Laureys, "The Locked-in Syndrome: What is it Like to be Conscious but Paralyzed and Voiceless," *Progress in Brain Research* 150, (2005): 497.
[309] Laureys, "The Locked-in Syndrome," 497.

head to move it from side to side. In total locked-in syndrome the person is left with "complete immobility including all eye movements."[310]

This third type of locked-in syndrome ushers in questions of diagnosis. How difficult is it to diagnose this disorder? Steven Laureys, who is recognized by many as an expert on locked-in syndrome, suggests that patients in locked-in syndrome may be mistakenly thought to be in a coma, a vegetative state, or have akinetic mutism.[311] A little more than half of the time, it is a family member of the locked-in person who first notices that their loved one is attempting to communicate.[312] Sadly, some patients have survived in a locked in state for up to six years without proper diagnosis.

Based on the description of the disease above and the problems of misdiagnosis, the reader may sense that locked-in syndrome presents us with a special case for ethical inquiry. Along with the problem of misdiagnosis, these patients, their family members, and the clinicians who care for them, are faced with the additional ethical issues that include establishing and providing adequate communication, determining decisional capacity, and providing opportunities for optimal quality of life. In a later section I will address these issues in detail, but first I will discuss some specific pathographies of locked-in syndrome. These personal stories offer us a glimpse of what it might be like to be locked-in.

Pathographies of Locked-in Syndrome

Pathographies as a subgenre of the autobiography began to emerge in book-length form in the second half of the twentieth century.[313] Both Hawkins and Frank agree that these books

[310] Ibid., 498.
[311] Ibid., 499.
[312] Ibid.
[313] Hawkins, *Reconstructing Illness*, 3.

play a significant role in restoring the patient's voice to medical conversations. As a subgenre of autobiography, pathographies are challenged with some of the same questions of truth that autobiographies are faced with. Can these books be taken as "true" stories or "real" stories? Hawkins suggests that they can, as long as the reader understands the limitations of the genre, limitations that all narrative forms have:

> It is important in analyzing pathography to remember that the narrative description of illness is both less and more than the actual experience: less, in that remembering and writing are selective processes – certain facts are dropped because they are forgotten or because they do not fit the author's narrative design; and more, in that the act of committing experience to narrative form inevitably confers upon it a particular sequence of events and endows it with a significance that was probably only latent in the original experience.[314]

The pathographer has had to leave certain events out of the narrative and highlight other events to attempt to tell a "good story." These stories do have truth-value but should not be taken as "factual" accounts.[315]

In this section of the chapter I review five pathographies about locked-in syndrome. The last of these books, *The Diving Bell and the Butterfly*, was the first locked-in syndrome pathography that I discovered. I originally read this book as an assigned reading for one of the courses that I completed in graduate school. After reading the book the first time, I was hooked. The prose is so wonderful, and the disease so intriguing. With the exception of *The Diving Bell and the Butterfly*, these books are covered in no particular order. I saved Bauby's book for last because I was most familiar with his work and because the book is written so well.

[314] Ibid.
[315] Ibid.

Allison O'Reilly. In her book, *Out of Darkness*, Allison O'Reilly describes her remarkable recovery after experiencing a brainstem stroke and being left in locked-in syndrome. In the fall of 2010 O'Reilly was the Director of Marketing for a Fortune 100 company. She was married with no children, and living with her husband Kevin in McLean, Virginia. On October 18, 2010, at the age of forty-nine, Allison suffered a brainstem stroke. Although Allison had a successful thrombectomy (a surgical procedure to remove the clot from the brainstem), she remained locked-in. The combination of fear, loneliness, indignity, the anxiety of being separated from her husband, and her inability to move made her terribly depressed. This is the "darkness" that she refers to in the title. But just twelve days after her stroke and surgery, Allison would be transferred to a nearby rehabilitation hospital to begin her long journey back to a sense of normalcy.

Allison's illness seems to have been brought on by the enormous amount of stress in her life. Allison, who was an only child, was working sixty hours per week and single handedly taking care of her elderly parents. Her mother, whom she describes as chronically ill, had a colostomy and was in and out of the hospital. In addition to visiting her mother daily at the hospital each evening, she was coordinating her care by phone with her mother's physicians throughout the day. Her stepfather Lou, who had been the caretaker for her mother, had been recently diagnosed with hydrocephalus and was requiring increased levels of care himself. So Allison was cleaning her parent's home, taking Lou to the grocery store, and paying her parent's bills. The day of her stroke she had visited her mother in the hospital, gone over to check on Lou, and started feeling a sharp pain in her left arm. Once she reached her home she became nauseated and dizzy, and after she fell on the floor, her neighbors called 911. Unfortunately, the emergency department misdiagnosed Allison with vertigo and being dehydrated, and she was

sent home, only to have her medical condition worsen and to return to the emergency room six hours later. This time an MRI of her brain was done, and she was diagnosed as having had a brain stem stroke. Once Allison reached the rehabilitation hospital, she would undergo four months of intense therapy, but eventually, she walked out of the building with the assistance of only a walker. The pinnacle of her comeback was the day she was able to drive her own car. There is no mistaking the fact, this is a remarkable story of recovery.

Out of Darkness is ninety-six pages long and Allison writes the book to accomplish four stated goals: "to help other stroke survivors cope with their new realities, to provide helpful information for spouses and families, to be a non-clinical voice to medicine about the needs of younger people experiencing strokes, and to provide inspirational insight from someone who has escaped the darkness of locked-in syndrome."[316] Of all of these stated goals, I think O'Reilly falls short in her attempt to help stroke survivors deal with their "new realities." I read her book as overly optimistic and unrealistic. When compared to other pathographies about locked-in syndrome, *Out of Darkness* offers no critique of the clinicians that O'Reilly had to work with or the institutions she was treated in. The reader leaves the book with the impression that her entire experience was positive, which does not seem plausible.

Out of Darkness uses what Arthur Frank calls a *restitution plot* (*OOD*, 77). These are stories that are characterized by the type of optimistic thinking that we see in O'Reilly's narrative: "yesterday I was healthy, today I am ill, tomorrow I'll be healthy again" (*OOD*, 77). These are the kinds of stories that we (our culture) like to tell ourselves about encounters with scientific medicine, and these narratives work for us as long as we get the results that we desire,

[316] Allison S. O'Reilly, *Out of the Darkness: An Inspirational Story of Survival in the Face of Stroke and Locked-in Syndrome* (Bloomington, Archway Publishing, 2014), xxi. All subsequent references to *Out of Darkness* in this chapter will be cited parenthetically in the text, with the abbreviation *OOD*, followed by the page number.

but most locked-in syndrome patients do not have these types of outcomes. Further, those who live with chronic disease (e.g., diabetes, COPD) can testify that the restitution narrative does little to encourage them. These sufferers of chronic illness understand that they will never be "as good as new".

Sandra Nette. The most frustrating of all the pathographies that I review in this section of the project is the story of Sandra Nette. Sandra, who lives in Edmonton, Alberta, Canada with her husband David, co-authored the book, *Blink: Life after Locked-in Syndrome.* On September 13, 2007, Sandra woke up a perfectly healthy forty-year-old woman. Later that afternoon life for Sandra and David would be changed forever. During a routine chiropractic visit, while having a common (but dangerous) chiropractic neck adjustment, Sandra apparently suffered damage to both vertebral arteries in her neck. These arteries are a major portion of the brain's blood supply. This damage led to Sandra's having a brainstem stroke. While it is outside the scope of the current project, there has been much discussion by those outside the chiropractic field of study and practice about the competence of chiropractors to perform this risky procedure and the procedure's unclear benefits. Perhaps this could be a rich area of ethical inquiry.

Sandra spent six months in the acute care hospital and another five and a half months as an in-patient at Glenrose Rehabilitation hospital.[317] Like O'Reilly, Nette's recovery and resumption of her past life may be viewed as remarkable and better than expected for locked-in patients, although she still suffers some residual and noticeable disability. Sandra had numerous surgeries to correct issues related to the sequela of stroke and locked-in syndrome. These surgeries included a jaw reconstruction intended to improve her speech, and a surgery to rebuild

[317] David Nette and Sandra Nette, *Blink: Life After Locked in Syndrome* (London: New Generation Publishing, 2015), 120. All subsequent references to *Blink: Life After Locked-in Syndrome* in this chapter will be cited parenthetically in the text, with the abbreviation *BLL*, followed by the page number.

her feet to correct the dramatic foot inversions that resulted from her lying in the bed for an extended amount of time.

Reading these pathographies about locked-in syndrome is a reminder that although "authors of pathographies are a heterogeneous group," these books are written primarily by those who fit socioeconomically into the middle class.[318] This fact reminds us that many of the positive outcomes in healthcare are related to issues of access and justice. All the pathographies in this section emphasize the importance of early detection of locked-in syndrome and aggressive rehabilitation. Even with insurance coverage most of these locked-in patients testify about the need to fight for essential rehabilitation as opposed to suggested nursing home care. One wonders how others who are less fortunate economically and less powerful socially fare when there is a long term need for rehabilitative services.

At 168 pages *Blink* is the second longest of the pathographies that I discuss here, but it is still short enough to be used to stir the clinician's moral imagination. This book would not be my first choice of a pathography about locked-in syndrome; it is not written well. But the authors do tell a balanced story and share both the good and bad about healthcare in the twenty-first century. Nette's purpose for writing the book includes her desire to admonish people about the dangers of neck manipulation and to encourage married couples, families and friends of ill persons, to support one another in good times and bad, to stick together, no matter what.[319]

Paul Allen. The most scientifically informative pathography in this group of books is *Locked-in Syndrome after Brain Damage: Living within My Head,* written by Barbara A. Wilson, her

[318] Anne Hunsaker Hawkins, "Pathography: Patient Narratives of Illness," *The Western Journal of Medicine* 171, no. 2 (August 1999): 127.

[319] Hawkins, "Pathography: Patient Narratives of Illness," 161.

colleagues, and Paul Allen, who has been locked-in since July 3, 2012. Wilson and her colleagues tell Allen's story as part of a larger project that includes a series of books that are meant to be *Survivor Stories.* These books are about an array of patients who suffer from various types of brain injuries. While some may see calling this particular book about locked-in syndrome a pathography as a stretch of the subgenre's definition, the book does contain the personal story of Paul Allen told in his own voice, and interviews with Paul's wife, Liz, that capture her perspective as Paul's primary care provider. There is also a complete chapter dedicated to interviews with Paul's friends. Alongside Paul's story, the book is infused with a thorough review of the literature, both academic and popular, concerning locked-in syndrome.

Before his stroke Paul Allen was a computer programmer for the Metropolitan Police Service in London, England. He was also a part-time wedding photographer and cake maker. Paul was gifted in music and was described as a "a good baritone singer with a passion for opera."[320] He starred in sixty "operas, operettas, and musicals" as both an amateur and as a professional.[321] At age fifty-three he took an early retirement which allowed him to focus more on his wedding photography business and his singing. Paul also was an avid motorcycle enthusiast and owned twelve different bikes over his twenty-nine years of riding motorcycles. He had been married to his wife Liz for ten years. They had no children together.

The day before his stroke he began to experience a headache that gradually grew worse. The next morning while still experiencing the headache, Paul woke up with a tingling sensation down one side of his body and some of the other classic signs of stoke, blurred vision, nausea, and vomiting. Paul was taken to the hospital where he had what he described as another

[320] Wilson, *Locked-in Syndrome After Brain Damage,* ix.
[321] Ibid., x.

"massive stroke."[322] He was intubated and placed in a medically induced coma for five days. Because he was misdiagnosed initially as having encephalitis, Paul never received tissue plasminogen activator (the clot-busting drug) that might have helped him avoid many of the long- term effects of the stroke. Paul would spend seven weeks in the intensive care unit and eventually be transferred to a rehabilitation hospital, the Raphael Hospital. He spent more than five years as an inpatient in the Raphael Hospital. Liz's desire was to take Paul home much sooner and have his therapy continued there, but because of disputes with the country's national health plan about covered home services, Paul had to remain in the hospital much longer than desired. Paul is still ventilator dependent and still locked-in.

It may be surprising to know that despite his physical condition, Paul rates himself as having a good quality of life (QoL). Paul is "rarely seen without a smile and he is eager to interact with those around him, often using humor to engage people."[323] High ranks in QoL are not an uncommon finding for patient's in locked-in syndrome (*RFB*, 71).

This pathography is only eighty-six pages long and should be a quick read for clinicians. Of all the pathographies about locked-in syndrome patients that I review here, this book ranks near the top; it is certainly a book that I would recommend for clinicians. The book is written cogently and includes a storehouse of helpful and reliable scientific information about locked-in syndrome. Most other pathographies cannot be relied upon for scientific insight. The authors tell Paul's story in a balanced and honesty way, blending both his hopeful outlook and the real challenges that he has physically and economically.

[322] Ibid., 34.
[323] Ibid.

Kate Allatt. Of all the pathographies about locked-in syndrome that I review here, Kate Allatt's story is the most troubling. The book is unnerving because Allatt was in such great physical condition when she had her stroke. At the time of the stroke Allatt was a thirty-nine-year-old avid fell-runner (hill-running), running an average of seventy miles per week. In addition, she was doing boot-camp training on the weekends as well as additional training to prepare to climb Mt. Kilimanjaro to commemorate her fortieth birthday. Kate was not the image of a person who might be thought of as at risk of having a stroke. But she did.

On February 7, 2010, Kate complained of a severe headache, visited the emergency room, but was sent home after being diagnosed as having a migraine headache. Just four hours later she returned to the same hospital in an ambulance, without the ability to speak, to move her extremities, or control her bodily fluids. A CT scan confirmed that she had suffered a dissection of her right vertebral artery and that she had a large blood clot in her brainstem. Surgery to remove the clot was thought to be too risky and clot-busting drugs were also ruled out. She was placed in a medically induced coma for three days, but when she did wake up, she was conscious of everything that was happening to her and around her, but she could not move or speak.

