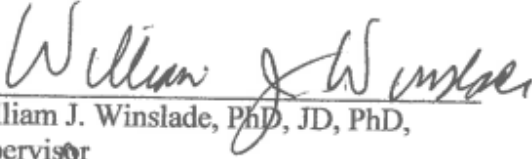


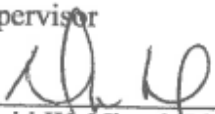
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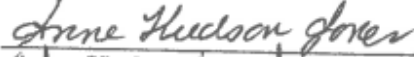
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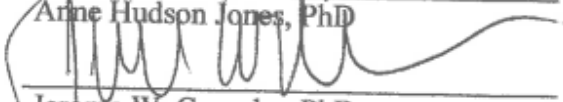
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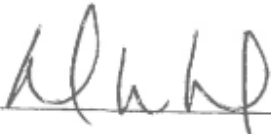
  
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**DECISION MAKING AT THE END OF LIFE: HEALTH CARE, AGING,  
AND END OF LIFE: USING COMMUNITY BIOETHICS DIALOGUES TO  
PROMOTE INDIVIDUALIZED PERSONAL DECISIONS AND  
ADVANCE CARE PLANNING**

**by**

**PEGGY L. DETERMEYER, MBA, MDiv, BCC**

**DISSERTATION**

Presented to the Faculty of the Graduate School of  
The University of Texas Medical Branch  
in Partial Fulfillment  
of the Requirements  
for the Degree of

**DOCTORATE OF PHILOSOPHY**

**THE UNIVERSITY OF TEXAS MEDICAL BRANCH**

**AUGUST 2016**

## **Dedication**

To my parents, Carl and Maisie Determeyer, for instilling in me a lifelong love of learning, and to my husband, Robert Livingston, for tolerating my educational pursuits with grace and good humor.

## Acknowledgments

In my original application to the Institute for the Medical Humanities, I explained my diverse background in the words of Alfred Lord Tennyson: “I am a part of all that I have met.” My journey during the program has magnified this statement, and none of it would have been possible without the mentorship and support of many people. Without Dr. Anne Hudson Jones’ assistance in navigating the academic bureaucracy, I would not have been able to continue coursework as a part-time student. Dr. William Winslade provided countless learning experiences that helped me to direct my frustrations with the modern health-care system into a passion for helping people to navigate those (sometimes) treacherous waters. Dr. Howard Brody and Dr. Jerome Crowder provided the opportunity for exploring Community Bioethics Dialogues, and learning first-hand the power of *sermo* for ordinary citizens. Dr. Arlene MacDonald exhibited patience through countless hours at Starbucks, as I wrestled to reconcile anthropological scholars’ work with my own. Dr. David Niesel and Dr. Bernadette McKinney provided one of my favorite learning experiences at IMH, providing an opportunity to learn with students from different parts of UTMB. I am grateful for Dr. Stacey Tovino for agreeing to serve as my outside mentor. I appreciate everyone’s patience, support, and encouragement through the roller coaster of life experiences that has brought us together for this dissertation.

# **HEALTH CARE, AGING, AND END OF LIFE: USING COMMUNITY BIOETHICS DIALOGUES TO PROMOTE INDIVIDUALIZED PERSONAL DECISIONS AND ADVANCE CARE PLANNING**

Publication No. \_\_\_\_\_

Peggy L. Determeyer, Doctorate of Philosophy

The University of Texas Medical Branch, 2016

Supervisor: William J. Winslade

In 1976, the New Jersey Supreme Court ruled that Joseph and Julia Quinlan could authorize removal of life support from their comatose daughter. Since that critical ruling, every state has passed legislation allowing individuals to articulate personal treatment preferences in anticipation of life's end. However, only a small percentage of people complete formal documentation or discuss their treatment preferences with family members or health-care providers. As a result, family members may be asked to make decisions under pressure without understanding the medical issues or the implications for the person. Numerous efforts focus on encouraging health-care professionals' understanding of their patients' treatment preferences but do not address the need for public awareness of medicine's limits and the effect on end-of-life choices. Community bioethics dialogues provide a means for sharing information regarding the importance of considering health-care ethics issues and articulating end-of-life concerns. My thesis is that personhood is central to all conscious individuals and is a critical consideration in making treatment choices. Advance Care Planning is an important component for these plans, but is not the sole task in making personalized health-care decisions. An understanding of the complexities of the health-care system is needed to provide a framework for assessing treatment options and making decisions. Community Bioethics Dialogues provide a viable platform for educating individuals on the health-care system and the importance of making individualized treatment choices. During the past three years, Community Bioethics Dialogues held in Galveston, Texas, provide a model for applying this example of deliberative democracy, demonstrating the initial efficacy of the platform. With education, I believe that some of the current problems associated with end-of-life treatment options can result in better care across the health spectrum, lower costs, and reduced suffering, and I offer a template for expanding dialogues to other groups.

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## **List of Abbreviations**

AAN	American Academy of Neurology
ACP	Advance Care Planning
CER	Comparative Effectiveness Research
CMS	Center for Medicare and Medicaid Services
DNR	Do Not Resuscitate
GAIN	Galveston Alliance of Island Neighborhoods
GCPAAA	Galveston Citizen's Police Academy Alumni Association
GICRAC	Galveston Island Community Research Advisory Committee
GS	Gaudium et Spes
ICU	Intensive Care Unit
IMH	The Institute for the Medical Humanities
IOM	Institute of Medicine
IRB	Institutional Review Board
LULAC	League of United Latin-American Citizens
OHD	Oregon Health Decisions
PCOR	Patient-Centered Outcomes Research
PSDA	Patient Self-Determination Act of 1991
TADA	Texas Advance Directives Act
UTMB	The University of Texas Medical Branch

## **Introduction**

At the beginning of my chaplain residency in 2003, the group had a daylong seminar with an experienced palliative-care physician who began the activities by distributing paper and drawing implements. The instructions were simple: we were told to imagine that we had less than one day to live and then asked to draw what we would like to spend that time doing. All of us drew different settings, in most cases focused on time with family and friends, some with background music, while others anticipated a quiet time together. The significant commonality is that of the group of eight participants, not one person drew a picture of an Intensive Care Unit (ICU) setting. Each of us had a sense of who we were and how we would like for that to manifest itself in our final day of life. Medical technology was not a part of that vision for anyone in the group.

Since that time, in many clinical encounters as a hospital chaplain, I have recalled that seminar and realized the disconnect between the data indicating that most people would prefer to die at home and the fact that most die in clinical settings. The incongruity arises because most people do not consider their own personhood when it comes to their prospective death. We talk about movies we like, books we have read, trips we have taken, and a plethora of other matters, but for the most part, we do not discuss important matters as we age and face the end of our lives. The denial of what matters to us as persons thrusts us into a health-care system that is focused on treatment, even when cures cannot be accomplished or sustained.

In the health-care setting, there are two parties: those who are providing care and those who are the recipients of that care. Much has been written about the need for health-care providers to be honest and forthright with families in providing information and avoiding medical jargon. In countless family meetings, I have witnessed the physician providing a list of

medical issues and closing with the statement, “What do you want us to do? Do you want us to do everything?” The question is incomplete at its most fundamental element. Those receiving care or their surrogates may not understand the implications of what it means to *do everything* in a technological society. Machines and medicines help failing lungs to work or a heart to continue beating, but they cannot always restore the body to health. Moreover, family members may believe that they are shirking their duty if they do not *do everything*. Finally, a person’s life is more than a collection of bodily functions. Consciousness provides the ability to have a narrative self and interact with others—in other words, to possess personhood. When the question about *doing everything* is asked, it does not place the person’s illness in the context of his or her life, accomplishments, hopes, and dreams, and the surrogates will typically not answer the question with another, asking what the most likely outcome of *doing everything* will be. Instead, the logical response for families and surrogates is, “of course we want you to do everything,” without knowing the implications of that mandate. The health-care system is structured to provide treatment, even when those therapies will serve more to prolong the dying process than to enhance life. However, many health-care practitioners do not like to address these questions and may give obfuscated answers. Patients and families are not taught to challenge the system. Difficulties with aging and end-of-life choices have been evolving over the past several decades and are reaching critical proportions as health-care costs increase and attention to the whole person is given secondary importance to continuing treatments.

Anthropologist Sharon Kaufman takes an in-depth look into the dying process in her book *And a Time to Die: How American Hospitals Shape the End of Life*. Her introduction characterizes “the problem of death” in the United States as one that has been shaped by time and bureaucratic processes that contradict the stated wishes of most people to die at home.

Kaufman characterizes death as a medical problem to be conquered, even though it cannot be avoided, and admits that she is unable to provide solutions for this problem due to the organization of medical care, the ways in which hospitals operate, the language of individualism, and the history of the ways doctors work.<sup>1</sup> The health-care system has grown to manage the dying process as much as possible, yet at the same time, people prefer not to discuss death. Instead of focusing on the individual's personhood and what makes his or her life important, clinicians tend to concentrate on physiological characteristics such as heart rate, kidney function, and blood pressure as the criteria for sustaining treatment. The system promotes physician-patient dialogue that focuses on maintaining those functions and proceeding with costly interventions that only prolong suffering and postpone death instead of optimizing a person's remaining time.

Since the 1970s, every state has promulgated legislation to formalize the means for identifying medical surrogates and specifying end-of-life treatment choices, which was further codified with the Patient Self-Determination Act of 1991 (PSDA), providing the legal basis at the federal level for a patient to either refuse or accept life support (Omnibus Budget Reconciliation Act, 1990).<sup>2</sup> Even with the option to accept heroic treatment options, many people do not complete the paperwork or have conversations with their families to express treatment preferences. When asked, most people do not deny that they will die; they just choose not to talk about the prospect, nor do they discuss personalized health-care decisions when prolonging meaningful life is no longer possible.

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<sup>1</sup> Sharon R. Kaufman, *And a Time to Die: How American Hospitals Shape the End of Life* (New York: Scribner, 2005), 17.

<sup>2</sup> S. M. Weber, "Implementation of Self-Determination Act Begins," *Pennsylvania Medicine* 94, no. 11 (November 1991): 26.

In *Being Mortal: Medicine and What Matters in the End*, the Harvard-trained physician and cancer surgeon Atul Gawande reflects on an experience in his early medical education with a patient dying of metastatic cancer but scheduled for surgery. The patient was adamant about *doing everything* even though he had watched his wife die in an ICU and on a ventilator and had told his son that he would not like to repeat her experience. Gawande expresses his frustration, stating “what strikes me most is not how bad his decision was but how much we all avoided talking honestly about the choice before him. We had no difficulty explaining the specific dangers of various treatment options but we never really touched on the reality of the disease.”<sup>3</sup> As a chaplain and as a daughter of aging parents, I have witnessed this type of occurrence repeatedly. Physicians shy away from providing insights on their best medical judgement for the likely outcomes of treatments or even the limitations of those therapies, and families are left in a state of confusion about the likely prognoses for their loved ones. This lack of certitude is compounded by the absence of serious communications among individuals about what the essence of life is for them and the parameters that they are willing to endure when medical science is no longer able to restore the body to complete health.

The task of considering an individual’s personhood and end-of-life wishes falls to both health-care providers and users, with both sides facing challenges. Much attention has been paid to physician responsibilities for communication and the challenges of improving training to enhance skills, as indicated by the Institute of Medicine’s recent report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. The system is simply not structured to have good communications across the health-care spectrum:

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<sup>3</sup> Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Hamish Hamilton, 2014), 3-5.

While most people have given thought to how they would like to die, many have found it difficult to communicate those views and choices to family and loved ones, and in many cases, family and loved ones have their own perceptions and views about death that can influence discussions about dying. Even when individuals and families are aligned, societal norms, expectations, and requirements are not always concordant with the patient's wishes and choices. No one really knows whether, in the end, the death of a loved one occurred with the dignity that was hoped for, or to what degree the dying experience was marred by pain, fear, and discomfort, emotional or physical.<sup>4</sup>

While it is impossible to ensure that an individual will achieve the desired type of death, it is possible to promote the conversations that will elicit values and matters of importance among families, friends, and communities, ultimately providing the individual with an opportunity to articulate treatment choices. We all have views about values, hopes, and dreams, and designating these to prospective surrogates enhances the likelihood that individual wishes will be met. The complexity of our lives intersects with the health-care system in a variety of ways, and opportunities are needed for individuals to learn about the challenges in a venue that emphasizes personhood and autonomy.

The health-care system crosses the boundaries of multiple disciplines. At the core is science with a basic understanding of how the human body works. However, a person is more than just a physiological being. A human has hopes, dreams, and aspirations, and lives in community with other persons--invoking a multitude of disciplines, including theology, the relationship of the person to the divine; philosophy, the examination of who the person is; anthropology, the understanding of human interactions; and history, the study of past events. The humanities integrate many of these disciplines with a look at how people consider the human experience, exploring the question, "What kind of a people do we want to be?" The

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<sup>4</sup> Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life* (Washington, DC: National Academy of Sciences, September 17, 2014), <http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx> (accessed June 2, 2016), xi.

question of a person's place in the health-care system and the task of identifying the essence of his or her personhood in that structure embody all of these disciplines and questions. Engaging in dialogue with each other about those goals provides an opportunity to articulate who a person is or considers himself to be and how these values affect health-care users throughout life, especially when facing the prospect of aging and illness.

Every individual with full consciousness has personhood, with an ability to relate to others and offer a narrative self. At the optimum, the person flourishes with age, although some experience brain decline, either from injury, disease, or the aging process. Every person also has autonomy to make many choices throughout a lifespan, including those relating to health-care preferences. Each person is different: for some people facing death, as with the group described earlier, the preference is to spend final time with family and friends rather than in a health-care setting, and especially not in an ICU. Unfortunately, with the medicalization of dying, many people die in an institutional setting. They are caught in the structure that *conducts the conduct* of dying, resulting in being tethered to machinery and medicines regulating heart rate, respiration, and other bodily functions. For some that is an acceptable preference, with an active choice to *do everything*. Some studies have shown that those who experience end-of-life treatments through video or experiences with family members will not make that choice. Instead, preferences can be expressed through Advance Directives, speaking to family members about important matters and treatments, or both. Education is an important tool in helping people consider and express their treatment options.

Applying deliberative democracy in the form of Community Bioethics Dialogues provides one means for expanding public understanding, not just of the importance of completing Advance Directives, but also regarding the health-care system, treatment options,

communications issues, and cost considerations. An informed public is the best way of creating good health-care users and, in turn, Community Bioethics Dialogues provide an opportunity that requires relatively few resources while engaging individuals regarding their personhood and health needs in a safe space. Rediscovering the art of conversation provides the means for discussing health-care options and sharing values about life. Forms of deliberative democracy, the dialogues provide an opportunity for members of a community to study and discuss various health-care issues. Several groups have met in Galveston, Texas, for enlightened, reasoned conversation, validating the humanities value of *sermo*, defined by Tulane University political science professor Gary Remer as “an inquiry into problems of some importance, in which different positions are explored.”<sup>5</sup> As Remer notes, *sermo* is an ancient form of rhetorical practice that differs from oratory, in which a particular position is promoted.<sup>6</sup> In addition, the intent is to provide a calm environment for the discussions. Remer considers “The decorum of conversation, which does not permit emotional manipulation, impels speakers, instead to seek an emotional equilibrium in the conversation, that is, to produce a condition of tranquility that would permit reason to come to the fore.”<sup>7</sup> The objective is not for those participating in the conversation to convince each other, but rather to present information promoting reasoned consideration of various viewpoints. Providing an open forum for conversation allows all voices and perspectives to be heard.

The Community Bioethics Dialogues follow the model for *sermo*. No single position is intended to be defined or promoted. The participants set the ground rules for the discourse, establishing basics such as turning off cell phones, hearing each person without talking over one

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<sup>5</sup> Gary Remer, *Humanism and the Rhetoric of Toleration* (University Park: Pennsylvania State University Press, 1996), 27-28.

<sup>6</sup> Ibid., 31.

<sup>7</sup> Ibid., 36.

another, and inviting multiple perspectives in the conversation without animosity (disagreeing without being disagreeable). The participants work together to identify their values in a safe space, using thematic readings to consider various health-care issues. Themes covering Patient-Centered Outcomes and Comparative Effectiveness Research; Mental Health and Seniors; and Aging and End of Life provide an opportunity for participants to discuss core values about the health-care system and their role. Regardless of the theme discussed, the participants concluded that every person has a right and responsibility to consider his or her treatment choices and to discuss those options with their families and loved ones.

In this dissertation, I consider Community Bioethics Dialogues as a means for educating the populace on personhood and the role that it plays in making health-care decisions. My thesis is that personhood is central to all conscious individuals and is a critical consideration in making treatment choices. Advance Care Planning is an important component for these plans, but is not the sole task in making personalized health-care decisions. An understanding of the complexities of the health-care system is needed to provide a framework for assessing treatment options and making decisions. Community Bioethics Dialogues provide a viable platform for educating individuals on the health-care system and the importance of making individualized treatment choices. With education, I believe that some of the current problems associated with end-of-life treatment options can result in better care across the health spectrum, lowering costs, and reducing suffering.

It is important to consider the nature of personhood in order to humanize the individual who can get lost in the modern medical arena. Consequently, the first three chapters examine various perspectives of personhood as they are considered by various academic disciplines. Chapter 1, The Humanities: The Evolution of the Self, examines personhood from the

perspective of the humanities. *Personhood* is a twentieth-century construct that has its roots in the Renaissance with the emergence of the self and the beginnings of humanist thought. The social sciences offer additional insights, particularly in the context of the contemporary world of medicine, and I examine these ideas in Chapter 2, Social Sciences: Producing Personhood. Chapter 3, The Complexities of Personhood, explores the contemporary context of more detailed characteristics of personhood. In the late twentieth century, representatives from ethics, medicine, history, and theology contributed to the discussion of what it means to be a person. I draw from these disciplines to identify three key characteristics as being especially important: the narrative self, relationality, and consciousness, contending that the last provides the underpinnings of personhood. Without consciousness, a person lacks environmental awareness, a narrative self, and communal relationships. As a result, consciousness is necessary for personhood to exist; thus, when consciousness is lost permanently, personhood is as well. The mechanization of life has made it possible to maintain the physical organism almost indefinitely, yet the characteristics that make us truly human are sometimes overlooked in the effort to try one more treatment in order to extend biological life. At the beginning of life, some suggest that personhood occurs at the moment of conception. I offer that the *potential* for personhood exists at this juncture and grows quickly once the human enters the world. In examining the aspects of personhood, I argue that the human organism is a complex entity that cannot be reduced to a zygote or beating heart. Moreover, the person cannot be reduced to the body-mind dualism proposed by Descartes. The person is a much more complex entity that needs to be considered as a unity for treatment choices, by both the individual and by surrogates.

During the latter part of the twentieth century, personhood gained momentum in health-care conversations in a variety of settings, especially in cases requiring an understanding of

patient wishes for life-extending or death-prolonging treatments. The discussion of right-to-die cases, beginning with Karen Quinlan in the mid-1970s, stimulated the conversation of what it means to be a person. Discussions regarding treatment wishes are pertinent for anyone, but especially for individuals known to have terminal illnesses. Chapter 4, Advance Care Planning and Personhood, considers those who are parties to the decision making process in Advance Care Planning (ACP), contemplates the implications when decision making fails, identifies challenges to implementing ACP, and reflects on the different types of programs that are utilized to promote ACP and end-of-life decision making. These choices may be different for each individual and cannot be made without adequate consideration of personhood. Thus, it is important for individuals to consider their choices and to communicate them to those called upon to act as surrogates.

Chapter 5, Community Bioethics Dialogues as an Educational Platform, discusses the theory behind deliberative democracy and community bioethics dialogues as a means for educating individuals about the issues associated with health-care decision making. *Deliberative democracy* is a process for sharing information and having conversations about key issues in different types of venues. It reintroduces the concept of *sermo* (thoughtful conversation) for specific topics and has been used in a variety of formats, “including citizens’ juries, planning cells, deliberative polling, consensus conferences, and citizens’ panels for discussing public concerns.”<sup>8</sup> While certain features (participant selection, number of participants, meeting frequency) vary, common components include providing information about the issue, with opportunities for open discussion prior to making a recommendation for action.<sup>9</sup> This model has

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<sup>8</sup> Julia Abelson et al., "Deliberations about Deliberative Methods: Issues in the Design and Evaluation of Public Participation Processes," *Social Science & Medicine* 57, no. 2 (July 2003): 242.

<sup>9</sup> Ibid.

been followed with Community Bioethics Dialogues on Patient-Centered Outcomes Research (PCOR), Comparative Effectiveness Research (CER), and Mental Health and Aging held in Galveston, Texas, during the past two years with seniors over the age of sixty-five. The results of these dialogues demonstrate the value of providing an educational forum for discussing health-care issues. Not only did the participants expand their understanding of the health-care system, but they also learned the importance of expressing their health-care wishes to family and friends, and the information is being disseminated among their friends and families, expanding the influence beyond the immediate participants in the dialogues.

In the Conclusion, I summarize the prospects and potential for Community Bioethics Dialogues, with the hope that this platform can be adopted by other sponsors, providing an opportunity to expand the public understanding of health care, its limits, and each person's role as a health-care user.

There are limitations to the task of using Community Bioethics Dialogues as a platform for educating the populace on health care, aging, and the end of life. Each person is unique, and there is no way to identify an educational platform for any subject that will address all people for every possible health issue encountered during the course of a lifetime. Because this is a dissertation in the medical humanities in the United States, the emphasis is on those who live in this country with a Western perspective of personhood. While the methods discussed may apply elsewhere, much more work is needed to integrate the understanding of the Western health-care system with other cultures. My hope is that we will continue the dialogue and be able to do so in a respectful way that meets everyone's notion of personhood and its meaning as we age and face mortality.

## Chapter 1. The Humanities: The Evolution of the Self

Our own true sense of self is historically unique, that it is not biologically determined, but is rather the manifestation of a great change in Western consciousness which may have begun around 1100 AD and which received perhaps its richest cultural expression during the Renaissance. The “studia humanitatis” constituted an important part of this cultural expression, for the Renaissance humanities arose as a curriculum for this new experience of the self.<sup>10</sup>

In 1999, University of Rochester medical professor Timothy Quill wrote about a long-time patient, Diane. Over the years, she had dealt with cancer, depression, and alcoholism but was able to overcome these afflictions and live life fully, both as an accomplished individual and in community with her work and family.<sup>11</sup> When diagnosed with a serious form of leukemia, Diane elected to forego treatment that would be unpleasant and unlikely to be effective, choosing instead to spend time with her family. As part of her deliberation, Diane considered her previous medical treatments and concluded that the low likelihood of remission (25 percent) was not consistent with her own wishes. She researched information from the Hemlock Society and requested a prescription from Dr. Quill for barbiturates so that when the pain became unbearable, she would be able to end her life, and did so.<sup>12</sup> While this is an extreme case of the exercise of personhood, Diane had a strong understanding of her own capacities, and with the blessing of her family, elected to forego noxious treatments. Dr. Quill recognizes his own lesson in Diane’s experience as well:

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<sup>10</sup> Robert Proctor, *Defining the Humanities: How Rediscovering a Tradition Can Improve Our Schools* 2nd ed. (Bloomington: Indiana University Press, 1998), 83.

<sup>11</sup> Dr. Quill notes in the article that he provided information on how to use the medications for insomnia as well as to commit suicide. Timothy E. Quill, "Death and Dignity. A Case of Individualized Decision Making," *New England Journal of Medicine* 324, no. 10 (March 7, 1991): 692.

<sup>12</sup> *Ibid.*, 692-693.

Diane taught me about the range of help I can provide if I know people well and if I allow them to say what they really want. She taught me about life, death, and honesty and about taking charge and facing tragedy squarely when it strikes. She taught me that I can take small risks for people that I really know and care about. Although I did not assist in her suicide directly, I helped indirectly to make it possible, successful, and relatively painless.<sup>13</sup>

This example of an individual exercising her personhood for treating a medical condition received more public acknowledgment than most. Others have followed, setting parameters for some of the ways in which individuals face a health crisis. Not everyone will choose to forego treatments; some may want to pursue all avenues. However, in this case, the individual exercised her personhood by making specific life-and-death choices, soliciting and receiving help from qualified health professionals.

Personhood is a twentieth-century construct with a rich history. Medieval scholar Colin Morris describes the Western sense of individuality as “exceptional among the civilizations of the world.”<sup>14</sup> The expression of the self, described by numerous scholars as *personhood*,<sup>15</sup> has evolved over human history, with different perspectives and emphases emerging over time and across disciplines. The definition of personhood is descriptive rather than prescriptive: as an example, philosophers and theologians provide moral claims associated with the notion of person rather than describing it in the context of specific circumstances. Anthropologists look to the collective, considering that personhood is conferred in a group context rather than by the individual. In the contemporary health-care context, personhood is most often characterized as autonomy, the individual’s right to self-determination in treatment choices. While important, autonomy is but one manifestation of personhood, the exercise of one’s personal choices when

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<sup>13</sup> Ibid., 694.

<sup>14</sup> Colin Morris, *The Discovery of the Individual* (Toronto, Canada: University of Toronto Press, 1987), 1.

<sup>15</sup> There are many definitions and descriptions of personhood that I draw upon in this dissertation.

selecting health-care treatments. Personhood is far more complex, integrating the entirety of the individual. Diane's personhood included not just her physiology and the treatments she was willing to have on her body, but also her own story and relationships with family and friends. Different manifestations of personhood provide a complex context for describing its evolution, with each period providing additional insights.

In this chapter, I describe the sources of the self, a concept that does not appear spontaneously in the twenty-first century; rather, it evolves from the humanistic and social science traditions, including the classics, historical developments in the Middle Ages, Renaissance thought, and contemporary Western society. The various influences provide a background for the remaining discussion of this dissertation, including ways in which health-care choices are understood and articulated, and how Community Bioethics Dialogues might provide a platform for public education on various issues.

The Western concept of personhood has its roots in the Renaissance. Proctor argues that “a unique, autonomous, personal self” that could be shaped by the *studia humanitatis* to seek virtue, wisdom, and excellence differs from the ancient Greek and Roman *extensive self* and the Medieval Christian *transcendent self*.<sup>16</sup> Examining this evolution is helpful in understanding the context and definition of personhood that I offer in Chapter 3. As philosopher Charles Taylor notes, the search for an orientation to the good can be found only in our life story.<sup>17</sup> The foundational narrative is found in the texts of our forebears, who provide insights for the qualities of the human condition and how they evolve through the centuries. This section of my dissertation considers the ways in which the idea of the self is represented in various texts,

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<sup>16</sup> Proctor, *Defining the Humanities*, 13.

<sup>17</sup> Charles Taylor, *The Sources of the Self: The Making of the Modern Identity* (New York: Cambridge University Press, 1989), 52.

including the classics, and its historical development in the Middle Ages, Renaissance thought, and contemporary usage.

### **The Ancients: The Extensive Self**

Contemporary Western notions of personhood and the individual self were not present with the ancients, who looked to the community as a whole as the source of identity. Proctor notes that the ancients “had a self, but it was an extensive, not an intensive self. Individual lives were experienced as *parts* of a greater whole, the whole of the cosmos, the whole of the *polis*, the whole of the *civitas*.”<sup>18</sup> Humans acted as a functional unit in the entirety of the community, and the individual’s role was to serve. Individuality was not a valued characteristic, and the language reflects the emphasis on the communal nature of humans. As Morris notes, the Greeks had no equivalent to the Western concept of *person*, although they had many words that expressed community of being.<sup>19</sup> In addition, the closest words to *individual* (*individuum*, *individualis*, and *singularis*) related to logic rather than definitions of a person.<sup>20</sup> Thus, the descriptive vocabulary focused on the group rather than the individual. A useful approach for considering the ancient perspectives of community is achieved by examining sample texts, including Sophocles’ play *Philoctetes*.

Pennsylvania State University professor emerita of humanities Anne Hunsaker Hawkins identifies two claims in moral learning from *Philoctetes*: emotions have utility and moral life shares relationships with others.<sup>21</sup> All of the major characters in the play, Odysseus,

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<sup>18</sup> Proctor, *Defining the Humanities*, 109.

<sup>19</sup> Morris, *The Discovery of the Individual*, 2.

<sup>20</sup> *Ibid.*, 64.

<sup>21</sup> Anne Hunsaker Hawkins, “The Idea of Character,” in *Stories Matter: The Role of Narrative in Medical Ethics*, ed. Rita Charon and Martha Montello (New York: Routledge, 2002), 72.

Neoptolemos, and Philoctetes, demonstrate facility in choosing communal values over individual ones. In the Trojan War, Philoctetes has been left behind, but with the capture of the seer Helenos, Odysseus learns that Philoctetes' bow is needed to defeat Troy.<sup>22</sup> Odysseus admits to following orders in banning Philoctetes to the island Lemnos following an infected snakebite that makes him smelly and generally unpleasant to be near. The noxiousness of an individual injury is trumped by the requirement for Philoctetes' warfare expertise. Odysseus commands Neoptolemos to use trickery to bring Philoctetes back from the island. Initially, Neoptolemos demurs, preferring to avoid deceit, but considers the benefit that will accrue to the community. Ironically, while communal benefit is driving choices, Neoptolemos also realizes that his own career will suffer if he does not follow orders. Nevertheless, the prospect of communal benefit drives the choice to retrieve Philoctetes.

Upon arriving on Lemnos, Neoptolemos befriends Philoctetes, gaining his trust and using chicanery to steal his bow in order to persuade Philoctetes to return to the larger community. As the play unfolds, Neoptolemos chooses to switch from trickery to honesty, calling for service to the larger good in attempting to convince Philoctetes to return to help fight the battle with Troy. The attempted rhetoric fails to work. University of Houston English professor and creative writing program director James L. Kastely identifies the source of the rhetorical crisis: "By the time a sincere persuasion is attempted, public discourse has been so discredited that Philoctetes cannot give credence to anything he hears."<sup>23</sup> Neoptolemos is unable to provide a convincing argument for Philoctetes' return. At the same time, Philoctetes must overcome his own isolation and anger at being exiled. At the end, the god Herakles comes from the mountain and promises

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<sup>22</sup> Clay Diskin, "Introduction," in *Philoctetes*, trans. Carl Phillips (New York: Oxford University Press, 2003), 5.

<sup>23</sup> James L. Kastely, "Sophocles' Philoctetes and the Crisis of Rhetoric," in *Rethinking the Rhetorical Tradition: From Plato to Postmodernism* (New Haven, CT: Yale University Press, 1997), 81.

Philoctetes that good things will happen to him if he returns, including access to the best medical treatment.<sup>24</sup> In supporting the communal objective for military victory, Philoctetes must move beyond isolation to rejoin his community. Individual suffering is overcome by serving the common good.

The individual anxieties and emotions end up being decided by godly intervention although the relational complexities remain. Neoptolemos feels compassion for Philoctetes while trying to trick him. Neoptolemos knows this concern affects his own career, since Odysseus is direct in explaining the likely impact if Philoctetes fails to accomplish the mission. Neoptolemos' moral life is conflicted: on the one hand, he wants success for his own career; on the other hand, he has developed an appreciation, even empathy, for Philoctetes' suffering. Moreover, he also appreciates the community's need to win in battle. At the same time, Philoctetes must be convinced that returning to the community to help the war effort will allow him to reengage with the community as well as obtain treatment for his infection. There is a power differential between Neoptolemos, supported by Odysseus, and the ill Philoctetes. As Kastely notes, "the law of the universe in which the powerful rule is that everything and everyone exist only as an instrumentality to be used as the needs of the powerful dictate."<sup>25</sup> The power schema would dictate that Philoctetes immediately return, but the messenger Neoptolemos fails. A higher authority must intervene, and Herakles reminds Philoctetes that "each of you must guard the other even as two lions that feed together" and promises to send Asklepios to heal Philoctetes.<sup>26</sup> Power rules while providing the promise of potential healing.

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<sup>24</sup> Sophocles, *Philoctetes*, trans. Carl Phillips (New York: Oxford University Press, 2003), 96.

<sup>25</sup> Kastely, 79.

<sup>26</sup> Sophocles, *Philoctetes*, 97.

Working together benefits the individual protagonists in the process. Philoctetes is removed from exile and has the potential for healing. While powerless to heal himself, Philoctetes is able to do so with the support of others. It is in being part of the whole that Philoctetes will realize his best self. His own suffering pales in comparison to the greater need for military victory, with the underlying promise that Philoctetes will be taken care of if duties are fulfilled. The moral conclusion of the play is that people do not survive in isolation. There are no personal goals, only those of the entire community. Success is a communal enterprise, integrating individual skills and desires into those of the greater whole.

Other classical texts, notably those from Plato and Aristotle, provide further insights into manifestations of the extensive self. In Book IV of *The Republic*, Plato identifies two critical groups for the community: the rulers and the soldiers. Rulers are expected to excel at directing warfare. The members who can contribute the most to the group as a whole are to be targeted for leadership positions. Plato suggests that the best warfare comes from the functioning of the band of soldiers as a whole. Although individual accomplishment contributes to the effort, it is not sacrosanct. If the group fails, everyone falters. However, soldiers are not just one-dimensional participants in their training: Plato notes that it is important for them to be educated in various arts.<sup>27</sup> The success of the community lies in its functioning as a unit, supported by individuals who are appropriately trained in all aspects of life. The individual can compete with the group and cause problems: “the power of each individual in the State to do his own work appears to compete with the other political virtues, wisdom, temperance, courage.”<sup>28</sup> Good fighting skills are not the sole contributor to success—warriors must also exhibit strong moral character if the

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<sup>27</sup> Plato, *The Republic* (360 BCE), trans. Benjamin Jowett (Boston, MA: Massachusetts Institute of Technology, 2011), <http://classics.mit.edu/Plato/republic.html> (accessed June 5, 2016), Book IV.

<sup>28</sup> Ibid.

community is to flourish. Other roles are also proscribed by the state for individuals, including child-bearing: women are to begin to conceive at age twenty, while men are to wait until age twenty-five before fathering a child.<sup>29</sup> Members of the community are to “live dear to one another and to the gods, both while remaining here and when, like conquerors in the games who go round to gather gifts, we receive our reward. And it shall be well with us both in this life and in the pilgrimage of a thousand years which we have been describing.”<sup>30</sup> Life is an enterprise between the sexes and all community members, and common success requires cooperation. The society succeeds only with mutual effort, requiring skill and good moral character.

Aristotelian ethics do not differentiate between the good for one and for the group. The best possible outcome for the individual is defined by the success of the community. Excellence is defined as having both intellectual and moral prowess that supports the group. Moral virtues arise because humans have the capacity for receiving and perfecting qualities through custom that is supported by the collective.<sup>31</sup> Aristotle notes that the young man is unable to contribute significantly, since he has insufficient life experiences from which to draw and is likely to be influenced by his passions. Consequently, the young man must be educated in the ways of the community, and the group is responsible for inculcating values in its younger members.<sup>32</sup> Bringing young men into the group is beneficial as a means of training and perpetuating the existence of the society. Aristotle sees evidence of this in the Greek tragedies: actions are part of a larger whole, imitating life and not a particular person.<sup>33</sup> The discussion of *Philoctetes*

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<sup>29</sup> Ibid., Book V.

<sup>30</sup> Ibid., Book X.

<sup>31</sup> Aristotle, *Nicomachean Ethics* (350 BCE), trans. W. D. Ross (Boston, MA: Massachusetts Institute of Technology, 2009) <http://classics.mit.edu/Aristotle/nicomachaen.html> (accessed June 2, 2016), Book I.

<sup>32</sup> Ibid.

<sup>33</sup> Aristotle, *Poetics* (335 BCE), ed. J. A. Smith and W. D. Ross, trans. S. H. Butcher, Aristotle's Collection (London, UK: Catholic Way Publishing, 2015), Kindle Locations 30060-30062.

certainly echoes this view. Individuals benefit only if the greater community succeeds.

Philoctetes must overcome his own isolation to support the community's military effort.

Aristotle purports that life begins with the community, with the city (*polis*) being the natural unit of society.<sup>34</sup> For the ancient Greeks, the essence of human life is community and the extensive self supports the enterprise. Achieving success requires the efforts of all—older members educate younger ones, and each person knows the roles that he or she is expected to fulfill.

The Romans also designate the community as the center of life, with individuals governing to work for the good of all. Individuals are not allowed to disrupt the community with issues pertaining to the individual. Cicero demonstrates the view requiring individuals to control their emotions in order to avoid harming the group. Perturbations of the mind, including grief, anger, compassion, envy, joy, and lust, should be eschewed in order to avoid disrupting the society. The formula for achieving happiness is nothing more than ensuring that the society prospers. When the virtuous society is achieved, all benefit, as Cicero commends Brutus in Book V of the *Tusculan Disputations*, "that virtue is of itself sufficient for a happy life."<sup>35</sup> When individuals practice virtue, the good of the community is achieved. Tranquility, leading to wisdom and happiness, is accomplished when outside emotions are avoided.<sup>36</sup> Conquering one's perturbations is a virtue, which is sufficient for a good life and happiness.<sup>37</sup> Cicero demonstrates the quality of attempting to conquer grief upon the death of his daughter, believing that this will be too disruptive for the community. For Cicero, a man (*vir*) uses reason to conquer the lower

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<sup>34</sup> Morris, *The Discovery of the Individual*, 3.

<sup>35</sup> Marcus Tullius Cicero, "Whether Virtue Alone Be Sufficient for a Happy Life," (45 BCE) in *Tusculan Disputations*, trans. C. D. Yonge (New York: Harper & Brothers, 1877), Book V, Section 1.

<sup>36</sup> Ibid., Book V, Section XV.

<sup>37</sup> Ibid., Book V, Section XVIII.

part of the soul that does not respond to reason, where grief resides.<sup>38</sup> Conquering individual disturbances from the lower part of one's being results in a successful communal enterprise.

For the ancients, life is grounded in the extensive self. It is by working together that the good life is achieved for all. Acts of individual courage are done for the sake of the polis. Individual emotions only interrupt the smooth workings of the polis, so they should be avoided. Effective societal functioning is accomplished by training the young, performing one's roles, and avoiding any action that disrupts the functioning of the whole. In achieving communal virtue, happiness will be achieved for the group. Today's contemporary medical practice adopts the notion of conquering one's grief. Health-care professionals are taught to avoid showing their own emotions. I worked with a palliative-care physician who was crying outside the room of a young female patient dying of metastatic cancer. The physician was adamant that the family could not see her cry, because that would be unseemly and unprofessional. My suggestion that tears showed a level of care was not accepted. The physician had been taught that tears were unprofessional and might disturb the family, so her professional role demanded that emotions be suppressed. My conversations with health-care professionals at all levels have yielded similar results, with an emphasis on stoicism throughout the health-care spectrum. There may be instances where the greater good demands conquering one's emotions, but these responses are still part of who we are. All of the modern tools for practicing medicine revert back to the need for shielding the community from one's emotions—the professional image provided to the community is more important than the person who bears it. However, little is said about the implications of this practice and the possible contribution to professional burnout when one has no avenues for expressing emotions during or following different cases.

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<sup>38</sup> Proctor, *Defining the Humanities*, 67.

## The Middle Ages: The Christian Transcendent Self

The Western Roman Empire fell in the fifth century, beginning the Middle Ages. At this juncture, the extensive self begins to transform into the *transcendent self*, with a focus on following a spiritual rather than mortal path, particularly for those adhering to the Christian tradition. Just prior to the beginning of the period, in 398 CE, Christian theologian and philosopher St. Augustine writes a personal reflection considered to be the first autobiography, providing evidence of the transcendent self. In providing an autobiographical reflection of his life, Augustine demonstrates self-reflection in his role and responsibilities to self and the divine. Augustine considers his relationship to God and the areas of shortfall in his life, concluding that the way for attaining virtue is not with the ancients, but in following God's laws. His identity is achieved in following a divine purpose. In *Confessions*, St. Augustine laments his personal shortcomings resulting from seeking pleasure, causing him to fall in "sorrow, confusions, errors."<sup>39</sup> In the journey towards the transcendent self, Augustine aims to conquer his individual shortcomings in order to realize the spiritual goal of being one with God. As an individual, he struggles with the need to make choices and identify goodness in his own life. Augustine concludes that humans cannot do this alone—they must rely on God, applying a personal faith that is supported by grace. The relationship with God governs the individual; success in achieving spiritual oneness supports the general good. Morris attributes another Augustinian work, *The City of God*, with providing a starting point for characterizing the views of the medieval period as "controlled by purposes which may be advanced by human participation, and which are in the

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<sup>39</sup> Saint Augustine, *Confessions* (398 CE), trans. R. S. Pine-Coffin (New York: Penguin Books, 1961), Kindle Locations 253-255.

long term designed for the salvation of man.”<sup>40</sup> Humans are not only capable of considering their individual place in the world; they should also work together towards spiritual ends. In Augustine’s view, the community prospers if everyone achieves spiritual harmony and oneness with the Almighty. Morris characterizes Augustine’s *City of God* as the means of imagining “the course of history as controlled by purposes which may be advanced by human participation, and which are in the long term designed for the salvation of man.”<sup>41</sup> On balance, aiming towards the Almighty will solve all of society’s problems, and each individual is responsible for achieving this goal.

Despite Augustine’s lofty goals, during the Middle Ages the transcendent self is unable to resolve significant community issues. Achieving oneness with God does not meet with communal success. Despite Plato’s dictum for armies and the ruling class to govern, the examples of governmental breakdown from 900 to 1050 CE demonstrate the need to mind the affairs of the polis. Augustine’s desire to follow God is not enough. Morris believes that this period’s monarchs relied on their personal qualities, resulting in shortcomings of leadership.<sup>42</sup> The lessons from the ancients in managing the life of the community are not followed, and the emphasis on getting closer to God does not help with leadership shortcomings. Augustine believes that worldly matters take second place to spiritual concerns. Morris concludes that the era’s aristocracy had rigid ideals, providing little room for individual initiative.<sup>43</sup> In failing to meet the needs of the polis, the transcendent self looks to the world beyond, but the one on earth falters.

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<sup>40</sup> Morris, *The Discovery of the Individual*, 7.

<sup>41</sup> Ibid., 17.

<sup>42</sup> Ibid., 26.

<sup>43</sup> Ibid., 33.

In modern medicine, the transcendent self is expressed in a variety of ways. In terms of the prescribed conduct, The Joint Commission requires that spiritual needs be met but does not provide specific requirements, only that patients' spiritual, cultural, and religious needs be addressed.<sup>44</sup> Various faith-based hospitals offer more prescribed rules, some of which are related to core beliefs, such as Roman Catholic hospitals' not providing abortion services. Certainly, my role as a chaplain in a secular hospital suggests that spiritual care services are attributed with some importance (at least for that particular health system), but overall, take second place to providing health-care services for the physical body. Many physicians would call the chaplain only when there was nothing else left to offer or when the family was having difficulty accepting a terminal prognosis. More could be said about the application of spiritual concerns in the health-care setting, but is beyond the scope of my dissertation. I do want to acknowledge the transcendent self in health care, and consider it an integral element of care for the person.

The increase in learning as well as social fluidity, which Morris identifies as beginning in 1050, provides the next great catalyst for change.<sup>45</sup> By the twelfth century, Latin literary culture expands, introducing European languages as expressive means for literary works.<sup>46</sup> The propensity towards self-reflection multiplies, increasing the different types of autobiographies for individuals to examine their own experiences.<sup>47</sup> Morris identifies the discovery of the individual as

One of the most important cultural developments in the years between 1050 and 1200. It was not confined to one group of thinkers. Its central features may be found in many different circles: a concern with self-discovery; an interest in the

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<sup>44</sup> Joint Commission, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals* (Oakbrook Terrace, IL: Joint Commission, 2010), <https://www.jointcommission.org/assets/1/6/ARoadmapforHospitalsfinalversion727.pdf> (accessed June 5, 2016), 15.

<sup>45</sup> Morris, *The Discovery of the Individual*, 36.

<sup>46</sup> *Ibid.*, 8.

<sup>47</sup> *Ibid.*, 79.

relations between people, and in the role of the individual within society; an assessment of people by their internal intentions rather than by their external acts.<sup>48</sup>

As time passes, the concept of the individual begins to emerge, providing the foundation for conditions that will flourish during the Renaissance. The ability to reflect and know one's self and to grasp the ways that the individual fits into the greater community provides an impetus for expanding arts, letters, and science, encouraging the power of self-expression while broadening human understanding. Additional attention to the human body establishes a foundation of knowledge, leading to many of the subsequent medical breakthroughs that will create potential conflicts among the individual, society, and science, in turn establishing the need for greater understanding of complex issues.

### **The Renaissance: The Emerging Personal Self**

The Renaissance period is a time for the emerging personal self, as the Church's influence is reshaped and humanism develops, creating the foundation for the contemporary notion of personhood. There are numerous examples where the personal self is considered. I examine Francesco Petrarch, Giovanni Pico della Mirandola, Desiderius Erasmus, and William Shakespeare in order to demonstrate the ideas that emerge from the period.

#### **Francesco Petrarch**

Francesco Petrarch is an interesting blend of someone who looks to the past as well as the present, considering the ancients as part of his identity while noting the importance of self-

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<sup>48</sup> Ibid., 158.

reflection in order to achieve understanding. For Proctor, Petrarch exemplifies the transition from solely serving society to fulfilling one's self:

Petrarch had to experience his own being as a unique and autonomous self which he could objectify, act upon, and compare to other such autonomous selves. In other words, he had not only to experience his own consciousness as an autonomous center of thought and feeling, he had to believe that others, including the ancients, experienced themselves in this way as well. Petrarch thus had to presume, as most people still do today, that inner consciousness, individual uniqueness, and experiential autonomy are part of human nature.<sup>49</sup>

Humans are a product of their own experiences and feelings, as well as the collective actions and perspectives of those who have gone before. Petrarch's writings offer a glimpse into the ways he integrates his own being.

Early in his life, Petrarch's 1336 ascent of Mont Ventoux introduces his narrative identity: "I rejoiced in my progress, mourned my weaknesses, and commiserated the universal instability of human conduct."<sup>50</sup> Petrarch reflects on himself as well as the community at large, noting that looking within the person replaces all of the efforts made by humans to look around for answers.<sup>51</sup> The individual does not just look to society as a source for identity: self-reflection is a tool for understanding. At the same time, the problems of human conduct create issues. The progress that Petrarch makes provides an opportunity for him to contribute to that human condition. As he ages, Petrarch recognizes the frailty of the mortal human condition and extends his reflections to handle significant personal losses experienced during the plague.

In "The Ascent of Mont Ventoux," instead of reveling in the glory of man, Petrarch acknowledges the fragile nature of life: "How heavy, how slow, how fragile is our body, how

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<sup>49</sup> Proctor, *Defining the Humanities*, 49.

<sup>50</sup> Francesco Petrarch, "The Ascent of Mont Ventoux," (1336) in *Petrarch: The First Modern Scholar and Man of Letters*, ed. James Harvey Robinson, trans. James Harvey Robinson (New York: G. P. Putnam, 1898), <http://history.hanover.edu/texts/petrarch/pet17.html> (accessed June 2, 2016), 5.

<sup>51</sup> *Ibid.*, 6.

confused and how restless is our mind, how changeable and how uncertain and voluble is our destiny? How long shall we be concerned about these things?”<sup>52</sup> He even challenges Cicero: “What shall we be after terminating our life here? An important and doubtful matter, indeed, but certainly neglected!”<sup>53</sup> For Petrarch, suppressing questions and doubts does not promote virtue. Reflection is an integral part of the life well lived. Cicero might mark Petrarch as one of the weaker souls who needs to be consoled. However, Petrarch shares with Cicero the understanding that death will bring an improvement over earthly tribulations.<sup>54</sup> Despite the strength found in the individual, the promise of eternal life provided by the Church continues as a source of hope for Petrarch.

Letter VII of *Letters on Familiar Matters* provides further evidence of human limitations, as Petrarch reflects bluntly on his feelings regarding the deaths of those near to him: “I am deeply troubled from within and take pity on myself.”<sup>55</sup> Petrarch makes no effort to rationalize his feelings or to try to cover them up, as Cicero requires. However, Petrarch acknowledges the apparent weakness, noting the likely response:

You who seem to offer comfort and aid to others, who had promised us things that were superior, who ought to have formed a thick skin from your constant misfortunes and to have become calloused against all the blows of fortune and hardened to something like a flintstone, see how weakly you bear your burdens, see how often you direct your frequent failings to us. Where is that loftiness of soul which now especially should mark your profession? Where are the magnificent words, which, if intended rather to extol your genius than as advice for life, can be no more than empty sounds and curious charms for the ears? We

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<sup>52</sup> Francesco Petrarch, *Letters on Familiar Matters (Rerum Familiarium Libri)*, trans. Aldo S. Bernardo (New York: Italica Press, 2005), 420.

<sup>53</sup> Ibid.

<sup>54</sup> Ibid., 427.

<sup>55</sup> Ibid., 415.

expected from you a heroic poem, we get elegiac verses; we hoped for biographies of illustrious heroes, we are getting the story of your sorrow.<sup>56</sup>

Petrarch sees the personal flaw while providing the rationale for his grief: “I realize that a man must either drive away grief or destroy it, or control it, or finally conceal it. But what can I do? I shall die if I cannot pour out my grief in tears and words.”<sup>57</sup> The physical acts of crying and writing are outlets for Petrarch. Cicero’s requirement to suppress human emotions is not an option.<sup>58</sup> Petrarch’s humanity does not just look to the next world; rather, grief is present and acknowledged in the here and now in all of its raw reality. Petrarch’s grief is part of his experiences, but he chooses to proceed with life, while acknowledging the raw pain of loss.

Petrarch considers the possibility that he is somehow failing the ancients with his grief, asking for his long-time friend Socrates’ (Lewis of Campinia) forgiveness as well as that of any others who read his words:<sup>59</sup> “There are times when silence is noble; but others when words are necessary.”<sup>60</sup> Writing is the salve for Petrarch’s troubled soul: “I am compelled to write, nor am I able to restrain myself, for a deep sorrow presses upon my mind and wrenches out of me words mixed with tears.”<sup>61</sup> Petrarch’s narrative provides insight into his personal grief and supports an individual’s feelings as having meaning, without reducing contributions to the community. The individual’s personal feelings matter and should not be covered or discounted. Avoiding self-expression is not a requirement; rather, articulating one’s emotions is integral to the human condition. A portion of the health-care system has acknowledged this necessity at the end of life for family members of those who die. The Center for Medicare and Medicaid Services has

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<sup>56</sup> Ibid.

<sup>57</sup> Ibid., 416.

<sup>58</sup> Cicero’s own challenges in controlling his emotions provide evidence of the difficulty of the task.

<sup>59</sup> Petrarch dedicated his *Letters on Familiar Matters* to Lewis of Campinia.

<sup>60</sup> Petrarch, *Letters on Familiar Matters*, 427.

<sup>61</sup> Ibid., 428.

promulgated requirements that surviving family members for those receiving hospice services under Medicare have access to bereavement support for up to one year after the death.<sup>62</sup> Other hospice services have also adopted this requirement. Thus, this sector of the health-care system acknowledges the need for families to articulate their grief. While assessing the efficacy of these groups is beyond the scope of this dissertation, from my experiences, the need for humans to speak of their grief and share it with others contributes to healing. Petrarch is right—there are times when grief needs to be articulated. Regardless of the person’s personal strength, the ability to share communal grief provides tools for healing.

### **Giovanni Pico della Mirandola**

In 1486, Giovanni Pico della Mirandola’s *Oration on the Dignity of Man* draws attention to the person with his comment, “nothing to be seen more marvelous than man.”<sup>63</sup> Pico marvels at his own qualities: he is young, bright, and his future lies ahead. He believes that there are several keys to successful living: avoid impulses of passions through moral science; infuse souls with the light of natural philosophy; and seek theological knowledge.<sup>64</sup> He draws from many philosophical traditions, including writings from the Arabians, expressing pride in his ability to study different philosophical schools, finding value in all.<sup>65</sup> His own faith is not broken; wisdom is available from many sources. The purpose of existence is to integrate knowledge into life, and

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<sup>62</sup> Centers for Medicare and Medicaid Services, *Medicare Benefit Policy Manual*, Chapter 9 - Coverage of Hospice Services under Hospital Insurance (Baltimore, MD: Center for Medicare and Medicaid Services, May 8, 2015), <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Internet-Only-Manuals-Ioms-Items/Cms012673.html> (accessed June 5, 2016), 30.

<sup>63</sup> Giovanni Pico Della Mirandola, *Oration on the Dignity of Man* (1486), trans. A. Robert Caponigri (Chicago, IL: Henry Regnery/Gateway Editions, 1999), [http://www.andallthat.co.uk/uploads/2/3/8/9/2389220/pico\\_-\\_oration\\_on\\_the\\_dignity\\_of\\_man.pdf](http://www.andallthat.co.uk/uploads/2/3/8/9/2389220/pico_-_oration_on_the_dignity_of_man.pdf) (accessed June 2, 2016).

<sup>64</sup> Ibid.

<sup>65</sup> Ibid.

the person should integrate sources that benefit the community. While the classics continue as a source of wisdom for Renaissance man, new knowledge is available for informing the populace. The basis for sharing knowledge is essential to the humanist tradition, the premise for educating the populace on health-care issues that I present later in this dissertation.

### **Desiderius Erasmus and Martin Luther**

During the Renaissance, the Reformation allows individuals to find strength from their own selves and various sources of knowledge, with shifting relations to the Church. A major source of conflict between the transcendent and the personal selves is the notion of free will and the sources of choices that humans make. Some of the controversies are evident in exchanges between the Dutch Catholic priest and humanist Desiderius Erasmus and the German theologian and Reformation principal Martin Luther. Erasmus explicates the power of individual choice, engaging in an exchange with Luther over the power of free will. He disagrees with Luther's notion that the individual is bound to a formula for being good. While defending the need to recognize God's gifts, Erasmus believes that one of the greatest human characteristics is the individual's ability to make choices. Erasmus approaches free will from both historical and theological perspectives, with the goal of presenting the requirements for leading a morally good life, ultimately resulting in the person's salvation. Erasmus is open to many avenues of learning, indicating that he wants to "analyze and not to judge, to inquire and not to dogmatize," with a readiness to "learn from anyone who advances something more accurate or more reliable, though I would rather persuade mediocre minds not to argue too stubbornly on such matters. It harms

Christian concord more than it helps piety.”<sup>66</sup> Sources of knowledge come from a multitude of places, and although the sources of information should be considered and evaluated, individuals are invited to consider choices without harming their status as God-fearing, rule-abiding members of creation. Erasmus does not believe that the freedom of the will detracts from adherence to Scripture:

In my opinion the implications of the freedom of the will in Holy Scripture are as follows: if we are on the road to piety, we should continue to improve eagerly and forget what lies behind us; if we have become involved in sin, we should make every effort to extricate ourselves, to accept the remedy of penance, and to solicit the mercy of the Lord, without which neither the human will nor its striving is effective; for all evil let us consider ourselves responsible, but let us ascribe all good to Divine Benevolence alone, for to It we owe even what we are; and in all things must we believe that whatever delightful or sad happens to us during life, God has caused it for our salvation, and that no injustice can come from Him who is by nature just, even if something should befall us which we deem undeserved; nobody should despair of forgiveness by a God who is by nature most merciful. In my opinion, it used to be sufficient for Christian piety to cling to these truths.<sup>67</sup>

Free will is as much a gift from God as other human blessings, providing an opportunity to live well. Human choices are integral to creation, so individuals should consider them to be part of the general condition. When humans fall short, which Erasmus also attributes to creation, God’s mercy provides relief. Making bad choices is not an automatic ticket to perdition; human frailty is to be accepted as part of nature.

Freedom of the will is not Erasmus’ sole concern; he also proposes an explanation for theodicy. The person’s life works for good or ill and all actions and experiences can be used towards one’s salvation. Ultimately, the precepts for the good life are found in “the word of God which one does not have to fetch down from high heaven, or a distant sea, but which one rather

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<sup>66</sup> Desiderius Erasmus and Martin Luther, *Discourse on Free Will*, trans. Ernst F. Winter (New York: Bloomsbury Academic, 2013), Kindle Locations 252-254.

<sup>67</sup> *Ibid.*, Kindle Locations 264-271.

finds near at hand, namely in our mouths and in our hearts.”<sup>68</sup> Achieving salvation is not a formula; rather, it is found within the individual engaging a life with reflective choices. Understanding the will of God should influence the choices that are made, but free will allows the consideration of all of the options, even the “bad” ones.

Erasmus defines freedom of the will as “the power of the human will whereby man can apply to or turn away from that which leads unto eternal salvation.”<sup>69</sup> This definition is supported with substantial scriptural references taken from the Hebrew Scriptures and New Testament, beginning with Adam and Eve. The narrative in Genesis demonstrates for Erasmus that the human will has been “worsened to a degree, so that it could not improve itself by its own natural means; it had lost its freedom and was obliged to serve the sin to which it once willingly assented.”<sup>70</sup> However, this loss can be ameliorated by grace, the driver for good works.<sup>71</sup> While God’s law places sanctions on disobedience, through creation, the power of choice is given, “free and moveable in both directions.”<sup>72</sup> The emergence of God’s law gives humans the power to choose—without it, all actions are not voluntary—and it is grace that spurs humans with the strength to make good choices. Humans are not simply God’s puppets; they are free-standing individuals who make choices on a daily basis.

Erasmus takes exception to those believing that the “will in itself can only commit sin” and “only grace can cause good,” reflecting that this establishes “a fear of and distrust of meritorious human acts.”<sup>73</sup> He notes that “God shows what is good and what is evil. He offers as recompense death or life. He relinquishes to man the freedom of choice. It would be ridiculous to

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<sup>68</sup> Ibid., Kindle Locations 281-283.

<sup>69</sup> Ibid., Kindle Locations 476-477.

<sup>70</sup> Ibid., Kindle Locations 536-538.

<sup>71</sup> Ibid., Kindle Locations 556-558.

<sup>72</sup> Ibid., Kindle Locations 576-574.

<sup>73</sup> Ibid., Kindle Locations 638-641.

command one to make a choice, if he were incapable of turning in either direction.”<sup>74</sup> Choices are meaningless if they are pre-determined. For members of the human community, choices are necessary for the individual’s direction to have meaning. If humans have the ability to make choices, they are fully part of creation.

Erasmus’ arguments for free will provide a blend of theological and humanistic considerations. The individual has moral standing and makes choices but must also deliberate his spiritual place within creation. If the person does not make choices, Erasmus concludes that “God works in man not only the good works, but also the evil ones.”<sup>75</sup> Only in having choices does the human person live out the fullness of God’s glory. God cannot make evil choices, so these must be part of the human condition. At the same time, God’s creative power is evident in human abilities to make choices.

Erasmus’ position contrasts with that of Luther, who holds that individuals are required “to distinguish most clearly between the power of God and our own, between God’s works and ours, if we are to live a godly life.”<sup>76</sup> In doing so, “consciences are bound by the law of God alone.”<sup>77</sup> If the individual is not tied to God, everything done by humans is evil: “if it is not we ourselves, but God only, who works salvation in us, it follows that nothing we do before His working in us avails unto salvation.”<sup>78</sup> The human will is unable to change itself; rather, “when God works in us, the will is changed under the sweet influence of the Spirit of God. It desires and acts not from compulsion, but responsively of its own desire and inclination.”<sup>79</sup> All good human actions come from God, not from the will. Grace is the driving factor guiding the person,

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<sup>74</sup> Ibid., Kindle Locations 660-662.

<sup>75</sup> Ibid., Kindle Locations 1571-1572.

<sup>76</sup> Ibid., Kindle Location 1808.

<sup>77</sup> Ibid., Kindle Location 1822.

<sup>78</sup> Ibid., Kindle Location 1883.

<sup>79</sup> Ibid., Kindle Locations 1890-1891.

without which one cannot be bound to good: “With regard to God, and in all things pertaining to salvation or damnation, man has no free will, but is a captive, servant and bonds slave, either to the will of God, or to the will of Satan.”<sup>80</sup> The only human option is deciding whose will is to be followed, which is a choice as well. Once the individual chooses God’s will, no other options are possible. Luther would have everyone respond to God, and thus make only good selections. In addition to limiting the power of an immortal deity, Luther does not acknowledge the totality of human capacities. It makes humans look like the puppets of a capricious and arbitrary deity.

Ironically, Luther views himself as being unable to make good choices using his own strength. Perhaps this speaks more to Luther’s own demons than to those present in most humans. At the same time, he is unable to see the possible good in humans on their own account. The person must be bound to God in order to live to his fullest. Despite his issues with the hierarchical church, Luther is unable to allow the individual to have choices. At the same time, he does not address an underlying issue that the person still makes the choice to be bound to God and does not accept that something is operative. Luther exhibits the characteristics of the transcendent self: life is to be lived for the purpose of following God’s laws, while Erasmus takes a turn to humanistic thought. While humans are their best selves when they work for the good of the human condition as commanded by God, their creation includes the ability to make choices that are not commanded.

Free will is a critical characteristic for the evolving personal self. Once man can focus on his own behavior, individual goals can be considered. Erasmus does not advocate abandoning the spiritual self; he advocates using the personal self to magnify God. If creation is marvelous, the humans in it must aspire to individual strength. The importance of the personal self

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<sup>80</sup> Ibid., Kindle Location 1911.

translates to human choices when receiving medical care. The individual is deemed to be autonomous and, when having capacity, able to choose among the available treatment options. In the twentieth century, the concept of autonomy further expands to allow humans the right to forego treatments that medical authorities recommend. The ability to make choices is an essential constituent for the human condition. No one exists as the instrument of another, whether human or spiritual. A person has the autonomy to make choices, but information is needed to provide a foundation.

### **Renaissance Theater**

Other developments support increased secularism and introspection among humans. Renaissance theater demonstrates different ways in which the individual is depicted. The play becomes a spectator event that does not necessarily attempt to teach a religious or moral lesson. European Renaissance scholar William J. Bouwsma notes that performances were held in a unique location designed for the purpose, viewable by anyone for the price of a ticket.<sup>81</sup> As a result, plays attracted many different types of people who are able to watch many different types of selves. As an example, in Shakespeare's tragedy *Hamlet*, a variety of characters are presented, including a murderer (King Claudius), a ghost, and a girlfriend (Ophelia), to name a few. In experiencing his father's murder, Hamlet is not sure how to defend his family's honor. In the third scene of the opening act, Polonius tells his son Laertes, "this above all, to thine ownself be true. And it must follow, as the night the day, thou canst not then be false to any man."<sup>82</sup> Since Polonius has a dubious character, the source of these words is questionable, but

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<sup>81</sup> William J. Bouwsma, "Renaissance Theater and the Crisis of the Self," in *The Waning of the Renaissance, 1550-1640* (New Haven, CT: Yale University Press, 2000), 130.

<sup>82</sup> William Shakespeare, *Hamlet* (1603), (Chicago: NTC Publishing Group, 1994).

that does not mean that they hold no wisdom for Hamlet. Honoring one's self is essential to life. At the same time, Hamlet is unable to be honest with his own questions, resulting in chaos for a number of the characters. As an observer, it is possible to make judgements about what Hamlet could or should do, but he is unable to focus on the important considerations, such as supporting his mother or being a loving partner to Ophelia.

Hamlet experiences considerable anguish, contemplating whether to "suffer the slings and arrows of outrageous fortune" or by taking "arms against a sea of troubles" end his life.<sup>83</sup> The spectator may have opinions about ways to approach the problems, but ultimately Hamlet must decide. He concludes that man is no better than a beast if all he does is sleep and eat, so at the very least, decision is necessary.<sup>84</sup> At the end of the play, Hamlet, Ophelia, Polonius, and King Claudius all lie dead. Hamlet's reflections fail to protect him from ill fortune. It is a secular representation of what happens when people are unable to make good choices. For Hamlet, self-reflection gains little although the audience is able to assess the situation. The audience reflects, while the characters complete the performance. Hamlet demonstrates the choices made in a moral context. However, despite his knowledge of what to do, Hamlet is unable to deal with Claudius. If he believes the ghost, Hamlet's stepfather is guilty of murder and should be dealt with according to the Elizabethan justice. Instead, Hamlet struggles with indecision and innocent people die as the result. In Act V, Prince Fortinbras' statement, "Take up the bodies: such a sight as this becomes the field, but here shows much amiss," summarizes the concern.<sup>85</sup> The presence of numerous corpses represents the product of Hamlet's indecisiveness.

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<sup>83</sup> Ibid., Act III, Scene 1.

<sup>84</sup> Ibid., Act IV, Scene 4.

<sup>85</sup> Ibid., Act V.

Hamlet's excessive introspection focuses on the negative: instead of trying to improve the circumstances of his community, he is indecisive. He does not stop to decide whether to believe the ghost or consult meaningfully with his advisers; instead, he chooses to act in a manner that is detrimental to those around him. Proctor argues that Petrarch finds meaning by "looking outside the self to other selves"<sup>86</sup> and suggests that the challenge is to "rethink and define what we mean by the word 'human', a task which demands, I believe, questioning the usefulness of the concept of an *exclusively* (emphasis added) personal, inward-turning 'self'."<sup>87</sup> Harvard humanities professor Stephen Greenblatt notes the relationship of the individual to the society: "Whenever I focused sharply upon a moment of apparently autonomous self-fashioning, I found not an epiphany of identity freely chosen but a cultural artifact. If there remained traces of free choice, the choice was among possibilities whose range was strictly delineated by the social and ideological system in force."<sup>88</sup> We do not just live as individuals—humans are a part of a wider community and as such, have an obligation to each other. Hamlet is so overcome with his indecisiveness that he forgets any responsibility to those around him. One of the objectives of the Community Bioethics Dialogues that I will be discussing later in this dissertation is helping members to consider themselves as well as the community in the context of health care and consider the system while making their own treatment choices. In contemporary society, theater provides one of the ways for disseminating information and sharing values about the health-care system. Many productions, both live and recorded, have depicted various illnesses and profiled individuals facing terminal illnesses. As I will discuss in Chapter 5, a reader's theater production depicting family struggles with Alzheimer's was used in the Community Bioethics Dialogues in

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<sup>86</sup> Proctor, *Defining the Humanities*, 153.

<sup>87</sup> *Ibid.*, xxviii.

<sup>88</sup> Stephen Greenblatt, *Renaissance Self-Fashioning* (Chicago: University of Chicago Press, 2005), Kindle Locations 5387-5391.

Galveston. While most theatrical and movie productions do not provide an immediate opportunity for viewer feedback, the reader's theater is designed to do so, inviting conversation from the audience. In *The Conversation Project*, Dr. Angelo Volandes, an active internist at Massachusetts General Hospital and faculty member at Harvard Medical School, uses videos of patients with chronic illnesses to provide information on how the conditions progress.<sup>89</sup> The accurate dramatization of medical events provides an opportunity for individuals to compare their personal views and goals with those of potential treatment schemes. Visual information may provide more compelling information than a verbal description. Unfortunately, at this point, these videos are only accessible to physicians, so individuals are not able to use these resources on their own. Other video materials, such as the play *Wit* and the movie, *Whose Life Is It Anyway?* provide potential resources. The ability to depict conditions for others to watch is an important vehicle for allowing the general populace to witness and comment.<sup>90</sup>

### **Knowledge of the Body**

During the Renaissance, changes in religious and philosophical understandings of the self are supplemented by increasing knowledge of the anatomy of the human body. Until the Renaissance, second-century Greek writings by Galen are the foundation of understanding, providing important information on the spinal cord, breathing mechanisms, and the cardiovascular systems. However, based more on animal physiology rather than human dissection, Galen's errors were perpetuated until the sixteenth century as later physicians

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<sup>89</sup> Angelo E. Volandes, *The Conversation: A Revolutionary Plan for End-of-Life Care* (New York: Bloomsbury, 2015).

<sup>90</sup> As part of my work, I hope to develop a complete library of sources for health-care educators to use.

concentrated less on new research than on codifying previous writings.<sup>91</sup> As a result, Galen's errors regarding the human body were perpetuated.

Before Andreas Vesalius documents the results of his visual explorations of the human body by surgically exploring cadavers, Leonardo da Vinci uses art to provide powerful images, which are translated by the eye: "the primary instrument by which to achieve knowledge of the world, and painting is the handmaiden of sight."<sup>92</sup> The rendering is an intellectual undertaking, rational in its procedures, whose products are evaluated on the basis of tangible experience."<sup>93</sup> This artistic view moves beyond the words so valued by the humanists. The message is rational—the person's eye acquires the knowledge, taking on a new power in the hands of the person who uses it, for good or evil. The expansion of understanding also requires new methods, in which the explorer uses tools to explore the human body.

Leonardo relates morality to his work. In notes to one of his drawings, he rationalizes his work of cutting into a skull by noting:

Nothing compared with the soul that dwells in this structure; for that, indeed, be it what it may, is a divine thing. Leave it then to dwell in its work at its good pleasure, and let not your rage or malice destroy a life—for indeed, he who does not value it, does not himself deserve it.<sup>94</sup>

Acquiring knowledge is not forbidden, but the person engaging in the acquisition needs to honor the life being observed. Leonardo concentrates on information that is accessible to the senses and progresses to a place where concepts such as the soul, heaven, and God do not concern

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<sup>91</sup> Allen G. Debus, *Man and Nature in the Renaissance* (Cambridge, UK: Cambridge University Press, 1978), 57.

<sup>92</sup> A. Richard Turner, *Inventing Leonardo* (Berkeley and Los Angeles: University of California Press, 1994), 75.

<sup>93</sup> Ibid.

<sup>94</sup> Ibid., 199.

him.<sup>95</sup> Leonardo's art is a science: the eye sees what is, and the pen or brush records the observation. Leonardo's observations convert the individual's body into a work of art as well as an item to be studied. The human form is both subject and object of life. Others take this methodology for acquiring knowledge and apply it to further study, evolving into modern medicine and becoming the basis for the body as an object to be studied and understood, independent of the person whose physiology is being examined.