In addition to her extreme exercise regimen Kate's life before the stroke included her husband of thirteen years (Mark), three children (India, Harvey, and Woody), a close circle of friends (Alison, Jaqui, and Anita), and a fledgling digital marketing business. She and her family lived in the village of Dore in South Yorkshire, England. This is how she describes herself in her own words: "I would always set my goals above what most people would expect. I always wanted to push myself harder in my work and my personal life."[324] Throughout the book she

[324] Kate Allatt, *Running Free: Breaking Out from Locked-in Syndrome* (United Kingdom: Accent Press, 2011), 8. All subsequent references to *Running Free: Breaking Out from Locked-ed Syndrome* in this chapter will be cited parenthetically in the text, with the abbreviation *RFB*, followed by the page number.

describes herself as being driven, dogmatic, and always pushing herself to the limit. These characteristics were both an asset to Kate during her rehabilitation, and an obstacle for clinicians and family members to maneuver around.

What Allatt does do masterfully is bring her reader into the locked-in state with her. Better than any of these other pathographies on locked-in syndrome, except for Bauby's, Allatt lets us know what it must feel like to be locked-in. For three weeks after she had the stroke Allatt was conscious, but no one had noticed. She describes her attempts to signal the medical staff with her eyes and their seeming inattentiveness. Allatt tells us how slowly time moves in the locked-in state, how minutes seem like hours and an hour seemed like an eternity (*RFB*, 21). Like other locked-in pathographers, Allatt testifies to how lonely and long the nights are. Because no one knows she is conscious, she wonders if her family will allow clinicians to turn off her life support. She describes this time as filled with "fright and frustration" (*RFB*, 26). It is during this time that she exclaims in silence, "If death means an end to this agony, bring it on" (RFB, 27).

It is the human element of this book, visits from her friends and her children, that make the book powerful. Her friends are the first people to notice that she may be conscious as their personal connection before the stroke allows them to tune in to Kate's eye communication. Her children, who were not allowed to visit their mum early on after the stroke, are fearful of her overt appearance and extremely emotional after their initial visits.

Kate is careful to tell her reader that as she began to recover movement in her body, she started to use special communication devices and eventually started to use the computer at the nurse's station to slowly and painstakingly tap out emails to her family members. She also reconnected with many of her family and friends through Facebook. Her daily messages served

as sort of a journal from which she was able to document many of the events that took place in the second half of her book. By alerting her reader to these notes about her illness, Kate sidesteps some of the common criticisms of autobiographies and pathographies, but there is still a large portion of the book that the reader struggles to understand how she can possibly remember the specific dates that she documents.

With a total of 205 pages, *Running Free* is the longest of these pathographies and the book is written well. It may be at the upper limit of pages to be useful in the kinds of projects that I intend, but Allatt certainly tells a balanced story that includes the ups and downs of long-term rehabilitation, and the failures and successes of clinicians. Her overall tone in the book though is one of anger. She always seems to be angry with someone or about something, and while this emotion is probably an asset to her in the long run, this reader leaves her project wanting more from Allatt, more in the area of personal development.

Jean-Dominique Bauby. *The Diving Bell and the Butterfly* is a piece of literary art. It was the first of the pathographies of locked-in syndrome. Even for the untrained literary eye, the book stands apart as unique and distinctive from the rest of the books in this section. Unlike the typical pathography that tells the ill person's story in three parts (I was healthy, I became ill, and now I am either healthy again, or still ill), Bauby lays his book out as a collection of short vignettes that are not in chronological order. In fact, he keeps his reader in suspense until the very end of the book before he discloses the events of the day of his stroke.

Bauby's stroke occurred on December 8, 1995, on a day that for all intents and purposes was just an average, run-of-the-mill day. He rose early in morning, reported to work, joined his colleagues for a luncheon, stole away early to pick up his son so that they could spend the weekend together, and headed to the theater to begin their night out. Then suddenly, without any

warning, at forty-three years old, he suffered a massive stroke to his brainstem and was left in locked-in syndrome. After being in a coma for twenty days, and then being semiconscious for another several weeks, Bauby reports that he was not fully conscious until the end of January (*DBB*, 4).

Bauby would never have the remarkable recovery of an O'Reilly or Allatt, but his misfortune has value for our benefit. Bauby's story is as much about life as it is about being locked-in. It is a testament to the unquenchable human spirit and the "unkillable self".[325] Despite the fact that his body is useless to him, Bauby uses his mind to take the reader on exciting vacations he has either already been on or plans to take. He shares his plans for future writing projects and whets the reader's appetite with descriptions of delectable foods. In health Bauby liked nice clothes, fast cars, good food, beautiful women, and long baths, and after his stroke he still shows an appreciation for all these attractions.

Bauby tells a balanced story about his interactions with clinicians; there is praise for the many and condemnation for the few. The clinicians are of "two kinds" he says, "the majority, who would not dream of leaving the room without first attempting to decipher my SOS messages; and the less conscientious minority, who make their getaway pretending not to notice my distress signals" (DBB, 39). There is Sandrine the speech therapist whom Bauby refers to as his "Guardian Angel," and on the other hand the ophthalmologist who begins to sew Bauby's right eye closed without waking him up or explaining the procedure to him.

All the other pathographies in this section make mention of Bauby's project. Either the locked-in persons themselves read the book, or more often, the family members of the one

[325] This term, the "unthinkable self," was borrowed from Francine Prose who reviewed the book for Newsday.

locked-in drew inspiration and understanding from the book. But Kate Allatt offers what I consider an unfair critique of Bauby's story. As Allatt began to recover from locked-in syndrome she admits that she read Bauby's story and was inspired by his account to write her own pathography, but she considered his use of his imagination as a poor example for her:

> Unlike Bauby I could not and would not allow my imagination to run away with me. In my mind imagination was an indulgence, and time spent daydreaming of how things once were, and might never be again, only distracted me from the road ahead – getting better (*RFB*, 149).

Characteristically Allatt misses the point. She fails to realize that not all locked-in patients will be as fortunate as she was. Most patients will not be able to return to their pre-stroke lives without any noticeable disability. The blessing of recovery that Allatt experiences, without surgery or medication to dissolve the clot in her brainstem, is nothing short of miraculous, but she seems to interpret her restoration as self-driven. This is the real tenor of her book. Perhaps Bauby did the best he could with what he had left, and many have assessed that his attempt was also pretty miraculous.

At the end of Bauby's story he sees a new day dawning. In the chapter titled "Season of Renewal," Bauby notices that the seasons outside are changing (from summer to fall) but he is also experiencing a personal change. He has decided to leave bitterness and anger about his illness behind and press forward to experience life as it is. Bauby is being transformed into what Frank calls a "communicative body."[326] The communicative body embraces the contingency of the body and offers the self in service.[327] As mentioned above, "the communicative body accepts its contingency as part of the fundamental contingency of life. The human body, for all

[326] Frank, *The Wounded Storyteller*, 48.
[327] Ibid., 50.

its resilience, is fragile; breakdown is built into it. Bodily predictability if not the exception, should be regarded as exceptional. Contingency ought to be accepted as normal."[328]

But the communicative body does not stop with this recognition of contingency. The communicative body-self also desires to connect with others; the body-self lives for the other and wants to serve the other. The body-self turns outward in "dyadic relatedness" and "sees reflections of its own suffering in the suffering of others."[329] In the struggle to complete this project we see Bauby's attempt to turn outward, to connect with others who are suffering. The balm that Bauby offers is not just for those who are paralyzed because of locked-in syndrome, but can be helpful for others who suffer a paralysis of the soul, a paralysis of the spirit. Our common human condition precludes any successful arguments against the fact that we need this balm.

Sadly, Bauby died just two days after his masterpiece was published in French. He dedicated the book to his two children, Theophile and Celeste, but he left all those who read the book, some of us who read it over and over, a well-spring of inspiration. The book is only 130 pages long, and unlike the other pathographies in this section, the reader is left with a sense of not wanting the book to end; I wish the experience could go on and on. The book is short but unspeakably powerful. Its brevity should prove useful to clinicians.

All these pathographies of patients who have experienced locked-in syndrome are helpful in their own way, but Bauby's book is in a class by itself. Perhaps this is because Bauby was a professional writer, and words were the tools of his craft. At any rate these books, some more

[328] Ibid., 49.
[329] Ibid.

than others, can be used to stimulate and fertilize the moral imagination. There are certain repetitive themes that we see in all these works, and they also point us to some unavoidable truths about our common human condition. In addition, the ethical issues that one can expect to encounter when caring for a patient with locked-in syndrome should be explored. In the next section I want to explore these essential moral elements of pathographies.

Teaching the Essentials in Pathographies

I will admit that I was somewhat ambivalent about my theory regarding the moral work that pathographies can do, until I started reading these stories of patients who have endured stroke and locked-in syndrome. These readings have convinced me that pathographies can indeed leave a lasting impression on readers, that they can be used to fertilize the moral imagination. What particular aspects of the pathographies should be emphasized so that the moral imagination of those who read these books is fertilized? This is the question that must be answered in this section of the chapter. In addition, I will explain the common ethical challenges that arise when patients are locked-in.

Contingency. The first characteristic of the pathography that deserves our attention is *contingency*. *Contingency*, Frank says, "is the body's condition of being subject to forces that cannot be controlled."[330] Nussbaum, in *Love's Knowledge,* points out that contingency has ethical relevance in the novel. I posit here that readers can be guided to appreciate this same

[330] Frank, *The Wounded Storyteller*, 31.

facet of pathographies. In the novel, Nussbaum says, there is "an emphasis on the significance, for human life, of what simply happens, of surprise, of reversal."[331] Coles in *The Call of Stories* also points toward the significance of contingency in the novel. Using George Eliot's craftmanship as an example, Coles points out that the work of the novelist helps readers understand that "life can be exceedingly hard to tie down with abstract, categorical formulations, and hard as well to predict" (*TCS*, 90). The fact is, perhaps particularly in the West, we abhor predictability on one hand, but when tragedy strikes, we yearn for a sense of normalcy. We want life to return to something that is certain, regular, consistent. When students begin to recognize the characteristic of contingency in the lives of the characters of novels, the students themselves begin to see their own life choices differently. Understanding the inevitable nature of contingency motivates students "to take matters of choice and commitment more seriously than they might otherwise have done" (*TCS*, 90).

Over and over, we see in the pathographies about locked-in syndrome the presence of *contingency* and life's uncontrollable nature. In each pathography that we have reviewed above the persons with locked-in syndrome have described life before their illness experience as being pretty pedestrian. The writers were going about their business and pursuing their own sense of the "good life," when suddenly, surprisingly, there was a reversal of fortune. This characteristic of *contingency* is present, I suspect, in most pathographies; it is certainly present in the ones I use here. In *Running Free*, for example, Allatt's friends are frightened by the presence of contingency as they reflect on Kate's current condition and how quickly she had fallen ill. After visiting her in the intensive care unit one of her friends asks, "How can someone so full of life, be so incapacitated" (*TCS*, 40)? She continues, "I can't believe we were having such a laugh at

[331] Nussbaum, *Loves Knowledge*, 43.

our workout the morning before it happened and now, she may never walk again. It's just not fair" (*TCS*, 40). Alison O'Reilly in her book, *Out of Darkness*, was also arrested by life's contingency. O'Reilly says, "It's still amazing to me how quickly my daily life and identity were taken away. One week, I was a woman engaged in work, family, and the challenges of daily life. Then over what should have been a normal weekend, my life radically changed" (*OOD*, 3).

These comments make it obvious that contingency makes us uncomfortable and it is difficult to comprehend how life can be going perfectly well at one moment but turn drastically for the worse the next. Perhaps what bothers us about contingency, and what I think is gnawing at Kate's friends above, is the sense that these unpredictable and horrible events that have disturbed the tranquility of Kate's life, could just as easily have shaken their lives.

Vulnerability. The second characteristic of these books that must be highlighted is vulnerability. Frank chooses to talk about contingency and vulnerability in tandem, explaining that these conditions are inescapable requisites for living in our universe.[332] Nicole Piemonte in her book, *Afflicted: How Vulnerability can Heal Medical Education and Practice*, stresses the importance of the acknowledgement of a shared vulnerability between patients and clinicians. *Vulnerability* is the act of being exposed to potential harm, harms such as "illness, suffering, loneliness, and death."[333] Piemonte argues that "the tendency to ground medicine within a scientific, objective, and anatomo-biological worldview is in fact a manifestation of a fundamental and ontological or existential desire to turn away from our shared vulnerability of being human."[334] Instead of turning away from suffering and death, clinicians turn toward

[332] Frank, The Wounded Storyteller, 19.
[333] Piemonte, *Afflicted*, xxi.
[334] Ibid.

suffering, both in their patients and in themselves, and by doing so, live and work more authentically.[335] A clinician's education that focuses primarily on the scientific and technical development of the student misses the opportunity to help the student develop in other essential ways: self-awareness, critical thinking, and existential reflection.[336] Piemonte suggests that clinician education needs to be reimagined so that more expansive notions of care can be utilized, ones that encourage reflection and authentic engagement with others. As human beings our tendency is to turn away from suffering and death, but we must learn to embrace the truth about our human condition and to turn toward those in need.