Vesalius takes insights about the body to a new level, beginning with a revision of Guinther's *Introduction to Anatomy*, a translation of Galen's *Anatomical Procedures*, "claiming that previous editions had been badly in need of correction."<sup>96</sup> Vesalius describes "the *fabrica* of the human body in all senses of the Latin word, as the structure that underlies the body, as the created fabric that constitutes it, and as the 'workshop' that allows humankind to function properly."<sup>97</sup> Vesalius turns the body into an object for intensive study, and later scientists enhance the details. Understanding the form of the human body is the precursor to comprehending more about the functions of the various organs and systems. Once recognized, the body's functions can be managed. Modern imaging and testing technologies provide extensive insights into the operation of the human body. Many physical markers such as the properties of blood are understood and managed. If the bodily functions can be maintained by managing the physiological factors, the human can still be considered to be alive. As a physical being, a person's body can be managed and manipulated to respond to interventions. The challenge is that many people do not grasp the limits of medical technology, and health-care

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<sup>95</sup> Ibid., 75

<sup>96</sup> Vivian Nutton, "Introduction to Vesalius," in *Vesalius*, ed. Daniel Garrison and Malcolm Hast (Evanston, IL: Northwestern University, 2003), <http://vesalius.northwestern.edu/books/FA.aa.html> (accessed June 2, 2016).

<sup>97</sup> Ibid., 18.

teams do not always articulate those limits when facing terminal conditions. The focus on physiological evidence trumps the total person.

### **Limits and Possibilities of the Emerging Self**

As the Renaissance unfolds, characterizations of humans become much more complex. The Roman Church is facing challenges, not just from within its own walls but from secular perspectives on what the individual can do and be. Political ideals are shifting. A “New World” is emerging an ocean away, establishing the government as a secular space, integrating classical ideals of communal decision making by free men with the prospect for individual rights. No longer will the Roman Church stand at the center of political life; ideologies codify a “Bill of Rights” for individuals, covering free speech, free religious association, and the right to bear arms. The community is no longer the center of moral consideration. A new type of democracy is born, based on individuals working independently and together in a schema where some legal precepts are defined for the whole, and others by local entities. Concurrently, science gains respect, with investigatory powers and capabilities to examine the operation of the human body. However, the scientific enterprise takes a step away from the complexities of the human organism: as British neurologist and author Oliver Sacks notes, “The disease-the-man-the-world go together, and cannot be considered separately as things-in-themselves.”<sup>98</sup> Sacks recognizes the interrelationship of the human body, its function, and the elements that may cause dysfunction. As time progresses, it becomes necessary to remind the scientific establishment that the person is more than just the operating physiological body, the challenge considered in my third chapter on “The Complexities of Personhood.”

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<sup>98</sup> Oliver Sacks, *Awakenings* (New York: Vintage Books, 1990), 229.

## **The Twentieth Century and Beyond: The Autonomous/Narcissistic Self**

During the twentieth century, the understanding of the human body expands exponentially. Not only are all critical body parts identified, science provides the means for examining body systems and elements, not just by hands, but by machines and tests to uncover functions not visible to the naked eye. To this body of knowledge, University of Pennsylvania sociologist Phillip Rieff adds the quest for knowing more about each individual's psyche. He imagines the "wisdom of the next social order" to "not reside in right doctrine, administered by the right men, who must be found, but rather in doctrines amounting to permission for each man to live an experimental life."<sup>99</sup> The resulting "psychological man is likely to be indifferent to the ancient question of legitimate authority, of sharing in government, so long as the powers that be preserve social order and manage an economy of abundance."<sup>100</sup> The *narcissistic self* is deemed to be the critical form, providing an inward look for the person as the critical understanding. Only present knowledge matters and no wisdom can be gleaned from the ages. The facts of science provide the basis for the human condition: our collective past and our stories no longer have meaning.

Other voices enter the discussion of the constituents of a person. Social scientists expand the discussion of personhood. Ironically, the focus returns to the collective, and the next chapter will consider those perspectives, especially those offered by anthropologists, who accept the task of explaining how humans come to be who they think they are. Chapter 2 will consider the anthropologists' notion of personhood, how this idea is attenuated by the collective, and the ways

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<sup>99</sup> Philip Rieff, *The Triumph of the Therapeutic: Uses of Faith after Freud*. (Wilmington, DE: Intercollegiate Studies Institute, 2006), 20.

<sup>100</sup> Ibid.

in which the medical community strives to *conduct the conduct* of persons in the context of illness.

## Chapter 2. Social Sciences: Producing Persons

Anthropologists have approached the study of personhood differently than have philosophers, ethicists, theologians, and biologists...Anthropologists want to know how different societies produce, confer, attenuate, and rescind personhood...[they] look at how personhood is produced, contested, and continually reinvented through social action...personhood is a practice.<sup>101</sup>

*Personhood is a practice.* These four words provided by Mount Holyoke anthropology professor Lynn Morgan offer a succinct summary of the anthropological definition of *personhood*. Anthropological perspectives of personhood differ from those offered by other disciplines: Morgan identifies a critical concern with the process in which personhood is conferred rather than the historical practice, asking the question, “How does culture produce the scripts that people use to decide which elements of personhood are socially significant and which are irrelevant?”<sup>102</sup> With concern for the individual’s function within the group, social scientists provide critical perspectives on personhood that emphasize the collective’s impact on the *conduct of conduct*, a consideration that is particularly useful when examining the operations for a particular sector. Morgan is but one representative of the voice of social scientists discussing personhood, providing insight on how we have come to be who we think that we are. Multiple influences affect the formation of persons, one of which is the health-care community. In the context of contemporary health care, this includes the structures under which that care is provided. In considering the effect that the collective has on individuals, modern medicine’s effect is significant. This chapter considers the practice of personhood, including consideration

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<sup>101</sup> Lynn M. Morgan, “‘Life Begins When They Steal Your Bicycle’: Cross-Cultural Practices of Personhood at the Beginnings and Ends of Life,” *Journal of Law, Medicine & Ethics* 34, no. 1 (Spring 2006): 13.

<sup>102</sup> Ibid.

of voices that do not agree on the importance of the collective, and offers an example of how the anthropological lens illuminates present practices of personhood in contemporary health care.

## **The Practice of Personhood**

As Morgan notes, the anthropological perspective focuses on the ways in which personhood is put into practice rather than focusing on moral conceptions:

We have been primarily interested in the intersections between ideology and action, that is, the situations in which personhood is conceptualized and enacted. This distinguishes us from philosophers or theologians or clinicians who look for the relevant and morally persuasive attributes of personhood in the metaphysical, cognitive, or biological attributes of individual minds and bodies. Anthropologists want to know how different societies produce, confer, attenuate, and rescind personhood.<sup>103</sup>

Morgan identifies a critical concern with the process of conferring personhood rather than invoking historical practice, asking the question, “How does culture produce the scripts that people use to decide which elements of personhood are socially significant and which are irrelevant?”<sup>104</sup> Social scientists consider that the individual’s function in the group provides critical perspectives on personhood that emphasize the collective’s impact on the *conduct of conduct*. Morgan believes the discipline

is relevant because while the thresholds of life and death provide an opportunity for introspective personal contemplation, they also spark intense social conflicts, the meanings of which anthropologists can help to illuminate. Answers to universal questions—“Who are we? What are we doing here? How do we cope with problematic persons and concepts that do not fit easily into our existing templates of personhood?”—are answered not by autonomous individuals reasoning in isolation, but by diverse groups of people who will necessarily disagree.<sup>105</sup>

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<sup>103</sup> Ibid.

<sup>104</sup> Ibid.

<sup>105</sup> Ibid., 14.

The notion of the person becomes an assembly of the physical, social, and cultural factors operating for a particular group that is forming over time. The discipline is descriptive rather than prescriptive: as an example, philosophers and theologians provide moral claims associated with the notion of person rather than defining it in the context of specific circumstances. In the case of health care, anthropologists believe that describing the conduct of the system or its principals is more important than defining a moral course of action.

Personhood covers the gamut of life and includes multiple influences that work together to form the person. Together with medical anthropologist and University of California San Francisco professor Sharon Kaufmann, Morgan notes that “producing persons is an inherently social project,” beginning at birth and progressing through death.<sup>106</sup> In the former, “anthropologists have shown that social reproduction is effected through the cultural production of persons. Personhood, they argue, is a process conferred, attenuated, contested, and withheld by the collective. It does not reside in the physical or cognitive attributes of individuals.”<sup>107</sup> Thus, personhood may be ascribed during social birth rituals and related processes through which personhood may be conferred.<sup>108</sup> Morgan and Kaufman note that “the disposition and memorialization of the dead profoundly informs the social identity of the living.”<sup>109</sup> This premise provides the starting point for understanding all manner of relationship between those who are and those who have been, including at the edges of life.

Other voices expand the notion of understanding the process of personhood. In *Inventing Our Selves: Psychology, Power, and Personhood*, British biologist-turned-sociologist and King’s

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<sup>106</sup> Sharon R. Kaufman and Lynn M. Morgan, "The Anthropology of the Beginnings and Ends of Life," *Annual Review of Anthropology* 34 (October 2005): 320.

<sup>107</sup> Ibid., 320-321.

<sup>108</sup> Ibid., 321.

<sup>109</sup> Ibid., 322.

College (London) professor Nikolas Rose wants “to begin to question some of our contemporary certainties about the kinds of people we take ourselves to be, to help develop ways in which we might begin to think ourselves otherwise.”<sup>110</sup> Rose examines the regime of the self and its consideration in ethics, particularly the role of autonomy. Rose does not deny that individuals make autonomous choices, but wants to enforce that this is only the starting point for understanding—the accumulation of experiences that make us who we think we are. In *Inventing Ourselves*, Rose establishes his fundamental thesis regarding some of the challenges towards the definition of the person:

A series of profound challenges have been directed toward an image of the self that appears, for so long, to have formed the horizon of ‘our’ thought. The self: coherent, bounded, individualized, intentional, the locus of thought, action, and belief, the origin of its own actions, the beneficiary of a unique biography. As such selves we possessed an identity, which constituted our deepest, most profound reality, which was the repository of our familial heritage and our particular experience as individuals, which animated our thoughts, attitudes, beliefs, and values.<sup>111</sup>

While all three of these social scientists acknowledge the role of the collective setting, Rose expands the discussion by challenging whether the self is in fact bounded by the individual or whether there are other influences with multiple contexts. He contends that “notions of personhood vary greatly from culture to culture, and there are many ways of accounting for such variation, connecting personhood to religious, legal, penal, and other practices bearing upon persons, and to wider social, political, and economic arrangements.”<sup>112</sup> Autonomy is characterized as being connected with liberal democratic forms of government in which the

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<sup>110</sup> Nikolas Rose, *Inventing Ourselves: Psychology, Power, and Personhood* (New York: Cambridge University Press, 1998), 1-2.

<sup>111</sup> Ibid., 3-4.

<sup>112</sup> Ibid., 151.

individual is “*obliged to be free.*”<sup>113</sup> Rose sees the formation of persons as a deliberate enterprise established not by individual choices but by collective influences. As I discuss in greater detail in the next chapter, relationality is an important element of personhood. All humans are born into a family, which establishes the fundamental process of conferring personhood. However, as the individual matures, other influences intervene and an autobiographical self is formed that tells the person’s story, including his or her personal history and aspirations. Consequently, personhood is not just about the factors conferred by the collective, but also how those events are experienced, and each person’s journey augments and may even reshape the notions that have been formed. As an example, the way the person responds to a traumatic illness or accident may be shaped by his or her acculturation, but the event may revise the notions of personhood and the important events that are anticipated for the future. Even considering the differences between Cicero and Petrarch provides some insights—Cicero considered all tribulations to be resolved only at death, while Petrarch wants to actively wrestle with his grief as part of life, and both use their writings to articulate these perspectives. For an individual dealing with a chronic or terminal illness, the redefinition of life may be influenced by available therapies, the health-care team, or a support group with individuals who have faced similar incidents. However, the individual’s response is still his or her own.

### **Historians and Personhood**

Philosopher Charles Taylor provides the contemporary Western context for framing personhood, explaining the ways that humans evolve from a long line of historical ideas. He examines human history, notably in “the ways people imagine their social existence, how they fit

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<sup>113</sup> Ibid., 100.

together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations.”<sup>114</sup> Historical people provide the backdrop for explaining Western ideals and ideology. Individuals are not selves simply by having human bodies, but by our orientation to the good. It is in looking to our place in history that we see our own story. This is integral to the formation of the person, and a critical element in the way that I consider personhood in the remainder of this dissertation.

The term that Taylor formulates is *social imaginary* as a means of focusing on the ways in which people construct “their social surroundings” as carried in “images, stories, and legends,” which can be “shared by large groups of people, if not the whole society” giving them “common practices and a widely shared sense of legitimacy.”<sup>115</sup> Taylor deems this to be a complex construct that integrates communal expectations and understandings.<sup>116</sup> Understanding this background also provides the means of providing a sense of moral order.<sup>117</sup> Communities provide stories and meanings in the context of a person’s life, becoming part of his or her personal narrative. In the historical lineage, we find selves as well as understand those who have gone before and particular contributions they made. To that degree, Taylor draws on a multitude of various philosophers and scholars to understand the sources of the Western self, extending from the Roman Church through the Middle Ages and expanding to Renaissance philosophers.

All persons live in a culture that has a role in socializing them through history in whatever way that is manifest. It is the role of relationships that dictate the sources of the self.

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<sup>114</sup> Charles Taylor, *Modern Social Imaginaries* (Durham, NC: Duke University Press, 2004), Kindle Location 250.

<sup>115</sup> Ibid., Kindle Locations 252-256.

<sup>116</sup> Ibid., Kindle Location 258.

<sup>117</sup> Ibid., Kindle Location 304.

Along the same lines as Rose, French sociologist Marcel Mauss speaks of the difference between the *role* (*personage*) and the place of the *person* (*personne*), expanding the illustration using the Pueblos, the American Northwest, and Australia as examples.<sup>118</sup> Mauss shows that social history is taken on “according to their systems of law, religion, customs, social structures and mentality.”<sup>119</sup> For the Pueblos, the persons in every clan each have a superimposed role. The notion of the person is “absorbed in his clan, but already detached from it in the ceremonial by the mask, his title, his rank, his role, his survival, and his reappearance on earth.”<sup>120</sup> In the American Northwest, different Indian tribes have varying traditions for the group in which individuals participate.<sup>121</sup> In Australia, the clan is represented by the totem, and Mauss notes that the notion of the *role* (*personage*) is “played by the individual in sacred dramas, just as he plays a role in family life.”<sup>122</sup> In each, the person has an observable role within the community that has evolved through history. In understanding the sources of various traditions, the effect of collective actions provides the understanding for who we take ourselves to be. However, the importance of the collective is not shared by all, especially as the understanding of different groups and power structures expands. Different groups take umbrage with the notion, in part because of the disproportionate influence of particular segments: more attention is given to the influence of race, class, and gender as recipients of influence. The feminist perspective provides a notable example of a group that contests the importance of the collective.

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<sup>118</sup> Marcel Mauss, "A Category of the Human Mind: The Notion of Person; the Notion of Self," in *The Category of the Person: Anthropology, Philosophy, History*, ed. Michael Carrithers, Steven Collins, and Steven Lukes (Cambridge, UK: Cambridge University Press, 1985), 4-12.

<sup>119</sup> *Ibid.*, 3.

<sup>120</sup> *Ibid.*, 6.

<sup>121</sup> *Ibid.*, 7-9.

<sup>122</sup> *Ibid.*, 11-12.

## The Feminist Perspective

The feminist challenge shifts the focus from the collective to one that may not include the whole group. When looking at the history of humans and humanist thought in the Western world, arguably, most of the emphasis has been on male viewpoints. This emphasis incurred criticism during the latter part of the twentieth century as a group of feminist social scientists questioned the rationale of a collective record giving short shrift to about half of the population.

Rose notes that University of Sidney philosophy professor Moira Gatens differentiates the sexes with males whose universality is based on the general order, while the female is the dependent being.<sup>123</sup> In Rose's view, "for many who write as feminists, this politico-philosophical and patriarchal illusion of universal 'disembodied' person is to be redressed by an insistence upon the *embodiment* of the subject."<sup>124</sup> He goes on to note that feminist theorists oppose "the image of the unified, individualized, psychological self, this time effected through examining the links between subjectification, sexuality, and psychoanalysis."<sup>125</sup> When one speaks of relationships and the ways that selves are formed through them, it is impossible to ignore the silencing of women's voices through the ages. As an example, consider the absence franchise for women through much of U.S. history. Regulations were formed by men for the community, while socializing educational systems were also targeted to men until the late nineteenth and early twentieth centuries. Thus, the entity engaged in the forming persons is male-oriented and might need to be adjusted to consider male and female perspectives.

The complex views of feminism consider the nature of persons using different parameters. Feminist philosopher Annette Baier has argued for a naturalist view of persons,

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<sup>123</sup> Rose, *Inventing Ourselves*, 6.

<sup>124</sup> Ibid.

<sup>125</sup> Ibid., 7.

since “persons are born to earlier persons, and learn the arts from other persons.”<sup>126</sup> She considers this perspective to be broader, acknowledging the person’s physical being, having the ability to think, and participating with others through language. In this, persons are viewed as “intelligent, talkative, playful mammals who have become conscious of ourselves, of our mammalian nature, its possibilities and the constraints it imposes.”<sup>127</sup> The social nature of persons that is a critical feature, where “our personhood shows in the way we are responsive to one another, responsive to earlier and later generations, responsive to the presence of other groups of persons, groups with different histories and interestingly different self-understandings.”<sup>128</sup> Baier acknowledges the scientific origins of persons as well as the social and cultural influences on them. If Rose wants to emphasize the nature of relationships, it is important to acknowledge the silenced voices and understand the impact on the notions of the self, as well as integrate the changes in modern history. As an example, one of the foundations of modern medicine, research into various conditions and illnesses, has incurred feminists’ wrath for not considering female issues sufficiently.<sup>129</sup> The feminist arguments are far more complex than provided in this short space. However, the viewpoint is valid and needs to be considered in any discussion of personhood. Ultimately, the social construction of different groups within the community will affect the definitions offered for personhood and affects the meanings ascribed to terminal illnesses, in turn, affecting the treatment choices that may be seriously considered by an individual.

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<sup>126</sup> Annette Baier, *Moral Prejudices: Essays on Ethics* (Cambridge, MA: Harvard University Press, 1996), 313.

<sup>127</sup> Ibid., 325.

<sup>128</sup> Ibid., 326.

<sup>129</sup> Similar arguments have been presented for people of color. As an example, some of the research pertaining to treatments of heart conditions is being discounted for women and those of color, but that discussion is beyond the scope of this dissertation.

## Social Construction

Social construction affects the ways that persons are formed in conjunction with their gender, race, or class. Emerita social anthropology professor at the London School of Economics Jean Sybil (J. S.) LaFontaine differentiates the *individual* (the mortal human being) from the person, who has social significance.<sup>130</sup> This serves to differentiate the physical specimen from the communal, social being who has relationships with others. A healthy new baby is human but is socialized into relationship by various practices. Yale University psychology professor Paul Bloom notes that young infants have a preference for their mother's face, but are social beings by their first birthday.<sup>131</sup> Both Taylor and Rose take this deeper, using historical and social science constructs to articulate the influences on the person.

Notre Dame sociology professor Christian Smith has observed, "Personhood is dependent in emergent origin and continuation upon intersubjective social interaction, communication, and communion with other human persons. Human persons are irreducibly socially constituted, even though at lower levels of reality they are composed of particles of matter."<sup>132</sup> Smith also observes that "persons are centers of subjective experience, durable identity, moral commitment, and social communication."<sup>133</sup> The lives of persons are "complex webs" that are sustained mutually. Smith concludes, "Only personally grounded human social structures involve the exercises of creativity, moral judgments, language use, complex meanings, symbolization, self-reflexivity, narratives, technologies, deep intersubjective understanding, and major change over

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<sup>130</sup> J. S. Lafontaine, "Person and Individual in Anthropology," in *The Category of the Person: Anthropology, Philosophy, History*, ed. Michael Carrithers, Steven Collins, and Steven Lukes (Cambridge, UK: Cambridge University Press, 1985), 126.

<sup>131</sup> Paul Bloom, *Descartes' Baby: How the Science of Child Development Explains What Makes Us Human* (New York: Basic Books, 2004), 15-16.

<sup>132</sup> Christian Smith, *What Is a Person? Rethinking Humanity, Social Life, and the Moral Good from the Person Up* (Chicago: University of Chicago Press, 2010), Kindle Location 198.

<sup>133</sup> Ibid., Kindle Location 744.

history that makes them so distinctive and powerful.”<sup>134</sup> These characteristics will vary with specific groups and types of experiences. Different communities provide various means of formation, and these are characterized as part of the task of understanding how we come to be who we think we are. Modern medicine has its own characteristics that are explored later in this chapter.

### **The Role of Subjectification**

Subjectification arises out of French philosopher and social theorist Michel Foucault’s notions of the effects of power on individuals. Understanding the ways in which a community’s systems educate, reward, and punish provides the approach. It is how the individual is located within that system that provides the description of whether they are recipients of or act with power. Rose believes that subjectification needs to be understood “in a complex of apparatuses, practices, machinations, and assemblages within which human being has been fabricated, and which presuppose and enjoin particular relations within ourselves.”<sup>135</sup> He posits that the “psy” disciplines, including psychology, have “played a rather fundamental part in ‘making up’ the kinds of persons that we take ourselves to be,” further indicating that “the growth of the intellectual and practical technologies of psychology in Europe and North America over the period since the late nineteenth century is intrinsically linked with transformations in the exercise of political power in contemporary liberal democracies” and is “part of the history of the ways in which human beings have regulated others and have regulated themselves in the light of certain games of truth.”<sup>136</sup> Thus, the individual’s whole formation is tied to means established by the

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<sup>134</sup> Ibid., Kindle Locations 4092-4094.

<sup>135</sup> Rose, *Inventing Ourselves*, 10.

<sup>136</sup> Ibid., 10-11.

community, including the ways in which illness and disease are addressed. In understanding the ways in which knowledge flows and power is exercised, the community acts upon the individual and vice versa. In the remainder of this chapter, I consider the case of medicine and the ways that persons become subjects and objects of power.

### **Practices of Personhood: The Case of Medicine**

Social scientists find areas of agreement and disagreement in understanding the notion of person. The focus is on understanding the ways in which personhood is granted in different communities and circumstances. Medicine is one particular discipline for observing the practice of personhood. Modern medicine is managed by the *conduct of conduct* as the means for providing diagnoses and treatments of diseases and related processes are established by standards at many levels, beginning with the primary care physician and extending to the federal government, where health-care providers are regulated and disease protocols are approved. The modern practice of medicine creates structures that can be confusing to ordinary users of health care.

The expanding practice of medicine results from technological developments, creating a new structure to *conduct the conduct* of persons, termed *governmentality*. Much of Foucault's work has centered on understanding the ways that governmentality is accomplished, with a focal point on organizations that support technological improvements, especially medicine. In the interview entitled "Truth and Power," Foucault speaks to the problem of understanding the regime that governs scientific efforts, believing that it is important to understand the constitution

of internal regimes of power and how it evolves over time.<sup>137</sup> He identifies the seventeenth and eighteenth centuries as key periods during which power begins to affect social services, necessitating acquisition of “productive service from individuals” and, in turn, creating the need to “gain access to the bodies of individuals, to their acts, attitudes and modes of everyday behavior.”<sup>138</sup> Foucault identifies five types of *truth* that need to be understood:

*Truth* is centered on the form of scientific discourse and the institutions which produce it; it is subject to constant economic and political incitement (the demand for truth, as much for economic production is for political power); it is the object, under diverse forms, of immense diffusion and consumption (circulating through apparatuses of education and information whose extent is relatively broad in the social body, notwithstanding certain strict limitations); it is produced and transmitted under the control, dominant if not exclusive, of a few great political and economic apparatuses (university, Army, writing, media); lastly, it is the issue of the whole political debate and social confrontation (“ideological” struggles).<sup>139</sup>

Foucault holds that each regime has its notion of truth that includes accepted matters and types of discourse. These are the guiding principles for an organization at a particular time and place.

Recognizing institutional apparatuses is important in comprehending the ways in which we come to be the way that we think we are. Rose defines three specific areas that emanate from Foucault’s approach:

- Political. Foucault considers the political enterprise to be governmentality, which includes the ways that “diverse authorities – political, military, economic, theological, medical, and so forth – have sought to act upon the lives and conducts of each and all in

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<sup>137</sup> Michel Foucault, *Power/Knowledge: Selected Interviews & Other Writings 1972-1977*, ed. Colin Gordon, trans. Colin Gordon (New York: Vintage Books, 1980), 113.

<sup>138</sup> Ibid., 125.

<sup>139</sup> Ibid., 131-132.

order to avert evils and achieve such desirable states as health, happiness, wealth, and tranquility.”<sup>140</sup>

- In *Governing the Present: Administering Economic, Social and Personal Life*, together with professor of accounting at the London School of Economics Peter Miller, Rose expands on the task of characterizing governmentality: “If the conduct of individuals or collectivities appeared to require conducting, this was because something in it appeared problematic to someone. Thus, it makes sense to start by asking how this rendering of things problematic occurred.”<sup>141</sup> In the example of medicine, the technology is identified as the problem, requiring interventions to *conduct its conduct*. The world of medicine is too complex to be left to chance, so structures are needed to define the context for practicing medicine. Standards of practice, protocols, and reimbursement rules provide the framework.
- Institutional. Construing the structure as *human technologies* refers “to all those devices, tools, techniques, personnel, materials and apparatuses that enabled authorities to imagine and act upon the conduct of persons individually and collectively, and in locales that were often very distant.”<sup>142</sup> Establishing hospitals as a place for the professional practice of medicine rather than a warehouse for the poor with no one to care for them is an example of the ways in which human technologies are formalized. As a location, hospitals, rehabilitation, and skilled nursing facilities provide a detailed framework for offering health services.

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<sup>140</sup> Rose, *Inventing Ourselves*, 153.

<sup>141</sup> Peter Miller and Nicholas Rose, *Governing the Present: Administering Economic, Social and Personal Life* (Cambridge, UK: Polity Press, 2008), Kindle Location 414.

<sup>142</sup> Ibid., Kindle Location 466.

- *Ethical field.* Insofar as ethics is understood as a mode of evaluating and acting upon one's self, Rose attributes the rise in bioethics to somatic expertise, "claiming the capacity to evaluate and adjudicate on these activities, which has been enrolled in the government and legitimation of biomedical practices from bench to clinic and marketplace."<sup>143</sup> In the clinic setting, however, ethicists are consultants, and do not claim the authority that Rose believes them to have. The debate over whether to certify clinical ethicists is an example of the absence of standardized acceptance of somatic expertise.

Rose defines the resulting interaction of these three dimensions as the *enterprise culture*, the way that "we are governed by others and the way we should govern ourselves."<sup>144</sup> We need to understand how conduct is established, promoted, and controlled by external and internal forces. In a medical setting, the ways in which medicine is practiced must be observed, with expertise as the critical element, which Rose considers to be important for three reasons:<sup>145</sup>

- Grounds authority in a claim to scientificity and objectivity to provide the balanced blend of self-regulation and external power structure required in "democratic" rationalities of government.
- Can be mobilized in the political argument to create a relationship between knowledge and government.
- Operates through the relations with self-regulating capacities of subjects.

Expertise is the characteristic providing authority from the structure in a way that it can be recognized and acknowledged by those who become the subjects participating in the health-care system. Most professional medical providers--physicians, nurses, therapists, and other

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<sup>143</sup> Nikolas Rose, *The Politics of Life Itself* (Princeton, NJ: Princeton University Press, 2007), 310.

<sup>144</sup> Rose, *Inventing Ourselves*, 154.

<sup>145</sup> Ibid., 156.

specialists have educational and licensing requirements that *conduct the conduct* of those individuals.

Rose believes the reshaping of authority in medicine has five different causal factors tied to new technologies: molecularization, optimization, subjectification, somatic expertise, and economies of vitality. I discuss each of these below, integrating examples from Sharon Kaufman's specific considerations for health care.

### **Molecularization**

Life is identified, isolated, manipulated, mobilized, and recombined at a minute level (as opposed to a molar or mass level), creating new forms of technology for diagnostic and therapeutic purposes, including the possibility of the reverse engineering of life.<sup>146</sup> Kaufman considers biomedical research to be foundational for the present practice of medicine. Once evidence for a particular treatment option is obtained through clinical trials, Medicare accepts its efficacy, and it becomes the standard of care, which then becomes difficult to refuse.<sup>147</sup> The ability to choose ends up being compromised, in turn, defeating the person's consideration of what is important and overriding true autonomy, and creating a potential conflict:

Clinicians often do not see that the choices they offer to patients—choices they are obligated to offer in our era of patient-centered care, individual autonomy, and shared decision making—represent an off-loading of ethical responsibility onto those patients and their families, that is, off-loading onto those with the least ability to understand prognosis, the purpose of specific treatments, and the implications of crossing the line.<sup>148</sup>

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<sup>146</sup> Rose, *The Politics of Life Itself*, Kindle Location 1963.

<sup>147</sup> Sharon R. Kaufman, *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line* (Durham, NC: Duke University Press, 2015), 24.

<sup>148</sup> *Ibid.*, 40.

Moreover, the amount of information that can be considered in managing the medical life of the human is extended, providing copious amounts of information on bodily elements and how those are contributing to the organism's functioning. The advent of computerized medical records enhances the understanding of the organism's function. In some cases, physicians can access information, both for historical data and for results and input from other providers. When available, information can be provided for test results spanning numerous years. More recently, larger health-care providers have established websites where the individual can access medical records, although an explanation of the information may not be provided, and those who do not have internet access are unable to use this resource.

### Optimization

Life is no longer limited by existing conditions; interventions can be made to achieve a future in some envisioned *optimal* state. Genetic testing, plastic surgery, and other practices provide the means for redefining what it means to be human or at the very least, changing the appearance or packaging. The capacity exists to calculate the risks associated with medical intervention. In turn, the system invites someone with problems to "direct his or her path to a different, and more desirable—less diseased—future."<sup>149</sup> Rose characterizes the genetic challenge as presenting a family matter that induces *genetic responsibility*, reshaping "prudence and obligation, in relation to marriage, having children, pursuing a career, and organizing one's financial affairs."<sup>150</sup> Kaufman expands on this concept, noting that "As individuals, we are expected to decide on prevention and health-maintenance strategies for ourselves and our family members and act on our decisions. Failure to do so is, without question, understood by many to be a moral

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<sup>149</sup> Rose, *The Politics of Life Itself*, Kindle Location 2043.

<sup>150</sup> Ibid., Kindle Location 2522.

transgression.”<sup>151</sup> In addition, Rose considers that women are required to submit themselves to genetic testing in order to permit “informed choices over their own reproduction in the light of expert knowledges and techniques,” in turn creating a need to reshape the ethical field within which “genetically risky individuals must govern themselves and their lives.”<sup>152</sup> Some health-care challenges transcend the individual person; the effect on the community must also be considered. One challenge is the necessity of identifying steps to be taken once the information is gathered. As an example, the genetic marker for numerous conditions can now be identified, but there is no well-defined path for what to do with the information. As an example, a person diagnosed with the breast cancer gene must consider whether to undergo a prophylactic mastectomy, with no assurance that some other form of cancer will not appear elsewhere in her body. Other decisions follow: the woman will need to consider whether to undergo additional surgeries for breast reconstruction, which has other ramifications on risks, costs, and personal image. Many diagnoses come with options that affect the person, some of which are narrowed by the health-care hierarchy.

### Subjectification

The construction of the individual subject changes dramatically with new technologies. Rose uses the term “*biological citizenship*” “to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as men and women, as families and lineages, as communities, as populations and races, and as species.”<sup>153</sup> New concepts of biological citizens redefine humans in relation to

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<sup>151</sup> Kaufman, *Ordinary Medicine*, 34.

<sup>152</sup> Rose, *The Politics of Life Itself*, Kindle Location 2700.

<sup>153</sup> *Ibid.*, Kindle Location 3038-3040.

their illnesses as well as “life itself, reorganize the relations between individuals and their biomedical authorities, and reshape the ways in which human beings relate” to their own bodies.<sup>154</sup> New expectations and responsibilities are created; humans are supposed to be proactive in caring for themselves, not only presenting themselves for identification of potential illnesses, but committing themselves to pursuing therapies as recommended by physicians.<sup>155</sup> The availability of information does not assure that actions will be for the individual or the communal good. However, the availability of information increases the interaction between patient organizations and scientists. The latter become more active in seeking particular actions from the technical community regarding their particular perspective, creating new forms of political activism.<sup>156</sup> As I will discuss later in this dissertation, the need for public understanding of health care is great. There is much information regarding treatment options, which may be available but are not necessarily accessible to all people.

### **Somatic Expertise**

The understanding of the body provides new means of governing human conduct, in turn creating a new expertise in bioethics for providing guidance on matters of the body and health or illness. Rose identifies the need to scrutinize the expertise that bioethicists claim, along with having an understanding of the process for issues that become topics of investigation.<sup>157</sup> Foucault differentiates ethics from morality, with the claim that the latter is concerned with behaviors to do or not do, rather than ethics practice which “refers to the domain of specific practical advice on how one should concern oneself, make oneself the subject of solicitude and

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<sup>154</sup> Ibid., Kindle Locations 299-300.

<sup>155</sup> Ibid., Kindle Location 2572.

<sup>156</sup> Ibid., Kindle Location 3385.

<sup>157</sup> Ibid., Kindle Location 837.

attention, conduct oneself in the aspects of one's everyday existence."<sup>158</sup> An individual's ability to ask questions becomes a critical skill in order to understand matters of health. The ability to question experts regarding one's health keeps individuals from being overtaken by the system.

### **Economies of Vitality**

Rose believes "a new economic space has been delineated—the bioeconomy—and a new form of capital—biocapital."<sup>159</sup> The ability to quantify benefits for a particular biotechnology brings new abilities to identify and rank order activities. Rose expresses concern over the authority that commercial enterprises have on the choices made in biomedicine, noting that "reshaping of human beings is thus occurring within a new political economy of life whose characteristics and consequences we have yet to map."<sup>160</sup> Yet, the bio-economy is described as having "emerged as a governable, and governed, space."<sup>161</sup> The biological citizens created in the new space also have a financial vote, with a *market economy of health* that is reshaping the regulated *political economy of health*.<sup>162</sup> Activities are driven by governmental officials and health-care technicians but also affected by the grass-roots presence of activists with a particular agenda. Kaufman notes:

Different kinds of factors contribute to the process through which payments for treatment are decided. New discoveries in the laboratory, clinical trial results, and data on additional evidence-based outcomes are all central to the making of reimbursement decisions, but pressures brought to bear by members of Congress,

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<sup>158</sup> Rose, *Inventing Ourselves*, 30.

<sup>159</sup> Rose, *The Politics of Life Itself*, Kindle Locations 288-289.

<sup>160</sup> Ibid., Kindle Location 857.

<sup>161</sup> Ibid., Kindle Location 892.

<sup>162</sup> Ibid., Kindle Location 3431.

physician lobbying groups, proactive consumers, the device and pharmaceutical industries, and the private insurance industry also play their part.<sup>163</sup>

In theory, all health-care users have choices; in fact, those choices are influenced by governmental policies, including personal factors such as availability and affordability of health-care services. Much can be said about health disparities, but that is beyond the scope of this dissertation. Suffice it to say that expanding knowledge of the health-care system provides at least one way of enhancing access and understanding.

These characteristics affect the ways that health systems operate and how the individual participates and is treated. Life is not lived extemporaneously: there are ways and means of improving, measuring, monitoring, and controlling. If, as Rose indicates, liberal democratic societies oblige men to be free, there is a conflict with governmentality and autonomy. If we understand the *conduct of conduct* in health care through Rose and Kaufman, true autonomy never exists. Individuals are required to follow recommended treatments and never seek another opinion. Ironically, the need to seek second opinions is mandated for some of the procedures recommended by the protocols. If the medical system's authority is shaped by molecularization, optimization, subjectification, somatic expertise, and economies of vitality, there is not much room for autonomy. Everyone becomes controlled by the system that is designed to meet its own needs. In this complex environment, humans live out their lives, eventually finding their way into the hospital, possibly at the end, even when further treatments are believed to lack benefit. Kaufman devotes her skills as an anthropologist to spending extended periods of time following the workings of hospitals, particularly in end-of-life situations, providing an anthropological lens of Rose's views on governmentality in medicine, concluding that, "The

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<sup>163</sup> Kaufman, *Ordinary Medicine*, 106.

ways we think and talk about the *dying process* and the dying person and the ways we prepare for death, stave it off, and respond to medical treatments for those near death are all shaped by social institutions and bureaucratic practices.”<sup>164</sup> Despite all of the good words used in the clinical setting and by ethicists, there is limited autonomy. Individuals are frequently affected by the expectation that treatment will continue, without a detailed explanation of the implications of those practices. In the following section, I examine Kaufman’s anthropological perspectives in more detail.

### **Kaufman’s Anthropological Lens of Health Care**

The process of health-care governance evolves with that of the role of the hospital. Disease becomes a social ill to be eliminated, requiring a degree of regulation. Foucault provides insight into the evolution in France: the Comité de Mendicité de l’Assemblée Nationale was influenced by economists and doctors who joined forces to promote treatment of the sick as a natural part of social life, centered on the family. In turn, the family’s obligation to care for the sick also bound the nation’s social collective duty to provide assistance.<sup>165</sup> Health-care matters require intervention to influence the *conduct of conduct*. The history lesson provides insight on how disparate professionals work in concert to change the way that health care is governed. In the United States, the government also plays a critical role in addressing the health care arena: growth in hospital construction provides the place, and Medicare provides the funds, particularly for the elderly. The scene is set for policy to control the ways in which services are provided.

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<sup>164</sup> Kaufman, *And a Time to Die*, 2.

<sup>165</sup> Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, trans. A. M. Sheridan Smith (New York: Vintage Books, 1994), 39-40.

The actual buildings are only one element of the infrastructure. Advances in medical technology require additional physicians, technicians, caregivers, and many other types of support personnel. Education is anterior to the entire structure—this professional capacity must be developed in order for the system to have the technical capacity for managing the organization. Professional health-care operations managers, possessing medical or business degrees or both, become integral to the system of caring, directing budgets for staffing and equipment that will set the framework for how the organization operates. As a result, the process of being sick is not just a human condition: it is one to be organized, managed, and controlled in order to take advantage of the multiple technologies while managing the human organism. In *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where To Draw the Line*, Kaufman identifies three formative developments in the evolution of modern health care: the increased role and influence of industry, which covers more than half the cost of investigating new therapies; the proliferating number of treatment options, with increasing trials investigated, approved by the Food and Drug Administration, and approved by Medicare and other insurers; and “Americans’ perspective on aging and the timing of death,” where deaths are considered premature regardless of the person’s age.<sup>166</sup> While the system works together to provide patient care, Kaufman identifies the physician as the center. It is the physician who provides the diagnoses for the patient and makes treatment recommendations. Nevertheless, in the present age of patient-centered care, Kaufman acknowledges that patients and families are at the core of decisions.<sup>167</sup> The patients or their surrogates become the stage on which all constituencies work together. This creates a conundrum in which one or more treatment options are presented by

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<sup>166</sup> Kaufman, *Ordinary Medicine*, 3-5.

<sup>167</sup> *Ibid.*, 47.

physicians who have been identified by industry research but are decided upon by patients, families, and surrogates who may not understand all of the ramifications of the treatment plan.

Kaufman's study of hospital practices at the end of life in an earlier book, *And a Time to Die: How American Hospitals Shape the End of Life*, provides an insight into which the governance of dying is understood. She identifies the elements of the hospital's culture that supports an environment in which there are multiple contradictions:<sup>168</sup>

- Patient autonomy is applied only in decision making about specific medical treatments offered by individual physicians, with constraints imposed by institutional imperatives.
- Death is rarely mentioned until shortly before it occurs.
- Aggressive treatments exist alongside palliative care.
- Hospitals are not structured to provide the kinds of death that people claim to want.

The hospital exists not only as a place but as a bureaucracy in which rules, regulations, procedures, and protocols exist for treatment. The structure standardizes and manages so that the organization does not falter. The organization is not structured to personalize treatments but provides a framework in which the practice of medicine occurs. Each human body can be measured and monitored in order to manage the performance and attempt to optimize the function to a level established by accepted *Standards of Practice* that are generally recognized by the medical community. Research identifies new and better ways of treating or managing particular conditions, but always with a control group that serves as the metric of how well the new procedure, treatment, or medication functions. Kaufman cautions about the limitations of that research, noting that “there will never be enough evidence from clinical trials to answer all the questions about what to do that emerge for patients and doctors in the clinical setting”; in the

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<sup>168</sup> Kaufman, *And a Time to Die*, 128-129.

absence of perfect knowledge, consensus committees wind up making final decisions about various treatment protocols, weighing various types of evidence.<sup>169</sup> In turn, the evidence determines Medicare treatment policies, which are adopted by other insurers.<sup>170</sup> In totality, the *conduct of conduct* is defined for all matters by various constituents of the health system, with each member having a defined function and performance expectations.

Part of the improved standing of physician authority has been via implementation of education and licensing requirements, requiring teaching hospitals as places where the learning occurs. In these places, the number of required participants expands substantially, with the presence of medical students and others tasked with learning the various aspects of the art of medicine. In addition to serving as targets for learning, patients may become the guinea pigs for new forms of treatment. Critics contend that these practices dehumanize the patients, making them solely targets of scientific inquiry.<sup>171</sup> Proponents argue that this is needed in order to test new edges of medical treatment. In fact, both groups are right, and it is up to the institutional governance to assure that individual rights are protected. Rose identifies the laboratory as the place where biopolitics depends on

the laboratory in the creation of new phenomena, the massive computing power of the apparatus that seeks to link medical histories and family genealogies with genomic sequences, the marketing powers of the pharmaceutical companies, the regulatory strategies of research ethics, drug licensing bodies committees and

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<sup>169</sup> Kaufman, *Ordinary Medicine*, 71-72.

<sup>170</sup> *Ibid.*, 98.

<sup>171</sup> Much has been written on research ethics, a field that creates a whole new set of issues within technology. In writing about the importance of patent protection for new discoveries, a *Hastings Center Report* concludes that “to significantly improve the health status of their citizens, countries need strong and well-run health systems and disease prevention programs; well-functioning drug approval, procurement, and distribution programs; sufficient numbers of well-trained health personnel; and the political will to address health problems. They also need affordable access to new and existing treatments.” Supporting this venture is perceived as a critical need. Josephine Johnston and Angela A. Wasunna, “Patents, Biomedical Research, and Treatments: Examining Concerns, Canvassing Solutions,” *Hastings Center Report* 37, no. 1 (January/February 2007): S7.

bioethics commissions, and, of course, the search for the profits and shareholder value that such truths promise.<sup>172</sup>

As noted previously, Kaufman agrees with the importance of the research enterprise in identifying treatments offered to persons. Significant opportunities for long-term medical improvements come from the laboratory, a part of the process that needs to be controlled and managed.

Added to the technological challenges is the description of the hospital as a business, with the patients and their families identified as the *customers*. The media includes a substantial number of examples of various medical facilities promoting their particular brand of medicine. The process of delivering medical care with accompanying noxious treatments causing pain and suffering is combined with the need to provide good customer service. The government expands the emphasis on customer service, tying Medicare reimbursements with customer service results, creating a tension: the management of disease processes must be accomplished in a manner that satisfies the patient and their families.

The processes that the system purports to manage involve a variety of outcomes, some of which are uncertain. It is much easier to provide good customer service when the desired outcome is known. Buying a car is relatively easy: knowing the price parameters and desired features narrows the targeted range of available options. All the customer needs to do is identify a dealership with the product and negotiate the price. In health care, the effort is more challenging. Kaufman notes that patients and/or families frequently do not know what to want, other than recovery or an end to suffering.<sup>173</sup> Patients and surrogates must rely on information provided by health-care professionals who have the expertise, the training, and the know-how for

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<sup>172</sup> Rose, *The Politics of Life Itself*, Kindle Location 767.

<sup>173</sup> Kaufman, *And a Time to Die*, 34.

conducting the conduct of the organization. Information regarding specific choices is not always clear-cut or understandable by patients or families. Health-care providers' ability to serve is performed (and some might say limited) in an environment "constrained by professional relations, hospital regulations, standards of practice, finance arrangements, the legal implications of their treatment choices, and the demands made by patients' families."<sup>174</sup> Websites designed to inform the public may only cause more confusion. Thus, the ability to provide customer service is constrained in part by the structure that *conducts the conduct*.

Kaufman's hospital research regarding the end of life was conducted ten years ago, yet there is no evidence that governmentality of the medical system has changed substantially for end-of-life care. The system that Kaufman describes in her more recent book, *Ordinary Medicine*, provides further explanations of the system, including the drivers that are identified earlier in this chapter. The structure responsible for managing the system continues to expand and the ways in which patients are able to respond is restricted. My own experiences in a hospital setting confirm Kaufman's observations. Most patients and families accept physician recommendations and hospital rules without question. When conflicting information from differing specialists is given, confusion ensues. Many patients and families are not able to sort through the morass to make knowledgeable decisions. As an example, an ICU patient will typically have several physicians, each with a perspective of the patient's progress: the cardiologist has one report, the pulmonologist another, and another specialist may have yet a different perspective on the patient's condition. As a result, the family is left in a confused state about the patient's overall condition, and may even want to believe the most optimistic report that they receive on the patient's condition. An understanding of the workings of the whole

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<sup>174</sup> Ibid., 34-35.

person can provide the framework by which treatment recommendations are understood, and communications among the various experts is important.

## Summary

The humanist notion of personhood described in Chapter 1 has its roots in the Renaissance. Prior to that time, the emphasis was on the community. The social science perspective emphasizes how the community attenuates personhood. Both approaches provide considerable contributions to the contemporary underpinnings that I use to go into more detail about defining personhood in the next chapter. Kaufman echoes the fundamental question of, “What kind of a people do we want to be” regarding the health system: “What values do we want to govern that enterprise?”<sup>175</sup> She asks a related question, “How, ultimately, do we want to live in relation to medicine’s tools?”<sup>176</sup> The medical community has a significant effect on the ways in which individuals live in the face of critical illnesses. Collectively and individually, persons are bound to the system that treats issues pertaining to their bodies, but the physiological self is not the only consideration. In making choices, the individual must weigh matters that support specific life elements. In looking at the totality of the person, I provide a framework for considering a succinct definition of personhood that individuals can relate to their health treatment options and that can be used to educate the populace about the health-care system, aging, and end-of-life planning.

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<sup>175</sup>Kaufman, *Ordinary Medicine*, 238.

<sup>176</sup> Ibid., 246.

### Chapter 3. The Complexities of Personhood

I have defined persons as individuals with the capacity for consciousness and other forms of mentality. This capacity necessarily depends on the normal functioning of the cerebral cortex and supporting subcortical brain structures.<sup>177</sup>

When two people are discussing a third, and the question is asked, “What is Georgia like?” most likely, the respondent will not describe the person in terms of her biological functions. Unless diagnosed with a specific illness, the answer to the question will not address how well Ms. Brown’s brain controls her heart rate and respiration; how well her brain stem controls her neuro-hormones; or describe her consciousness level. The response will not be limited to Ms. Brown’s physical body. More likely, the answer will consider elements of her personhood: how she earns a living, what her family is like, things she enjoys doing, or her personal history. In short, the response will relate to Ms. Brown’s personhood: the elements included in her narrative self and place in community—characteristics that are enabled by her consciousness. As her life progresses, Ms. Brown’s consciousness may change—she may experience brain decline in the form of dementia or even experience an injury that causes a temporary or permanent lapse in consciousness. In turn, her personhood will be affected.

Persons do not exist as solitary beings. As philosopher H. Tristram Engelhardt notes, “It is persons who are the constituents of the secular moral community. Only persons are concerned about moral arguments and can be convinced by them, or can make agreements and convey authority to common projects through their occurrence. To choose, to make an agreement, is to be conscious of what one is doing.”<sup>178</sup> The person makes choices, and is supported in the mental

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<sup>177</sup> Walter Glannon, *Bioethics and the Brain* (New York: Oxford University Press, 2007), 146.

<sup>178</sup> H. Tristram Engelhardt Jr., *The Foundations of Bioethics*, 2nd ed. (New York: Oxford University Press, 1996), 136.

capacity for doing so via the brain's functions. The narrative self allows one to describe an experience of a lived history as well as an anticipated future. The narrative self is, in turn, experienced in community. Every person comes from a family in a particular place and lives relationally. The ability to interact with others provides the means by which persons come to be who they think they are. The characteristics of the narrative and relational selves are supported by consciousness, characterized by University of Southern California neuroscience professor Antonio Damasio as "our beginner's permit into knowing all about the hunger, the thirst, the sex, the laughter, the kicks, the punches, the flow of images we call thought, the feelings, the words, the stories, the beliefs, the music and the poetry, the happiness and the ecstasy."<sup>179</sup> As the foundation, consciousness permits all of the other features of personhood to be enjoyed and observed.

Personhood is particularly important in contemporary medicine because the practitioners sometimes overlook the essence in considering treatment protocols. The advent of mechanical and chemical supports provides the means for continuing essential bodily functions in the absence of consciousness, leading to treatments that serve to prolong death instead of restoring health. Essential bodily functions are emphasized over the nature of the person in continuing treatments. Consequently, families are put in a situation of following false hopes as well as incurring nonbeneficial expenditures for nonproductive health care. By recognizing and integrating the nature of personhood into medical treatment considerations, the health-care team and family members have a better foundation for decision making.

This chapter explores the contemporary context of personhood and the role played by each of the three characteristics—the narrative self, relationality, and consciousness—providing a

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<sup>179</sup> Antonio Damasio, *Self Comes to Mind: Constructing the Conscious Brain* (New York: Vintage Books, 2010), 5.

pragmatic definition that is supported by the humanistic and social science traditions discussed in the previous two chapters. While each of the elements is important, consciousness provides the underpinnings of personhood. Without consciousness, a person's communal complex nature with an ability to articulate his or her story and environmental awareness ceases. As a result, consciousness is necessary for personhood to exist. Thus, when consciousness is lost permanently, personhood is as well.

To provide a framework from which this definition of personhood has been drawn, I first examine various perspectives of personhood that augment my understanding. In the prior chapters, I concentrate on the humanistic and social science views of personhood. Many other disciplines have contributed to the contemporary perceptions of personhood, and some of these are particularly helpful in supporting the definition of personhood that is used in this dissertation. Following the discussion of these perspectives, an in-depth description of consciousness will be presented, followed by a discussion of the elements of the narrative self and relationality.

## **Perspectives of Personhood**

As described in the first chapter, personhood and consciousness are late twentieth-century constructs in the United States and other Western cultures. Many experts, including representatives from sociology, anthropology, the law, and the humanities, have contributed to the consideration of the qualities of a person and personhood. In this section, I describe five contemporary perspectives of personhood from a variety of disciplines to augment those from the humanities: ethics, medicine, history, and theology, concluding with Glannon's definition, which I consider to be particularly useful in summarizing the nature of personhood and recognizing its complexity. In all cases, these perspectives integrate the three characteristics

used in the opening definition, confirming that personhood encompasses more than the corporeal body.

## **Ethics**

Joseph F. Fletcher, the first professor of ethics at the University of Virginia and one of the signers of the *Humanist Manifesto*, provides one of the first definitions of humanhood, published in 1972. The list includes thirteen criteria to support Fletcher's definition of uniquely human characteristics, ranging from "minimal intelligence," "self-awareness, "a sense of time" (the past and the future), and "balancing rationality and feeling."<sup>180</sup> This extensive list represents Fletcher's notion of what makes humans unique and addresses the complexity of the human being and notes the characteristics that are present beyond the physiological being. Fletcher expresses the understanding that humanhood (or personhood) requires reflection, planning, moral choices, and interaction with others. Two years following the publication of his detailed list, Fletcher reconsiders and narrows it to four: self-consciousness; human relationships; cerebral function; and neocortical function.<sup>181</sup> With both lists, Fletcher considers neocortical function to be most important, since it is foundational for the other characteristics, as well as being the only one that can be identified medically.<sup>182</sup> Fletcher thus blends the human's physiological, psychological, and social functions to identify those that can be considered unique. In defining these characteristics, Fletcher expresses the hope that these qualities will prove to be useful for

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<sup>180</sup> Joseph F. Fletcher, "Indicators of Humanhood: A Tentative Profile of Man," *Hastings Center Report* 2, no. 5 (November 1972): 1-3.

<sup>181</sup> Joseph F. Fletcher, "Four Indicators of Humanhood: The Enquiry Matures," *Hastings Center Report* 4, no. 6 (December 1974): 4-6.

<sup>182</sup> *Ibid.*, 6-7.

ethicists in defining principles involved in humanhood (and personhood).<sup>183</sup> Fletcher's definition provides an existential foundation from which others, including this writer, consider the meaning of personhood. Fletcher sets the stage for considering the ways in which personhood is experienced at the individual level.

## **Medicine**

In 1982, emeritus professor of public health at Weill Medical College of Cornell University and physician Eric Cassell postulates that the individual is not an isolated entity—he or she exists as a person with relationships and lives with others in community. He has considered the meaning of personhood in conjunction with efforts to encourage medicine to improve its efforts to serve people, communicate more effectively with persons receiving treatment, and to address and alleviate suffering. In this endeavor, Cassell wants to abandon mind/body dualism, believing that it has influenced medical care by making person synonymous with mind, placing it off-limits to science.<sup>184</sup> For Cassell, the person's relational existence includes the following:<sup>185</sup>

- Personality and character: appear in the first few weeks of life. In most cases, these remain until the end of one's life.
- A past: include both remembered and unconscious life experiences that are aggregated in the body as well as the mind.
- Life experiences: include medical situations, some of which may have ended, and some of which are continuing.

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<sup>183</sup> Ibid., 7.

<sup>184</sup> Eric J. Cassell, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306, no. 11 (March 18, 1982): 640.

<sup>185</sup> Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine, Second Edition* (New York: Oxford University Press, 2004), 642-643.

- Family: the source of the individual, providing a variety of influences, including hereditary diseases.
- A cultural background: definition of how one understands their own characteristics (such as what it means to be masculine or feminine) as well as affect one's view of what it means to be sick or well.
- Roles in relation with others: includes rules that guide the performance of one's actions.
- Relationship with others: guides working consciously or unconsciously in the way one acts.
- Political being, with rights and responsibilities: may be eliminated by illness, causing one to have a feeling of powerlessness or exclusion.
- Agency: supports how persons act.
- Regular behaviors: include assumptions about what one will do.
- Connections to the body: are altered when the organism dies.
- A secret life: includes one's hopes, fears, and past actions.
- Perceived future: provides expectations for activities that will occur.
- A life of the spirit (transcendent dimension): may be expressed in a religious life or in bonding with a particular group.

Cassell does not address consciousness or cerebral function in the list of qualities. Rather, he focuses on the nature of persons in order to establish a stronger framework in which the physician and other health-care practitioners can serve the patient. Cassell believes that recognizing the total person, including the history, relationships, and personality, is foundational in understanding the patient's perspectives in dealing with illness, and these are of import to health-care providers in trying to heal.

Cassell emphasizes the narrative and relational selves as the means of defining personhood. His descriptors provide detailed elements of the narrative and relational selves that comprise the person. From Cassell's perspective, these are fundamental considerations when addressing the person with an illness. The underlying assumption is that the person is conscious of his or her environment, and appreciating personhood provides a means for understanding the illness journey and providing care. Cassell is on the right track in identifying the multitude of characteristics that affect our being. When I ask groups to define a person in a brainstorming session, they frequently identify many of the same qualities, serving as confirmation of the significance. The major shortfall is Cassell's lack of consideration for consciousness, which is foundational—it is impossible to have agency or a sense of connectedness to one's body if one lacks consciousness.

## History

In the previous chapter, I described philosopher Charles Taylor's perspectives on persons as part of the community, a compendium resulting not just from individual identity but from the preceding members of humanity. We are not selves simply by having human bodies, but by our orientation to the good. It is in looking to our place in history that we see our own story and are able to frame a narrative self that describes one's ability to chronicle events. Taylor also provides detailed characteristics for a person, and this definition is important to understanding our civilization and has the following elements:<sup>186</sup>

- Consciousness: necessary for any of the other characteristics.

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<sup>186</sup> Charles Taylor, "The Person," in *The Category of the Person: Anthropology, Philosophy, History*, ed. Michael Carrithers, Steven Collins, and Steven Lukes (Cambridge, UK: Cambridge University Press, 1985), 258-275.

- Agency: the organism has a sense of purpose, including the ability to set and attain goals that have a sense of significance, thus making life plans, holding values, and making choices.
- Reflexivity: the individual can be self-aware and understand the choices that he or she is making.
- Holding values: one not only values goods, but understands the goals they should seek that will contribute to the life plans being made.
- Language: the ability to have awareness of the standards being held and articulate them in a public space.

By understanding these characteristics, individuals can recognize “goods which are seen to be intrinsically worthy, that is, goods or ends which are not valued insofar as they are objects of choice or desire, but are rather seen as ends we should seek.”<sup>187</sup> For Taylor, understanding personhood is a part of the task of establishing our formation as members of the larger community, and he values the contributions of various theologians and philosophers, especially humanists. The person’s individual qualities contribute to the formation of the community, and he or she must be conscious in order to do so. The narrative self has values and sets goals that are articulated in private and public spaces to describe a person’s history as well as identify a hoped-for future. Thus, personhood consists of a mix of qualities that are physiological, personal, and communal, which are, in turn, influenced by the course of history and ideas and ideals that have been articulated. In having an orientation to the good, a person can meet the expectations held by their family and by members of the community at large, but without

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<sup>187</sup> Ibid., 266.

consciousness, agency, reflexivity, values, and language, it is difficult to have a framework for defining personhood.

### **Theology**

Providing a single theological perspective of personhood is challenging. Every religion defines personhood differently, although there may be common elements. For the United States and Western Europe, the dominant influence is the Judeo-Christian tradition, whose creation story fashions humans last but grants them unique characteristics. From a moral perspective for these traditions, persons are distinguished from other beings—God talks to them, and they are able to make choices. Without a single definition of personhood, it is only possible to provide examples of viewpoints from these traditions.

Conservative Rabbi and Jewish Theology Professor (American Jewish University) Elliot Dorff presents the Jewish tradition that man is an integrated whole composed of physical elements and intelligence, emotions, intellect, and spirituality. Physical life and consciousness are breathed into human bodies by God, and the soul (*nefesh*) is separate, although rabbinic scholars disagree on whether the soul can exist apart from the body.<sup>188</sup> Regardless of this disagreement, it is understood that the person is a complex entity that is more than a corporeal body. It is in relating to each other that community is achieved and the person is fully formed in God's image.

The Roman Catholic position on personhood is far more complex, with positions shifting over the centuries, although grounded in thoughts expressed by St. Thomas Aquinas. Former professor of moral theology at the Catholic University of Leuven, Louvain (Belgium) Louis

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<sup>188</sup> Elliot N. Dorff, *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics* (Philadelphia, PA: Jewish Publication Society, 2003), 21-22.

Janssens uses the final Vatican II pastoral constitution, *Gaudium et Spes* (GS) to summarize the salient characteristics of a person, noting that “we can only speak of morality insofar as man is a moral subject, one who is competent to act knowingly and willfully and as such is the principle of his acts or in control of his conduct.”<sup>189</sup>

- The human person is a subject, not an object, called to be conscious and act in conscience in freedom, and in a responsible manner.<sup>190</sup> In GS, Pope Paul VI relates this back to natural law, indicating that “in the depths of his conscience, man detects a law which he does not impose upon himself, but which holds him to obedience,” with the reason for human dignity based “in man’s call to communion with God.”<sup>191</sup>
- The person is corporeal, charged to take care of our health and bodily integrity, as well as that of others.<sup>192</sup> GS notes that despite man’s constitution of body and soul, he is one, with the requirement that “man is not allowed to despise his bodily life, rather he is obliged to regard his body as good and honorable since God has created it and will raise it up on the last day.”<sup>193</sup>
- Our body is not only who we are, but a part of the material world—our being is being-in-the-world.<sup>194</sup> Here, Janssens refers to paragraphs 33-39 and 53-62 of *Gaudium et Spes*. Man’s culture is the way in which full humanity is realized, and includes “whereby man

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<sup>189</sup> Louis Janssens, "Artificial Insemination: Ethical Considerations," *Louvain Studies* 8 (1980-1981): 5.

<sup>190</sup> Ibid.

<sup>191</sup> Pope Paul VI, *Gaudium Et Spes: Pastoral Constitution on the Church in the Modern World* (December 7), (Vatican City: The Holy See, 1965), [http://www.vatican.va/archive/hist\\_councils/ii\\_vatican\\_council/documents/vat-ii\\_const\\_19651207\\_gaudium-et-spes\\_en.html](http://www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_const_19651207_gaudium-et-spes_en.html) (accessed June 2, 2016), Para. 16 and 17.

<sup>192</sup> Janssens, "Artificial Insemination: Ethical Considerations," 5-6.

<sup>193</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14.

<sup>194</sup> Janssens, "Artificial Insemination: Ethical Considerations," 6-7.

develops and perfects his many bodily and spiritual qualities; he strives by his knowledge and his labor, to bring the world itself under his control.”<sup>195</sup>

- Human persons are directed towards each other, and live fully only through contact with those who have already become.<sup>196</sup> *GS* places this within the Genesis story of humans created male and female for the purposes of companionship. “Their companionship produces the primary form of interpersonal communion. For by his innermost nature man is a social being, and unless he relates himself to others he can neither live nor develop his potential.”<sup>197</sup>
- Human beings are not only in relationship, but also need to live in social groups.<sup>198</sup> The opening statement to the *GS* chapter on “The Community of Mankind” notes that “one of the salient features of the modern world is the growing interdependence of men one on the other, a development promoted chiefly by modern technical advances. Nevertheless brotherly dialogue among men does not reach its perfection on the level of technical progress, but on the deeper level of interpersonal relationships. These demand a mutual respect for the full spiritual dignity of the person.”<sup>199</sup>
- Created in the image of God, the human person is called to know and worship Him and to glorify Him.<sup>200</sup> A person’s created status presents obligations, to “justly consider that by their labor they are unfolding the Creator's work, consulting the advantages of their

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<sup>195</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

<sup>196</sup> Janssens, "Artificial Insemination: Ethical Considerations," 8-9.

<sup>197</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

<sup>198</sup> Janssens, "Artificial Insemination: Ethical Considerations," 9.

<sup>199</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

<sup>200</sup> Janssens, "Artificial Insemination: Ethical Considerations," 9.

brother men, and are contributing by their personal industry to the realization in history of the divine plan.”<sup>201</sup>

- The human person is a historical being, with each stage characterized by special possibilities. An ethics of responsibility on a personalist foundation must necessarily be a dynamic ethic.<sup>202</sup> *GS* makes the requirement for continued communion with God clear, “for without the Creator the creature would disappear. For their part, however, all believers of whatever religion always hear His revealing voice in the discourse of creatures. When God is forgotten, however, the creature itself grows unintelligible.”<sup>203</sup>
- All human persons are fundamentally equal, but each is an original being.<sup>204</sup> *GS* acknowledges that “all men are not alike from the point of view of varying physical power and the diversity of intellectual and moral resources. Nevertheless, with respect to the fundamental rights of the person, every type of discrimination, whether social or cultural, whether based on sex, race, color, social condition, language or religion, is to be overcome and eradicated as contrary to God's intent.”<sup>205</sup> Each person’s uniqueness provides different gifts; at the same time, the society is required to treat each person with respect, regardless of their station.

In *GS*, the specter of the *transcendent self* from the Middle Ages is present. Humans exist to serve God at the same time that the temporality and relationality of the human organism is recognized. Humans do not exist as sole beings. The body is the temple through which personhood is realized, but is fully lived out in the faith community. Consequently, humans have

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<sup>201</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

<sup>202</sup> Janssens, "Artificial Insemination: Ethical Considerations," 10-11.

<sup>203</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

<sup>204</sup> Janssens, "Artificial Insemination: Ethical Considerations," 12.

<sup>205</sup> Pope Paul VI, *Gaudium Et Spes*, Para. 14

a mutual responsibility to care for creation. By tending to each other, persons realize the Creator's intentions.

A decade after Janssens' article, Joseph Cardinal Ratzinger (later Pope Benedict XVI) uses the same essential argument to claim that humans are in dialogue and relational. In fact, he specifies that "the person exists only as relation."<sup>206</sup> Post-Vatican positions present the person as a complex character who exists in community. Relationality and community are noted as the critical characteristics that need to be present. Over the past thirty years, the Church has shifted the emphasis on relationality in its pronouncements on the treatment of persons in a vegetative state, characterizing artificial nutrition and hydration as *ordinary care* that must be maintained.<sup>207</sup> This dictum has the effect of emphasizing the person's corporeal nature, and not that of being a complex creature with a personal narrative and relationality in community. While the debate continues, the pronouncements from Vatican II continue to provide foundational support on the theological nature of personhood for the Roman Catholic community.

The Protestant Christian traditions provide a broad range of understanding, with no single position adopted within the various denominations. Asbury Theological Seminary Professor James Thobaben provides the Evangelical Christian's definition that the body, soul, and spirit are a unity comprising the individual, and that entire entity is a moral concern for believers. Categories of mind, body, soul, and spirit are not to be understood in a rigid, exclusive manner; the ultimate concern is relationship, not philosophical constructs.<sup>208</sup> Human functioning requires moral recognition of self and others that is simultaneously natural, socially shaped, and a matter

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<sup>206</sup> Joseph Cardinal Ratzinger, "Concerning the Notion of Person in Theology," *Communio* 17 (Fall 1990): 443-444.

<sup>207</sup> Thomas A. Shannon and James J. Walter, "Assisted Nutrition and Hydration and the Catholic Tradition," *Theological Studies* 66, no. 3 (2005): 655.

<sup>208</sup> James R. Thobaben, *Health Care Ethics: A Comprehensive Christian Resource* (Downers Grove, IL: IVP Academic, 2009), 94.

of choice.<sup>209</sup> While consciousness is specified as a prerequisite for personhood, to meet the condition of being in relationship and requiring recognition of others would seem to make the definition inherent. However, the response to the Terry Schiavo case in Florida indicates otherwise: her parents rejected the permanent vegetative state diagnosis, believing that she responded to their stimulation so that she had full personhood. Schiavo's parents enlisted the support of Christian conservatives in advocating for this position.<sup>210</sup> For evangelical and conservative Christians, consciousness does not provide the same level of importance as other segments, which has implications for broader health-care policy to be discussed later in this chapter.

Lutheran Theologian and Loma Linda University professor of ethical studies James W. Walters (1997) articulates a position for personhood that sets more specific parameters. Walters considers personhood to be a particularly important construct in today's technological society because the capacity to extend life needs parameters in order to avoid abuse. Walters' fundamental thesis is "that the more nearly an individual human or animal approximates a life of self-consciousness (such as yours or mine), the greater the claim of that individual to maximum moral status."<sup>211</sup> Walters considers physicalist and personalist perspectives, concluding that "a developing individual's right to life increases as he or she approaches the threshold of indisputably personal life, the life of the normal adult in any society. That is, the more a fetus, a newborn, or an infant approximates—or is proximate—personhood, the greater his or her moral

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<sup>209</sup> Ibid., 116.

<sup>210</sup> Bonnie Steinbock, *Life before Birth: The Moral and Legal Status of Embryos and Fetuses*, Second Edition Kindle ed. (New York: Oxford University Press, 2011), 22.

<sup>211</sup> James W. Walters, *What Is a Person? An Ethical Exploration* (Chicago: University of Illinois Press, 1997), 4.

value and hence the greater the implicit claim to life.”<sup>212</sup> Termed *proximate personhood*, three elements are considered critical: the potential for a full cognitive life; limited physical development; and social bonding.<sup>213</sup> Thus, Walters not only considers existing qualities, but also the capacity for achieving them. His specific area of interest is the ethics of developing personhood. A fully-formed baby has proximate personhood, but one born with anencephaly does not. Walters believes that this builds on the views of personhood supported by mainstream thinking. This definition approximates the one that I use, although I question whether the term *proximate* is necessary as part of the definition. I believe that personhood includes the implicit assumption that the characteristics are either present or will be in the foreseeable future.

Despite the variety of pronouncements, in the Judeo-Christian traditions, the person is acknowledged as a complex creature whose uniqueness extends beyond their corporeal existence. Humans have a valued role in their place in creation, and it is the ability to interact with others and make moral decisions that gives humans a unique perspective.

### **Twenty-First Century Ethicist**

In reaching his definition of person as “having the capacity for consciousness and other forms of mentality,” Glannon considers a modified definition of personhood developed by V. S. Ramachandran, Professor and Director of the Center for Brain and Cognition at the University of California San Diego. In the 2003 Reith Lectures broadcast by the British Broadcasting Company, Ramachandran identified four qualities characterizing the self:<sup>214</sup>

- Continuity: a sense of time, a sense of past, and a sense of the future.

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<sup>212</sup> Ibid., 63.

<sup>213</sup> Ibid., 72.

<sup>214</sup> V. S. Ramachandran, *Lecture 5: Neuroscience - the New Philosophy*, The Reith Lectures - 2003 (London, UK: BBC Radio, 2003), <http://www.bbc.co.uk/radio4/reith2003/lectures.shtml> (accessed June 2, 2016).

- Unity or coherence of self: despite a diversity of sensory experiences, a person experiences him or herself as one person.
- Embodiment: one is anchored to one's body.
- Agency (free will): a sense of being in charge of one's personal behavior and destiny.