One of the characteristics of vulnerability that Piemonte points us toward above is the state of loneliness. The loneliness of the patients that are locked-in is a recurrent theme in their pathographies. David Nette, who co-authors *Blink*, describes his sense of loneliness during the period that his wife Sandra was acutely ill and locked-in. As Sandra spent each night alone in her room, David was left alone at home. David says, "over the many coming nights, I would not be able to sleep thinking about Sandy all alone in her hospital room. She had been transferred to a private room and while this had many benefits during the day, it brought with it much fear for the long and lonely nights" (*BLL*, 43). In *Out of Darkness* O'Reilly describes one of her encounters with loneliness as she is transferred from one hospital to another because of a new development of pneumonia. She explains that she "was transported in the underground tunnel to the hospital and left to wait in the emergency room corridor. I thought that they would forget about me. I was alone and felt isolated and scared. I watched the machines, as it was all I could do" (*OOD*, 42). Kate Allatt describes her encounters with loneliness in relation to the volatile

[335] Piemonte, *Afflicted*, xxi.
[336] Ibid., 43.

nature of the arrival of visitors. She says that "some days visitors arrive like buses, three or four at a time, when the limit was two to a bed. Other times there were none at all, which made for lonely afternoons" (*RFL*, 102). These statements from pathographies of persons who were locked-in testify to the fact that loneliness and vulnerability are genuine characteristics that can be found in these books.

In addition to loneliness, these pathographies commonly speak to the vulnerabilities of suffering and death. Before these patients are recognized as being conscious, most of them document questions about whether their life-support will be turned off prematurely. They suffer emotionally as they make futile attempts to communicate with their eyes to no avail. In addition, these patients struggle with existential questions about the meaning of their lives. They wonder if they are destined to remain locked in and many of them are conscious long before they receive explanations about their conditions.

Thinking with Stories. The third way that pathographies can be used to fertilize the moral imagination is not so much a characteristic found in the stories themselves, but a way of "thinking with" these stories. Pathographies are stories told by ill persons that have the potential to assist us in our moral development, but they will not serve us this way if we only "think about" these stories. Frank explains the difference: "To think about a story is to reduce it to content and then analyze that content. Thinking with stories takes the story as already complete; there is no going beyond it. To think with a story is to experience it affecting one's life."[337] Thinking about a story in a medical context usually means turning that story into a case, to learn all that can be absorbed from the case, and then move on to the next case. Thinking with stories

[337] Frank, *The Wounded Storyteller*, 23.

on the other hand, requires that the stories that we hear stay with us, they are not readily abandoned. Frank explains this as a process of "becoming responsible to these stories."[338] Becoming responsible to the stories that we hear "depends on telling certain stories over and over, hearing different nuances of potential meaning as the story is told in different circumstances and at different ages of our lives."[339] These are not stories to be used and discarded, but they are stories that must stay with us if they are to have lasting moral import for us. "Thinking with stories," Frank says, "ultimately requires a highly personal sedimentation of experience: living with the stories and having them shape perceptions of various experiences over time."[340]

The stories of ill persons then, if taken seriously, can be taken up and used for long-term reflection and moral development of the clinician. Coles makes this same point about novels when he says, "We all remember in our own lives times when a book has become for us a signpost, a continuing presence in our lives."[341] Coles is reflecting on the way in which the stories that he has taught, novels, can be turned to for guidance and direction. During periods of life that are confusing, when knowing which way to turn is not clear, and when life is simply discouraging, novels offer their readers content for inward reflection and encouragement for living in the world.

Coles give us an example of this power that novels have when he describes one of his former Harvard law students, now a corporate lawyer, who reports to Coles the continual influence that these books have on him. When life crowds in on him and the pressures of work

[338] Ibid., 24.
[339] Ibid.
[340] Ibid.
[341] Coles, *The Call of Stories*, 68.

are overwhelming, this young lawyer does not turn to drugs or alcohol, he participates in what he calls "book binges."[342] Here is how the young lawyer describes his binges:

> Every once in a while, I tell them I've got to get away. I think at first they thought I was an alcoholic. . . I know my work. They know I'm good. But then one morning I'll wake up and feel like a dead man. I feel as hollow as one of T. S. Eliot's 'hollow men.' I'm ready to fold; I'm ready to go running and never in a million years come back. And that's when I throw the dice; I mean, I tell them at the office that I'm not feeling well. I call in. I stay home. I just read and think and take my walks. . . without those books I'd be locked up someplace, either a jail or a mental hospital.[343]

I posit here that pathographies can do this same type of work for clinicians. As clinicians continue in their life-work there will undoubtedly be periods of confusion, moments when the path forward is unclear, and times when discouragement cannot be avoided. Pathographies, those that are written well, can offer clinicians points for inward reflection, encouragement to move forward to fulfill their duties to their patients, and they can serve as reminders of why the path was chosen in the first place. These stories and the persons that tell them can become companions who speak to the clinician, and they can be spoken to. In this sense pathographies can be books that really make a difference.[344]

Because each story is told about a unique person's illness experience, the moral lessons and messages of inspiration from each story will also be unique. But in reading these stories closely we can always find these messages in the narrative. In *The Diving Bell and the Butterfly*, for instance, Bauby's use of his mind, despite the fact that his body is useless to him, can serve as a reminder to the clinician that patients are much more than their physical bodies. All

[342] Ibid., 134.
[343] Ibid., 135.
[344] Coles, *The Call of Stories*, 36.

patients, regardless of their disability or prognosis, should be treated with respect and dignity. In each pathography there are points of inspiration and points for moral reflection, points that can be returned to over and over.

On Family and Friends. Several of the locked-in syndrome pathographers tell stories about close family members and friends who abandoned them during their illness. Frank, in his book *At the Will of the Body*, testifies to this same reality. Frank reflects on the period during which he was diagnosed with testicular cancer and had to endure subsequent surgery and chemotherapy. It is expected that there will be some physical losses during illness, but Frank and his wife Cathy lament the loss of human relationships. Frank says:

> Cathie and I had always hoped that if the worst happed, friends and relatives would respond with care and involvement. Then the worst did happen, and we no longer expected what others would do, we knew. Some came through; others disappeared. We now find it hard to resume relationships with those who could not acknowledge the illness that was happening, not just to me but to us. Those relationships were a loss.[345]

There are all kinds of reasons that people may offer for these disappearing acts, but the fact is that they are noticed by ill persons and they hurt. It is unfortunate that for Frank and his wife there seemed to be no space for reconciliation with those family members and friends.

On the other side of the coin of abandonment though, we see in the pathographies of locked-in syndrome other stories that can inspire us about our common humanity. While some family members and friends are noticeably absent, others make it their business to be present and accounted for. In Allatt's story *Running Free*, it was her family (her mother, father, and husband) who refused to have her moved to a long-term stroke ward and insisted that she go to

[345] Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (New York: First Mariner Books, 2002), 38.

rehabilitation immediately. It was Kate's friends who first recognize that she was locked-in. These same friends support her husband and children emotionally, give her beauty treatments while she is in the hospital, and plan shopping trips for her to the local mall. In *Living Within My Head*, Paul Allen's wife Liz is a consistent source of strength and care for him. Four of Paul's former coworkers, who are also friends, visit him every Thursday afternoon, two-by-two, on a rotating schedule, to offer him encouragement and to maintain their friendships.

For clinicians, these human relationships can be sources of inspiration. They serve as reminders that as human beings we need each other. While others make excuses about why they cannot visit, these committed ones push aside their own agendas and even their own fears, to *be with* the one who is ill. These stories can remind the clinician to take note of the interactions between the ill persons and their loved ones and to see these relationships as points of inspiration.

The Ethical Issues

Along with the characteristic of pathographies mentioned above, the ethical issues that one encounters when dealing with people who have locked-in syndrome will be helpful topics to focus on. The illness story of one who is locked-in presents family, friends, and clinicians with rich topics of discussion in the area of ethics. These stories bring together some of the classic historical issues that are discussed in bioethics and the medical humanities.

Differential Diagnosis

The first real hurdle for locked-in patients is a diagnostic one. As mentioned above, locked-in syndrome can be misdiagnosed as other neurologic disorders, namely coma, one of the

vegetative states, or akinetic mutism.[346] Physicians and other clinicians who have experience with and knowledge of locked-in patients can decrease the likelihood of misdiagnosis.[347] A delay in diagnosis or a misdiagnosis will inevitably lead to other critical delays in rehabilitation. Often, at least 50 percent of the time, family members are the first persons to recognize that locked-in patients are attempting to communicate.[348] Unfortunately, reports of these attempts are many times dismissed by clinicians as "wishful thinking." In a study of forty-four locked-in patients it was noted that the average time to diagnosis was two and a half months, with some patients being locked in as long as four years before an accurate diagnosis was made.[349] These unfortunate delays cause "stress and distress to the person in locked-in syndrome but also to the family and friends, leading to impoverished quality of life and reduced psychological well-being."[350]

Decisional Capacity

Once it has been determined that a person is indeed locked-in and proper communication has been established, it is essential to involve the patient in every decision about her care. Being locked in should never preclude a person from exercising his fundamental right to make his own medical decisions. As one of the foundational principles of bioethics, the autonomous person who is locked-in must be supported by family, friends, and clinicians so that the unencumbered wishes of the patient may be known. Once it has been determined that the locked-in patient has the capacity to make competent decisions about the future, these decisions should be honored,

[346] Laureys, "The Locked-in Syndrome," 499.
[347] Ugo E. Gallo and Phil B. Fontanarosa, "Locked-in Syndrome: Report of a Case," *The American Journal of Emergency Medicine* 7, no.6 (1989): 581.
[348] Jose Leon-Carrion, Philippe van Eeckhout, and Maria del Rosario Dominguez, "Review of Subject: The Locked-in Syndrome: A Syndrome looking for a Therapy," *Brain Injury* 16, no. 7 (2002): 556.
[349] Leon-Carrion, "Review of Subject," 557.
[350] Wilson, *Locked-in Syndrome*, 77.

even if they are decisions to refuse treatment. As Steven Laureys, a recognized expert on locked-in syndrome has said, "patients suffering from locked-in syndrome should not be denied the right to die – and to die with dignity – but also, and more importantly, they should not be denied the right to live – and live with dignity."[351]

Communication

Establishing adequate communication is of course critical for the patient who is locked-in. Because of the pathophysiology of locked-in syndrome discussed above, reading the eye movements as attempts to communicate is the gateway into effective communication. For those of us who have read *The Diving Bell and the Butterfly*, we are familiar with the alphabet chart that Jean-Dominique Bauby uses to communicate with those around him. We remember how Sandrine the speech therapist organized the common alphabet in such a way that the most common letters used in the French language were placed at the front of the list. Even in the twenty-first century, these types of charts are still widely used with locked-in patients. There are many variations to these charts that have taken place over time to make it easier for the locked-in patient to communicate, but these are still essential first order tools of communication.[352] The system referred to above requires a family member, friend, or clinician who is willing to demonstrate patience and work through what is sometimes a frustrating process for both patient and interlocuter. Both parties must persist in knowing that the effort to communicate is worth it and that having the patient involved in decision making about her care is ultimately what is best for her.

[351] Wilson, *Locked-in Syndrome*, 9.
[352] Wilson, *Locked-in Syndrome*, 9.

The field of health informatics has made other more sophisticated communication devices available to locked-in patients. Using infrared eye-movement sensors, computer-patient interfaces can be established which allow patients to formulate detailed messages for family members, friends, and clinicians.[353] One such device, the *EyeOn* tablet, an Augmentative and Alternative Communication (ACC) device, allows patients with all types of neuromuscular disorders (e.g., LIS, ALS, muscular dystrophy, cerebral palsy) to communicate and control their environment.[354] Patients can control common devices like their television, lights, fans, doors, and wheelchair.[355] The *EyeOn* tablet costs $14,500, and while many persons with disabilities that require these types of devices are able to access funding so that there is little to no out-of-pocket expense, even relatively small costs can be prohibitive to those who are most vulnerable.

Quality of Life

If you suffered a brainstem stroke and you were locked-in, would you want to live? Could you have an acceptable or even a satisfying quality of life? Many people who answer this question while they live "normal" healthy lives assume they know the answer to this question. They assume that life would not be worth living in a locked-in state. However, in a study of ninety-one locked-in patients, Bruno and his colleagues reported that the majority of these patients self-report good subjective well-being.[356] Wilson and her colleagues also report that "it is possible for patients with locked-in syndrome to maintain a positive quality of life despite their significant physical limitations."[357] These are important findings for family members, friends, and for

[353] Laureys, "The Locked-in Syndrome," 503.

[354] David R. Beukelmann and Janice C. Light. *Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs* (Baltimore: Brooks Publishing, 2020), 4.

[355] "EyeOn Tablet," Eyetech, accessed October 8, 2020, https://eyetechds.com/eye-tracking-products/the-eyeon-platform.

[356] Marie-Aurelle Bruno and Jan L Bernheim, "A Survey on Self-Assessed Well-Being in a Cohort of Chronic Locked-in Syndrome Patients: Happy Majority, Miserable Minority," *BMJ Open* 1, no. 1 (2011): 4.

[357] Wilson, *Locked-in Syndrome*, 69.

clinicians. In light of this knowledge regarding the potential quality of life for locked-in patients Steven Laureys offers clinicians what is hopefully sobering advice:

> Superficially involved for the short term when the patient is at his or her worst, clinicians may often tend to comfortably assume that these persons will die anyway, or would choose to die if they only knew what the clinicians knew. As a result, debates about cost, daily management , quality of life, withdrawal or withholding of care, end-of-life decisions and euthanasia often go on with prejudice and without any input from the conscious but mute and immobile patient. To "judge a book by its cover" is unfair. Clinicians should realize that quality of life often equates with social rather than physical interaction and that the will to live is strong when struck by an acute devastating disease.[358]

Laureys' words are a poignant reminder to those of us who work with patients that our jobs are not primarily meant as positions of judgment but of support and care. What we learn from some of the remarkable pathographies written by formerly locked-in patients, and from people like Jean-Dominique Bauby, is that the conditions under which one chooses to live is a unique choice that only the individual can make, and the contributions of severely disabled persons can rival those that are made by the others of us who consider ourselves "normal".