To these four characteristics, Glannon adds a fifth: the ability to perceive and respond appropriately to the external world.<sup>215</sup> Glannon integrates the neuronal activities of the brain with the psychological characteristics that constitute a person. For Glannon, personhood is integral with being conscious and able to interact with one's environment. With the integrated view, the person is not separated psychologically and physiologically, the human is one integrated organism where all characteristics work together and are present to qualify the individual as possessing personhood. In this regard, Glannon goes beyond the definition provided in his earlier work, providing an enhanced understanding of the complexities of personhood. Glannon's position on the importance of consciousness will be explored further in this chapter.

While other characteristics for personhood, selfhood, and humanhood exist, these five perspectives provide an understanding of the intricacies that exist in trying to define personhood in the contemporary context. It is noteworthy that most perspectives include some form of cognition with the definition of the person, acknowledging the role of consciousness in supporting personhood and noting its importance. Consciousness presents considerable complexities in its own regard. Consequently, the following section will consider the characteristics of consciousness for the person.

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<sup>215</sup> Glannon, *Bioethics and the Brain*, 33. Since these original lectures, Ramachandran has added privacy, social embedding, and self-awareness to the list of personhood characteristics. V. S. Ramachandran, *The Tell-Tale Brain: A Neuroscientist's Quest for What Makes Us Human* (New York: W. W. Norton, 2011).

## Consciousness: Essential to Personhood

Consciousness is a critical element of personhood, to the degree that the permanent loss of consciousness will result in the loss of personhood. Many of the questions regarding consciousness and the mind have roots in the Renaissance, with its emphasis on expanded understanding of the human organism, as well as blossoming scientific inquiry. University of Toronto philosophy professor William Seager identifies the birth of the modern problem of consciousness with seventeenth-century French philosopher and mathematician René Descartes.<sup>216</sup> The relationship between the mind and the body challenged him and while believing the two to be separate, Descartes distinguished the importance of the mind for the existence of an individual. In Meditation 2 of the *Meditations on First Philosophy in Which the Existence of God and the Distinction of the Soul from the Body Are Demonstrated* (hereafter *Meditations*), written in 1637, Descartes establishes the link between thinking and existing:

For as long as I am thinking; for perhaps it could also come to pass that if I were to cease all thinking I would then utterly cease to exist. At this time I admit nothing that is not necessarily true. I am therefore precisely nothing but a thinking thing; that is, a mind, or intellect, or understanding, or reason—words of whose meanings I was previously ignorant. Yet I am a true thing and am truly existing; but what kind of thing? I have said it already: a thinking thing.<sup>217</sup>

That thinking thing is also “a thing that doubts, understands, denies, wills, refuses, and that also imagines and senses.”<sup>218</sup> Descartes believes the mind supports human characteristics, and part of his struggle in understanding is identifying the ways in which the body and mind are related. For Descartes, being a thinking thing is the essence of the human condition.

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<sup>216</sup> William Seager, *Theories of Consciousness: An Introduction and Assessment* (New York: Routledge, 2001), 1.

<sup>217</sup> René Descartes, *Meditations on First Philosophy in Which the Existence of God and the Distinction of the Soul from the Body Are Demonstrated*, 3rd ed., trans. Donald A. Cress (Indianapolis, IN: Hackett Publishing, 1993), 19.

<sup>218</sup> *Ibid.*, 20.

Nearly a decade later, in his *Principles of Philosophy*, Descartes relates the physical acts of seeing and walking to being conscious of performing those acts. The highest form of things is comprised of those related to the intellect:

I do not, however, recognise more than two highest kinds (summa genera) of things; the first of intellectual things, or such as have the power of thinking, including mind or thinking substance and its properties; the second, of material things, embracing extended substance, or body and its properties. Perception, volition, and all modes as well of knowing as of willing, are related to thinking substance; on the other hand, to extended substance we refer magnitude, or extension in length, breadth, and depth, figure, motion, situation, divisibility of parts themselves, and the like.<sup>219</sup>

According to Descartes, it is the mind that rules the body. At that point in history, the understanding of neuroscience and the effect that the body has on the ability of the mind to work is not known. The knowledge of brain formation and operation evolves over the years, yet in a very fundamental way, Descartes understands the importance of the mind for the functioning human being. His body/mind dualism creates a position that will be discussed and debated by successive philosophers and theologians. Nevertheless, Descartes provides a starting place for considering the mind and its relationship to the function of the body and the individual.

In subsequent years, philosophers and scientists consider the the importance of the function of the brain, mind, and/or consciousness as qualities for the person. Glannon relates the brain and the person closely, noting that “it is not the brain but the person constituted by the brain, body, and mind that acts and interacts with others in the world.”<sup>220</sup> People have relationships and act in the world, not their brains. He redefines the mind-body problem as comprising “questions of how consciousness can arise from the brain, and how mental events

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<sup>219</sup> René Descartes, *Selections from the Principles of Philosophy*, trans. John Veitch (A Public Domain Book, 1646), 59.

<sup>220</sup> Glannon, *Bioethics and the Brain*, 13.

can causally interact with physical events in the brain.”<sup>221</sup> The contemporary understanding for consciousness expands as the general understanding for the workings of the brain and the mind increases.

Contemporary Western views of consciousness are varied and complex, with no single approach having wide-range acceptance. In this section, I will describe key forms of consciousness, as well as characterize consciousness based on different experts’ approaches.

### **Forms of Consciousness**

Levels of consciousness provide a description of the organism’s functional capabilities. Antonio Damasio has categorized forms of consciousness that serve as the basis for understanding the level of damage if the person becomes impaired. The most elementary form is identified as *core consciousness*, occurring “when the brain’s representation devices generate and imaged, nonverbal account of how the organism’s own state is affected by its processing of an object, and when this process enhances the image of the causative object, thus placing it saliently in a spatial and temporal context.”<sup>222</sup> In core consciousness, the individual has “a sense of self about one moment—now—and about one place—here.”<sup>223</sup> It is a prerequisite for working memory and necessary for language, and allows the manipulation of images. Core consciousness requires that an organism be able to relate to an object (person or thing). If impaired, the person will not be able to reveal their emotions. It can be impaired temporarily during anesthesia, coma, and slow-wave sleep. When returning to consciousness, the person will

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<sup>221</sup> Ibid., 8.

<sup>222</sup> Antonio Damasio, *The Feeling of What Happens: Body and Emotion in the Making of Consciousness* (New York: Harvest Book, Harcourt, 1999), 169.

<sup>223</sup> Ibid., 17.

likely be able to recall being unconscious but will not recall anything during the period of impairment. Core consciousness can be diminished for an extended period of time or permanently in the vegetative state, which results from damage to various parts of the brain.<sup>224</sup> Core consciousness is the most basic level—if the person is not in any form of coma, it is present. Thus, a person with late-stage dementia of the Alzheimer’s type will likely have core consciousness, while a person who is in a permanent vegetative state will not.

*Extended consciousness* (of the core) requires normal background and primary emotions, and is flanked by the past as well as anticipated future.<sup>225</sup> The person has a working and long-term memory, allowing for information and autobiographical memories to be held for an extended period of time.<sup>226</sup> As an example, Alzheimer’s patients’ extended consciousness is likely to be completely absent although the core consciousness is still intact. In the final stages of the disease, the person is awake but has limited memory for events and names. One of my stepmother’s limited pleasures in her final months was going for car rides, but she would go and then forget that she had been, and would ask, “When are we going for a ride?”

Damasio believes that core and extended consciousness are integral to the autobiographical self:

The autobiographical self hinges on the consistent reactivation and display of selected sets of autobiographical memories. In core consciousness, the sense of self arises in the subtle, fleeting feeling of knowing, constructed anew in each pulse. Instead, in extended consciousness, the sense of self arises in the consistent, reiterated display of some of our own personal memories, *the objects of our*

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<sup>224</sup> Antonio Damasio and Kaspar Meyer, "Consciousness: An Overview of the Phenomenon and of Its Possible Neural Basis," in *The Neurology of Consciousness: Cognitive Neuroscience and Neuropathology*, ed. Steven Laureys and Giulio Tononi (Amsterdam: Academic Press 2009), 6-11.

<sup>225</sup> Damasio, *The Feeling of What Happens*, 195.

<sup>226</sup> Ibid., 6-11.

*personal past*, those that can easily substantiate our identity, moment by moment, and are personhood.<sup>227</sup>

Consciousness gives rise to the ability to construct memories as well as recall them in their application to one's life. This ability is an integral part of personhood; articulating identity allows one to have a self and relate to others. The hopes and dreams identified by Cassell as being critical for understanding patients' suffering become real in consciousness. A person with dementia may no longer have an anticipated future and a limited recollection of the past. However, in many cases, people who provide care are still recognized as helpers, even though individual names may not be remembered. Those who have a permanent loss of consciousness have none of these qualities.

Consciousness supports the person's feelings and interaction with surroundings. Damasio notes that core consciousness is associated more with the physical body than the environment, while extended consciousness results more from the environment.<sup>228</sup> Extended consciousness can be lost while the individual retains core consciousness, while the latter is needed to support the former.<sup>229</sup> Consider the late-stage Alzheimer's patient—core consciousness is still present, but extended consciousness is gone. Many recollections of past history as well as a person's relationships will be compromised with the progression of the disease. These observable phenomena can be used to characterize the degree of damage. When severe, the person loses core consciousness for a period of time and possibly permanently. The characterization of "brain death" may result from traumatic or anoxic brain injury, which has different gradations that will be discussed later.

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<sup>227</sup> Ibid., 196.

<sup>228</sup> Ibid., 200.

<sup>229</sup> Ibid., 202.

## **Characterization of Consciousness**

The forms of consciousness identified in the previous section describe the states of consciousness. However, consciousness represents more than these definitions—there are effects that are seen, providing the basis for identifying the person’s experiences, either as a personal description in the first-person or as an observed attribute by a third person. Various discussions about consciousness consider the source: behavioral, the list of capabilities a conscious person should have; neuronal, the minimal physiologic mechanisms required for any one conscious sensation; or a combination of the two, considering that consciousness includes both neuronal and behavioral bases. Each of these approaches has proponents, which are discussed in greater detail.

### ***Behavioral***

The behavioral view holds that consciousness is determined by the way the person acts in the environment and how others in that environment observe those actions, thus creating a first-person/third-person viewpoint. This perspective emphasizes interpersonal activities, relegating technological tests such as scans to a lesser status in the schema of determining consciousness. The behavioral view is represented by neuroscientist Damasio and psychologist Kaspar Meyer, both professors at the University of Southern California, who combine their expertise to provide a working definition of consciousness as “a momentary creation of neural patterns which describe a relation between the organism, on the one hand, and an object or event, on the other.”<sup>230</sup> They believe that there are two aspects of consciousness, internal, representing the

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<sup>230</sup> Damasio and Meyer, 9.

first person, subjective; and external, representing third person and behavioral.<sup>231</sup> Damasio and Meyer note that external signs are observable, including “wakefulness, background emotions, sustained attention towards objects and events in the environment, and sustained, adequate, and purposeful behavior relative to those objects and events.”<sup>232</sup> Internal states are those where the “mental state represents objects and events in relation to itself, when the representation of objects and events is accompanied by the sense that the organism is the perceiving agent.”<sup>233</sup> The focus is on characteristics that are either observed by the third party or felt by the person. Damasio and Meyer caution against relying on scans as evidence of consciousness, as it is evident from behaviors that indicate the person self-aware and able to communicate with their surroundings.<sup>234</sup> For the behaviorist, observable behaviors determine whether consciousness is fully present, not a brain scan. Thus, a late-stage dementia patient still provides behavioral signs of consciousness, while the permanently unconscious person does not.<sup>235</sup> As we are learning in the expanding understanding of medicine, however, there are times when the interactions for an individual with their environment may be limited, but some elements of core consciousness are still present. The behavioral perspective fails to consider the possibility of the physiological characteristics that affect the person’s overall consciousness.

### *Neuronal*

The neuronal view concentrates on consciousness’ physiological determinants, focusing on oscillations in the cerebral cortex, with the theory that these actions provide the neurological

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<sup>231</sup> Ibid., 6.

<sup>232</sup> Ibid.

<sup>233</sup> Ibid.

<sup>234</sup> Ibid.

<sup>235</sup> The debate over the qualities of minimally conscious patients is purposely omitted. I am referring to those who have lost permanent consciousness.

bases. Christof Koch, Chief Scientific Officer of the Allen Institute for Brain Science in Seattle, believes the neuronal basis provides the most likely explanation for consciousness. In the early 1990s, Koch worked with Francis Crick on the “neural correlates of consciousness,” which are identified “as the minimal neural mechanisms jointly sufficient for any one specific conscious precept.”<sup>236</sup> The critical component is the reciprocal connection between higher-order regions (cerebral cortex) and the planning and decision making regions (pre-frontal cortex).<sup>237</sup> It is the movement of neurons across the brain regions that give rise to consciousness. Koch and Crick note that one of the scanning mechanisms for brain activity, functional Magnetic Resonance Imaging (fMRI), does not directly measure neuronal activity, but rather changes in the blood supply.<sup>238</sup> Consequently, the movement of neurons cannot be observed and/or measured. However, they consider significant that research comparing electroencephalographs for two brain-injured patients can help identify communication between the prefrontal areas in the brain and in the back cortical regions, contributing to unconsciousness and possible recovery.<sup>239</sup> Thus, Koch and Crick believe that communication across varied regions of the brain is a key to consciousness to be understood by comparison and observation. Continued work in the field has convinced Koch that consciousness depends on a complex system that is greater than its individual components.<sup>240</sup> Despite these areas of progress in understanding, Koch believes the complexities associated with consciousness do not allow all of the specific activities to be understood. Moreover, there are times when scans show activity, yet the person does not have a behavioral basis of consciousness, as indicated by the minimally conscious state, where

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<sup>236</sup> Christof Koch, *Consciousness: Confessions of a Romantic Reductionist* (Cambridge, MA: MIT Press, 2012), 42.

<sup>237</sup> *Ibid.*, 43.

<sup>238</sup> *Ibid.*, 47.

<sup>239</sup> *Ibid.*, 54.

<sup>240</sup> *Ibid.*, 152.

functional magnetic resonance imaging scan that detects changes in blood flow. Issues associated with the lack of ability to pinpoint consciousness with technological means emphasizes the complexity of understanding the nature of consciousness and the ways it exists, as well as the present limitations on using technological means to define its presence or absence.

### ***Integrated Perspective***

While no single perspective has been proven scientifically, consciousness is likely the result of complex interactions between the body and the brain. The body is an intricate combination of systems that work together to permit a variety of activities, including consciousness. John Searle, philosophy professor at the University of California at Berkeley, offers a view of consciousness focusing on neuronal activity, yet integrates elements of the individual's behaviors and being-in-the-world into the definition. Searle notes that "mental phenomena are caused by neurophysiological processes in the brain and are themselves features of the brain,"<sup>241</sup> but most people take these phenomena for granted. It is only when the processes stop working that they come to the forefront for attention. Searle further notes that "the tradition tries to study the mind as if it consisted of neutral phenomena, independent of consciousness and subjectivity."<sup>242</sup> Observable characteristics become the backbone of consciousness, and Searle includes twelve structural features of consciousness in the description:<sup>243</sup>

- Limited modalities include the five senses, bodily sensations, and the stream of thought.
- Horizontal and vertical unity allows us to make sense of experiences.
- Consciousness is intentional, and conscious experiences are perspectival.

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<sup>241</sup> John R. Searle, *The Rediscovery of the Mind* (Cambridge, MA: MIT Press, 1994), 1.

<sup>242</sup> Ibid., 19.

<sup>243</sup> Ibid., 128-141.

- Subjectivity is responsible for the philosophical puzzlement of consciousness.
- Intentional states are necessary to consciousness.
- Perceptions are organized into objects and features of objects.
- Consciousness involves categorization.
- Conscious states extend beyond content.
- The organism must distinguish between different levels of attention within conscious states.
- The mood provides tone for characterizing conscious states.
- There is a pleasure/unpleasure dimension.

These are all characteristics that affect a person's being-in-the-world. The ability for an individual to act intentionally changes the human from an automaton to being unique and having emotions. When these characteristics cease, the person's status changes measurably. Returning to the dementia patient example, mid to late-stage Alzheimer's patients have lost many of Searle's structural features, but retain core consciousness, while one in a permanent vegetative state does not. One of the challenges presents from articulating and defining the degree of each of the features and providing objective characterizations.

Glannon believes that consciousness emanates both within the brain and as the result of bodily influences on the brain. Physiologically, Glannon understands:

Consciousness appears to depend on distributed neural components acting in a functionally integrated way. Interactions of the neocortex, the most recently evolved region of the brain, with the thalamus and the upper midbrain appear to play a central role in these mechanisms. But it is still not known precisely how conscious awareness arises from these mechanisms.<sup>244</sup>

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<sup>244</sup> Glannon, *Bioethics and the Brain*, 8.

Although the physiological basis of consciousness is not completely understood, Glannon believes that the mind and brain do not function as independent substances, instead representing higher and lower level aspects of the human organism, cooperating for survival.<sup>245</sup> Glannon holds that the mind's biological basis is more than just a matter of neurobiology: the endocrine and immune systems are involved as well.<sup>246</sup> Glannon provides four reasons supporting the claim that the biological status of our mental states involves more than just our brains:<sup>247</sup>

- Chronic hypersecretion of cortisol from the adrenal cortex may lead to degeneration of neurons in the hippocampus, a region of the brain playing a role in various forms of memory, particularly of experienced events.
- Infectious agents such as viruses and psychological stress can activate the immune system and cause it to release cytokines, messengers for the immune system that respond to stimulation.
- The autoimmune system may play a role in psychiatric disorders by releasing autoantibodies in response to an infection, affecting messenger cells between nerve cells in the brain.
- Adrenaline, an adaptive mechanism, can affect unconscious emotional memory.

With these influences, consciousness is not reducible to a particular part of the brain; instead, several physiological matters influence mental states, a complex phenomenon affected by multiple parts of the body, including the brain. In turn, these states are unique for each individual, resulting in different responses to the same stimuli provided by the environment. Ultimately, Glannon contends that “Who we are as persons is determined by the nature and

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<sup>245</sup> Ibid., 24-25.

<sup>246</sup> Ibid., 13.

<sup>247</sup> Ibid., 29-31.

content of our mental states.”<sup>248</sup> Just as the human body consists of complex interaction of the organ systems, the nature of consciousness is affected by physiological and behavioral elements. Late stage Alzheimer’s patients lose the desire for eating, which can affect other organs. Artificial nutrition and hydration are an option for providing essential nutrients, but other issues arise, such as the patient’s inability to accept the external device and tendency to play with it, causing infections. On the other hand, an individual in a permanent vegetative state requires a feeding tube but does not interact with the device since conscious is not present and there is no response to external stimuli.

Whether consciousness is behavioral, neural, or both, continues to be discussed in the literature. I believe that consciousness includes both behavioral and physiological features. Consciousness has first- and third-person elements, which can be gleaned when we observe stimuli or people or they observe us. The ability to respond to an event or person requires the presence of consciousness. Concurrently, there must be a neurological basis, or consciousness would not be tied to mental processes. Consciousness is thus integral to personhood, and the two cannot be separated. Without consciousness, there cannot be a person, and without the person, consciousness has no meaning.

We know that severe brain damage alters the human organism so that most, if not all, of various brain features are eliminated. When extreme, portions of the brain may cease to function permanently, resulting in the need for external supports for breathing and other bodily functions. Multiple factors can cause this type of event, including traumatic or anoxic injuries to the brain. When an insult occurs to the brain, the organism’s operations change dramatically, requiring external support for respiration and circulatory function. Moreover, the human organism’s

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<sup>248</sup> Ibid., 29.

capacity for having a narrative self or relating with others is compromised or eliminated when consciousness is compromised.

Before continuing with the different aspects of the loss of consciousness, some additional attention is warranted of the role of the narrative self and relationality, as this is the source of stories about the past and anticipated future.

### **The Narrative Self and Relationality**

Stories are the crux of personhood, defining who we are, including where we have been, how we arrived, and where we are going. Stories present a person's history, starting with the earliest hieroglyphics that describe life without using words. Former Duke University professor of English Reynolds Price notes that the words *story* and *narrative* come from Proto-Indo-European roots for *weid* and *gno*, seeing and knowing, making narrative "an account of something known, especially by the narrator but partially by his audience."<sup>249</sup> Price rates the need for stories to be second only to that for nourishment, and ahead of love and shelter.<sup>250</sup> In story-telling, the person begins to define who they are, including their aspirations, hopes, and dreams. Stories also provide a key means for people to relate with each other. A simple greeting of "how are you doing" presents the opportunity for expressing one's present state as well as updating friends and family on the intricacies of life.

Narrative does more than articulate an individual's personhood. It provides the background for how we come to be who we think we are as well as being a tool for shaping who we want to become. Moral truths are presented and considered through schools, news channels,

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<sup>249</sup> Reynolds Price, *A Palpable God* (San Francisco: North Point Press, 1985), 14-15.

<sup>250</sup> *Ibid.*, 3.

and online. By virtue of consciousness, persons are able to relate to each other towards individual and communal ends.

Language plays a major role in the way that human beings express personhood in relating to the environment and being able to articulate stories. All language has a physiological basis supporting that personhood. Professor Adam Zeman of the University of Exeter observes that consciousness is shaped by language, believing that “key to the understanding of self-consciousness, its nature and possibility, lies not in neural self-scanning mechanisms in the brain, but in *the normal human mastery of language*.”<sup>251</sup> As noted earlier, one’s personhood requires consciousness, a complex physical state that evolves through an individual’s lifetime and is enhanced by language. Language provides the basis for narrative (Price calls it a “vehicle” rather than a “destination”),<sup>252</sup> both for the person and for the community that is shaping them.

Medicine has its own language, which provides the means of identifying an individual’s health condition. When a person enters the medical world, he or she will be asked to describe their medical history and present symptoms, which become the basis for identifying what might be happening and how the condition can be treated medically. Sometimes words are not available, creating additional difficulties. The man described in A. R. Luria’s book *The Man with a Shattered World* wishes for the words to be able to describe what is happening:

Perhaps, I thought, if I describe my illness in more detail and give them a record of what’s happened, the doctors will understand me. And once they understand me and my illness, they’ll certainly be able to cure it. After all, when I was in the hospital I wasn’t really able to remember and tell them what bothered me, so

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<sup>251</sup> Adam Zeman, *Consciousness: A User's Guide* (New Haven, CT: Yale University Press, 2002), 351.

<sup>252</sup> Price, *A Palpable God*, 6.

perhaps they still don't realize I'm suffering, since I can't give them any of the details.<sup>253</sup>

Words are important, but even conditions that are not understood have a descriptor—in medicine, diseases whose origins are not understood are defined as having an *unknown etiology*.

The narrative self and relationality are made possible through consciousness. Damasio identifies consciousness as providing the means for experiencing the autobiographical self and relate to the environment in unique ways.<sup>254</sup> The contributions to personhood come from two sources: traits that are present at birth and enhanced through experience, and interactions with the environment that become recorded in memory.<sup>255</sup> Without consciousness, none of these interactions and remembrances is possible. As previously noted, with brain decline, dementia patients may not experience loss of core consciousness, but lose the ability to relate a personal narrative, while modest relationship with the environment is still possible. With a permanent loss of consciousness, which can be caused by functional cessation or all or part of the brain, verbal language is lost to the individual as well as the ability to relate in any way with the environment. The next section will explore various forms of brain death, and discuss the impact on personhood.

## **Elements of Brain Death**

While much remains to be understood about causation, the absence of consciousness is known to result from a number of problems within the brain. At its most extreme, the cessation of any or all areas of the brain, commonly termed as brain death, causes consciousness to cease

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<sup>253</sup> A. R. Luria, *The Man with a Shattered World*, trans. Lynn Solotaroff (Cambridge, MA: Harvard University Press, 1987), 86.

<sup>254</sup> Damasio, *The Feeling of What Happens*, 198.

<sup>255</sup> *Ibid.*, 222.

for the person. Various definitions of brain death have been identified in U.S. medicine.

Philosophers, ethicists, sociologists, physicians, and others have contributed to the terminology, meanings, and effective parameters for considering brain death, continuing to discuss and debate these definitions. Among these, three characterizations of brain death are most often deliberated: *whole brain*, *brain stem*, and *higher brain (neocortical)*. These terms refer to lost capacities when all or part of the brain ceases to function, reflecting the following:

- Brain stem (mid-brain, pons, and medulla): “initiates and controls breathing, regulates circulation, and serves as the generator of conscious awareness through the ascending reticular activating system.”<sup>256</sup>
- Diencephalon (thalamus and hypothalamus): “provides the center for bodily homeostasis, regulating numerous neuroendocrine control systems, including body temperature, salt and water regulation, feeding behavior, and memory.”<sup>257</sup>
- Cerebral hemispheres (higher brain): supports awareness and “the conditions for all conscious behavior for assuring the health and survival of the organism.”<sup>258</sup>

The three characterizations of brain death will generally cause cessation of consciousness and form the basis for discussing the state of the body and the ethical treatments to be considered. As a result, it is important to understand the ramifications for the person’s function. For the remainder of this chapter, the following terms will be used: whole brain (total brain failure); brain stem; and higher brain (cerebrum).

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<sup>256</sup> James L. Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," *Journal of Law, Medicine & Ethics* 34, no. 1 (Spring 2006): 38.

<sup>257</sup> Ibid.

<sup>258</sup> Ibid., 38-39.

## Whole Brain Death

Once a person experiences whole brain death, consciousness is lost permanently and irreversibly. U.S. policy has adopted whole brain death as equivalent to bodily death. In all but two states, New Jersey and New York, once diagnosed with whole brain death, a person can be declared dead.<sup>259</sup> Whole brain death includes all functions of the entire brain, including the cerebral hemispheres, diencephalon (thalamus and hypothalamus) and brain stem.<sup>260</sup> The Uniform Definition of Death Act (UDDA) accepts whole brain death and has consensus in its application. The American Academy of Neurology (AAN) stipulates specific criteria as evidence for whole brain death: coma and evidence for its cause (drug ingestion may be considered as a reason to delay declaration of brain death); “lack of all evidence of responsiveness,” “absence of brain stem reflexes,” and “apnea—absence of a breathing drive.”<sup>261</sup> These criteria do not require the loss of all neuronal activities, since they may contribute to recordable brain activities but not clinical functions.<sup>262</sup> The presence of other somatic activities is a critical consideration with some of the critics of whole brain death, most notably Alan Shewmon, which will be discussed later.

Whole brain death is confirmed by various tests: apnea, which establishes the person’s drive to breathe; and brain stem reflexes, which test the persons gag, cough, and eye movement

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<sup>259</sup> New York and New Jersey allow religious objections to be factored into the decision. This has been noteworthy recently, when Jahi McMath was declared brain dead and moved from California to New Jersey over family objections to the declaration of death. See Eun-Kyoung Choi, Valita Fredland, Carla Zachodni, J. Eugene Lammers, Patricia Bledsoe, and Paul R. Helft, "Brain Death Revisited: The Case for a National Standard," *Journal of Law, Medicine & Ethics* (Winter 2008): 824-836; Michael Vitez, "Teen's Case Adds to Brain-Death Debate," *Philadelphia Inquirer* (October 24, 2014). [http://articles.philly.com/2014-10-24/news/55364267\\_1\\_brain-death-christopher-dolan-nailah-winkfield](http://articles.philly.com/2014-10-24/news/55364267_1_brain-death-christopher-dolan-nailah-winkfield) (accessed June 5, 2016).

<sup>260</sup> Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," 38.

<sup>261</sup> American Academy Of Neurology, *Update: Determining Brain Death in Adults* (St. Paul, MIN: AAN Member Services, 2016) <https://www.aan.com/Guidelines/home/GetGuidelineContent/433> (accessed June 29, 2016).

<sup>262</sup> Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," 39.

reflexes under certain conditions; and tests for blood flow to the brain.<sup>263</sup> While the latter tests are not always required, Dartmouth professor of neurology James Bernat believes that they should be established using “transcranial Doppler, ultrasonography, radionuclide angiography, or computed tomographic angiography, and become mandatory if there is any question about the diagnosis or if the examiner is inexperienced.”<sup>264</sup> In most cases, a repeat of the tests at an interval of six to twenty-four hours is recommended, but the time period is considered by some to be arbitrary.<sup>265</sup> The American Academy of Neurology recommends a six-hour interval. In my personal experiences in a hospital setting, I have seen periods extending to forty-eight hours between test periods, depending on the source of the person’s brain injury or family circumstances. When in doubt, it is reasonable to extend the length of time to allow recovery if it is going to occur. As noted above, in whole brain death, consciousness is lost permanently, so personhood also ceases to exist.

### **Brain Stem Death**

When the brain stem ceases to function, respiration, circulation, and the organism’s conscious life will be affected. Some consider brain stem death to be sufficient for the declaration of death.<sup>266</sup> The function is measured by most bedside tests for brain death such as “cranial nerve reflexes and apnea testing.”<sup>267</sup> A difficulty with brain stem death is possible misdiagnosis when consciousness is not apparent but may exist at a very minimal level.<sup>268</sup>

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<sup>263</sup> President's Council on Bioethics, *Controversies in the Determination of Death* (December 2008), (Washington DC: 2008) <https://bioethicsarchive.georgetown.edu/pcbe/reports/death/> (accessed June 2, 2016), 32-34.

<sup>264</sup> Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," 40.

<sup>265</sup> Steven Laureys, "Death, Unconsciousness and the Brain," *Neuroscience* 6, no. 11 (November 2005): 902.

<sup>266</sup> President's Council on Bioethics, *Controversies in the Determination of Death*, 31.

<sup>267</sup> Laureys, "Death, Unconsciousness and the Brain," 900.

<sup>268</sup> Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," 39.

However, in most cases, if the brain stem has stopped working, other, more fragile parts of the brain are likely to be affected as well.<sup>269</sup> The United Kingdom has adopted the standard that the permanent death of the brain stem constitutes death for the human organism, although no other governmental bodies have followed their standard.<sup>270</sup> If the diagnosis has been performed correctly, the failure of the brain stem may likely lead to whole brain death, since so many critical functions are controlled in this region of the brain. With the permanent loss of brain stem functions, the individual will not have consciousness—there will be no interaction with their environment on either a first-person experience or third-person observable basis, thus resulting in the permanent loss of personhood.

### **Higher Brain Death**

Higher (neocortical region) brain death results in the “irreversible loss of capacity for consciousness and social interaction.”<sup>271</sup> This standard for brain death has been the most controversial, primarily because experts have been unable to agree on the constituents of *higher brain functioning*.<sup>272</sup> Higher brain failure most often results in a persistent vegetative state (PVS), not brain death, since the functions of respiration may continue without mechanical ventilation. Complicating the medical presentation, patients in a vegetative state demonstrate a wider variety of motor activities and may also have facial expressions or utter sounds.<sup>273</sup> These

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<sup>269</sup> President's Council on Bioethics, *Controversies in the Determination of Death*, 32.

<sup>270</sup> K. G. Karakatsanis, "Brain Death: Should It Be Reconsidered?," *Spinal Cord* 46, no. 6 (June 2008): 397.

<sup>271</sup> Laureys, "Death, Unconsciousness and the Brain," 900.

<sup>272</sup> Amir Halevy and Baruch Brody, "Brain Death: Reconciling Definitions, Criteria, and Tests," *Annals of Internal Medicine* 119, no. 6 (September 1993): 519.

<sup>273</sup> Laureys, "Death, Unconsciousness and the Brain," 903.

qualities may lead family members to believe that the person has purposeful movements and therefore continues to be alive.

The U.S. Multi-Society Task Force on Persistent Vegetative State has established the following criteria for higher brain death:

(1) No evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic functions to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes and spinal reflexes.<sup>274</sup>

While these characteristics complicate the definition of the person's consciousness, they do not support death characteristics as defined by the irreversible cessation of respiration, heartbeat, or brain activity. While the person remains unconscious and is unable to interact with their environment, basic bodily functions can be maintained, with or without mechanical assistance.

Experts disagree regarding the implications for a person with higher brain death. Steven Laureys, director of the Coma Science Group at the Belgium's Liège University Hospital, believes neocortical death is insufficient for declaring death due to the lack of understanding about neural consciousness and the absence of confirmatory clinical tests.<sup>275</sup> Others have corroborated the uncertainty of supporting neocortical death. Drexel University's Health Law Program Director Barry Furrow notes the slippery slope that is created with higher brain death, since the question of how much neocortical damage is necessary for death is not defined. Some, including Glannon, have equated the loss of higher brain functions and the resulting loss of

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<sup>274</sup> The Multi-Society Task Force on Pvs, "Medical Aspects of the Persistent Vegetative State," *New England Journal of Medicine* 330, no. 21 (May 26, 1994): 1500.

<sup>275</sup> Laureys, "Death, Unconsciousness and the Brain," 904-905.

permanent consciousness with that of personhood, although Furrow considers this to be a vague concept.<sup>276</sup> The difficulty with the notion of personhood is that it is different for each individual, and may be interpreted differently by various family members. As discussed previously, there are many different conceptions of personhood, which contributes to the lack of authoritative means to identify a time when personhood ceases. The consideration that a permanent loss of personhood results when consciousness is irretrievably lost provides the means of having a standard definition and removes any vagueness. Thus, the Alzheimer's patient would not realize loss of personhood because in most cases, core consciousness is present until the end of the individual's life.

An additional argument, provided by Minneapolis neurologist Randolph Cranford and attorney David Randolph Smith, believe "consciousness is the most important characteristic that distinguishes humans from other forms of animal life, going beyond the vegetative functions of heartbeat and respiration."<sup>277</sup> Enhanced imaging capabilities may present areas for further understanding, particularly as the technological understanding of the brain increases. A skilled explanation by the attending neurologist or other physician is required to help family members understand the long-term implications for their loved one and make more informed decision regarding the person's wishes.

These whole brain, brain stem, and neocortical definitions of death focus on the physiological state of the person; only the latter concedes that there is more to the person than a functioning brain or beating heart. The fact that the human organism has extensive relationships

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<sup>276</sup> Barry R. Furrow, Thomas L. Greaney, Sandra H. Johnson, Timothy S. Jost, Robert L. Schwartz, *Bioethics: Health Care Law and Ethics*, 3rd ed. (1997), Third ed. (St. Paul, MN: West Publishing, 1997), 189.

<sup>277</sup> Ronald E. Cranford and David Randolph Smith, "Consciousness: The Most Critical Moral (Constitutional) Standard for Human Personhood," *American Journal of Law and Medicine* 13, no. 2-3 (1987): 234-235.

with other humans, as well as other species, would indicate that it is more than just a beating heart or neuronal activity.

### **Other Voices**

There are other voices in the discussion, raising additional questions about the nature of the self and how the organism relates to those around them. Some postulate ideas about what constitute a human; others raise issues about the physical nature of the organism and whether its vitality is a higher consideration, while others separate brain function from other cellular activities as a determination of the presence of life in the person. A brief review of some of these ideas follows.