In this chapter I have argued that pathographies, if used appropriately, can offer readers and discussants valuable moral instruction. In a similar way that novels are looked to as cherished sources of moral inquiry, pathographies can do this same type of moral work. The particular pathographies that tell the story of patients who have, or have come out of, locked-in syndrome has been my specific focus in this chapter. I have discussed five of these books and the close reading of this material has led to a further understanding of the essential components of pathographies that can be used for moral

[358] Laureys, "The Locked-in Syndrome," 503.

instruction. In the next chapter of this project I want to build on the things that I have learned about pathographies and apply some of this knowledge to the area of interprofessional education. It is proposed by those who give leadership in interprofessional education that a focus on virtues and ethics is necessary. A review of the current literature in interprofessional education, however, reveals that this area of research and practice is someone untapped. In the next chapter I hope to offer some guidance in this area.

Chapter 4

Stimulating Growth of the Moral Imagination: Using Narratives in Ethics-Oriented Interprofessional Education

. . . we spend our years as a tale that is told.

Psalm 90:9b

It is as if I had been going downhill while I imagined I was going up.

Leo Tolstoy

The Death of Ivan Ilych

The Young Asthma Patient

I was working per diem as a respiratory therapist in a small hospital in northwest Houston. A young black girl, about ten years old, was brought into the hospital through the emergency room. She was in moderate respiratory distress due to asthma, but as a lifelong asthmatic, she had been through the emergency room experience before. Her mother was with her, and I distinctly remember her mother apologizing to her daughter for not bringing her into the hospital sooner. Apparently, mom did not think her daughter's asthma episode was serious enough to bring her to the hospital. As I look back now and attempt to be objective, the girl really did not look that bad. When I first met the patient, she was sitting straight up in bed, breathing on her own, wheezing, but able to talk and respond appropriately to questions. But over the course of several hours my young patient's asthma exacerbation grew worse, and then worse. The interprofessional team of clinicians that included physicians, nurses, and respiratory therapists (I was one of four) worked tirelessly to help this little girl. Eventually, she had to be intubated (a breathing tube was place in her airway) and attached to a mechanical ventilator, but because of the severity of her asthma, the ventilator could not get air into her lungs without the

risk of severe damage. The girl was taken off of the machine and manually ventilated, but even this did not provide her with effective ventilation. Because of the increased pressure in her lungs which placed an increased amount of strain on her heart, the child's heart eventually stopped beating. Feverishly, the team tried to restart the child's heart, but none of our attempts yielded sustained success. Every medical device, every medication, and every idea that we had at our disposal was used for this young person and her waiting mother, but to no avail. We worked to save this young girl for more than two hours, but she eventually died in that emergency room. This girl's death bothered me then, and it bothers me, if I let myself think about it, now.

When my shift was over, I went home, but my young patient stayed on my mind, she stayed with me. Had we really done all we could? What else should we have done? What did we miss? These questions, and others, worked on me. I talked to my wife about my young patient and her mother, and I felt guilty; at the time I had three children at home who were the same age as my young patient. Why was this girl dead and my children, perfectly fine, without a care in the world, alive and well? As I look back on this event now, I think that I was asking all the right questions, but I did not have the answers to those questions, at least not the types of answers that could satisfy. Today, ten years later, my concern is not only for my own lingering questions about my young patient's outcome, but my focus turns to all those other clinicians who left my young patient's bedside that day with similar questions. How might clinicians be prepared, prepared interprofessionally, to embrace the contingencies and vulnerabilities that they will inevitably encounter in their work?

In this chapter I want to explore the work that is being done in interprofessional education, particularly the work that is taking place to develop interprofessional teams in the area of virtues and ethics. Virtues and ethics is one of four learning domains in interprofessional

education, and my question in this chapter has to do with whether or not attempts at training in this area are adequate. In this chapter I will refer to this type of training as *ethics-oriented interprofessional education*.

I will begin this chapter with an explication of what interprofessional education is and why it is felt that this type of education is important for the future of healthcare delivery. Next, I will review the literature related to ethics training in interprofessional education and delineate the types of ethics-oriented interprofessional education currently being embarked upon. My recommendation in this chapter will be for the inclusion of narratives in ethics-oriented interprofessional education because narratives have the ability to do the kind of moral work that can be valuable for interprofessional teams. Narratives, the right kinds of stories, can stimulate the growth of the moral imagination of clinicians, can help clinicians prepare for contingency and vulnerability as they do lifework, and can be used in interprofessional education as a tool for deep and rich moral inquiry.

What is IPE?

According to the World Health Organization, "interprofessional education occurs when students from two or more professions learn about, from, and with each other to enable effective collaboration and improve health outcomes."[359] Interprofessional education does not replace the need for profession-specific training, both didactic and practical. Interprofessional education requires intentionality. Students from various professions must not only occupy the same space at the same time, but the planned activities must "provide students with opportunities to learn

[359] World Health Organization, *Framework for Action on Interprofessional Education and Collaboration*, accessed October 8, 2020, https://www.who.int/hrh/resources/framework_action/en/.

and practice skills that improve their ability to communicate and collaborate."[360] The ultimate goal then of interprofessional education is to produce collaborative practice-ready graduates, graduates who have been prepared during their training to work in teams. In this way interprofessional learning can be distinguished from multidisciplinary learning, when students from various professions learn and work together in groups without a real focus on how they function as a team.[361] However, the terms *interprofessional* and *interdisciplinary* both seem to capture the spirit of the goals of interprofessional education. Students who are trained interprofessionally are said to be ready to serve the public more effectively, to see beyond professional silos, and to participate more fully in patient-centered care. In short, these professionals are ready for collaborative practice, which "happens when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care."[362]

The term *interprofessional education* and the significance of this type of education date back to the beginning of the Institute of Medicine (IOM) in the United States, now known as the National Academy of Medicine.[363] In 1972 the very first conference of the IOM was entitled, "Interrelationships of Educational Programs for Health Professionals."[364] Meeting on October 2 and 3, in Washington D. C., the conference brought together 120 health professionals from various backgrounds. At this time in the country there was a growing concern about the proliferation of both the numbers of health professionals in current fields and the addition of new

[360] Institute of Medicine of the National Academies, *Interprofessional Education for Collaboration: Learning How to Improve Health from Interprofessional Models Across the Continuum of Education to Practice*: Workshop Summary, (Washington DC: The National Academies Press, 2013), 7.

[361] IOM, *Interprofessional Education for Collaboration,* 8.

[362] Ibid.

[363] Interprofessional Education Collaborative, *Core Competencies for Interprofessional Collaborative Practice,* (2011), 3, accessed October 8, 2020, https://www.ipecollaborative.org/news---announcements.html.

[364] IPEC, *Core Competencies for Interprofessional Collaborative Practice, 3.*

disciplines in the health professions.[365] A related concern was how to ensure that a sense of cooperation and collaboration was instilled in new health professionals. More than forty-five years later the same goals outlined in the initial report of that conference, "Educating for the Health Team," are still being pursued.[366]

The chairman of the steering committee for the conference in 1972 was Dr. Edmond D. Pellegrino. In the report of the conference mentioned above, Pellegrino's introductory statements make clear the goals of the meeting and the barriers to interprofessional education. The IOM was motivated to help "fashion health care that was efficient, effective, comprehensive, and personalized."[367] It further sought to give guidance toward the design of educational endeavors that would provide a synergistic interrelationship of all who could contribute to the patient's well-being."[368] The IOM wanted future health professionals to be "better prepared to work cooperatively for the benefit of patients, families, and communities."[369]

There are four learning domains in interprofessional education that have been identified by the Interprofessional Education Collaborative. These domains include: values and ethics for interprofessional practice, roles and responsibilities, teams and teamwork, and interprofessional communication.[370] In this project I use the phrase, *ethics-oriented interprofessional education*, to refer to educational endeavors in the virtues and ethics domain. The World Health

[365] National Academies of Sciences, "*Educating for the Health Team*," (October 1972), accessed October 8, 2020, https://nexusipe.org/informing/resource-center/iom-1972-report-educating-health-team.
[366] IPEC, "*Core Competencies for Interprofessional Collaborative Practice," 3.*
[367] IOM, "*Educating for the Health Team,"* 12.
[368] Ibid.
[369] Ibid., 13.
[370] IPEC, *Core Competencies for Interprofessional Collaborative Practice,* 22.

Organization also lists ethics as one of six domains in which interprofessional learning can take place.[371]

I see the use of narratives as having great potential to assist in the education of interprofessional teams and also in the development of a deeper understanding of the human condition. But I argue here that the educational focus in ethics-oriented interprofessional education needs to be on the individual clinician. There are, however, still opportunities for interprofessional teams to meet the basic goals of interprofessional education: that students learn from, with, and about each other.

There are different types of interprofessional education experiences. In didactic interprofessional education, clinicians from more than one health profession are taught by a faculty member from one profession. In the clinical setting, interprofessional groups of students can participate in patient rounds and other clinical experiences. But the most common types of interprofessional education takes place during planned events, outside of patient care areas. These events can bring together hundreds of students from various professional programs in order that students might learn from, with, and about one another. Interprofessional education events typically take place in three phases: an introduction, the activity phase, and a debriefing session.

During the introduction faculty and facilitators usually present information about the significance of interprofessional education and the agenda for the specific event of the day. During the activity portion of the event, students are divided into small groups or teams so that they have an opportunity to learn from, with, and about each other. Finally, in the debriefing

[371]World Health Organization, *Framework for Action on Interprofessional Education and Collaboration*, accessed October 8, 2020, 26, https://www.who.int/hrh/resources/framework_action/en/.

phase, student learning continues as students either reassemble into the original large corporate group, or debriefing can take place in the small groups. Whether in small groups or one large meeting room, the major takeaways from the event should be reviewed at this time.

Reviewing the Literature on Ethics-Oriented IPE

When compared to the other domains of learning, there is a paucity of literature available in the area of ethics-oriented interprofessional education. However, there have been some attempts at scholarship in this domain. The scholarly endeavors in this domain could be grouped into three types: books or manuals (some exclusively on-line) published by national organizations that give leadership in interprofessional education, articles about interprofessional education events that were ethics-oriented, and articles that attempt to give a sense of direction in ethics-oriented IPE. I will focus on the last two types of scholarly endeavors in this section.

In 2014, pharmacist Judith Strawbridge and her interprofessional colleagues reported on the use of debate as a method of engagement in ethics-oriented interprofessional education. Their study involved pharmacy and physiotherapy students who were randomly divided into twelve debate teams and randomly assigned to argue for or against current attitudes towards ethical issues. The contemporaneous ethical issues were chosen based on their appeal to both clinician groups.[372] Standard pre-test and post-test surveys were done by the participants. The author's findings suggest that students liked participating in the debates, thought that debates

[372] Judith Strawbridge, Aileen Barrett, and James Barlow, "Interprofessional Ethics and Professionalism Debates: Findings from a Study Involving Physiotherapy and Pharmacy Students," Journal of Interprofessional Care 28, no. 1 (2014), 64.

were an appropriate way to learn ethics, and thought that they developed critical thinking skills during the interprofessional education event.

In "Interprofessional Ethics Education Seminar for Undergraduate Health Science Students," nursing professor Kathleen Cino and her interprofessional colleagues report on their pilot project from 2017. In this pilot project authors used ethics-oriented interprofessional education to help determine whether or not student's sense of self-efficacy, the extent of one's belief in their own ability to complete tasks and accomplish goals, can be improved in interprofessional education. The authors suggest that improved levels of self-efficacy lead to greater success in one's chosen field. Students from three professions - medical technology, nursing, and dental hygiene - were assigned to interprofessional groups, given a brief introduction to ethics and interprofessional education, and then asked to compare and contrast each profession's code of ethics. Students then reviewed case studies in their assigned small groups to determine if ethical codes were violated or supported. The Self-Efficacy for Interprofessional Learning (SEIL) survey was used before and after the event. The authors report a significant increase in self-efficacy in three areas: understanding the purpose of interprofessional education, confidence in working with interprofessional teams, and understanding the benefits of interprofessional collaboration for the patient.[373]

Nursing educator Cathy Rozmus and her colleagues describe the use of a novel resource for ethics and professionalism training, *The Brewsters*, at the University of Texas Health Science Center in Houston. Students from all schools and all degree program levels (BSN, MPH, MD, DDS, PhD) participated in their planned event. *The Brewsters* is a choose-your-own-adventure

[373] Kathleen Cino, Rita Austin, Cristina Casa, Christine Nebocat, and Adele Spencer, "Interprofessional Ethics Education Seminar for Undergraduate Health Science Students," *Journal of Interprofessional Care* 32, no. 2 (2018): 239.

novel that is designed to introduce students to professional ethics, clinical ethics, and research ethics. The book uses an "interactive narrative approach to teaching ethics and professionalism designed to help students connect their own personal lives with narratives of what it means to be a health professional."[374] Students who read the material consistently report that they enjoy this method of ethics instruction. The results from the pre-tests and post-tests from the pilot study and the campus wide implementation of the book showed a significant increase in ethics knowledge for all groups. *The Brewsters* focuses on integrating ethics and professionalism into the personal and professional lives of clinicians are encouraging and reminiscent of Robert Coles' ideas about lifework.

The second set of articles that I review here attempts to give ethics-oriented interprofessional education a sense of direction. Rob Irvine and his colleagues suggest what they call a *dialogical ethics of interprofessionalism*.[375] The authors suggest that the common ways of thinking about medical ethics, which include appeals to universal principles (e.g., autonomy and justice), appeals to universal philosophical theories like utilitarianism, and even appeals to virtue ethics are insufficient. They contrast these well-known attempts at ethics education with a more "imaginative form of ethical reasoning," the dialogical approach.[376] *Dialogical ethics* is based on extended notions of collegiality. It presupposes that all clinicians are invaluable members of the interprofessional team, and each clinician should have the freedom to express their beliefs, values, traditions, and perspectives. Mutual agreement is not a necessary precondition of dialogic ethics, but when it does occur, it is through a discursive process. This discursive

[374] Cathy L. Roxmus, Nathan Carlin, Angela Polczynski, and Richard Buday, "*The Brewsters*: A New Resource for Interprofessional Ethics Education," *Nursing Ethics* 22, no. 7 (2015): 818.