### ***Not by Brain Alone***

Since the late 1980s, UCLA pediatric neurologist D. Alan Shewmon has published a number of articles arguing against the entire concept of brain death. In the *Hastings Center Report* published in March/April 2009, he maintains that the position paper published by the President's Council on Bioethics does not successfully define the term *whole* in advocating for the acceptance of whole brain death (*total brain failure*, in the Council's term).<sup>278</sup> Taking exception to the Council's position that the cessation of the organism's ability to breathe could constitute death, Shewmon argues that this drive is "not a necessary feature of organismic wholeness," although agreeing with the Council that consciousness is also not required.<sup>279</sup>

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<sup>278</sup> D. Alan Shewmon, "Brain Death: Can It Be Resuscitated?," *Hastings Center Report* 39, no. 2 (March-April 2009): 20.

<sup>279</sup> *Ibid.*, 22.

In previous writings, Shewmon has argued that the brain's functions cannot necessarily be specified in death, positing that: (1) "most brain-mediated integrative functions are not somatically-integrating;" and (2) "most somatically integrative functions are not brain-mediated."<sup>280</sup> Moreover, it has been established that the posterior pituitary may continue to secrete an anti-diuretic hormone and thermoregulation.<sup>281</sup> Thus, neuro-hormonal activities may be evident despite cessation of the brain's central control functions. Shewmon also contends that integrative functions are not included in diagnostic criteria, citing brain dead patients who are maintained on life support and recover sufficiently to no longer require ventilation support.<sup>282</sup> For Shewmon, any evidence of cellular activity constitutes life.

In research performed in the late 1980s, Shewmon compiled known cases of brain death with survival periods longer than one week. Out of 175 cases, twenty-eight lived as long as six months, although the longest survivors were very young children, with those over age thirty surviving less than two and one-half months.<sup>283</sup> Shewmon concludes that the integrative functions of the brain are not necessary for the life of the organism, so brain death must "be on the basis of an essentially *non-somatic, non-biological* concept of death (e.g., loss of personhood on the basis of irreversible loss of capacity for consciousness)."<sup>284</sup> However, Shewmon fails to expand on the criterion for his view of what constitutes personhood. Without some insight of what personhood is or how it might be lost, the definition is meaningless. The relationality of humans needs to be integrated into the notions of consciousness and personhood; without them, a

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<sup>280</sup> D. Alan Shewmon, "The Brain and Somatic Integration: Insights into the Standard Biological Rationale for Equating 'Brain Death' with Death," *Journal of Medicine and Philosophy* 26, no. 5 (October 2001): 463,467.

<sup>281</sup> Choi, "Brain Death Revisited: The Case for a National Standard," 826.

<sup>282</sup> Shewmon, "The Brain and Somatic Integration," 466.

<sup>283</sup> D. Alan Shewmon, "Chronic 'Brain Death': Meta-Analysis and Conceptual Consequences," *Neurology* 51, no. 6 (December 1998): 1539-1540.

<sup>284</sup> Shewmon, "The Brain and Somatic Integration," 473.

person is nothing more than its individual cells. The cellular basis of personhood fails to consider the complexity of the person as an integrated being-in-the-world. While important in the function of the human organism, cellular function is not sufficient to support personhood. Some philosophers consider other factors as part of the total being, identifying non-physiological criteria that qualify the person as having life.

### ***Beyond Physiology and Consciousness***

Kennedy Institute of Ethics professor Robert Veatch argues that all of the proponents for the various definitions of brain death are missing the mark. For somatic survival, Veatch believes that it makes no difference whether certain bodily functions continue in the absence of a viable brain.<sup>285</sup> In assessing the definitions, Veatch concludes that the death debate is based “on one’s religious or philosophical worldview of the essence of the human.”<sup>286</sup> While there is more to life than biology, Veatch believes the “some recognition of mental function will be necessary.”<sup>287</sup> At the same time, Veatch does not agree that the individual’s mental functions are the *only* requirement to life, believing that personhood is too ambiguous to be helpful in its understanding.<sup>288</sup> Veatch concludes that people should “opt for their own particular definition of death, that is, their own particular view about when full moral standing ends.”<sup>289</sup> The difficulty with this position is that many individuals have not articulated their views in a manner known to other family members and physicians/care givers, resulting in continuing debate of the constituents for a person’s qualities. Medical technology’s ability to maintain physical life

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<sup>285</sup> Robert M. Veatch, "The Death of Whole-Brain Death: The Plague of the Disaggregators, Somaticists, and Mentalists," *Journal of Medicine and Philosophy* 30, no. 4 (August 30, 2005): 356.

<sup>286</sup> Ibid., 364.

<sup>287</sup> Ibid., 365.

<sup>288</sup> Ibid., 367.

<sup>289</sup> Ibid., 372.

almost indefinitely necessitates a stronger definition. A broader understanding of the relationship of one's personhood and the role that consciousness plays in the present technologically complex medical environment is important to establishing and understanding the limits of that technology.

### ***Life as Social Relationship***

Middlesex University sociologist Allan Kellehear contends that “most of the deliberations about brain death have been relatively closed conversations between medical, philosophical and legal communities and seldom ones that include the social sciences.”<sup>290</sup> Kellehear believes that personhood is established in relationships, not in academic categories. People engage with each other, “not only just giving but also receiving affirmation, feelings and love from others.”<sup>291</sup> Thus, the life cycle is not just about biology, but also about values that emanate from human traditions.<sup>292</sup> Kellehear concludes that the discussion regarding brain death needs to be enhanced by returning to the realm of relationships, “understanding death and dying at the place where biology and biography meet at their intersections with society and history.”<sup>293</sup> With this underpinning, it is possible to establish parameters of personhood that denote the significance of its being as more than cellular activities. Without the physiological body, there is no possibility of consciousness and those interrelationships do not exist.

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<sup>290</sup> Allan Kellehear, "Dying as a Social Relationship: A Sociological Review of Debates on the Determination of Death," *Social Science & Medicine* 66, no. 7 (April 2008): 1536.

<sup>291</sup> Ibid., 1538.

<sup>292</sup> Ibid., 1539.

<sup>293</sup> Ibid., 1541.

### *Not by Debate Alone*

Case Western Reserve University psychiatrist and ethicist Stuart Youngner and medical professor Robert Arnold conclude that death is not a simple biological fact to be discovered. As a result, death is to be considered in conjunction with other voices from the social sciences and philosophy, noting:

Death is ultimately a social construct, and in a pluralistic society that emphasizes individual rights and is increasingly suspicious of traditional founts of authority and wisdom, the controversies outlined above are unlikely to be intellectually resolved within the academic community or beyond.<sup>294</sup>

They posit that the concept of brain death has served two useful purposes, “allowing physicians to remove patients from life support without legal reprisal” and “allow[ing] organ procurement without violating the dead donor rule.”<sup>295</sup> Youngner and Arnold do not believe that the brain death debate is noteworthy to “the press or the public.”<sup>296</sup> Instead, Youngner and Arnold suggest that the public engage in the debate about the real moral issues: “how the medical system treats bodies near the end of life, what counts as harming a nearly dead person, and to what extent patient and family autonomy can protect against abuse and conflict of interest.”<sup>297</sup> Who we are as persons is more than an individual construct—all people exist in community, and there needs to be a communal understanding of the constituents of life. Without that understanding, it is impossible to construct health policy that will serve as the underpinning of what constitutes good care. In addition, the notion of what it means to live and what that means for individuals is not possible to understand. This establishes a question that needs to be addressed in health-care

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<sup>294</sup> Stuart J. Youngner and Robert M. Arnold, "Philosophical Debates About the Definition of Death: Who Cares?," *Journal of Medicine and Philosophy* 26, no. 5 (October 2001): 532.

<sup>295</sup> *Ibid.*, 533.

<sup>296</sup> *Ibid.*, 533-534.

<sup>297</sup> *Ibid.*, 535.

policy: how will individuals understand the limits of modern medicine, and how can these concepts be communicated in a non-threatening manner?

### *Special Case—Anencephalic Infants*

In most cases, babies are born with the capacity for expanding consciousness as they grow, which may peak and decline with age. Christof Koch notes that a baby's "physical substrate, the thalamo-cortical complex that provides consciousness with its highly elaborate content, begins to be in place between the 24th and 28th week of gestation."<sup>298</sup> Once born, "the baby processes complex visual stimuli and attends to sounds and sights in its world, preferentially looking at faces."<sup>299</sup> Studies have shown that babies less than one year of age make moral choices in selecting puppets that are friendly over those that are aggressive.<sup>300</sup> As the healthy infant grows, he or she will achieve full consciousness and awareness quite rapidly. One major exception is anencephalic infants, who are born missing most of both cerebral hemispheres. Professor James W. Walters notes that for these infants, "the condition is incompatible with a life of any self-consciousness and an early death is inevitable."<sup>301</sup> As a consequence, the harvesting of organs from these infants is debated, but that discussion is beyond the scope of this dissertation. Suffice it to say, these infants have no ability to grow into full consciousness, relate to their environment, or have a narrative identity, and will therefore never achieve personhood.

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<sup>298</sup> Christof Koch, "When Does Consciousness Arise in Human Babies?," *Scientific American* (September 1, 2009). <http://www.scientificamerican.com/article/when-does-consciousness-arise/> (accessed June 5, 2016).

<sup>299</sup> Ibid.

<sup>300</sup> Margaret Talbot, "The Baby Lab," *New Yorker*, September 27, 2006. <http://www.newyorker.com/magazine/2006/09/04/the-baby-lab> (accessed June 5, 2016).

<sup>301</sup> Walters, *What Is a Person?*, 116.

## **Consciousness and Brain Death**

The various views of brain death point to the complexity of the topic. At its best, the human organism is a dynamic, intricate, and integrated system that does not exist devoid of psychological and social elements, including relationships with others. However, it is difficult to dispute the critical role that consciousness plays in the life of the human organism, providing the capability for being aware of surroundings and allowing third person interactions. There are physiological, psychological, sociological, and anthropological characteristics in consciousness, and a simple explanation is not feasible.

For the most part, the debate on the various aspects of brain death has failed to integrate personhood and the complete needs of the human organism and its total environment, including the culture, political, and economic systems. The perspectives of the individual and the medical community continue to be different, with the former concerned about their existential condition and the latter about physiological conditions. What does this portend about the discussion? The preponderance of evidence would suggest that the organism experiencing whole brain death (total brain failure), is in fact, dead. Most often, humans diagnosed with this die shortly after mechanical ventilation is removed.

While less certain, brain stem death does not bode well for the organism, and close monitoring over a period of time provides the necessary information about the individual's long-term prognosis. However, the person's consciousness is likely to be affected, resulting in an inability to resume the quality of life that they once enjoyed. The outcome may be one in which the organism continues to deteriorate, with death as the result. In the event of brain stem failure, the prognosis is extremely poor, with likely life-long dependence on mechanical ventilation and

artificial nutrition and hydration. This will need to be addressed in greater detail as health care standards evolve.

The least clear path is for those who have neocortical failure. If one adheres to Glannon's view of consciousness, the likely outcome is that artificial life support measures would be withdrawn. The family members are faced with the difficult decisions of judging whether the person's *being-in-the-world* has meaning in a persistent vegetative state. Two hints are available: Advance Directives and the family members' understanding of what gave the ill person joy in their life. Some people might not choose to be maintained in a persistent vegetative state, but families might not be able to make the decision to withdraw or withhold supportive measures. Thus, it is necessary for the conscious, healthy person to communicate their personhood parameters to family members, either verbally or in writing. The need for this conversation will be discussed in greater detail in the following chapter.

## Summary

The preponderance of evidence suggests that death is not purely a physiological event. Glannon concludes that "we are essentially persons rather than human organisms.....defined in terms of the capacity for consciousness."<sup>302</sup> When a child is born healthy, his or her consciousness expands with time; in waning years or the event of injury, consciousness may be lost. When consciousness is lost permanently, the human is no longer able to interact with his or her environment and depending on the amount of brain damage, may not be able to exist without complex machines supporting vital functions such as breathing. Experience suggests that we are more than our bodies: the example of Descartes demonstrates the understanding that being a

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<sup>302</sup> Glannon, *Bioethics and the Brain*, 156.

*thinking thing* is critical to being human. A person is more than a corporeal entity: the definition that I have offered considers consciousness, narrative self, and relationality as critical constituents. When a person is fully conscious, there are physiological and social considerations: the neurological self is operational, and the person is able to tell their story and relate to their environment. Much evidence suggests the person dies with the demise of the brain, suggesting that death is more than a physiological phenomenon. An interdisciplinary understanding of the complexities of consciousness and brain demise is needed to extend this understanding. In the following chapters, I discuss some of the personal considerations in making decisions regarding one's potential condition, as well as the community issues that need to be addressed in order to enhance health-care policy in the United States.

## Chapter 4. Advance Care Planning and Personhood

Death is an inevitable aspect of the human condition. But let us never forget: while death is inevitable, dying badly is not.<sup>303</sup>

In the introduction to this dissertation, I described an event in my chaplaincy training in which the seminar participants were asked to draw the scene associated with their last day of life. Each person created an image reflecting their narrative and relationships associated with their individual personhood. No one imagined being in an ICU as part of the chosen description. Every person has aspirations, hopes, and dreams. As long as the person is conscious, all of these characteristics are an integral part of the person's being-in-the-world, and he or she is able to experience life in all of its dimensions: relationships and experiences are possible. Implicit with this life is the knowledge that someday a physical body will die. In today's medical environment, the absolute nature of a person's life is not as clear as it was in the past. The advent of life-prolonging machinery makes it possible for physiological life to continue even when consciousness is permanently lost. When this occurs, a person no longer exhibits the critical qualities that make him or her who they are. All that is left is the organic function of the body.

Over the past forty years, laws and practices have been promulgated to recognize each person's ability to identify treatment preferences when facing a chronic or terminal illness, which has evolved into Advance Care Planning (ACP), the process of identifying potential treatment decisions at the end of life, including (but not limited to) preparing Advance Directives. The opportunity to express treatment preferences requires specific consideration of one's personhood

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<sup>303</sup> Thomas H. Murray and Bruce Jennings, "The Quest to Reform End-of-Life Care: Rethinking Assumptions and Setting New Directions," *Hastings Center Report*, Special Report (November-December 2005): S57.

and the associated priorities for the meaning of one's life. However, only a small percentage of people engage in ACP—most fail to complete written advance directives, nor do they discuss preferences with family members or health-care providers. As a result, families may be asked to make critical decisions without understanding the medical issues or the implications for the person. This chapter provides an overview of legislative evolution, considers the parties to the decision making process, reflects on the implications when decision making fails, identifies challenges to implementing ACP, and identifies different types of programs that have been utilized to promote ACP and end-of-life decision making.

### **Legislative Evolution**

Acknowledgement of patient choices emerged in the late 1960s, when the Euthanasia Society of America introduced a template for expressing preferences, termed a *living will*, which preceded the Karen Quinlan court case in 1976.<sup>304</sup> In part to allow people to avoid the conundrum raised by the Quinlan case, between 1976 and 1986, thirty-seven states enacted legislation promulgating living wills, beginning with the state of California.<sup>305</sup> During this period, each of the states promulgated different parameters. As an example, the original California legislation allowed individuals to prepare documents “no sooner than two weeks after he/she has been diagnosed as terminally ill,” a provision that was ultimately removed.<sup>306</sup> Thus, the individual was not allowed to consider treatment choices unless already facing a terminal illness. By contrast, legislation in the state of Montana (1985) placed no time constraints on the

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<sup>304</sup> Henry R. Glick, "The Right-to-Die: State Policymaking and the Elderly," *Journal of Aging Studies* 5, no. 3 (Autumn 1991): 285.

<sup>305</sup> *Ibid.*, 289.

<sup>306</sup> *Ibid.*, 292.

preparation of living wills.<sup>307</sup> Early state legislative efforts thus identified a myriad of circumstances for preparing written treatment wishes.

Since that time, legal and health-care systems have acknowledged the fact that a person's existence changes inexorably once consciousness is permanently lost. The courts have recognized proxy decision making by family members for those who are no longer able to make treatment choices. This recognition extends to encouraging individuals to consider their own medical choices when facing a terminal or irreversible illness. Permission to discontinue life-prolonging treatments has become integral to the understanding of autonomous decision making in the United States, and formalized by the passage of the Patient Self-Determination Act of 1991 (PSDA), which provides the legal basis at the Federal level for a patient to either refuse or accept treatment (Omnibus Budget Reconciliation Act, 1990). All health-care facilities are required to:

(1) inform patients of their rights under State law to make decisions concerning their medical care; (2) periodically inquire as to whether a patient executed an advanced directive and document the patient's wishes regarding their medical care; (3) not discriminate against persons who have executed an advance directive; (4) ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by State law; and (5) provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives.<sup>308</sup>

Subsequent to this legislation, Out-of-Hospital Do Not Resuscitate (OH/DNR) orders were authorized in the 1990s in an effort to allow individuals to forego resuscitation in the event of cardiac arrest.<sup>309</sup> Further refinements were adopted by some states in establishing surrogate

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<sup>307</sup> Ibid.

<sup>308</sup> 101st Congress, *H.R.4449 - Patient Self Determination Act of 1990* (Washington, DC: Library of Congress, 1190), <https://www.congress.gov/bill/101st-congress/house-bill/4449> (accessed June 29, 2016).

<sup>309</sup> Charles P. Sabatino, "The Evolution of Health Care Advance Planning Law and Policy," *Milbank Quarterly* 88, no. 2 (June 2010): 215.

decision makers in the absence of Advance Directives.<sup>310</sup> Within these parameters, the stage is set for providing individuals with the capability for specifying their wishes and avoiding heroic health-care measures at the end of one's life.

## **Making Decisions**

With the legal qualifications in place, the process of planning for future health care parameters becomes more formalized. Completing Advance Directives is a critical element, although certainly not the only one, of ACP, which provides the means for an individual to integrate his or her wishes for medical treatments if incapacitated, typically including appointment of a health care proxy and/or expressing wishes in the event of a terminal or irreversible illness, and includes sharing that information with health-care providers and family members. ACP includes the entire spectrum of integrating one's personhood with health-care treatments and includes three constituencies: the individual, their families, and the physician/medical caregivers. Ideally, an individual's choices will be considered, discussed with family members, put in writing, and communicated with key caregivers, yet data indicate that relatively few people do so.

In the report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, the Institute of Medicine summarizes the challenges of having individuals consider their end-of-life wishes:

While most people have given thought to how they would like to die, many have found it difficult to communicate those views and choices to family and loved ones, and in many cases, family and loved ones have their own perceptions and views about death that can influence discussions about dying. Even when individuals and families are aligned, societal norms, expectations, and

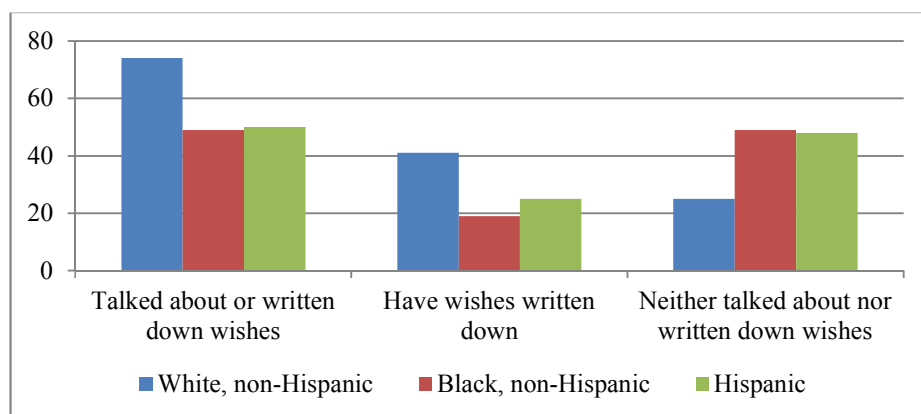
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<sup>310</sup> Ibid., 215-216.

requirements are not always concordant with the patient's wishes and choices. No one really knows whether, in the end, the death of a loved one occurred with the dignity that was hoped for, or to what degree the dying experience was marred by pain, fear, and discomfort, emotional or physical.<sup>311</sup>

The IOM report acknowledges the existence of different viewpoints regarding end-of-life planning and notes the need for specifying wishes. Despite the ability to specify one's medical treatment, relatively few people do so. The data show that a minority of people formalize end-of-life wishes in an Advance Directive. In the 2009-2010 HealthStyles data from nearly 8,000 respondents who participated in a mail survey, only 26 percent indicated that they had completed Advance Directives.<sup>312</sup> More recent data from the Pew Research Center show a slightly higher percentage (about one-third) and adds additional insight, including a category for those who have discussed wishes with family members, as well as determining whether individuals have completed directives as well as discussed them with family members. The results for adults discussing end-of-life wishes or writing them down are shown in Figure 1.<sup>313</sup>

Figure 1. Percentage of Adults Specifying End-of-Life Wishes, Race



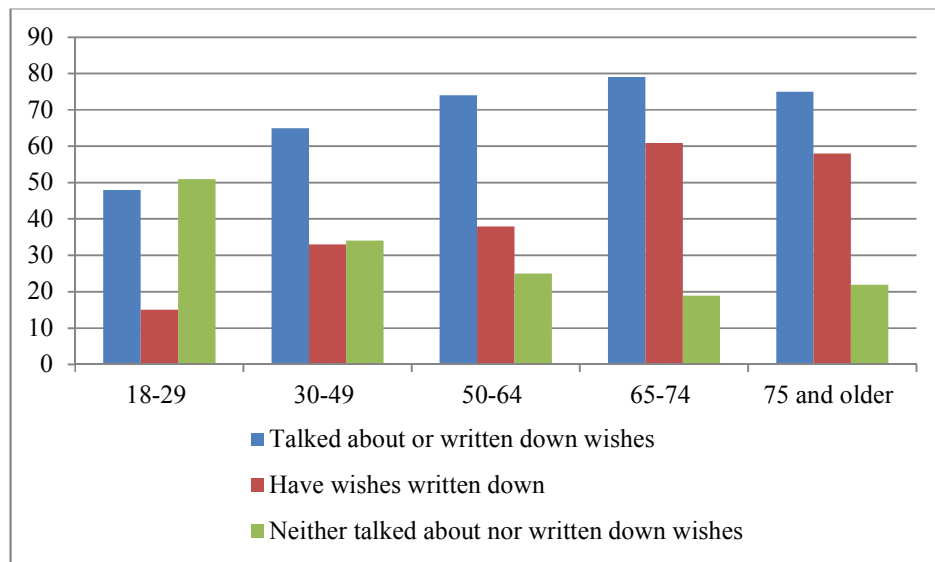
<sup>311</sup> Institute of Medicine, *Dying in America*, xi.

<sup>312</sup> Jaya K. Rao et al., "Completion of Advance Directives among U.S. Consumers," *American Journal of Preventive Medicine* 46, no. 1 (January 2014): 66.

<sup>313</sup> Luls Lugo, *Views on End-of-Life Medical Treatments* (Washington, DC: Pew Research Center, November 13, 2013), <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/#personal-wishes> (accessed June 5, 2016), 49.

Only one-third of all adults have their preferences at the end-of-life written down, with the highest percentage (41 percent) white, non-Hispanic, and the lowest percentage (19 percent) black, non-Hispanic. The percentage of all respondents expressing wishes in writing increased substantially from the onset of Advance Directives in 1990, increasing from 16 percent in 1990 to 35 percent in 2013, but represents only a one-percentage point increase (from 34 percent) in 2005.<sup>314</sup> Thus, the impetus behind writing one's wishes down has not increased significantly despite the increase in overall care costs and the continued expansion of high-level care. The black, non-Hispanic group also has the highest percentage (49 percent) that have neither discussed their wishes, nor written them down. Not surprisingly, as shown in Figure 2, those over age sixty-five are the most likely to have written down their wishes, and those aged twenty-nine or younger are the least likely to have done so, although a half or more have at least discussed their wishes for those aged thirty and older.<sup>315</sup>

Figure 2. Percentage of Adults Specifying End-of-Life Wishes, Age



<sup>314</sup> Ibid., 48.

<sup>315</sup> Ibid., 49.

When considering plans, a person indicates his or her preferences in the event of catastrophic medical illness that reflects personal values. There is no doubt that the best source of this information is the person. In the absence of this information, it is more challenging to make plans that honor a person's choices. The difficulty in taking advantage of the opportunity to consider the "what ifs" in the event of a terminal illness is difficult. Not only do relatively few people utilize ACP, many do not discuss the options with their families and friends. As a result, when critical illnesses strike, it is difficult for families to make reasoned decisions based on the individual's personhood. In countless family meetings, I have experienced the frustration and guilt experienced by family members, who in the absence of concrete information about the individual's wishes, will opt for continued treatment. Very few health-care practitioners begin family meetings with a discussion of the individual's personhood and unique characteristics. Instead, the health-care team focuses on physiological characteristics—heart rate, respiration, and organ function. The team is better able to offer care that is compatible with the individual's personhood when asking questions. In one case, a seventy-something patient had collapsed while playing tennis. He was resuscitated and brought to the ICU and maintained on life support, but the medical prognosis was grim. Both of the patient's children knew that the patient would not want to be sustained on life support, but his wishes were not in writing, and neither wanted to make the decision whether to continue or discontinue treatment. With coaching, the physician asked, "tell me about your dad." The daughter recounted the patient's love of sports, active lifestyle, and interest in current events. At this juncture, the physician, said, "in that case, as his physician, I recommend that we stop these treatments that will not allow him to return to his previous lifestyle." Both of the patient's children were grateful with the physician's

demonstrated care and allowed withdrawal of nonbeneficial treatments to stop. Nevertheless, with family discussions and wishes made in writing, much of the angst might have been avoided.

Discerning the limits of medicine provides a better basis for doing ACP and preparing for the end of life. Dr. Maria Silveira and her research team at the University of Michigan considered more than 3,700 subjects in the Health and Retirement Study.<sup>316</sup> The research team assessed outcomes to “persons 60 years of age or older who had died between 2000 and 2006 and for whom a proxy (a family member or knowledgeable informant) answered a study-directed exit interview after the participant’s death.”<sup>317</sup> The decedents had a variety of chronic illnesses likely to affect members of the targeted age group.<sup>318</sup> For respondents, those who had documented their wishes in writing were less likely to receive all possible treatments and more likely to receive limited therapy. Individuals who had prepared a living will and requested limited care were more likely to receive limited treatment than those who had not made this request. Of 417 subjects requesting comfort care, 405 received it. In the case of those who lost decision making capacity and had appointed a Medical Power of Attorney (MPOA), the latter was the surrogate in more than 90 percent of cases. These individuals were less likely to die in a hospital or receive all care possible.<sup>319</sup> The investigators concluded

Subjects who had completed living wills and requested all care possible were much more likely to receive all care possible than were those who had not requested such care. Similarly, subjects who had requested limited or comfort care were more likely to receive such care than were subjects who had not indicated those preferences. In addition, most subjects who had appointed a

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<sup>316</sup> “The HRS is a longitudinal project sponsored by the National Institute on Aging (NIA U01AG009740) and the Social Security Administration.” See National Institute On Aging, *Health and Retirement Study: A Longitudinal Study on Health, Retirement, and Aging* (Ann Arbor, MI: Institute for Social Research, 2016), <http://hrsonline.isr.umich.edu/> (accessed June 30, 2016).

<sup>317</sup> Maria J. Silveira, Scott Y. H. Kim, and Kenneth M. Langa, “Advance Directives and Outcomes of Surrogate Decision Making before Death,” *New England Journal of Medicine* 362, no. 13 (April 1, 2010): 1212.

<sup>318</sup> *Ibid.*, 1213.

<sup>319</sup> *Ibid.*, 1215-1216.

durable power of attorney for health care had a surrogate decision maker who matched their choice. Although a causal relationship cannot be inferred, our findings suggest that advance directives do influence decisions made at the end of life.<sup>320</sup>

Dr. Silveira and her cohorts further conclude “living wills have an important effect on care received and that a durable power of attorney for health care is necessary to account for unforeseen factors.”<sup>321</sup> Dr. Silveira and her team concentrate on the documentation, which is important. What the team does not discuss is the ancillary conversations with families that provide the means for articulating preferences. Once the Advance Directive documentation is completed, it is necessary for conversations to be held among the constituencies to make sure that (1) everyone knows that the documentation exists; (2) what the treatment wishes and considerations are; and (3) the MPOA is willing to honor the signatory’s wishes, not defer to others’ considerations. When implemented effectively, ACP works to avoid nonbeneficial treatments, minimize pain and suffering, and improve communications between health-care providers and those who are receiving care.

### **Constituencies and Considerations**

As the poet John Donne noted, “No man is an island, entire of itself.”<sup>322</sup> Every person lives in community, an essential element of the characteristics of personhood discussed in the previous chapter, which applies to health-care decision making as well. When faced with critical junctures, the individual’s wishes are important, but choices are made in the context of one’s family and the health-care team’s prognosis and treatment options. When personhood is lost, the

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<sup>320</sup> Ibid., 1217.

<sup>321</sup> Ibid.

<sup>322</sup> John Donne, “Meditation XVII,” (1624) in *Devotions Upon Emergent Occasions* (Ann Arbor: University of Michigan Press, 1959), <http://www.gutenberg.org/files/23772/23772-h/23772-h.htm> (accessed June 5, 2016).

family and/or friends become the decision makers acting on behalf of the individual. The following sections will consider the issues facing individuals and families in conjunction with the health-care team, as well as considering the ethical choices that might be faced.

## **Individuals**

There are many different considerations for an individual when embarking on ACP, including religious and cultural habits, the age at which plans are being undertaken, and health at the time of evaluation. A challenge is added for those already diagnosed with a terminal illness: most people do not know the timetable for their decline and eventual death when appointing a MPOA. The planning process can be complicated by religious and/or cultural factors that need to be considered in formulating plans, including the right to have others make the plans even if the patient is conscious and able to make his or her own decisions. In one case, a Pakistani, Muslim woman in the hospital where I worked asked the care team not to discuss her prognosis and treatment with her, only with her sons—she relied on them to make all necessary decisions. With autonomy in mind, the care team balked at the request but, with an ethics consult, was reminded that patient self-determination does allow the person to delegate decision making to others.

Care issues are integral to the individual's personhood and need to be considered in identifying the optimum surrogate decision-maker. As an example, in the State of Texas, the default decision makers are a person's spouse, adult children, parents, siblings, and other kin.<sup>323</sup> The completion of the MPOA allows the individual to consider special circumstances and appoint a person better able or more willing to make decisions. If an individual's spouse is

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<sup>323</sup> State of Texas, "Sec. 313.04 Consent for Medical Treatment," in *Chapter 313, Consent for Medical Treatment Act* (Austin, TX: 73rd Legislature, 1999), <http://www.statutes.legis.state.tx.us/Docs/HS/htm/HS.313.htm> (accessed June 5, 2016).

incapacitated, it is important to designate a person who is able to make decisions, as well as being willing to do so. Unfortunately, people do not always consider this possibility. Families assume that the healthy spouse will outlive a demented one, and this is not always the case. Alternatively, there may be multiple children, some of which have limited or conflicted interests in making decisions. I have seen multiple occasions when one child had been taking care of the parent and understood their personhood and wishes, but others, either out of lack of knowledge or guilt, would insist on continued heroic treatments. Finally, an individual with no next of kin should have a designated MPOA to avoid having an appointed guardian who does not know the individual's interests. In my experience, the guardianship system in the State of Texas fails individuals at the end of their lives, as the focus is always on continuing biological life, regardless of personhood. In one case, a patient with multiple medical issues coded and the team asked me to call the guardian, who in turn instructed me to have the team proceed at all costs. The patient died in spite of the heroic actions, and the experience (along with others) indicated that the guardianship system is not structured to deal realistically with dying patients.

Multiple influences affect choices in health-care decision making. As an example, the person may wish for an extension of time in order to achieve a particular goal or be able to perform particular tasks. Gawande speaks of a patient, a retired professor, who surprised his physicians by indicating that he wanted to be able to watch football games and eat chocolate ice cream. As long as this relatively simple ambition could be met, he was willing to pursue treatments. Physicians were able to provide this for him for two more years, before he was no longer able to swallow. Once the time came, the individual was able to transition to hospice care.<sup>324</sup> Understanding the person's objectives makes decision making much easier for family

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<sup>324</sup> Gawande, *Being Mortal*, 184.

members. If expectations cannot be met, invasive procedures can be avoided and the person's own expectations and desires can be honored.

Scholarly research has elicited the important features for individuals in considering their personhood. Penn State physician and philosopher Benjamin Levi studied three different focus groups ("suburban senior center," white middle-class population; "urban senior center," frail African American population; and "breast cancer support group") to consider end-of-life decision making.<sup>325</sup> The team identified four categories of influences: "concern for self; concern for others; expectations about the impact of ACP; and anecdotes, stories, and experiences."<sup>326</sup>

- "*Concern for self*:" includes autonomy, or wanting to be in charge of one's health-care treatments; needing to "maintain a meaningful existence included one's sense of dignity and respect;" having "the ability to enjoy everyday life;" understanding likely outcomes of treatment; and not wanting to be a "burden to self," including one's ability to tolerate pain and suffering.<sup>327</sup> In Gawande's example, the patient had relatively simple goals that were to be honored. By understanding those parameters, the health-care team and family members were able to meet the patient's goals for a period of time and were also able to terminate treatments that were not likely to prolong the person's life in a meaningful manner.
- "*Concern for others*:" participants recognized that families encounter consequences for the decisions. As a result, participants noted that they wanted to consult with family members as part of the decision process. Alternatively, individuals also wanted to use ACP "to exert their independence and to actively counter the pressure they felt from

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<sup>325</sup> Benjamin H. Levi et al., "What Influences Individuals to Engage in Advance Care Planning?," *American Journal of Hospice & Palliative Medicine* 27, no. 5 (August 2010): 306-307.

<sup>326</sup> Ibid., 307.

<sup>327</sup> Ibid., 307-309.

others.”<sup>328</sup> In Gawande’s example, the patient was concerned for his family members, which was reciprocated because by asking the person, guesswork was removed from the decision making process.

- “*Expectations about the impact of ACP:*” “participants expressed varying degrees of trust in the medical system;” consequently, the degree to which respondents were willing to listen to medical advice varied.<sup>329</sup> Gawande’s example points to the importance of the patient’s need to trust the information that he is given.
- “*Anecdotal, stories, and experience:*” “media stories”, “emotional responses to caregiving,” and “past experiences making decisions for others.”<sup>330</sup> Many people have not had the experience of seeing the implications of prolonged, nonbeneficial medical treatments. As a consequence, having a means of educating individuals on possibilities becomes an important element in ACP. More will be said about this later.

Levi notes “*concern for self*” emerged as the strongest influence for engaging in ACP.”<sup>331</sup>

Understanding one’s personhood helps the individual to consider longer-term decision making. Furthermore, having good communications among the individual, families, and the health-care team becomes tantamount—without this, information is incomplete and personal objectives may not be realized.

The challenge is that many individuals do not understand the available choices when articulating wishes for end-of-life care. Dr. Maria Silveira and her research team show that a significant number of individuals do not understand their options, demonstrating the need for community education. A survey of 728 individuals in Oregon showed that only 69 percent

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<sup>328</sup> Ibid., 309.

<sup>329</sup> Ibid., 309-310.

<sup>330</sup> Ibid., 310.