[375] Robert Irvine, I. Kerridge, and J. McPhee, "Towards a Dialogical Ethics of Interprofessionalism," *Journal of Postgraduate Medicine* 50, no. 4 (2004: 278.

[376] Irvine, "Towards a Dialogical Ethics of Interprofessionalism," 279.

process as discussed by Irvine and his colleagues is reminiscent of the way in which I described deliberative democracies and their function under the direction of the moral imagination in chapter one.

Machin and his colleagues share lessons learned from planning and implementing ethics-oriented interprofessional education events over a five-year period. The authors acknowledge that there is limited literature available to assist in the guidance of those who are interested in designing these types of interprofessional events. They suggest that planners of interprofessional education should attempt to format "interprofessional events so that they reflect real-world practice" and suggest that this is optimal.[377] However, for those educational institutions that are restricted both financially and spatially, this suggestion by the authors is probably an undue burden and may actually stifle attempts to host interprofessional events. The better suggestion may be for institutions to consider their available resources for interprofessional education and then plan accordingly. The reality is that interprofessional education does not have to be expensive to be effective. These authors also suggest a topical approach (e.g., what makes a good death) to ethics-oriented interprofessional education. Another method mentioned in this article is the use of interprofessional education debates on ethical topics. The authors encouraged planners to begin to think about evaluation for all interprofessional education events as early as possible. Students should also be prepared thoroughly to participate in these events.[378]

[377] L. L. Machin, K. M. Bellis, C. Dixon, H. Morgan, J. Pye, P. Spencer, R. A. Williams, "Interprofessional Education and Practice Guide: Designing Ethics-Oriented Interprofessional Education for Health and Social Care Students," *Journal of Interprofessional Care* 33, no. 6 (2019): 610.

[378] Ibid.

Catherine Caldicott and Eli Braun acknowledge the fact that accrediting bodies require ethics education and interprofessional education, but suggest that there are both benefits and challenges to overcome in both single professional and interprofessional ethics teaching. Because all health professionals (e.g., nurse, clinical laboratory scientist) will not face the same ethical challenges, an ethics course for a specific profession might allow coverage of profession-specific ethics information. The cases in these courses could also be tailored to the specific profession. Professional decorum may also take on different meanings for various groups. On the other hand, these courses may foster the formation of professional silos and prevent the fostering of more wide-ranging moral development like growth in "moral sensitivity, judgment, character, and commitment." The authors also posit the idea that the professional training of the faculty member who teaches these ethics courses is important. Not all instructors will be equipped to teach interprofessional ethics courses and gaining credibility from some student groups may be a challenge. The authors conclude that professional ethicists may be best situated to conduct interprofessional ethics teaching.

In "Core Topics of Health Care Ethics: The Identification of Core Topics for Interprofessional Education," Helen Aveyard and her colleagues attempt to identity topics for ethics-oriented interprofessional education. Using Nominal Group Technique, a discussion-oriented method that helps groups reach consensus, the authors brought together faculty from seven allied health programs to identify common ethical topics that might be taught interprofessionally. The result of the workshops was the discovery of seven common ethical topics that were identified by each program. The topics included ethical theory, professional duty of care and codes of ethics, informed consent and patient refusal, confidentiality, the

vulnerable patient, research ethics, and rationing scares healthcare resources.[379] It was suggested that this list of topics was ripe for interprofessional education because all allied health groups identified these topics as essential for their students. It was also posited that the case studies approach was preferable as a teaching method.

An analysis of the scholarship available in ethics-oriented interprofessional education requires certain comments. Efforts in this area of education have been primarily focused on the sharing of information with students: codes of ethics, principles and rules, topical ethics discussions, etc. These efforts supply students with needed information, but the question that remains for me is whether or not this type of ethics education is sufficient. I argue here that although there is utility in sharing ethics information of the above sort, there is a better, more excellent way, of doing moral inquiry in ethics-oriented interprofessional education.

Michael Hanna and physician-ethicist Joseph Fins seem to be in search of something better as well, a better way of preparing clinicians for genuine patient encounters. Writing about the limitations of using simulated or standardized patients in the training of medical students, the authors point to the difference between teaching students to *act like* good doctors as opposed to *being* good doctors.[380] In the course of educating medical students and other clinicians, the use of simulated patients in mock training exercises has become standard practice. While the authors (and the literature) point to the benefits of this kind of training and using these kinds of actors, they fear that an overuse of simulated patients does not prepare clinicians for authentic patient encounters. I agree with Hanna and Fins here as they argue that the formation of authentic

[379] Helen Aveyard, Sarah Edwards, and Sharon West, "Core Topics of Health Care Ethics: The Identification of Core Topics for Interprofessional Education," *Journal of Interprofessional Care* 19, no. 1 (July 2009): 67.

[380] Michael Hanna and Joseph Fins, "Power and Communication: Why Simulation Training Ought to Be Complemented by Experiential and Humanist Learning," Academic Medicine 81, no. 3 (March 2006): 267.

therapeutic relationships with real patients requires more than these simulated experiences can offer. It will require the further development of the clinician's human capacities. The simulated clinician-patient encounter teaches clinicians how to *act like* good clinicians on the outside, but when does the clinician learn to "create authentic relationships with their patients from inside themselves (from their hearts, so to speak)?"[381] Skeptics may wonder how this can be done and whether or not professional school is the appropriate place for this type of development. The authors explain: "Developing good relationships with patients requires knowing them not just as moving biochemical anatomy models, but as interesting, quirky, idiosyncratic persons, as human beings living in the human condition. The only way it is possible to know another human being as a human being though, is first to really and profoundly *know oneself* as a human being. But knowing oneself as a human being is not a process that just happens automatically with age; it must be somehow cultivated and acquired."[382] The authors purport that the value of knowing the self is connected to an understanding of one's human condition. Professional students, according to the authors, "must be given the opportunity to cultivate themselves as mature human beings before they can develop their capacity to deeply understand and truly care for strangers."[383] How does this happen? Where does this understanding come from? It comes from, according to the authors, humanistic learning. Learning about the "human experience in literature and art enables students to better understand their own experiences and lives, and ultimately to be better able to relate to other persons. Without this cultivation of self-knowledge, the student cannot be fully effective in interacting with patients, because the student does not yet have the inner personal capacity to handle all the joy and bereavement and responsibility and stress in a hospital, may

[381] Ibid.
[382] Ibid.,
[383] Ibid., 268.

therefore feel overwhelmed, and would then shut off to the patient."[384] Along with real encounters with patients in the clinic, exposing students to the humanities disciplines can foster a deeper and richer appreciation for the human condition. It is only through this deeper sense of "human understanding" that students will be prepared to understand themselves, understand the Other, and engage in authentic clinician-patient relationships.

Charles Bertolami is also in search of something more in ethics education and he causes quite a stir in his profession when he purports that, "No one has ever done the right thing because of taking an ethics course in dental school."[385] Bertolami, who was the dean of the School of Dentistry at the University California San Francisco when he expressed these sentiments in an article entitled, "Why Our Ethics Curricula Don't Work," also has concerns about the inner development of clinicians. Bertolami notes that the fundamental sources that transmit moral standards in society have declined (churches, families, and local communities) and suggests that based on the common knowledge of this void in moral guidance, universities and professional schools have an essential role to play in moral education. According to Bertolami there are three reasons that our current way of teaching ethics is ineffective. First, moral education is limited in its ability to foster ethical behavior. In other words, knowledge about ethical information does not automatically lead to the acquisition of wisdom. Wisdom is the application of the knowledge received. Secondly, ethics is boring. The traditional ways of teaching ethics with a focus on codes of ethics or ethical theory, does little to capture the student's attention or interest. Third, the way in which ethics is traditionally taught does not foster an "introspective basis for true behavioral change."[386] In other words, the way ethics is taught does not call for self-examination

[384] Hanna, "Power and Communication" 268.

[385] Charles Bertolami, "Why Our Ethics Curricula Don't Work," *Critical Issues in Dental Education* 68, no. 4 (April 2004): 414.

[386] Ibid. 416.

on the part of the student. While all of these points are valid, it is Bertolami's third point that I want to focus on more closely.

Bertolami argues that many times "the personal odyssey by which a student successfully negotiates the arduous path toward professional school does not encourage" this type of self-reflection.[387] Many students have made it to the point of professional school admission "reading the signs of the times and circumstances, responding to the pressures and preferences emanating from parents, peers, and professors."[388] No one has asked them to perform sustained self-reflection or to decide who they want to be, what type of person they want to become. Whether in the professional interviews before admission or in the current ethics courses that are taught, students always seem to know or be able to come up with the "right answers."[389] But the fact is, argues Bertolami, that students "have been so focused on succeeding in a highly competitive environment to gain admission that serious introspection is a luxury that just never arises or even worse, is interpreted as a sign of weakness."[390] This is truly unfortunate because serious introspection is seen as critical for the long-term success of the student in both their professional and personal life.[391]

Bertolami's prescription for dealing with the problems of ethics courses as they are currently taught partially includes a change in content. He suggests that students need "matter that provokes meaningful introspection so that students are continually incubating insights that they have discerned for themselves."[392] I believe that the matter that Bertolami refers to should

[387] Ibid. 418.
[388] Ibid.
[389] Ibid.
[390] Ibid.
[391] Ibid.
[392] Ibid.

include a focus on narrative, stories through which students uncover the facts about their common human condition so that they can better appreciate the condition of the Other.

Using Narratives in IPE

In "Linking Professionalism to Humanism: What It Means, Why it Matters," physician educator Jordan Cohen exhorts others who are involved in clinician education to think deeply about the need to connect professionalism and humanism when training future clinicians. Cohen defines professionalism as "a way of *acting* that comprises a set of observable behaviors."[393] Successful *acting*, according to Cohen, is achieved when clinicians overtly display allegiance to certain objective "principles of professionalism (e.g., the primacy of patients' interests, patient autonomy, and social justice)."[394] Professionalism is required of the clinician so that she might fulfill her duty to the public. But Cohen argues that it may be possible for her, under certain circumstances, to "act in such a way as to fulfill all the expectations of professionalism without actually believing in the virtues or principles that underpin them – going through the motions, so to speak."[395] In contrast, humanism is distinctly different from professionalism. According to Cohen, humanism is not a way of acting but "a way of *being*. It comprises a set of deep-seated convictions about one's obligations to others, especially others in need."[396] We can identify clinicians motivated by humanistic ideals as they display virtues of "altruism, duty, integrity, respect for others, and compassion."[397] Cohen's point is that professionalism is something that the public can observe, but humanism is an internal force. In other words, "humanism provides

[393] Jordan J. Cohen, "Linking Professionalism to Humanism: What it Mean, Why It Matters," Academic Medicine 82, no. 11 (November 2007): 1029.
[394] Ibid.
[395] Ibid.
[396] Ibid.
[397] Ibid., 1030.

the passion that animates authentic professionalism."[398] This is a powerful thought that Cohen is positing here, and I agree with him. When I cogitate about Cohen's thoughts on the way in which humanism inspires, empowers, animates, and gives life to professionalism, my mind runs quickly to another story about empowerment. It is a story about Jesus and his disciples.

Jesus had been with his disciples for three years. During that time, he taught them, he fed them, he loved them, he was their source of power. But at Calvary, when Jesus was crucified, his physical presence was taken from the disciples, but he promised them another Comforter. Jesus makes this promise in Acts 1:8, ten days after the resurrection as he met his disciples in Galilee: "Ye shall receive power, after that the Holy Ghost is come upon you: and ye shall be witnesses unto me, both in Jerusalem, and Judea, and in Samaria, and unto the uttermost part of the earth." The power that the disciples would need to be Jesus' witnesses, to do the work of the church, would be delivered to them in the form of the person of the Holy Ghost. The Holy Ghost would dwell inside of them and be a continual source of inspiration and sustenance for the difficult days of ministry that lie ahead. Without the Holy Spirit's enabling the disciples would not be able to accomplish the plans of their leader, but with the Spirit's presence, these unlearned fishermen would be empowered to spread the good news to the whole known world. In the course of doing ministry there would be difficult days, but the Spirit's presence would empower the disciples from the inside so that their outward expression of duty would be effective.

In a very real sense this is what Cohen is calling for in his article. For those individuals who teach clinicians, the attempt is made to train the clinician to be a professional. The methods that are used include such acts as ensuring each student knows the content of his or her code of

[398] Ibid.

ethics, teaching the rules and principles of ethics and professionalism, discussing the ethical topics that are pertinent for each specific clinician group, and even planning and executing interprofessional events that allow groups of clinicians to focus on common ethical issues. But none of these needed and useful attempts promotes the development of the *humanistic clinician*, the clinician that is both informed and empowered. Without a focus on humanistic ideals efforts that attempt to teach professionalism risk creating what Cohen calls a "thin veneer," and when the inevitable difficulties of lifework arise, the ill-prepared professional will be "in constant danger of deviating from the ethical commitments" that she has made.[399]

How can this precarious circumstance be avoided and how can ethics-oriented interprofessional education be a part of the solution? What I envision is interprofessional education that touches the heart, that goes beyond the nominal requirements of rules, principles, and codes and that attempts to develop what I have called the *humanistic clinician*. The *humanistic clinician* is one who has "a deep-seated empathy and respect for the human condition,"[400] the common condition of both her patients and herself. She recognizes, with help, that her patient's experience of illness is the experience of a person, a person who had a life before she encountered the medical world, and a person who is striving to persevere in life despite the realities of illness. The *humanistic clinician* recognizes that the contingency and vulnerability that has influenced her patient's life, will inevitably, sooner or later, influence her life as well. This is the kind of ethics-oriented interprofessional education that I am arguing for, and below I want to give some examples of how narratives can be used to help develop the humanistic clinician.

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[399] Ibid.
[400] Ibid., 1031.

***Metamorphosis*.** Franz Kafka's classic novella tells the story of Gregor Samsa, his sudden transformation, and his family's inhumane response to him. Gregor, who had been the sole financial provider for his family, is overnight changed into an unrecognizable insect (e.g., cockroach). This acute and unexpected change of Gregor's presents his family (his father, mother, and sister) with problems of finance and feeling. His sister Grete, who was the only member of the family that made a real attempt to care for Gregor after his change occurred, soon wanes in compassion. Gregor's mother makes one attempt to help care for him, but the site of her son in his changed condition was too traumatizing for her. Mr. Samsa, Gregor's father, only directed anger and harm toward Gregor, and he physically injured his son on more than one occasion. Progressively Gregor's family moves toward total disregard of his needs and wonders how they might get rid of him. Gregor's eventual death is an emancipation for his family, and they look forward to life without him as having great prospects. In the one place where Gregor should have been able to receive care and compassion, he finds neglect, loneliness, and cruelty.

In *Metamorphosis* we clearly see the contingency of life. Gregor, who went to bed perfectly fine the night before, wakes up the next morning changed forever. Kafka never explains why this has happed to Gregor or whether or not Gregor deserves this tragic transformation in some way. We only know that Gregor and his family members are left to deal with the sudden change the best they can. We leave our experience with *Metamorphosis* with a certain sense of the contingency in our own lives and by extension the lives of our patients.

The clinician will also hopefully notice that Gregor's outward change led to changes in attitude and caring of his family members. The reader is disappointed by the actions of the man's family, and Kafka does nothing to relieve our disappointment. Kafka points us toward the potential in ourselves as human beings to be cruel and heartless. Commenting on

Metamorphosis Robert Coles asks certain questions: "Do we profit handily from the human degradation of others? Is our comfort earned at the expense of terrible suffering? If so, what happens to us, what 'metamorphosis' falls upon us?"[401] Coles continues with his analysis of the moral work that this book of fiction is doing when he says that "Kafka's story is of immense and continuing moral significance – a means by which each of us can take a demanding look at what we are and yes, what we might become."[402]

Bertolami suggests that the reason courses in ethics are so ineffective is that they fail to answer the one critical question on the minds of students, and I suspect the question is also on the minds of those who teach ethics: "Why? Why be good? Why be ethical?"[403] Kafka helps us answer these questions. He suggests to us that being ethical matters. The way we treat other human beings matters. We are appalled by the callous ways in which the Samsas treat a member of their own family, but we know that the work that Kafka is doing is not just a fictional tale. We recognize the potential for human cruelty all around us, and we recognize that potential in ourselves.

This is the point that Yale professor of psychiatry Michael Rowe wants to drive home in his article, "*Metamorphosis*: Defending the Human." Using Gregor Samsa's experience, Rowe points his reader toward a defense of humanity in our relationships with those who are critically and chronically ill. The article serves as a pathography of sorts as Rowe shares the story of his deceased son Jesse, who died at the age of nineteen after a long battle with ulcerative colitis and cirrhosis of the liver. Jesse, who was first diagnosed with these chronic illnesses at the age of

[401] Robert Coles, *The Mind's Fate: A Psychiatrist Looks at His Profession* (New York: Little, Brown & Company,1995), 312.
[402] Ibid.
[403] Bertolami, "Why Our Ethics Curricula Don't Work," 416.

fifteen, would eventually have two failed liver transplants.[404] In the article Rowe posits what he calls the *Gregor Samsa problem*.

Rowe suggests that clinicians and loved ones may experience feelings of horror, shock, and or disgust when they observe "the physical transformations" of the critically or chronically ill.[405] It is essential that caregivers not allow these feelings to taint their care of the ill in passive ways, through decreased contact with the patient or neglect of their physical needs (e.g. wounds). When clinicians and loved ones yield to these temptations, this yielding leads to the dehumanization of both the patient and her caregivers. Rowe suggests that the origin of this yielding begins with a *crisis within.*[406] The crisis within is a crossroads for the clinician, a place at which a decision must be made. Do I succumb to the feelings of horror, shock, and disgust or do I persist in performing the tasks that I have been called to do?

One prescription for avoiding or overcoming this crisis within is a continual development of the clinician's moral imagination as I have defined it above. When the moral imagination is at work in the clinician or the family of the ill person, the caregiver reflects meaningfully on what it must actually to be the one who is ill, and the caregiver then will seek to display genuine love, compassion, and empathy for the one who is ill. When the moral imagination is at work, clinicians can display courage when others might be fearful. Those who care for the ill can be a witness for the ill person and seek to make a difference, to do the best they can, even in the most extreme situations.

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[404] Rowe gives a more complete account of Jesse's illness experience in a full-length pathography, *The Book of Jesse: A Story of Youth, Illness, and Medicine*.

[405] Michael Rowe, "*Metamorphosis*: Defending the Human," *Literature and Medicine* 21, no. 2 (Fall 2002): 270.

[406] Rowe, "*Metamorphosis:* Defending the Human," 265.

The Death of Ivan Ilych. In this novella Russian author Leo Tolstoy tells the story of Ivan Ilych Golovin, a member of the Court of Justice (a judge) who dies at the age of forty-five. Ivan Ilych, along with his wife of twenty years and his two children, live in St. Petersburg, Russia during the latter part of the nineteenth century. He is described by Tolstoy as an "intelligent, polished, lively, and agreeable man," but this seems to be his public persona, for at home he appears detached emotionally, particularly with his wife.[407] Ivan Ilych's greatest pleasure is playing bridge, and he seeks this distraction from his real life as often as is possible.

One day while preparing the family's new home, Ivan Ilych slips off of a ladder and slams into the frame of a nearby window, injuring the left side of his abdomen. He complains of only minor pain at the time, but the pain from the injury grows progressively worse. Soon Ivan Ilych is being seen by physicians, but he never receives a definitive diagnosis of his disorder. Physicians do Ivan Ilych no good at all; the more physicians he consults, the worse he gets.

There are two themes that Tolstoy deals with in this project that I see as having great utility for the type of ethical inquiries that are important for ethics oriented interprofessional clinician learning. First, Tolstoy masterfully underscores the human vulnerabilities of pain, suffering, loneliness, and death. An example of this is seen in Tolstoy's description of Ivan Ilych's emotional low point in chapter nine:

> He wept on account of his helplessness, his terrible loneliness, the cruelty of man, the cruelty of God, and the absence of God. "Why hast Thou done all this? Why hast thou brought me here? Why, why dost Thou torment me so terribly?"[408]

[407] Rowe, "Metamorphosis: Defending the Human," 16

[408] Leo Tolstoy, *The Death of Ivan Ilych,* trans. Louis and Aylmer Maude (Kyiv, Bulgaria: Demetria Publishing, 1886), 73. All subsequent references to *The Death of Ivan Ilych* in this chapter will be cited parenthetically in the text, with the abbreviation *DII,* followed by the page number.

The words of Ivan Ilych are reminiscent of another lonely dying sufferer, Jesus Christ, as he dies on Calvary and utters the words, "My God, my God, why hast though forsaken me?" For Jesus, this question is in response to the loss of the closeness and intimacy of his Father as he bore the sins of the world, a separation that was theologically necessary. During the most vulnerable point in his life, his crucifixion, Jesus felt abandoned. Ivan Ilych has this same sense of abandonment. He feels abandoned by his friends and family at a time when he needs them most. In this lonely state, Ivan Ilych begins to hear the voice within, what Tolstoy calls "the voice of his soul" (*DII*, 73). This voice is "the current of thoughts arising within him" (*DII,* 73). The voice has questions and Ivan Ilych has an unacceptable answer:

> "What is it you want?" was the first clear conception capable of expression in words, that he heard. "What do you want? What do you want?" he repeated to himself. What do I want? To live and not to suffer," he answered. And again, he listened with such concentrated attention that even his pain did not distract him. "To live? How?" asked his inner voice. "Why, to live as I used to live – well and pleasantly." "As you lived before, well and pleasantly?" the voice repeated (*DII*, 74).

This questioning of his inner voice eventually leads Ivan Ilych to use his imagination and perform a type of moral inquiry into his past. From his childhood until his present circumstances he reflects on the fact that the things in life that are truly "good" have waned progressively to this point. He has been preoccupied and distracted by things that really do not matter: his career, money, his reputation. A return to his life as he lived it before is surely the wrong answer.

Despite the use of available pain medications, opium and morphine, Ivan Ilych's pain continues to grow worse. Eventually, he begins to speak to his pain: "Go on! Strike me! But what is it for? What have I done to Thee? What is it for" (*DII,* 72)? In addition to his physical pain Ivan Ilych suffers emotionally and psychologically. This suffering is in part due to the

inability of Ivan Ilych to find solace and consolation in the things that formerly served well as distractions, what Tolstoy calls *screens* (*DII*, 55). These *screens* had been formerly used in health to distract him from the thought of death and they allowed him to think of death as something that only happened to others. But now the thought of death is his constant companion. Death is omnipresent.

The second theme that we see in *The Death of Ivan* Ilych is the theme of caring or empathy. Tolstoy masterfully contrasts the aloof and seemingly uncaring attitudes of Ivan Ilych's family and friends, with the tender and empathetic actions of Ivan's servant, Gerasim. Gerasim is the butler's assistant and is described as "a clean, fresh peasant lad, grown stout on town food and always cheerful and bright" (*DII*, 56). When Ivan Ilych is too weak to pull up his trousers after having used the commode, it is Gerasim who assists him. When Ivan Ilych is embarrassed about the disposal of his bodily waste and apologizes to Gerasim for having to do this "disgusting task," it is Gerasim who reassures Ivan Ilych that it is not necessary to apologize for being ill. Gerasim is patient with Ivan Ilych, he allows Ivan Ilych to rest his feet on his shoulders (elevating his feet eased Ivan Ilych's discomfort), he engages him in meaningful conversation, and he stayed awake with Ivan Ilych during his long nights of suffering.

Charlton Blake and Abraham Verghese in their article "Caring for Ivan Illych," tell us that the clinician would do well to emulate Gerasim's care of Ivan Ilych. First, in contrast to Ivan Ilych's physicians and family, Gerasim does not participate in what these authors refer to as the "polite lie," the failure to acknowledge that Ivan Ilych is actually dying.[409] The compassionate and candid acknowledgment of his actual prognosis allows Ivan Ilych to move

[409] Charlton Blake and Abraham Verghese, "Caring for Ivan Ilych," *Journal of General Internal Medicine* 25, no. 1 (January 2010): 94.

from the denial of his death, to an understanding of death's significance. This recognition is essential for Ivan Ilych because it allows his story to end, not in chaos, but with a "deathbed discovery of compassion for his wife and family."[410]

Secondly, Gerasim takes time to *be with* Ivan Ilych, he is not hurried or distracted by other tasks or responsibilities. "Gerasim is successful," say the authors, "because his status enables him to spend more conflict-free time with Ivan Ilych."[411] In the twenty-first century the short supply of extra time is well understood by most clinicians, but the answer to the dilemma of time may be learning how to appear conflict-free when the clinician is actually not. By this I mean that the clinician must "use time creatively" so that he can make the patient feel like the priority, even when time is limited.

Gerasim should also be commended for using his moral imagination, for understanding the similarities between himself and his master. As Ivan Ilych speaks to Gerasim about his sense of helplessness and the tasks that Gerasim must perform for him, Gerasim's moral imagination is on full display. When considering our common human condition Gerasim says:

> "We shall all of us die, so why should I grudge a little trouble?" – expressing the fact that he did not think his work burdensome, because he was doing it for a dying man and hoped someone would do the same for him when his time came. (DII, 60)

Certainly, clinicians should understand that although they may not be the one being cared for today, the contingencies and vulnerabilities of life ensure that their time in the role of patient is forthcoming. Clinicians need to be encouraged to deliver the same type of compassionate, empathetic care that they would want to receive.

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[410] Ibid.
[411] Ibid.

When Breath Becomes Air. In, *When Breath Becomes Air*, neurosurgeon Paul Kalanithi shares the story of his life, his illness, and with his wife's help in the *Epilogue*, his death. The question that drives Kalanithi throughout his life is an existential question, a question about what makes life meaningful. The pursuit of an answer to this question gives Kalanithi educational direction, and this is why he chooses to major in both English and biology as an undergraduate at Stanford. Ultimately this same question leads him to pursue medicine in general, and neurosurgery in particular. In the interim between his undergraduate degree and his medical training, Kalanithi received master's degrees in English literature and the history and philosophy of science. In Kalanithi's search for meaning he learns much about the brain, but settles on the fact that the brain does not equal the mind, the brain is not identical to the self or personal identity as some would suggest, but the brain does give rise to our ability to form relationships and make life meaningful (DII, 38).

After spending his entire adult life preparing for a future in medicine, and possibly as a writer, Kalanithi is diagnosed with lung cancer at the age of thirty-six, in his sixth year of neurosurgical residency. Describing his outlook on his life after the diagnosis Kalanithi says, "I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced."[412] The contingency of life is evident for Kalanithi: "My carefully planned and hard-won future no longer existed" (*WBA*, 120). Paul's bleak outlook on his future is reversed, temporarily, when he begins to respond favorably to treatment for his lung cancer. After some time on the chosen therapy his lungs actually appear radiologically clear and he resumes his fast-paced and grueling responsibilities as a neurosurgical

[412] Paul Kalanithi, *When Breath Becomes Air: What Make Life Living in the Face of Death?* (London: Vintage, 2017), 120. All subsequent references to *When Breath Becomes Air* in this chapter will be cited parenthetically in the text, with the abbreviation *WBA*, followed by the page number.

chief resident. Despite the uncertain nature of his future health, he and his wife also decide to attempt to conceive a child. Their rationale for having a child is explained best by Kalanithi's answer to his question regarding what makes life meaningful: "If human relationality formed the bedrock of meaning, it seemed to us that rearing children added another dimension to that meaning" (*WBA*, 142). Unfortunately, not long after Kalanithi responded so well to treatment, his body became resistant to all attempts to send his cancer into remission.