<sup>331</sup> Ibid.

understood options “regarding refusal of treatment,” fewer than half (46 percent) for “withdrawal of treatment,” and 41 percent regarding the principle of “double effect.”<sup>332</sup> Dr. Silveira concludes:

A significant proportion of outpatients at university-affiliated clinics in Oregon appear to misunderstand options in end-of-life care. Our results suggest that greater public knowledge about end-of-life care is needed, and advance care planning must be preceded by education about options in end-of-life care.<sup>333</sup>

In my experience, the corollary to this conundrum is that surrogates fail to understand the implications of continuing heroic treatment. Treatment is equated with cure, and the surrogates fail to appreciate that the person will not be able to return to the previous life activities. Maintenance of physiological functions does not equate to personhood. If individuals fail to understand the options when well, making decisions becomes even more difficult during times of stress in an ICU setting. If an individual does not understand his or her choices, it will not be possible to articulate preferences to family members or to the health-care team, much less put them in writing. Even being asked the question of whether to complete Advance Directives when being admitted to the hospital is unlikely to yield much success. As a chaplain, I helped hundreds of people to complete Advance Directives, but I had a continuing concern that the documents were being completed without full understanding of their implications. In a few cases, patients and family members would acknowledge the intent to complete the documents prior to the hospital admission; they simply had not had an occasion to do so. While I believe the requirement is well-intentioned to ask people being admitted to the hospital whether they would like to complete Advance Directives if they have not done so, I am not sure that the

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<sup>332</sup> M. J. Silveira et al., "Patients' Knowledge of Options at the End of Life: Ignorance in the Face of Death," *Journal of the American Medical Association* 284, no. 19 (November 15, 2000): 2483.

<sup>333</sup> *Ibid.*, 2487.

timing is right. Even when asking for information, patients express confusion, believing that they are being asked to do the documentation because their condition is more serious than understood, in turn asking, “Does this mean that I am dying?”

Consideration of one’s own personhood allows for articulating lifestyle goals and objectives. An individual with a diagnosed terminal illness faces the immediate prospect that the characteristics that define his or her personhood are likely to change in a significant way. Providing the information for family members and being able to articulate desires is challenging. Being able to talk to family members about one’s own aspirations becomes an important element in ACP, and waiting until a terminal illness is present or one is entering a hospital for treatment with uncertain prospects may be too late. As a result, finding the means for educating the public on some of the issues that may arise is important. Different programs have attempted to do this, a subject to be explored in greater detail.

## **Families**

Most people have families who will be affected by their ACP activities, sometimes directly by having to act as surrogate decision makers or as supporters for making treatment decisions. In either case, the family members need to have knowledge of the person’s wishes. Without this information, the family is left guessing regarding the treatment options. The benefit of sharing information is substantial. The Gundersen Lutheran Health System in LaCrosse, Wisconsin, enacted a study with a group of geriatric patients, in which one group “received only the Massachusetts Health Care Proxy form” and the others “discussed ACP with a trained nurse

facilitator.”<sup>334</sup> Not surprisingly, the group with the trained facilitator had a better understanding of treatment options, “less willing to undergo life-sustaining treatments for a new serious medical problem, more willing to undergo such treatments for an incurable progressive disease, and less willing to tolerate poor health states.”<sup>335</sup> However, the investigators noted that patients and families were reluctant to discuss the issues. Consequently, the researchers advocate for “encouragement of such discussions on the part of patients and families by civic and religious groups and the medical profession.”<sup>336</sup> More venues need to be created where individuals can learn about the importance of health-care decision making from a knowledgeable perspective in an environment that promotes reasonable discussions.

The importance of family involvement and understanding is underscored by evidence that while wanting surrogate decision makers, people are reluctant about placing an undue responsibility on family and friends.<sup>337</sup> Most end-of-life decisions affecting patients lacking capacity are discussed by families and physicians rather than the patient, so it is important for potential surrogates to understand the person’s aspirations.<sup>338</sup> The challenge is that many family members do not want to have these difficult conversations. Most people prefer to celebrate life, not discuss the eventuality of death.

The irony is that research has shown health-care decision makers focus on appropriate considerations when called upon to do so. Dr. Elizabeth Vig of the Department of Gerontology at the University of Washington studied surrogates for a group of fifty older, chronically ill

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<sup>334</sup> Carolyn E. Schwartz et al., "Early Intervention in Planning End-of-Life Care with Ambulatory Geriatric Patients: Results of a Pilot Trial," *Archives of Internal Medicine* 162, no. 14 (July 22, 2002): 1611.

<sup>335</sup> Ibid.

<sup>336</sup> Ibid., 1617.

<sup>337</sup> Gary S. Winzelberg, Laura C. Hanson, and James A. Tulsky, "Beyond Autonomy: Diversifying End-of-Life Decision-Making Approaches to Serve Patients and Families," *Journal of the American Geriatrics Society* 53, no. 6 (June 2005): 1047.

<sup>338</sup> Ibid., 1049.

veterans, identifying five bases for making decisions: (1) “conversations”; (2) “relying on documents;” (3) “shared experience;” (4) “surrogates’ own values and preferences about life;” and (5) “surrogates network.”<sup>339</sup> A combination of informed discussions with documentation can assist in the health-care decision making process. In Gawande’s example, the patient’s daughter realized that she did not have a clear understanding of her father’s wishes and made it a point to ask him prior to a critical surgical procedure.<sup>340</sup> This is an instance where consideration was given prior to the event, albeit at the last minute. Having a critical exchange while the person is conscious is an important milestone in understanding wishes. Sharing information provides the means for removing difficult choices from the surrogate and allowing preferences to originate from the person who will be the recipient of the treatment plans. Understanding the values associated with one’s personhood and relating personal values to health-care decision making provide the basis for good end-of-life planning.

Not having the basic understanding of a person’s priorities creates a more difficult environment for making decisions. Veterans Administration physician Ursula Braun led a research team in which respondents identified the stress associated with making medical decisions with potentially uncertain clinical outcomes, particularly when their values, beliefs, and preferences were not known.<sup>341</sup> Dr. Braun’s team identified three factors that increased the difficulties associated with making end-of-life decisions for family members.<sup>342</sup>

- Problems with doctor-patient communications, identifying the need for providing health information in a manner that is understandable and free of medical jargon. Medicine has

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<sup>339</sup> Elizabeth K. Vig et al., "Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making," *Journal of the American Geriatrics Society* 54, no. 11 (November 2006): 1688.

<sup>340</sup> Gawande, *Being Mortal*, 184.

<sup>341</sup> Ursula K. Braun et al., "Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End-of-Life Decision Making," *Journal of General Internal Medicine* 23, no. 3 (2008): 268.

<sup>342</sup> *Ibid.*, 269-270.

its own language that is used naturally by health-care team members, but confuses patients and families. Telling a family member that the patient is on three pressors is not nearly as useful as explaining that the heart is not pumping well enough and needs three medicines to keep it going.

- Organizational issues, including the lack of care continuity in the setting of a teaching hospital. When a patient's time spans months, the care team frequently changes. Even in a normal setting, the patient is attended by a variety of physicians, most of whom have not been seen prior to admission to the care setting.
- Cost-benefit tradeoffs, with respondents desiring aggressive treatment only if functional independence or cognitive capacities could be maintained, with some concerned about the cost burden.<sup>343</sup> Moreover, many patient families fail to understand the care progression associated with an acute care hospital. Past a certain point, the patient is likely to be moved to a Long-Term Acute Care Hospital or other secondary facility.

In my experience as a hospital chaplain and attending numerous family meetings, in many cases, the physician will provide a list of issues faced by the patient and then will look to the family to ask, "What do you want us to do, do you want us to do everything?" The natural response to this question is "we want you to make our family member well." Kaufman believes the practice of asking the patient, family, or surrogate what should be done creates additional problems:

Clinicians often do not see that the choices they offer to patients—choices they are obligated to offer in our era of patient-centered care, individual autonomy, and shared decision making—represent an off-loading of ethical responsibility onto those patients and their families, that is, off-loading onto those with the least

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<sup>343</sup> Robin Yabroff and study team note the challenges of measuring quality of life in seriously ill patients, since many are too ill to complete surveys. See K. Robin Yabroff, Jeanne S. Mandelblatt, and Jane Ingham, "The Quality of Medical Care at the End-of-Life in the USA: Existing Barriers and Examples of Process and Outcome Measures," *Palliative Medicine* 18, no. 3 (April 2004): 209.

ability to understand prognosis, the purpose of specific treatments, and the implications of crossing the line.<sup>344</sup>

Asking the patient or family what path to take does not generate the kind of collaborative response that is needed to provide high-quality care, particularly for one who is dying. However, the family members are caught in a quandary. They get lost in the jargon, do not understand what the realistic options are, and do not comprehend what the phrase “do everything” means. At a time of high stress, family members are placed in the position of having to make decisions when they do not know what all of the decision parameters are. The challenge is that the conversations associated with this type of planning needs to happen long before the family meeting occurs. The discussions associated with end-of-life choices need to occur before the circumstances present that require key choices to be made.

These research studies and perspectives point to the notable confusion that exists for families in understanding decision-making parameters for their loved ones at critical times. This is exacerbated by the institutions that provide medical care: the issue of care continuity has already been identified. In addition, hospitals are noted for emphasizing life-sustaining equipment and techniques instead of patient and family needs.<sup>345</sup> In some instances, the technology may be serving the health-care system instead of people, and they are the ones who need to relate health care to the patient’s personhood. One research cohort led by Benjamin Stump, medical student; Craig Klugman, associate director at the University of Texas Health Science Center in San Antonio; and Barbara Thompson, professor emeritus for Ethics and Health Policy at the University of Nevada, aggregated data from a 1996 questionnaire on “The Last Hours of Life.” Administered to 466 people, with ages ranging from eighteen to ninety-four, the

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<sup>344</sup> Kaufman, *Ordinary Medicine*, 40.

<sup>345</sup> Murray and Jennings, “The Quest to Reform End-of-Life Care,” S54.

respondents answered a range of questions regarding person(s) they would want present, what they feared about dying, whether they wanted to be told they were dying, whether they believed in an after-life, and where they would like to die. A “good death” included factors such as dying at home (63 percent), awareness of one’s impending death (92 percent), surrounded by family/friends (30 percent), and having discussed the situation with their spouse/partner (68 percent), while concerns included facing fears of the unknown (13 percent), things left undone (17 percent), pain (20 percent), suffering (17 percent), and seeing family/friends grieve (20 percent).<sup>346</sup> Ironically, although nearly two-thirds of people indicated that they wanted to die at home, in 2007, over 60 percent died in an institutional setting, although this represents a decline of about ten percentage points since 1989.<sup>347</sup> Thus, the expression of wishes does not always meet the reality for individuals. As people age and their baseline health declines, it becomes important for them to consider the factors that may affect their lifestyles and values.

Additional perspectives are provided by former Hastings Center president Thomas Murray, who identifies two issues associated with end-of-life decision making: it has been “excessively rationalistic” and “individualistic,” indicating that “most Americans find planning for their own deaths exceedingly hard to do,” and fails to recognize that death is a blend of medical science with cultural meanings.<sup>348</sup> Consequently, the complexities of end-of-life decision making should be explained carefully in the medical setting in order to provide good care, and those providing the requisite information need to be knowledgeable of the various religious and cultural settings in which people live. Understanding and articulating one’s values,

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<sup>346</sup> Benjamin F. Stump, Craig M. Klugman, and Barbara Thornton, “Last Hours of Life: Encouraging End-of-Life Conversations,” *Journal of Clinical Ethics* 19, no. 2 (Summer 2008): 152-154.

<sup>347</sup> National Center for Health Statistics, *United States Health, 2010: With Special Feature on Death and Dying* (Hyattsville, MD, 2011), 85.

<sup>348</sup> Murray and Jennings, “The Quest to Reform End-of-Life Care,” S53.

both verbally and in writing, provides the means for communicating treatment preferences. In the best case, people discuss what their choices are with family or other appropriate individuals before a time decisions need to be made. By taking advantage of ACP, individuals and family members have an opportunity to discuss their choices in the context of personhood and what that means in that life in community, removing the burden of decision making from families or other surrogates. Those choices can then be communicated to health-care providers, the third element of the health-care triumvirate.

### **Physicians**

Ultimately, medical diagnoses and treatment recommendations, which need to be communicated to the patient and/or family members, fall to the physician and members of the medical team. A critical element is the role that the physician takes in advising patients and/or families in the case of end-of-life decision making, and there are different approaches. Dr. Douglas White of the Department of Critical Care Medicine at the University of Pittsburgh Medical Center led a team studying ICUs at Seattle, Washington (four hospitals), and in San Francisco, California (two hospitals). Four roles were identified in sixty-three cases: (1) “informative” (seven of sixty-three), “in which the physician provided medical information but did not elicit information about the individual’s values or make a treatment recommendation;” (2) “facilitative” (twenty-three of sixty-three), “in which the physician refrained from providing a recommendation but actively guided the surrogate through a process of clarifying the patients’ values and applying those values to the decision;” (3) “collaborative” (thirty-two of sixty-three), “in which the physician shared in deliberations with the family and provided a recommendation;” and (4) “directive” (one of sixty-three), “in which the physician assumed all

responsibility for, and informed the family of, the decision.”<sup>349</sup> In my experience, physicians more often take the informative or facilitative roles. As in the example that I provided previously, physicians ask, “What do you want us to do?” Seldom do physicians have the training to relate an individual’s personhood to care decisions.

In White’s research, “no physician engaged surrogates in an explicit discussion about the family’s preferred role in the decision-making process.”<sup>350</sup> Not only did the physician avoid making a recommendation in half of the cases, when families explicitly requested one, only half complied.<sup>351</sup> The investigators attribute the reluctance to provide recommendations due to “the moral burden entailed in decisions to forego life-sustaining treatment,” while others “may be concerned that their recommendations will be too influential and that families may acquiesce to decisions that are contrary to the patient’s interests.”<sup>352</sup> While flexibility in approach is appropriate when dealing with patients and families, it is important to be honest about the ultimate prognosis. Detailing a list of medical issues and then asking “what do you want us to do” avoids the physician/caregiver’s responsibility in providing information and effectively asks the patient and/or family members to make medical judgements. In the optimum case, care decisions should be collaborative, with the health-care providers working with the family to identify treatment decisions in consort with the individual’s personhood. The need for improving communications in medical practice is not likely to change unless those responsible for training inculcate the values of helping patients and families to make decisions in a framework that integrates an understanding of the person with the treatment plan.

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<sup>349</sup> Douglas B. White et al., "Expanding the Paradigm of the Physician's Role in Surrogate Decision-Making: An Empirically Derived Framework," *Critical Care Medicine* 38, no. 3 (March 2010): 743-747.

<sup>350</sup> Ibid., 747.

<sup>351</sup> Ibid., 748.

<sup>352</sup> Ibid.

Providing candid facts has been shown to have benefits for patients and their families. Dr. Alexi Wright, Department of Medical Oncology/Psycho-Oncology/Palliative Care Research at Dana-Farber, led a team of researchers “to determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions.”<sup>353</sup> The team found that the least beneficial outcomes were realized with families who did not have good conversations with the medical team. Instead, “patients who reported having end-of-life discussions received less aggressive medical care and were more likely to receive hospice services for more than a week.”<sup>354</sup> Integrating personalized care with the person’s activities, relationships, and objectives provide the means for establishing consistent care goals with the individual’s personhood. In one of my hospital assignments, I had the pleasure of working with a skilled palliative-care physician who started every family meeting with the statement, “tell me about your mom/sister/father/brother.” With this opening, the family is invited to share unique elements of the person’s life. The medical prognosis is placed in the context of that life, and if the person will be unable to do the things that gave them joy, the family is more able to make decisions that will reflect the individual’s life. There is no guarantee that the family will not opt for futile care, but the communications are more likely to promote an environment of trust.

As noted above, research supports the advantages for discussing plans with families. Ongoing communications between the patient (if capable), families, and physicians are expected to result in better outcomes for individuals. In Gawande’s example, the health-care team approached the daughter asking what the patient’s wishes might be. Since he was still fully competent and conscious, a more appropriate step might have been to approach the patient

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<sup>353</sup> Alexi A. Wright et al., “Associations between End-of-Life Discussions, Patient Mental Health, Medical Care near Death, and Caregiver Bereavement Adjustment,” *JAMA* 300, no. 14 (October 8, 2008): 1665.

<sup>354</sup> *Ibid.*, 1670.

directly, including his family in the discussions. Allowing his daughter to participate provides the opportunity to exchange information and have questions answered prior to proceeding with the selected treatment protocol. In addition, it is helpful to have the family members be aware of the patient's wishes with first-hand knowledge.

When an individual has a long-standing relationship with a physician, the latter is likely to know what the patient's history is and what his or her preferences are. However, as noted by Dr. Gary Winzelberg, from the Division of Geriatric Medicine at the University of North Carolina, ACP discussions with primary-care physicians may not transfer when an individual is admitted to the hospital, since the hospitalist typically assumes general care when the PCP lacks admitting privileges.<sup>355</sup> When an unfamiliar physician is leading care, the patient's personal qualities and wishes are not foremost on the physician's mind in making medical recommendations. If the key medical personnel lack familiarity with personal details, it is critically important that the individual and family members have pertinent care discussions prior to the onset of a life-threatening illness. Without these conversations, the ensuing family meetings become a guessing game for identifying care priorities.

Physicians are further challenged by the diversity of religious, ethnic, and cultural practices in the United States. Dr. Braun (VA Medical Center and Baylor College of Medicine) led a research team using focus groups with Caucasian, African American, and Hispanic internists and subspecialists, and identified matters of physician care that transcended race and ethnicity and those that needed special consideration. Themes common to all ethnic backgrounds included:

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<sup>355</sup> Winzelberg, Hanson, and Tulskey, "Beyond Autonomy," 1049.

- The need for evidenced-based, jargon free communications by physicians with family members.<sup>356</sup>
- Families need to understand the treatments that are coordinated, and that some procedures are mutually exclusive (“accepting CPR but not intubation”).<sup>357</sup>
- Physician challenges with initiating end-of-life care discussions: while acknowledging it was “part of their job” and “had to be done.” Of concern is “the lack of knowledge that the physicians expressed the legal aspects or the paper work involved in advanced planning and relied on the help of social workers for completion of such documentation.”<sup>358</sup>

The need for jargon-free communications transcends a person’s race, culture, or ethnicity.

Everyone needs to understand the words and terms that are being communicated, as well as recognize the treatments that flow from each other. Educating the public on the general nature of health care becomes important, and more will be said about this. Themes specific to race and ethnicity included:

- *Surrogate decision making.* Hispanic physicians emphasized the need for patients and families to discuss prospective wishes in order to avoid future family conflicts. African-American physicians attempted to establish a trusting relationship with the family and make decisions easier, noting the importance of supporting ultimate decisions. Caucasian physicians made an effort to counsel families regarding their own approaches with family members.<sup>359</sup> Without trust, the caring paradigm is difficult to manage. In addition to the

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<sup>356</sup> Ursula K. Braun et al., "The Physician's Professional Role in End-of-Life Decision-Making: Voices of Racially and Ethnically Diverse Physicians," *Patient Education & Counseling* 80, no. 1 (July 2010): 4.

<sup>357</sup> Ibid.

<sup>358</sup> Ibid., 5.

<sup>359</sup> Ibid., 6.

terms being used by the health-care professionals, family members need to be able to trust those providing the information. This is sometimes difficult when prior care has been substandard or information provided previously turned out not to be true. Someone who has not received good care in the past is more likely to be distrustful of a prognosis that no further care is available.

- *Please Do Everything.* Physicians identified requests for “doing everything” as a “red flag” requiring further counseling. Caucasian physicians believed that this was an indication that the family “might be in denial and unrealistic about the patient’s situation and physicians’ abilities to cure.”<sup>360</sup> Hispanic physicians observed that it was important to communicate to families that “‘doing everything’ might inflict additional pain and suffering.”<sup>361</sup> African-American physicians observed that requests to “do everything” might be rooted in “expressions of guilt on the part of family members” or “distrust stemming from unequal treatment and a history of discrimination in the past.”<sup>362</sup> All groups noted the importance of communicating that comfort care was treatment, even if not curative. African-American physicians acknowledged that they approached end-of-life discussions differently with “patients of their own race,” even though the “content would be the same.” These physicians thought trust was greater with those of the same race, since they would share a similar cultural background and religious beliefs. This becomes a difficult situation. Not only do patients and families have diverse backgrounds, but the health-care providers do as well. Consequently, the likelihood is reduced that a patient will have a physician who is of the same background, necessitating

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<sup>360</sup> Ibid.

<sup>361</sup> Ibid.

<sup>362</sup> Ibid., 7.

a better overall educational effort to explain components of health care to potential users.

The research did not address physicians who ask the families whether they want

“everything” done without explaining the implications of that action.

- *The Role of Spirituality.* Most physicians indicated that it was important to understand the patients’ values, spiritual beliefs, and faith. However, Caucasian physicians reported that these qualities had minimal impact on discussions, believing that location in a diverse area (Houston, Texas) provided broad exposure to issues. Some Caucasian and Hispanic groups denied that these had any influence on decision-making processes. Caucasian clinicians remained “indifferent” in an effort to avoid “projecting their own values.” Hispanic physicians indicated that they asked about religious beliefs in order to enhance communications. African-American physicians raised issues about God and spirituality and made an effort to respect others’ beliefs even if they were not consonant with their own.<sup>363</sup>

People bring their own experiences to critical health-care treatment junctions, requiring education prior to the time that a critical illness strikes. Integrating religious, spiritual, and cultural understanding is critical for all medical practitioners in helping patients and families to navigate ACP and potential end-of-life decision making. The complexity of ACP in a diverse nation requires exceptional communication skills for medical practitioners, which is not a one-time conversation. The conversation about the health-care system and its limits needs to be integrated into the ongoing conversation with policy. Simply handing out Advance Directive documents is not enough to prepare people for ACP or difficult conversations at the time of a critical illness. Moreover, completing Advance Directives without informing identified

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<sup>363</sup> Ibid.

surrogates of treatment preferences does not help with decision processes. Communications need to occur in which all of the parties to directives are made aware of treatment choices: the individuals completing the documents, families/surrogates who may be asked to follow them, and physicians who will assist with treatment recommendations. In the absence of an integrated communications plan, decision making may fail, which has significant policy implications.

### **When Decision Making Fails**

In Gawande's example, the best possible outcome is realized: the patient, family, and health-care team all understand the patient's aspirations. If this effort fails, some states provide the means for establishing medical futility; the best-known example is the Texas Advance Directives Act (TADA), enacted in 1999 and amended in 2003. This legislation establishes procedures for reviewing cases that are deemed to involve futile treatment.

If the patient or the person responsible for the health care decisions of the patient is requesting life-sustaining treatment that the attending physician has decided and the ethics or medical committee has affirmed is medically inappropriate treatment, the patient shall be given available life-sustaining treatment pending transfer under Subsection (d) [Another physician or alternative care setting]. This subsection does not authorize withholding or withdrawing pain management medication, medical procedures necessary to provide comfort, or any other health care provided to alleviate a patient's pain. The patient is responsible for any costs incurred in transferring the patient to another facility. The attending physician, any other physician responsible for the care of the patient, and the health care facility are not obligated to provide life-sustaining treatment after the 10th day after both the written decision and the patient's medical record ... are provided to the patient or the person responsible for the health care decisions of the patient unless ordered to do so.<sup>364</sup>

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<sup>364</sup> State of Texas, "Texas Advance Directives Act," in *Procedure If Not Effectuating a Directive or Treatment Decision* (1999, Amended 2003) <http://www.statutes.legis.state.tx.us/Docs/HS/htm/HS.166.htm> (accessed June 5, 2016), Section 166.046.

TADA has been criticized because decision making is placed in the hands of hospital ethics/review committees, which might be construed as representing the hospital's interests solely. In addition, although several cases have been appealed, in most cases, the process is designed to operate outside of the legal system. In addition, the process is time consuming and complex, to the extent that many physicians do not want to undertake the futility process. The Children's Hospital of Boston follows TADA, including an appeals avenue to the courts that offers to assist families requiring legal representation.<sup>365</sup>

The State of Ohio has taken a different approach:

If the patient did not previously express an intention with respect to the use or continuation, or the withholding or withdrawal, of life-sustaining treatment should the patient subsequently be in a terminal condition or in a permanently unconscious state, whichever applies, and no longer able to make informed decisions regarding the administration of life-sustaining treatment, a consent given pursuant to this section shall be valid only if it is consistent with the type of informed consent decision that the patient would have made if the patient previously had expressed an intention with respect to the use or continuation, or the withholding or withdrawal, of life-sustaining treatment should the patient subsequently be in a terminal condition or in a permanently unconscious state, whichever applies, and no longer able to make informed decisions regarding the administration of life-sustaining treatment, as inferred from the lifestyle and character of the patient, and from any other evidence of the desires of the patient, prior to the patient's becoming no longer able to make informed decisions regarding the administration of life-sustaining treatment. The Rules of Evidence shall not be binding for purposes of this division.<sup>366</sup>

Once a patient has been in a persistent vegetative state for more than twelve months, medical treatment may be withdrawn, with any challenges managed through the court system.<sup>367</sup>

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<sup>365</sup> Robert D. Truog, "Counterpoint: The Texas Advance Directives Act Is Ethically Flawed: Medical Futility Disputes Must Be Resolved by a Fair Process," *Chest* 136, no. 4 (October 2009). It should be noted that several Texas cases have been appealed to the courts, and in one publicized case, Texas Children's Hospital also provided the plaintiff, the patient's mother, with independent legal advice.

<sup>366</sup> State of Ohio, *2133.08 Consenting to Withholding or Withdrawing Life-Sustaining Treatment from Patient*, Ohio Revised Code, Chapter 2133 (Columbus, OH: 129th General Assembly, 1999, Amended 2012), <http://codes.ohio.gov/orc/2133.08> (accessed June 5, 2016), Section D(3).

<sup>367</sup> *Ibid.*

A recent case demonstrates the complexities associated with futility. At the age of twelve, Jahi McMath incurred heart stoppage during a medical procedure. Physicians in California declared her brain dead, and the courts concurred, resulting in issuance of a death certificate. However, McMath's mother found a facility to accept her in New Jersey, one of two states (the other is New York) to allow rejecting brain death on religious reasons. However, since then, McMath's mother has been trying to get the death certificate revoked so they can return to California. However, with sophisticated imaging tests, physicians continue to maintain that McMath is brain dead.<sup>368</sup> This situation presents an ethical conundrum: significant funds continue to be spent to support McMath, and the family remains in turmoil.

This case illustrates the complexities with medical futility. There are many reasons why family members do not want to accept the terminal condition for their loved ones. Some believe that a miracle will be imminent, one that will heal their loved one. Others do not trust the health-care system to provide good care and honest information. Some family members have told me, "the doctor told me that I was going to die, but I am still here." As a result, families insist on maintaining individuals on life support, believing that healing is imminent. In many cases, hospital staff members hold the option to declare futility in the background, but most do not want to invoke the condition. Since only a physician can invoke futility under TADA, the possibility is limited, and many believe that this will have no good outcome and will simply raise the possibility of animosity with family members.

While futility remains a possibility in extreme cases, it is not a good option for anyone—it sets up an adversarial position between the care team and the family. It also illustrates the need for better understanding by health-care users of the limits of modern medicine, as well as the

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<sup>368</sup> Vitez.

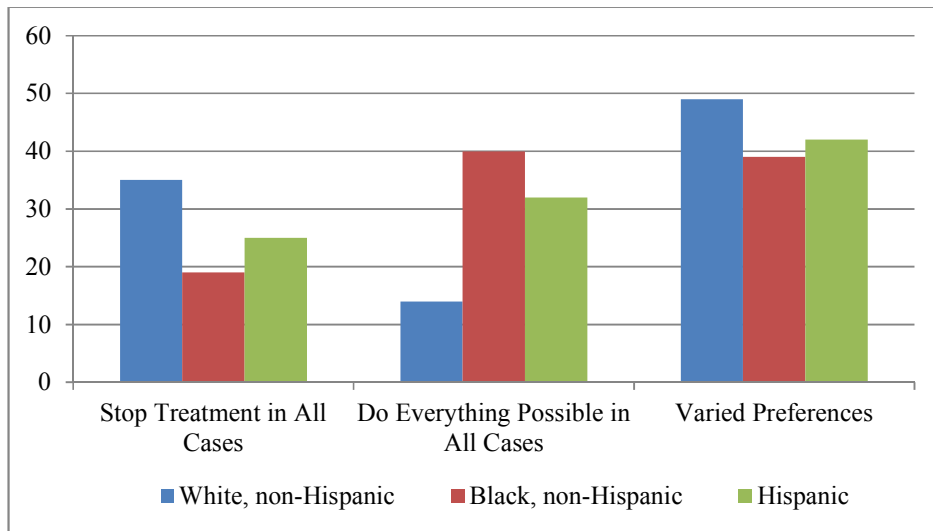
need for a high-quality exchange of information between the health-care team and family members. However, the foundation for better understanding needs to occur before the onset of a critical or terminal illness. There are different avenues for improved communications to occur, and one will be discussed later in this dissertation.

### **Challenges with Advance Care Planning**

As noted in the previous section, experience shows that those employing ACP are less likely to undergo nonbeneficial treatments and more likely to transition to hospice as part of coordinated end-of-life care. Unfortunately, the implementation of the techniques is still lacking. Some issues are associated with the general nature of advance plans, while others relate to particular religious and/or cultural groups.

The need for communication cannot be understated, applying to conversations between the individual and physician, the individual and family members, and family members and medical team. The ability to make sound medical decisions is predicated on the ability of all parties to speak from a common understanding of the individual's personhood in the context of their medical prognosis. More specific issues arise with particular religious and/or cultural groups. In the Pew Research Study discussed previously, the respondents were asked whether they would stop treatment in all cases, do everything possible in all cases, or have varied preferences .

Figure 3. *Expression of Preferences by Race*



White, non-Hispanic respondents were the most likely to stop treatment in all cases (35 percent), and least likely to do everything possible in all cases (14 percent). Black, non-Hispanic respondents were the most likely to do everything possible in all cases (40 percent) and least likely to stop treatment in all cases (19 percent). The Hispanic respondents fell between the two groups, with 25 percent indicating that they would stop treatment, and 32 percent that they would do everything possible. There are many reasons that might explain these differences, but more work is needed. As an example, a group of researchers from the University of Washington examined more than 3,000 patient charts, 79 percent white and 21 percent non-white, concluding that the latter were less likely to have Advance Directives and more likely to experience family discord, a finding supported by the Pew Center Research data presented earlier in this chapter.<sup>369</sup> In addition, the research team found that non-white families were less likely to have discussed the patient's preferences.<sup>370</sup> Moreover, symptom management was less rigorous, supporting

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<sup>369</sup> Sarah Muni et al., "The Influence of Race/Ethnicity and Socioeconomic Status on End-of-Life Care in the ICU," *Chest* 139, no. 5 (May 2011): 1025.

<sup>370</sup> *Ibid.*, 1028.

other studies that have identified disparities in end-of-life care management.<sup>371</sup> This demonstrates the differences that exist among different groups and the need to improve patient care across all segments as well as tailor educational efforts towards understanding end-of-life planning. As long as disparities exist, trust issues are likely to impede end-of-life care planning education.

### **Ethical Choices in Making Plans**

When facing a terminal illness, the patient or surrogate has several ethical choices that are considered in communicating plans, either verbally or in writing. These options come to the forefront in decision making, frequently in a critical-care setting when decisions need to be made:

- Continue aggressive care without a DNR order. Arguably the most difficult case, the care team continues to provide full treatment, and if the patient stops breathing, CPR must be performed. In most cases, if the patient is terminal, CPR may serve to do further harm to the patient with little chance of full recovery. In this case, physicians might be faced with the difficult task of considering invoking medical futility. As described above, invoking futility is a difficult case for all: the patient (even if unconscious), family members, and the health-care team. Consequently, this is the least attractive alternative for all parties, but is well within the realm of U.S.-based care.
- Continue aggressive care with a DNR: with the progression of a terminal illness, the patient is likely to die. It is contingent on the care team to work with the family to

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<sup>371</sup> Ibid., 1031.

maintain good communication and provide supportive care to the patient and family members.

- Withdraw aggressive care: eliminating nonbeneficial treatments must be accompanied by good hospice care in order to minimize suffering. Benefits from a good hospice include: educating the family about the disease trajectory; recognizing and supporting family grieving; advance planning for expected losses; and addressing guilt.<sup>372</sup>

In the U.S. health-care system, the emphasis on patient (and surrogate) decision-making autonomy allows any of the above choices to be made. When the patient is unable to make decisions, the difficult task of determining which one is the least onerous and most in keeping with the patient's wishes falls to the surrogate(s). The role of the care team is providing the best possible information at various decision points, while supporting the patient and family members throughout the decision-making process. As Sharon Kaufman notes, in today's highly technical health-care environment, patient autonomy is typically applied at critical decision-making points, and include constraints imposed by the medical institution.<sup>373</sup>

The difficulty in making decisions is that the family may not understand the definition of the terms being discussed by the health-care team. As noted previously, families are frequently asked if they want to continue to "do everything", to which the natural response is likely to be in the affirmative. However, family members frequently do not understand what this means. To provide an educational opportunity as part of *The Conversation Project*, Dr. Angelo Volandes, began providing tours of the ICU to show patients with potentially life-threatening disease processes what might occur. On the first tour with a terminally ill individual and her spouse

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<sup>372</sup> Joseph Klager et al., "Huntington's Disease: A Caring Approach to the End of Life," *Care Management Journals* 9, no. 2 (June 2008): 78.

<sup>373</sup> Kaufman, *And a Time to Die*, 28-29.

considering care options, an ICU patient happened to code, and Dr. Volandes responded, asking the visitors to wait elsewhere. Upon returning to the family, he apologized for the interruption but was assured that the visit was helpful. The next day, Dr. Volandes learned that the patient had returned home with hospice care.<sup>374</sup> He continued to provide tours of the ICU and of dialysis units, but eventually, the visits proved to be burdensome for the hospital staff even when done during quieter evening times. Instead, Dr. Volandes made a series of videos of different medical events for showing to patients (or surrogates) and their family members. After viewing these videos, 92 percent of the patients opted for comfort care, none of the patients elected life-prolonging care, and a few decided to pursue limited medical treatment.<sup>375</sup> Numerous studies have replicated these results for various disease processes, pointing to the importance of educating patients, surrogates, and family members on the actual occurrence in a critical-care setting. In a randomized control trial of 150 patients with advanced cancer, those viewing a video of CPR and intubation were less likely to want to choose CPR than those who had a verbal description.<sup>376</sup> However, there were racial and social differences: 73 percent of white participants chose against CPR, while only 56 percent of nonwhite participants did so. Education had an impact as well, with 70 percent of those with higher than a seventh- or eighth-grade education electing against CPR, while only 40 percent of those with less than a sixth grade education made the election.<sup>377</sup> Even with significant educational efforts, some people may choose to pursue heroic measures. A shortfall with Dr. Volandes' videos is the lack of general

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<sup>374</sup> Volandes, *The Conversation*, Kindle Locations 1064-1079.