Pathographies are usually not books that we should look to for medico-scientific information as the authors of these books are most often not scientists or medical professionals. So, in a very real sense, Kalanithi is the ideal author of a pathography; he has in his person the perfect blend of scientific knowledge and expertise and a deep appreciation for his own illness experience. Add to these attributes mentioned above a rich passion for the power of the humanities, and it is no wonder why this project has such great utility. The book is a joy to read.

A few examples are worth mentioning. Early in the narrative as Kalanithi describes his experiences as a new medical student in the gross anatomy lab, we see a glimpse of his brilliance as he describes an experience that is at once exciting but at the same time cause for reverence:

> The scalpel is so sharp it doesn't so much cut the skin as unzip it, revealing the hidden and forbidden sinew beneath, and despite your preparation, you are caught unawares, ashamed, and excited. Cadaver dissection is a medical rite of passage and a trespass on the sacrosanct, engendering a legion of feelings: from revulsion, exhilaration, nausea, frustration, and awe, to as time passes, the mere tedium of academic exercise (*WBA*, 44).

Later as Kalanithi recalls having to deliver bad news to one of his patients, a patient who thought she was having a stroke but whom, based on the MRI images most likely had the worst possible type of brain tumor, a glioblastoma. Kalanithi, who had not yet performed the surgery to remove the tumor, avoided speculating on the type of cancer that the patient had, although he was fairly

sure about the diagnosis. When asked by the patient, Mrs. Lee, whether or not the tumor might be cancerous, Kalanithi is purposefully evasive. His comments about this approached reveal a compassionate intent: "A tureen of tragedy was best allotted by the spoonful" (*WBA*, 94).

The last example comes from a different part of Kalanithi's story, when he is reminding himself of the importance of human relationality. As a surgeon Kalanithi felt that technical excellence was not enough, but that his duty to his patients required him to connect with them as human beings. He felt that his ability to use language and to help families understand illness and death could have a lasting effect on how that family remembered the experience of their love one's illness. Reflecting on these emotional moments Kalanithi says, "When there's no place for the scalpel, words are the surgeon's only tool" (*WBA*, 75).

Abraham Verghese, who wrote the forward for this project, was also very taken by Kalanithi's writing. When describing his own response as a reader to other shorter pieces that Kalanithi had written for the *New York Times* and for *Stanford Medicine*, Verghese said that "the prose was unforgettable. Out of his pen he was spinning gold" (*WBA*, *Preface*, iv). I agree with the high praise that Verghese gives Kalanithi for his writing ability, and I would add that his widow, Lucy Kalanithi, is also a gifted writer. In the *Epilogue* to this project Lucy Kalanithi allows the reader to see behind the veil as Paul is taken into the hospital for the final time. Paul, along with his family, bravely decided against heroic attempts to extend his life and choose comfort care instead. With his wife, eight-month old daughter, and his other close relatives at his bedside, Paul succumbs to his disease. The human relationality that Paul was in search of during his life surrounded him in during his final act of dying.

Kalanithi's story teachers us an additional lesson about the human vulnerability of death, something about the wise use of time. He teachers us that we may not have as much time as we

think we do. We never really know if our well-laid plans will every come to fruition. With this in mind the clinician who is learning to know himself should be reminded to redeem the time, to use time wisely because tomorrow is not promised.

In the Scriptures in psalm number ninety, we get clear instructions regarding this matter of redeeming the time. Moses, who is the author of the psalm, explains to his reader that our lives are like stories, tales that are told. He explains to us that only God, who is the author of our story, knows how much time we have in the story. So, Moses implores God to "teach us to number our days, that we may apply our hearts to wisdom." In a sense Tolstoy is doing the same type of work when he shares with his reader Ivan Ilych's thoughts about how he has spent his time, spent his life. Ivan Ilych says, "It is as if I had been going downhill while I imagined I was going up. And that is really what it was. I was going up in public opinion, but to the same extent life was ebbing away from me. And now it is all done and there is only death" (DII, 75). Kalanithi chimes in on this same theme at the end of his life. As death surely approaches and Kalanithi makes an assessment of the things that are most important, he says, "Money, status, all the vanities the preacher of Ecclesiastes described hold so little interest: a chasing after wind indeed" (*WBA*, 198).

In this chapter I have argued that the current methods used in ethics-oriented interprofessional education are insufficient. I suggest that there are deeper and richer ways that moral inquiry might be accomplished that both assist the individual learner in developing a more robust appreciation for the common human condition while allowing the interprofessional team to meet its goals. Moral growth and development are not things that can be assessed for groups but must be evaluated on an individual level.

Considering the nature of the readings that I am proposing for ethics-oriented interprofessional education, these groups should be as small as possible, ideally with no more than fifteen students. Larger groups will impede attempts to authentically engage in group discussions. For ethics-oriented interprofessional education it may be more beneficial to allow students to remain in their small groups for the debriefing session. Students that have discussed moral development in their small groups may be more apt to continue participation in the debriefing session if these cohesive small groups are allowed to stay together. Whether students remain in their small groups or reassemble in large auditoriums, the major take-aways of the activity should be discussed during the debriefing period.

The three narratives that I use in this section are examples of the kinds of books that can be used to assist in the development of the humanistic clinician. These books are relatively short and should not present an undue burden on the clinician who may see herself as overwhelmed with extensive amounts of "scientific" information to learn. Second, it is also important that the faculty who plan these events make space in the curriculum for these readings. If the goals of ethics-oriented interprofessional education are important, this should be clearly reflected by providing time for students to accomplish the reading. Third, these books are written well, are interesting, and enjoyable to read in their own right. Students should be able to both enjoy the reading experience and learn essential things about themselves that foster deeper and richer relationships with their interprofessional team and their patients.

In the conclusion of this project I want to return to the illustration that I began with in chapter one, my story about Sharon. Perhaps along the way we have learned some things that will help her in her time of need.

Coda

When we left Sharon in chapter one, she was experiencing an existential crisis about her patient and the value of the care that she was able to provide for him. The patient is a seventy-eight-year-old man with multiple medical problems. The patient has been ventilator-dependent for several months and cannot be weaned from the machine. He has a tracheostomy tube in place that is intended to help facilitate weaning from mechanical ventilation and he has a Foley catheter (for urine collection), a rectal tube (for stool collection), a percutaneous endoscopic gastrostomy or PEG tube (for feedings), and he had multiple intravenous lines. He is bed-ridden and has skin breakdown in several places on his body. The patient is minimally conscious, but not well orientated to person, place, and time. The issues that Sharon is struggling with include feelings of her own inadequacy as a clinician, frustration about her patient's medical condition and his family's perceived lack of understanding about his prognosis, and an ultimate question regarding how to go on as a clinician in moments when she believes that the medial care that she provides is not only insufficient, but possibly inappropriate. After the work that we have done in this dissertation, what things have we learned that can help Sharon and other clinicians who are likely to experience these same types of crises?

One of the issues that I believe Sharon is dealing with is perhaps something that she herself is not fully aware of. As a clinician who is embedded in a culture of scientific medicine it may be difficult to admit, even when the evidence is right before you, that the narrative of Western medicine, a narrative of progress, is not a true narrative. Despite the current crisis that she is experiencing, admitting to the limitations of modern medicine may lead to deeper questions about the nature of her work and her ultimate purpose as a clinician. Ultimately

though, the recognition of, and admission of, the limitations of modern medicine will be a step in the right direction.

Paul Kalanithi, to whom we also were introduced in chapter four, in his book, *When Breath Becomes Air*, has some helpful advice for Sharon. Kalanithi, after having a particularly stressful day and admitting that he could not fight back the tears during his drive home, offers clinicians this exhortation:

> Being *with* patients in these moments certainly had its emotional cost, but it also had its rewards. I don't think I ever spent a minute of any day wondering why I did this work, or whether it was worth it. The call to protect life – and not merely life but another's identity; it is perhaps not too much to say another's soul – was obvious in its sacredness . . . Those burdens are what makes medicine holy and wholly impossible: in taking up another's cross, one must sometimes get crushed by the weight (*WBA*, 97-98).

As I identify with where Sharon is emotionally, having been there myself as a clinician, I find Kalanithi's words extremely therapeutic, particularly his pointing us toward our duty to protect life, life's sacredness, and the incredible privilege we have as clinicians to bear this burden. As clinicians we don't have the luxury of deciding when to care and when not to, but we are called to protect the life and identity of those who many times are unable to exercise their own rights or to speak for themselves. Yes, this is sometimes an unspeakable burden, and yes sometimes tears and frustration are our lot, but we are not cursed, we are privileged to do for these patients what one day may have to be done for us.

Later in his narrative Kalanithi exhorts the clinician again. Patient identity is still on his mind, but now he also has the death of the patient in view. As he struggles to come to grips with the ultimate futility of the clinician's work he offers us these words of consolation:

> Our patients' lives and identities may be in our hands, yet death always wins. Even if you are perfect, the world isn't. The secret is to know that the deck is stacked, that you will lose . . . and yet still struggle to win for your patients. You can't reach perfection, but you can believe in an asymptote toward which you are ceaselessly striving (*WBA,* 114-115).

Kalanithi's words here remind us of Arthur Frank's exhortation about the need of the storyteller to embrace contingency. He says in *The Wounded Storyteller* that "contingency is the only real certainty" in life."[413] This is Kalanithi's message to his reader and my advice for clinicians. The clinician should not allow herself to be repeatedly surprised by the contingencies of the work she does, but she should embrace contingency as a means of change and growth.

Kalanithi's words also remind me of the theological *doctrine of sanctification*. In Christianity, the *doctrine of sanctification* is the idea that the believer is constantly striving for a level of perfection that he will never reach. From the very moment that the believer comes into a relationship with God, he begins to strive to be more like Jesus, not to be sinless, but to sin less. The believer knows that a sinless perfection is not possible in her mortal flesh that she inhabits, but that knowing does not preclude the believer's striving for perfection. This is how I read Kalanithi's exhortation above. The clinician can embrace contingency and the inevitable mortality of both himself and his patients, but at the same time strive to be the very best clinician that he can be and to deliver the most compassionate care that he can provide. He can strive to be a humanistic clinician.

In this project I have learned that the moral imagination and its development can be an invaluable asset to the clinician. The ability to imagine what it must be like to be

[413] Frank, *The Wounded Storyteller*, 126.

the one who is suffering will enable the clinician to think broadly about the implications of the care that she is providing for her patient. In a real sense her caring for the Other is a caring for herself and for the humanity and identity that the particular patient is representative of. I have learned that the moral imagination needs to be cultivated and that with proper attention, the moral agent can flourish and be a help to her patients, the patient's family, and even to herself. Pathographies, those stories of illness, especially the ones like Kalanithi's and Jean Dominique-Bauby's, can be a particular help to clinicians. They can cultivate the moral imagination and remind the clinician of the common human condition that we share with our patients. I have attempted to apply all of these lessons to interprofessional education and posit an idea for a more excellent way of approaching ethics-oriented interprofessional education. My prayer for this work is that whether they are student clinicians or active practitioners, this work will be of help to those who continue to strive toward becoming humanistic clinicians.

BIBLIOGRAPHY

Albom, Mitch. *Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson*. New York: Broadway Books, 1997.

Allatt, Kate. *Running Free: Breaking Out from Locked-in Syndrome.* United Kingdom: Accent Press, 2011.

Andre, Judith. "The Medical Humanities as Contributing to Moral Growth and Development." In *Practicing the Medical Humanities: Engaging Physicians and Patients*, edited by Ron A. Carson, Chester R. Burns, and Thomas R. Cole, 39-69. Hagerstown: University Publishing Group, 2003.

Aristotle. *The Nicomachean Ethics.* Translated by Harris Rackham. Ware: Wordsworth Editions, 1996.

———. *Rhetoric.* Translated by W. Rhys Roberts. New York: Barnes & Noble Books, 2005.

Aveyard, Helen, Sarah Edwards, and Sharon West. "Core Topics of Health Care Ethics: The Identification of Core Topics for Interprofessional Education." *Journal of Interprofessional Care* 19, no. 1 (July 2009): 63-69.

Bauby, Jean-Dominique. *The Diving Bell and the Butterfly.* New York: Vintage Books, 1998.

Bertolami, Charles. "Why Our Ethics Curricula Don't Work." *Critical Issues in Dental Education* 68, no. 4 (April 2004): 414-425.

Bessette, Joseph. *The Mild Voice of Reason: Deliberative Democracy & American National Government.* Chicago: The University of Chicago Press, 1994.

Beukelmann, David R. and Janice C. Light. *Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs.* Baltimore: Brooks Publishing, 2020.

Bishop, Jeffrey P. "Rejecting Medical Humanism: Medical Humanities and the Metaphysics of Medicine." *Journal of Medical Humanities* 29, (2008) 15-25.

Blake, Charles, and Abraham Verghese. "Caring for Ivan Ilych," *Journal of General Internal Medicine.* 25, no. 1 (January 2010): 93-95.

Bloom, Paul. *Against Empathy: The Case for Rational Compassion.* New York: HarperCollins Books, 2016.

Borba, Michele. *Building Moral Intelligence: The Seven Essential Virtues that Teach Kids to Do*

the Right Thing. San Francisco: Jossey-Bass, 2001.

Bauby, Jean-Domonique. *The Diving Bell and the Butterfly.* New York: Random House, 1998.

Brody, Howard. "Defining the Medical Humanities: Three Conceptions and Three Narratives." *Journal of Medical Humanities* 32, (2011): 1-7.

Bruno, Marie-Aurelle and Jan L Bernheim. "A Survey on Self-Assessed Well-Being in a Cohort of Chronic Locked-in Syndrome Patients: Happy Majority, Miserable Minority." *BMJ Open* 1, no. 1 (2011): 1-9.

Burke, Edmond. *Reflections on the Revolution in France*. Edited by L. G. Mitchell. New York: Oxford University Press, 1993.

Campo, Rafael. "'The Medical Humanities,' for Lack of a Better Term." *Journal of the American Medical Association* 294, no. 9 (September 2005): 1009-1011.

Carson, Ronald A. "Educating the Moral Imagination." In *Practicing the Medical Humanities: Engaging Physicians and Patients*, edited by Ron A. Carson, Chester R. Burns, and Thomas R. Cole, 25-37. Hagerstown: University Publishing Group, 2003.

———. "Engaged Humanities: Moral Work in the Precincts of Medicine." *Perspectives in Biology and Medicine* 50, no. 3 (2007): 321-333.

Cino, Kathleen, Rita Austin, Cristina Casa, Christine Nebocat, and Adele Spencer. "Interprofessional Ethics Education Seminar for Undergraduate Health Science Students." *Journal of Interprofessional Care* 32, no. 2 (2018): 239-241.

Cohen, Jordan J. "Linking Professionalism to Humanism: What it Mean, Why It Matters." Academic Medicine 82, no. 11 (November 2007): 1029-1032.

Coles, Robert. *The Call of Stories: Teaching and the Moral Imagination.* Boston: Houghton Mifflin Company, 1989.

———. *Dorothy Day: A Radical Devotion.* New York: DA CAPO Press, 1987.

———. "Engaged Humanities: *Moral Work in the Precincts of Medicine," Perspectives in Biology and Medicine* 50, no. 3 (2007): 321-33.

———. *Lives of Moral Leadership: Men and Women Who Have Made a Difference.* New York: Random House, 2000.

———. "Medical Ethics and Living a Life." *The New England Journal of Medicine* 301, no. 8 (April 23, 1979): 444-446.

———. *The Moral Intelligence of Children: How to Raise a Moral Child.* New York: Plume Publishing, 1998.

———. *The Moral Life of Children.* New York: Atlantic Monthly Press, 1986.

Day, Dorothy. "Introduction." In *Dorothy Day: Selected Writings*, edited by Robert Ellsberg, xvii-xliii. Maryknoll: Orbis Books, 1983.

———. Loaves and Fishes: The Inspiring Story of the Catholic Worker Movement. Maryknoll: Orbis Books, 1963.

Dumas, Alexandre. *The Count of Monte Cristo.* New York: Bantom Dell, 2003.

Dzeng, Elizabeth. "Navigating the Liminal State Between Life and Death: Clinician Moral Distress and Uncertainty Regarding New Life-Sustaining Technologies." *The American Journal of Bioethics* 17, no. 2 (February 2017): 22-25.

EyeTech. "EyeOn Tablet." Eyetech, Accessed October 8, 2020. https://eyetechds.com/eye-tracking-products/the-eyeon-platform/.

Fox, Daniel M. "Who We Are: The Political Origins of the Medical Humanities," *Theoretical Medicine* 6, (1985) 327-342.

Frank, Arthur W. "The Voices that Accompany Me." *The Journal of Medical Humanities* 41, (2020): 171-178.

———. *At the Will of the Body: Reflections on Illness.* New York: First Mariner Books, 2002.

———. *The Wounded Storyteller: Body, Illness, and Ethics.* Chicago: The University of Chicago Press, 1995.

Gallo, Ugo E. and Phil B. Fontanarosa. "Locked-in Syndrome: Report of a Case." *The American Journal of Emergency Medicine* 7, no.6 (1989): 581-583.

Gilligan, Carol. *In a Different Voice: Psychological Theory and Women's Development.* Cambridge: Harvard University Press, 1982.

Groves, James E. "Taking Care of the Hateful Patient." *The New England Journal of Medicine* 298, no. 16 (April 1978): 883-887.

Gutman, Amy and Dennis Thompson. *Democracy and Disagreement: Why Moral Conflict Cannot be Avoided in Politics, and What Should be Done About It.* Cambridge: Harvard University Press, 1996.

Hanna, Michael, and Joseph Finns. "Power and Communication: Why Simulation Training Ought to Be Complemented by Experiential and Humanist Learning." *Academic Medicine* 81, no. 3 (March 2006): 265-270.

Hawking, Michael. "Courage and Compassion: Virtues in Caring for the So-Called 'Difficult' Patients." *Medical Education* 19, no. 4 (April 2017): 357-363.

Hawkins, Anne Hunsaker. "Pathography: Patient Narratives of Illness." *The Western Journal of Medicine* 171, no. 2 (August 1999): 127-129.

———. *Reconstructing Illness: Studies in Pathography.* West Lafayette: Purdue University, 1999.

Himmelfarb, Gertrude. *The Moral Imagination: From Adam Smith to Lionel Trilling.* 2nd ed. Lanham: Rowman & Littlefield, 2012.

———. "Reflections on Burke's Reflections." *The New Criterion* 27, no. 6 (February 2000): 4-6.

Institute of Medicine of the National Academies. *Interprofessional Education for Collaboration: Learning How to Improve Health from Interprofessional Models Across the Continuum of Education to Practice*: Workshop Summary, Washington DC: The National Academies Press, 2013.

Interprofessional Education Collaborative, *Core Competencies for Interprofessional Collaborative Practice*, (2011), 3, accessed October 8, 2020, https://www.ipecollaborative.org/news---announcements.html.

Irvine, Robert, I. Kerridge, and J. McPhee. "Towards a Dialogical Ethics of Interprofessionalism." *Journal of Postgraduate Medicine* 50, no. 4 (2004): 278-280.

Jameton, Andrew. *Nursing Practice: The Ethical Issues.* Englewood Cliffs: Prentice Hall, 1984.

Jones, Anne Hudson, and Ronald Carson. "Medical Humanities at the University of Texas Medical Branch at Galveston." *Academic Medicine* 78, no. 1 (October 2010): 1006-1009.

Kalanithi, Paul. *When Breath Becomes Air: What Make Life Living in the Face of Death?*. London: Vintage, 2017.

Kohlberg, Lawrence. *The Philosophy of Moral Development: Moral Stages and the Idea of Justice.* New York: Harper & Row, 1981.

King, Martin. *Letter from Birmingham Jail.* London: Penguin Books, 2018.

———. "The Purpose of Education." *The Marron Tiger* (1947), 123-124.

———. *Strength to Love.* Philadelphia: First Fortress Press, 1981.

———. *Why We Can't Wait*. New York: Berkley Publishing, 1963.

Kress, Michael. “Dorothy Day.” in *Spiritual Leaders Who Changed the World*, edited by Ira Rifkin, 174-177. Woodstock: Skylight Paths, 2008.

Kutac, Julie, Rimma Osipov, and Andrew Childress. “Innovation Through Tradition: Rediscovering the ‘Humanist’ in the Medical Humanities.” *Journal of Medical Humanities* 37, no. 4 (2016): 371-387.

Lachman, Vicky. “Moral Resilience: Managing Moral Distress and Moral Residue.” *MedSurg Nursing* 25, no. 2 (March-April 2016): 121-125.

Laureys, Steven. “The Locked-in Syndrome: What is it Like to be Conscious but Paralyzed and Voiceless.” *Progress in Brain Research* 150, (2005): 497-511.

Leon-Carrion, Jose, Philippe van Eeckhout, and Maria del Rosario Dominguez. “Review of Subject: The Locked-in Syndrome: A Syndrome looking for a Therapy.” *Brain Injury* 16, no. 7 (2002): 555-569.

Lewis, C. S. *The Four Loves* New York: HarperCollings Books, 1960.

Liao, Shen-yi, and Tamar Gendler. "Imagination." *The Stanford Encyclopedia of Philosophy* (Summer 2020 Edition), Edward N. Zalta (ed.), accessed October 3, 2020, https://plato.stanford.edu/archives/sum2020/entries/imagination.

Machin, L. L., K. M. Bellis, C. Dixon, H. Morgan, J. Pye, P. Spencer, R. A. Williams. “Interprofessional Education and Practice Guide: Designing Ethics-Oriented Interprofessional Education for Health and Social Care Students.” *Journal of Interprofessional Care* 33, no. 6 (2019): 608-618.

MacIntyre, Alasdair. *After Virtue*. Second Edition Notre Dame: University of Notre Dame Press, 1984.

Marcum, James A. “The Role of Prudent Love in the Practice of Clinical Medicine.” *Journal of Evaluation in Clinical Practice* 17, no. 5 (October 2011): 877-882.

Montaigne, Michel de. *The Complete Essays of Montaigne.* Translated by Donald M. Frame. Stanford: Stanford University Press, 1958.

Moustakas, Clark. *Being-In, Being-For, Being-With.* Northvale, NJ: Jason Aronson Inc., 1995.

National Academies of Sciences, *Educating for the Health Team*, (October 1972), accessed October 8, 2020, https://nexusipe.org/informing/resource-center/iom-1972-report-educating-health-team.

Nette, David and Sandra Nette. *Blink: Life After Locked in Syndrome.* (London: New Generation Publishing, 2015.

Nussbaum, Martha C. *Love’s Knowledge: Essays on Philosophy and Literature.* New York: Oxford University Press, 1992.

———. *Upheavals of Thought: The Intelligence of Emotions.* Cambridge: Cambridge University Press, 2003.

Obama, Barak. *The Audacity of Hope: Thoughts on Reclaiming the American Dream.* New York: Broadway Paperbacks, 2006.

Oliner, Samuel P. and Pearl M. Oliner. *The Altruistic Personality: Rescuers of Jew in Nazi Europe.* New York: The Free Press, 1992.

O'Reilly, Allison S. *Out of the Darkness: An Inspirational Story of Survival in the Face of Stroke and Locked-in Syndrome*. Bloomington, Archway Publishing, 2014.

Pedersen, Reidar. "Empathy Development in Medical Education." *Medical Teacher 32, no. 7 (*2010): 593-600.

Piemonte, Nicole M. *Afflicted: How Vulnerability Can Heal Medical Education and Practice.* Cambridge: The MIT Press, 2016.

Plato. *Meno*. Translated by George Anastaplo and Laurence Berns. Newburyport: Focus Publishing, 2004.

Pojman, Louis P. and James Fieser. *Ethical Theory: Classical and Contemporary Readings.* Boston: Wadsworth, 2011.

Rowe, Michael. "*Metamorphosis:* Defending the Human," *Literature and Medicine.* 21, no. 2 (Fall 2002): 270.

Rozmus, Cathy L., Nathan Carlin, Angela Polczynski, and Richard Buday. "*The Brewsters*: A New Resource for Interprofessional Ethics Education." *Nursing Ethics* 22, no. 7 (2015): 815-826.

Strawbridge, Judith, Aileen Barrett, and James Barlow, "Interprofessional Ethics and Professionalism Debates: Findings from a Study Involving Physiotherapy and Pharmacy Students," *Journal of Interprofessional Care* 28, no. 1 (2014), 64-65.

Strong, James. *Strong's Exhaustive Concordance of the Bible.* Peabody, MA: Hendrickson Publishers, 2007.

Tolstoy, Leo. *The Death of Ivan Ilych.* Translated by Louis and Aylmer Maude. Bulgaria, Demetria Publishing, 1886.

Walvoord, John and Roy Zuck. *The Bible Knowledge Commentary.* Colorado Springs: Cook Publishing, 1983.

Wiersbe, Warren. *The Wiersbe Bible Commentary.* Colorado: Cook Publishing, 2007.

Wilson, Barbara A., Paul Allen, Anita Rose, and Veronika Kubickova. *Locked-in Syndrome After Brain Damage: Living Within My Head.* New York: Routledge, 2019.

World Health Organization, *Framework for Action on Interprofessional Education and Collaboration*, accessed October 8, 2020, https://www.who.int/hrh/resources/framework_action/en/.

VITA

Andrew J. Taylor was born on July 26, 1973, in Houston, Texas. He is the son of Joe and Diane Taylor, the husband of Dietra Taylor, and the father of Ashley Pickens, and Hannah, Elizabeth, and Caleb Taylor. In 1997 he graduated from Texas Southern University in Houston, Texas, with a B.S. degree in Respiratory Therapy. In 1999 he completed a master's degree in health education. Andrew became a licensed Respiratory Therapist in Texas in 1997 and has held various practice positions in all facets of respiratory therapy. Andrew is a Registered Respiratory Therapist and holds specialty credentials as a neonatal-pediatric specialist and as a pulmonary function technologist from the National Board for Respiratory Care.

In the fall of 2014 Andrew matriculated into the Medical Humanities program at the Institute for the Medical Humanities at the University of Texas Medical Branch-Galveston (UTMB) in pursuit of the Ph.D. He completed his graduate course work in the summer of 2016. He passed his qualifying exam in the summer of 2018. During his time in graduate school at the IMH Andrew served as president of Students for Bioethics and Humanities and served as an organizer for the Student Research Colloquium in 2016, 2017, and 2019. Andrew also received the David C. Eiland, Jr. MD, Award in Health Care and Humanistic Medicine, and the Endowed Scholarship for the Medical Humanities, both in 2016.

Andrew has taught respiratory therapy and bioethics for twenty years. He has extensive experience in interprofessional education and has served as the chair of the interprofessional education committee in the College of Pharmacy and Health Sciences at Texas Southern University for the last five years. He has also chaired the department's curriculum committee and served on the university's curriculum council.

Publications

Dabi, Alok, and Andrew J. Taylor. "Machine Learning, Ethics, and Brain Death: Concepts and Framework." *Archives of Neurology & Neurological Disorders* 3, no. 2 (October 16, 2020): 119-128.

Permanent address: 2611 Tidenhaven Dr., Pearland, Texas 77584

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