<sup>375</sup> Ibid., Kindle Locations 1421-1424.

<sup>376</sup> Angelo E. Volandes et al., "Randomized Controlled Trial of a Video Decision Support Tool for Cardiopulmonary Resuscitation Decision Making in Advanced Cancer," *Journal of Clinical Oncology* 31, no. 3 (January 20, 2013): 380.

<sup>377</sup> Ibid., 384.

availability. While the videos are on a website, at this juncture, only physicians are able to gain access.

Emphasizing education among the citizenry has been shown to be effective. In LaCrosse, Wisconsin, Gundersen Health System implemented a community-wide educational effort to increase the number of people completing Advance Directives. At this juncture, 95 percent of individuals who die in the area have the directives in their medical file, substantially higher than the national average of one-third of individuals found in the Pew Research cited previously.<sup>378</sup> Educating the populace on the importance of understanding how the health-care system functions and ways of expressing one's wishes is important and can help improve health care, including costs. The program, titled *Respecting Choices*, is available to the general public, but detailed materials must be purchased, which may limit their accessibility. Consequently, there is a need to not only inform community members about issues but also to make resources available.

## Conclusion

The concept of personhood provides the means for expanding ethical considerations beyond the person's physiological condition(s), acknowledging that humans are more than the bodies that they inhabit. The multiple perspectives demonstrate the multiple factors considered to be a person, although each one includes acknowledgement that some form of consciousness is necessary. At the present time, personal autonomy plays a large role in health-care decision making. Once that capacity is lost, MPOA or legal surrogate assumes the responsibilities for fulfilling the patient's wishes. The case and scholarly press demonstrate that this is not always

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<sup>378</sup> Chana Joffe-Walt, *The Town Where Everyone Talks About Death* (Washington DC: National Public Radio, March 5, 2014), <http://www.npr.org/sections/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis> (accessed June 5, 2016).

easy: wishes are not always clear or family members may not choose to follow them. At the very worst case, medical futility may need to be invoked, which is likely to be a cumbersome process, and may cause further stress on families.

Research indicates individuals using ACP and completing Advance Directives are more likely to forego nonbeneficial care when facing terminal illnesses. However, while the number of people completing written documentation of their preferences has increased, most do not, nor do they discuss those wishes with family members. When serving as a hospital chaplain, I worked with many people to complete the documents. At the time, it was surprising to me how few people knew about their ability to express their wishes in writing. The IOM's report suggests that meaningful conversations about end-of-life care are not occurring often enough, resulting in too many patients receiving aggressive and costly care at the end of life. The IOM offers recommendations for addressing this problem, including: improving patient-clinician communication, ensuring clinician education, and informing the public about end-of-life planning. Much attention has been given to the first two needs. Fewer activities are geared towards increasing public understanding and the need for ACP. The IOM acknowledges that increasing public education encompasses three tasks: building public support for constructive public policy; raising public awareness at the community and family levels; and at the individual level in order to promote completion of documentation and holding discussions with family members.<sup>379</sup> Within the past ten years, the concept of allowing physicians to be paid for speaking with their patients about their end-of-life wishes was described as "death panels" that would be making decisions for individuals. Fortunately, rules have now been enacted to allow

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<sup>379</sup> Institute of Medicine, *Dying in America*, S14.

physicians to bill Medicare when speaking with their older patients about ACP.<sup>380</sup> Nevertheless, more education is needed to inform the public of the complexity of health care treatments and the need to consider their wishes and to discuss those preferences with family members. Experience shows that this increases the number of people articulating their wishes in writing, which has additional benefits of reducing nonbeneficial care and might also reduce health-care costs.

The challenge is identifying the means for improving public education about health care, aging, and end-of-life planning. It is clear from the data that some groups are less likely to apply this model of decision making. Thus, it is important to design a means of public education that allows individuals to speak to those within their own communities. Having a safe place to engage in discourse about the health-care system in general and the implications for personal treatment choices is critical to expanding understanding about the importance of ACP, both for one's own peace of mind and for the benefit of the community at large. It is apparent from the Gundersen Health Care experience in Lacrosse, Wisconsin, that one way of doing this is by individualized instruction from a health-care professional. The disadvantage of this approach is the lack of speed and expense in implementing the program across large, diverse communities with differing needs. From a health-care policy perspective, one approach is the application of the deliberative democracy model, engaged through the implementation of Community Bioethics Dialogues. The next chapter will consider this approach and provide a model for implementation.

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<sup>380</sup> Centers for Medicare and Medicaid Services, *Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016* (Washington DC: Federal Register, November 15, 2015), <https://www.federalregister.gov/articles/2015/11/16/2015-28005/medicare-program-revisions-to-payment-policies-under-the-physician-fee-schedule-and-other-revisions> (accessed June 6, 2016).

## Chapter 5. Community Bioethics Dialogues as an Educational Platform

If we are ever to make progress toward creating policy that incentivizes physicians to engage in constructive end of life conversations, we need to do so in a way that appeals to the shared values of those across the political spectrum.<sup>381</sup>

Patient autonomy has become one of the hallmarks of contemporary bioethics. The ability to make choices regarding one's health-care treatments, including the decision to discontinue or limit treatments, is central to the exercise of autonomy. Much of the present discourse is associated with educating and empowering physicians to have difficult conversations with patients and families regarding the limits of health care treatments. Concurrent with this conversation, it is necessary to help individuals understand their role in making health care treatments. The recent case of Chris Dunn, stricken with several serious conditions including pancreatic cancer and end-stage liver disease, in Houston shows the importance of patients and families understanding the limits to health care. Dunn's family engaged the services of a right-to-life organization to fight the hospital's position that continued treatment would not be beneficial.<sup>382</sup> As described in the previous chapter's discussion of health-care futility under Texas law, the hospital took the steps to inform the family of the prognosis, engaged the ethics committee, and searched for alternative hospitals that would accept Dunn.<sup>383</sup> The family maintained that Dunn was being discriminated against and that prominent citizens would not be placed in the situation of having futility declared.<sup>384</sup> This case

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<sup>381</sup> Nicole M. Piemonte and Laura Hermer, "Avoiding a "Death Panel" Redux," *Hastings Center Report* 43, no. 4 (July-August 2013).

<sup>382</sup> Dylan Baddour, "A Right-to-Life Fight over Man's Fate," *Houston Chronicle*, December 18, 2015, B1.

<sup>383</sup> Allan Turner, "Man Dies While Awaiting Hearing," *Houston Chronicle*, December 24, 2015, B1.

<sup>384</sup> Baddour, B1.

demonstrates multiple points that have been discussed thus far, including the need for families and caregivers to have good communication and the occasional absence of understanding of the limits of health care. It is apparent that the family did not trust the system to take good care of the patient, nor had the patient considered what his treatment preferences might be in the event of a critical illness. Dunn's case is just one example of a myriad of issues that arise with the current system. Little opportunity is available for the general public to study and discuss the health-care system in general or the issues associated with aging and the end of life in particular. When thrust into the role of decision-maker, families may receive a variety of messages that are not clear or conflict, and not know the ways to ask questions to get clarification.

In considering treatment options, the economics of health care are complex and expensive. Expenditures for health care in the United States are expected to increase by 5-6 percent per year through 2020. Part of the growth is attributed to the implementation of the Affordable Health Care Act; the remainder is a result of general cost increases.<sup>385</sup> A portion of the general increases is associated with the aging population. As an example, 67 percent of people who die are older than sixty-five, and 48 percent of those deaths occur in acute care hospitals. Of those who die, 63 percent use hospitals during their last year of life, and a considerable portion of these expenditures are incurred in an ICU setting.<sup>386</sup> The aging population will increase the burden on health expenditures for the Medicare age group that is growing. The costs are inflated by ICU days: among those sixty-five and older, 44 percent of

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<sup>385</sup> Cms.Gov, *National Health Expenditure Data* (Baltimore, Maryland: Centers for Medicare & Medicaid Services, 2016), [https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/index.html?redirect=/NationalHealthExpendData/25\\_NHE\\_Fact\\_Sheet.asp](https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/index.html?redirect=/NationalHealthExpendData/25_NHE_Fact_Sheet.asp) (accessed June 5, 2016).

<sup>386</sup> Anne A. Scitovsky, "'The High Cost of Dying': What Do the Data Show?," *The Milbank Quarterly* 83, no. 4 (December 2005): 828.

ICU patients account for 56 percent of days.<sup>387</sup> At an average cost of \$2,600 per day, the number of patients increased from 2.1 million in 1994 with an average stay of 4.15 days to 2.9 million patients in 2004 with an average stay of 4.26 days.<sup>388</sup> Overall, studies indicate that Medicare patients who die account for 30 percent of expenditures, nearly 80 percent of which occur in the final month of life.<sup>389</sup> These factors are contributing to Medicare cost increases, and are not likely to decline as the population ages. While economics are not the sole issue for fostering conversations about the end of life, the economic drivers are sufficiently compelling to understand that any health plan policy needs to consider costs. One way of controlling costs without imposing forced rationing is increasing community understanding of the death-prolonging measures that occur in the ICU. These data are provided solely as an example of the issues associated with health-care costs, not to switch the focus to economics. Suffice it to say, the economic issues are complex, and an understanding of patient-centered outcomes in health care includes the consideration of costs, many of which occur at the end of life.

In the report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, the IOM identifies needs for both health-care providers and health-care users. On the caregiver side, the IOM notes that knowledge gains have been significant regarding good end of life care, but this understanding has not been transferred to all levels of the infrastructure and community, resulting in the need for general practitioners and other specialists

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<sup>387</sup> Eric B. Milbrandt, Alexander Kersten, Malik Rahim, Tony T. Dremsizov, Gilles Clermont, Liesl M. Cooper, Derek Angus, Walter T. Linde-Zwirble, "Growth of Intensive Care Unit Resource Use and Its Estimated Cost in Medicare," *Critical Care Medicine* 36, no. 9 (September 2008): 2504.

<sup>388</sup> *Ibid.*, 2506.

<sup>389</sup> Kevin B. O'Reilly, "End-of-Life Care Provision Stirs Angst in Health Reform Debate," *American Medical News* (August 24, 2009). <http://www.ama-assn.org/amednews/2009/08/24/prsa0824.htm> (accessed June 5, 2016).

to assume the responsibility for communicating options.<sup>390</sup> For health-care users, three levels are identified: at the societal level, to understand policy needs and have the means for sustaining good health care practices; at the community and family level, in order to understand care options at the end of life; and at the individual level, to expand advance care planning and promote meaningful conversations regarding options.<sup>391</sup> The experience with the discussions of death squads that occurred at the onset of the Affordable Care Act demonstrates the importance of educating both health-care providers and the public on the need for good medical care and its limits. The process of educating health-care providers is being addressed by many, and is not the objective of this dissertation. Rather, I focus on the importance of educating the public, and offer one means, through Community Bioethics Dialogues.

Over the past few decades, a movement has surfaced which re-introduces the concept of having thoughtful conversations about topics of general interest. As noted in the introduction, deliberative democracy is a process for sharing information and conversations about key issues in different types of venues. It reintroduces the concept of *sermo* for topics covering general information and has been used in a variety of formats. While features (participant selection, number of participants, meeting frequency) vary, common components include providing information about the issue, with opportunities for open discussion of all sides of an issue prior to making a recommendation for action. The process enables a particular topic to be explored in detail, expressing the community's values, identifying various perspectives, and making recommendations for policy.

In this chapter, I provide a discussion of deliberative democracy through Community Bioethics Dialogues as a platform for educating the public on health care, aging, and end-of-life

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<sup>390</sup> Institute of Medicine, *Dying in America*, S-10.

<sup>391</sup> *Ibid.*, S-14.

planning, proposing that this practice provides a consequential way of encouraging open discussion within a particular community that can extend to the familial and individual level, meeting the need for community education identified by the Institute of Medicine. By actively educating the populace on matters of health care and how these apply to their personhood, Community Bioethics Dialogues empower users to be more active participants in health planning, including in issues associated with the end of life.

In evaluating the opportunity that Community Bioethics Dialogues provide, I examine key features and characteristics of deliberative democracy that underlie the process of conducting community bioethics dialogues; required elements for the dialogues; experiences with various dialogues held in Galveston, Texas; and options for implementing the model in additional settings.

### **Key Features and Characteristics of Deliberative Democracy**

Present-day society is complex, with people facing health-care issues faced as the product of capabilities not available to prior generations. As has been the case through human history, everyone will die, but the circumstances under which this occurs have changed dramatically. Harvard medical professor and surgeon Atul Gawande notes that during the first half of the twentieth century, hospitals were largely custodial, a situation which changed dramatically with the advent of medications, procedures, and equipment:

From World War II onward, the picture shifted radically. Sulfa, penicillin, and then numerous other antibiotics became available for treating infections. Drugs to control blood pressure and treat hormonal imbalances were discovered. Breakthroughs in everything from heart surgery to artificial respirators to kidney transplantation became commonplace. Doctors became heroes, and the hospital transformed from a symbol of sickness and despondency to a place of hope and cure. Communities could not build hospitals fast enough. In America, in 1946, Congress passed the Hill-Burton Act, which provided massive amounts of

government funds for hospital construction. Two decades later the program had financed more than nine thousand new medical facilities across the country. For the first time, most people had a hospital nearby, and this became true across the industrialized world.<sup>392</sup>

The improvements in medical treatments are a double-edged sword. On the one hand, disease processes that were previously fatal can now be managed with treatments, sometimes for a period of years. At the same time, medical treatments are also able to maintain the physical body long after consciousness and personhood have been compromised or have ceased to exist. The availability of medications and machinery that can extend biological life almost indefinitely requires an educated populace regarding care, treatment options, and the limits of technology. Recipients of health care need to understand the options and limitations for various treatments, particularly at the end of life, and in many cases, this is missing. As previously noted, research by Dr. Silveira concludes that these recipients of health care do not understand their options completely, and may be caught in a system where the technicalities of treatment options are not made clear.<sup>393</sup> This finding is confirmed by my experiences as a hospital chaplain, while the lack of understanding about treatment options is exacerbated by the specialization of body parts; the plethora of specialists attending to the patient may provide conflicting reports on the different body organs and systems while not addressing the overall person, and family members are left in a state of confusion without knowing the questions to ask. Moreover, the outcomes are not explained in the perspective of an individual's personhood—it is not made clear that the ramifications of being on permanent life support will not allow the individual to pursue the activities that have given them joy.

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<sup>392</sup> Gawande, *Being Mortal*, 69.

<sup>393</sup> Silveira et al., "Patients' Knowledge of Options at the End of Life: Ignorance in the Face of Death," 2487.

Physicians also face challenges in discussing end-of-life issues. As an example, Daniel Sulmasy, professor of medicine and ethics at the University of Chicago, led a team that studied the confidence that physicians have in discussing Do Not Resuscitate (DNR) orders with patients and their families. While 78 percent of physicians expressed confidence in discussing “routine medical procedures,” only 57 percent felt confident in “talking to patients and their surrogates about DNR orders,” with lower percentages for in-house officers (versus attending), women (versus men), and younger practitioners.<sup>394</sup> Sulmasy concludes that ongoing assessment is required to identify communications needs, and additional training is needed for health-care professionals at all experience levels.<sup>395</sup> Other researchers have identified the absence of formal training in end-of-life care and the need for jargon-free communications with families during discussions. Based on these examples, education is needed for health-care providers and health-care users. In this dissertation, I am suggesting that Community Bioethics Dialogues, a form of deliberative democracy, provide a viable platform for educating the populace on these complex issues. St. Louis University professor James Bohman defines deliberative democracy as “any one of a family of views according to which the public deliberation of free and equal citizens is the core of legitimate political decision making and self-government.”<sup>396</sup> The intent is to validate the importance of public dialogue as recognition that the public vote is not the only means of understanding private preferences.<sup>397</sup> Considered, informed, respective dialogue provides the means for evaluating various aspects of social, political, and ethical issues, invoking *sermo* instead of less productive forms of communication. When groups of people congregate for the

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<sup>394</sup> D. P. Sulmasy, J. R. Sood, and W. A. Ury, "Physicians' Confidence in Discussing Do Not Resuscitate Orders with Patients and Surrogates," *Journal of Medical Ethics* 34, no. 2 (February 2008): 98.

<sup>395</sup> *Ibid.*, 100.

<sup>396</sup> Albert W. Dzur, "Democratic Professionalism: Sharing Authority in Civic Life," *The Good Society* 13, no. 1 (2004): Kindle Locations 163-165.

<sup>397</sup> *Ibid.*, Kindle Locations 166-68.

purpose of reasoned discussion, it is possible to identify core values, even if there is disagreement. University of Pennsylvania president and political science professor Amy Gutmann and Harvard government professor Dennis Thompson have written extensively on deliberative democracy. In the book, *Why Deliberative Democracy?*, Gutmann and Thompson identify the following purposes for deliberative democracy: “promote the legitimacy of collective decisions;” “encourage public-spirited perspectives on public issues;” “promote mutually respectful processes of decision-making;” and “help correct” errors from prior decision making efforts.<sup>398</sup> The latter point is critical—few issues are resolved permanently, so it is important that a platform be kept open for ongoing discussions. I also propose that the term “citizen representatives” needs to be broader to include non-citizen constituents, as all are affected by the decisions that are being debated. Some individuals lack the ability to vote but are still affected by policy-making, so those voices need to be included.

In the case of the proposal to provide payment to physicians for discussing end-of-life care preferences, open dialogue might have consisted of various forums around the country where different groups would have the opportunity to hear the reasoning for the proposal, learn more about the issues, discuss the options, and provide a recommendation to lawmakers. If this had been accomplished prior to the passage of the Affordable Care Act, there might have been a different outcome, with decisions made based on reasoned consideration instead of emotional responses. The path the process takes is important. As noted by Bowling Green State University political science professor Albert Dzur, it is necessary that the participants be rational, respect each other, and treat the process with integrity:

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<sup>398</sup> Amy Gutmann and Dennis Thompson, *Why Deliberative Democracy?* (Princeton, New Jersey: Princeton University Press, 2004), 10.

- Rationality requires that evidence and reason be used to support positions.<sup>399</sup>
- Respect serious consideration for the positions presented by others.<sup>400</sup>
- Integrity necessitates that all participants present positions with merit and consider them in the light of others' arguments.<sup>401</sup>

Only when people have a safe space to consider key issues and matters are discussed in a calm environment where all voices are respected can it be possible to consider different perspectives. Health care is a complex subject, as many have been underserved and significant efforts are needed to help those with different perspectives understand the various issues that are present in evaluating and selecting treatment options. The need to have educational discussions is prior to the time that critical services are needed or decisions need to be made. At that juncture, it is difficult to stop and explain the complexities of the system. People need to be informed prior to the time that decisions need to be made, and having constructive decisions in a safe space can be invaluable to helping people to become their own best advocate.

Instead of characterizing physician discussions with individuals as “death panels,” a forum for discussing critical issues and values might have been valuable. The discussion attendees would be expected to prepare by reading views from various perspectives that could be discussed in public forums, and exchange ideas having merit that might be considered and discussed, understanding the various advantages and disadvantages.

As Gutmann and Thompson note, deliberation allows participants to expand their own knowledge base while discussing issues.<sup>402</sup> The conversation thus serves as a means for

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<sup>399</sup> Albert W. Dzur, *Democratic Professionalism: Citizen Participation and the Reconstruction of Professional Ethics, Identity, and Practice* (University Park, Pennsylvania: The Pennsylvania State University Press, 2008), Kindle Locations 178-180.

<sup>400</sup> Ibid., 182-183.

<sup>401</sup> Ibid., 184-185.

educating individuals in order to clarify their values and options for expressing them. For health care, the discussions would serve as the platform for educating the populace about the complexities of modern technology in medicine and assisting in dispelling notions of distrust about the specific topic, including the medical system in general. At the same time, the opportunity to empower individuals to ask questions is an important element in promoting autonomy that is based on knowledge. The means of accomplishing this, including an example, will be discussed in the following section.

### **Requirements for Deliberative Democracy**

Providing an open forum on discussing various issues allows participants to consider aspects of different issues, and identify areas of consensus and points of divergence. This information can be used in developing policy at the local, regional, and national levels. Gutmann and Thompson identify the primary aim for deliberative democracy as justifying “decisions and laws that citizens and their representation impose on one another,” aiming “at least at a thin conception of the common good.”<sup>403</sup> Since the development of knowledge is a process and not a product, it is important to provide the means of communication on an ongoing basis. Gutmann and Thompson believe that different decisions and related processes are accommodated by deliberative democracy, with its open-ended nature allowing the process to challenge earlier decisions.<sup>404</sup> Achieving this goal necessitates a number of qualities that are illustrated by a *Community Bioethics Dialogue on Patient-Centered Outcomes Research and Comparative Effectiveness Research (CER)* conducted during the past two years in Galveston, Texas. Four

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<sup>402</sup> Gutmann and Thompson, *Why Deliberative Democracy?*, 12.

<sup>403</sup> Ibid., 27.

<sup>404</sup> Ibid., 19.

different groups have met in dialogues thus far: (1) representatives from St. Vincent's Clinic, a largely African-American, lower-economic-status community; (2) a combined group representing the Galveston Alliance of Island Neighborhoods (GAIN) and the Galveston Citizens Police Academy Alumni Association (CPAAA), a mix of two more affluent white communities; a group formed by the Galveston Island Community Research Advisory Committee (GICRAC), an organization that serves as a gatekeeper for health research in the African-American community; and a local group sponsored by the League of United Latin American Citizens (LULAC). It is important to note that one particular demographic facet was constant—all members were over age 65, since that was specified in the grant that funded the research. The four groups that discussed *Patient Centered Outcomes (PCOR)* and *Comparative Effectiveness Research (CER)* met the criteria identified above: participants were provided with readings and recordings summarizing the issues, with groups meeting in two-hour sessions each week for six weeks. A facilitator selected by each of the groups led the discussions, providing an opportunity for all voices to be heard. During the final week, each group summarized the values that had been discussed and prepared a report that was presented at a public forum and posted on the University of Texas Medical Branch (UTMB) PCOR website. The groups are encouraged to take the report and identify matters of critical importance with community leaders, lawmakers, as well as family and friends.

As an extension of these dialogues, one small group from GAIN/GCPAAA met in November 2015 to discuss aging and end-of-life issues. Two groups (a mix of participants from St. Vincent's and GICRAC and another from GAIN/GCPAAA) met in January and February 2016 to discuss mental health issues among the senior populations. In the feedback from the first round of dialogues, the groups decided that they wanted to include expert instruction on the

topics, and invited individuals with expertise on mental health issues to provide an additional one-hour lecture prior to the time of discussion.

These dialogues have achieved a number of important concerns in providing for a model of deliberative democracy: public education, accessibility, respect for the process, and integrating various cultural and religious perspectives. Furthermore, the individuals' experiences inspired them to want to consider future topics as well as share outcomes with family and friends.

### **Public Education**

The first element required to implement a deliberative democracy model is public education, to support Michigan State University philosophy professor and ethicist Leonard Fleck's position that discussions be supported with accurate scientific information.<sup>405</sup> For deliberative democracy to work, participants must be willing to expand their understanding of the issue being discussed and able to engage in dialogue on various perspectives. In the Community Bioethics Dialogue in Galveston, all groups were provided with articles and summaries outlining the topics being discussed, as well as recordings of discussions of the issues between project investigators. Although different members had challenges in understanding the materials, the group members worked effectively to educate each other. In addition, the researchers concluded that they would re-work the materials to reflect a "third- to eighth-grade reading level" in order to facilitate understanding.<sup>406</sup> This was accomplished for the second round of dialogues, and it is apparent that this is a matter of continuing concern. As an example,

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<sup>405</sup> Howard Brody, *The Future of Bioethics* (New York: Oxford University Press, 2009), 94.

<sup>406</sup> Howard Brody et al., "Ethical Issues in Patient-Centered Outcomes Research and Comparative Effectiveness Research: A Pilot Study of Community Dialogue," *Journal of Empirical Research on Human Research Ethics* 10, no. 1 (January 2015): 28.

in order to help participants expand their understanding of terminology, a glossary was provided for both the PCOR and Mental Health rounds.

One of the challenges is in the use of technology. The researchers conducting the first round of the dialogues found that the group representing lower socioeconomic individuals was not as likely to have access to computers and technology resources. As a result, this group was less likely to conduct their own research on the topics being discussed and obtain access to additional information and perspectives.<sup>407</sup> One of the methods for deliberative democracy is using web-based dialogue sessions, so a system that relies solely on technological means for discussion and advocacy would exclude a portion of the populace. This becomes an argument for expanding public access to technology, which while a consideration with Community Bioethics Dialogues, is beyond the scope of this dissertation. It is a matter to be considered when establishing future dialogue groups.

### **Accessibility**

Building on the earlier theme, deliberative democracy must be accessible to a variety of people. Even though citizens are the only individuals allowed to vote, health care affects all individuals, so the process should not be limited to citizens. Different perspectives have been presented among those who promote deliberative democracy. Dzur notes that accessibility to the process requires hearings and open public forums for all citizens affected by a decision.<sup>408</sup> However, Dzur does not identify what portion of the citizenry need be involved in order to constitute an acceptable quorum. In reality, it is not reasonable to believe that every person in an area affected by a decision would be able to participate in deliberating a particular issue. An

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<sup>407</sup> Ibid.

<sup>408</sup> Dzur, *Democratic Professionalism*, Kindle Locations 196-199.

additional obligation is proposed by University of Pennsylvania political science professor Jack H. Nagel, who narrows the obligation by requiring that representatives be chosen systematically in order to meet representational goals.<sup>409</sup> Furthermore, Nagel believes that participants in a given group should have a similar socioeconomic status, believing that group discussion is less inhibited when members “have similar socioeconomic status.”<sup>410</sup> Having access to deliberative processes provides an opportunity for representatives from many different groups to participate. Grouping people by roughly equivalent standings may open the process to be more equitable so that no one is overwhelmed or intimidated by other group members.

The approach taken by the state of Oregon during the *Oregon Health Decisions (OHD)* process provides an example of how the process can be compromised. Meetings were set up to allow participants to discuss ways of addressing health disparities by prioritizing various health treatments. In the initial “grassroots” meetings, most of the participants were not only well-educated, but also involved in health care, limiting the amount and diversity of representation that was achieved. Very few current Medicaid recipients (less than 5 percent) were represented at the meetings. The Health Service Commission (HSC) subsequently commissioned an extensive telephone survey of more than 1,000 respondents and used that data to prioritize the medical services, a list that was considered to provide more equitable representation of the community and those who might specifically be using the provided health-care services. Over time, the list has been refined, and service recipients have been polled on their opinions about the services, with the result that overall, there is satisfaction with system’s implementation.<sup>411</sup> The effort to include more people in the decision process without including everyone is supported by

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<sup>409</sup> Jack H. Nagel, "Combining Deliberation and Fair Representation in Community Health Decisions," *University of Pennsylvania Law Review* 140, no. 5 (May 1992): 1980-1981.

<sup>410</sup> *Ibid.*, 1982.

<sup>411</sup> *Ibid.*, 1975-1979.

Dzur, who notes that “public opinion be formed on the basis of adequate information and relevant reasons and that those whose interests are involved have an equal and effective opportunity to make their own interests (and the reasons for them) known.”<sup>412</sup> Fundamental to the process is allowing all stakeholders to have a voice. In difficult cases, it may be impossible to please everyone, although having general acceptance of the decisions is more likely if those affected consider themselves to have a voice in the outcome.

In the Galveston dialogues, four different groups representing different ethnicities and socioeconomic standing have met. Despite the variety of representatives, all of the area’s ethnicities have not been represented. Over time, it would be important for an essential topic such as health care to be made available to a variety of groups, and means of doing this will be addressed later. Having more voices engaged in the activity will provide more opportunities for the issues to be discussed and understood. As is apparent from the experiences in Oregon, providing an opportunity to access information is a key means of educating the populace.

### **Respect for the Process**

Those who accept the responsibility of participating in any deliberative activity must be willing to respect the process. While disagreement is permitted, regard for differing viewpoints must be maintained. Gutmann and Thompson set the requirement that participants be willing to provide each other with valid reasons for justifying adopted laws and policies, employing the term *reciprocity* and including four standards: “reasons that are accessible, moral, respectful, and revisable.”<sup>413</sup> While citizens are permitted to have moral disagreements about public policy, they must deliberate from a perspective that mutual respect is maintained even when disagreeing

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<sup>412</sup> Dzur, *Democratic Professionalism*, Kindle Location 394.

<sup>413</sup> Gutmann and Thompson, *Why Deliberative Democracy?*, 139.

on policies.<sup>414</sup> This requires effective facilitation of the process so that all communications are respectful. In the Galveston dialogues, facilitators set ground rules at the beginning of each series that allowed opinions to be expressed openly while having respectful boundaries. According to the exit survey held at the end of the six-week sessions, it is believed that everyone felt they had the opportunity to be heard.

### **Cultural and Religious Differences**

In addition to respecting the deliberation process, individual cultural and religious differences must be considered. Fleck articulates this within the context of health care, specifying that “we cannot permit any coerced health care bargains.”<sup>415</sup> Some discussions may benefit from having different groups with a variety of backgrounds for the purpose of comparison. The Galveston dialogues were somewhat homogeneous, although different economic backgrounds were held by participants within the groups. One of the considerations for future dialogues is testing the prospects for having groups with a variety of cultural backgrounds. At the same time, discussions with a colleague about extending the dialogues into the Korean community expressed the limitation that it would need to be homogeneous, with a Korean facilitator. These are perspectives that I would like to examine in future research.

### **Engagement Availability**

Participants must be available to engage in dialogue, which means that they must be willing to learn about the issue(s) and have the time to explore various perspectives. In order to

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<sup>414</sup> Ibid., 142.

<sup>415</sup> Leonard M. Fleck, *Just Caring: Health Care Rationing and Democratic Deliberation* (New York: Oxford University Press, 2009), 193.

offset this issue, Nagel believes that participants should be compensated for their time and trouble.<sup>416</sup> This raises other issues, including the budget to pay participants and assuring that those who engage with the process are not just doing so for the money. A related position is offered by Dzur, who proposes the establishment of a specific “Deliberation Day” that establishes a specific time when citizens are provided a paid day off from their normal work to participate in discussions.<sup>417</sup> This may not always be possible. In the Galveston dialogue, participants engaged in a two-hour meeting each week for six weeks, with modest payment of \$20 per event, and a bonus for completing all sessions. It should be noted that participants did not attend because of the payment, but for some, it validates the importance of their time. The members of the GAIN/GCPAAA group used the funds to support their respective organizations. Participants in the smaller group that met in November to discuss aging and end-of-life issues were not paid—the participants engaged because of the importance of the topic and their willingness to help this researcher. The only active interest in compensation was communicated by one of the African-American groups, who asked “When will we be paid?” following the completion of the last session. Compensation for participation should be geared to the needs of the particular group and available funding.

### **Skilled Facilitation**

Deliberations need to be facilitated by someone who is skilled at eliciting thoughtful responses from the participants, and able to manage the discussions so that ideologues’ voices do not shut down thoughtful dialogue. Fleck believes that the facilitators should be specifically

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<sup>416</sup> Nagel, “Combining Deliberation and Fair Representation,” 1981.

<sup>417</sup> Dzur, *Democratic Professionalism*, Kindle Locations 381-386.

trained in ethical discourse.<sup>418</sup> These facilitators must assure the fair treatment of all representatives. While it may not always be possible for the facilitators to be of the same cultural, religious, or socioeconomic status of the group that is meeting, it is important the leaders must be sensitive to the variety of health care experiences incurred by various members. In the Galveston dialogues, all groups were culturally, although not necessarily economically, homogeneous; in two of the four larger sessions, the group selected their own facilitator who was trained, while all of the GAIN/GCPAAA sessions used one of the researchers as the facilitator. In all cases, the intent was to provide adequate facilitation from someone able to allow all views to be heard in a respectful manner. As noted previously, different ethnic groups may have their own facilitation needs, which should be considered in the planning process as the offering of dialogues expands.

### **Additional Communications**

Results from the discussions must be communicated to the community at large, including various positions that have been discussed. Fleck emphasizes the importance that all of the reasons behind a decision be made public, not just the outcome.<sup>419</sup> By maintaining open communications, it is more likely that the outcome of the process can be respected and accepted by those who may not agree with specific decisions. The Galveston dialogues have benefited from press in the local news outlets, a website with public availability of both reports, publications in scholarly journals, and presentations at various national professional meetings. The groups have discussed various means of disseminating their knowledge to family, friends,

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<sup>418</sup> Brody, *The Future of Bioethics*, 94.

<sup>419</sup> Fleck, *Just Caring*, 185.

and others. As an example, two of the GICRAC group members are working with their church to prepare an information pamphlet on the changes that occur when one reaches the age of 65.<sup>420</sup>

A substantive representation of those affected by the pertinent issues who are engaged in thoughtful, educated dialogue can provide the necessary platform and discussion of issues. Using the experience of the Oregon Health Decisions (OHD) initiatives, once the information-gathering effort expanded, there was sufficient good information in developing the prioritization list so that there were no major implementation issues. Those affected felt that they had a voice and more importantly, expressed satisfaction with the services that were ultimately made available as the result of the discussions. The OHD plan met one goal of expanding health-care services to the uninsured; however, cost control efforts were not realized with the expanded service base, resulting in continued health plan revisions. The Community Bioethics Dialogues in Galveston demonstrate the importance of providing a safe place for discussing health-care issues and values. Understanding health care options and Advance Care Planning provide topics that should be applied to deliberative processes. The subject of health care affects everyone, and policy issues are complex and ever-changing. By offering individuals the opportunity to discuss issues and values in a reasoned forum, more voices can be heard in the development of health-care policy. The challenge is to have a forum that incorporates many people with different backgrounds and perspectives into the discussions, with objective information available to use in educating participants. The remainder of this chapter will summarize the methodology and address the specific results from the various dialogues to demonstrate the types of information

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<sup>420</sup> Galveston Island Community Research Advisory Committee, *Community Bioethics Dialogue: Patient-Centered Outcomes Research* (Galveston: Partnership between Galveston Island Community Research Advisory Committee and the Institute for the Medical Humanities, University of Texas Medical Branch, 2015), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016).

that can be made available and the types of values that the groups have identified as being critical for the health-care system in general and Advance Care Planning in particular.

## **Implementing Community Bioethics Dialogues**

Implementing a Community Bioethics Dialogue program requires several elements: a topic of interest to a particular group, a sponsor, a knowledgeable facilitator, a timeframe, and a place to meet. Any group can sponsor a dialogue session. Likely candidates include community groups, churches, and adult education offerors, to name a few. Once a sponsor is identified, they can recruit a facilitator and members who would like to participate, as well as a place for the group to meet regularly. The resource requirements for sponsoring community dialogues are relatively simple. In this section, I will present additional information on the dialogues in Galveston, providing a discussion of the format that was used and the lessons learned; identify some of the specific values that came out of the dialogues that we have held thus far; and provide a curriculum that could be used by different groups in establishing their own Community Bioethics Dialogues on the health-care system in general and end-of-life planning in particular.

The Community Bioethics Dialogues conducted in Galveston, Texas, have spanned a period of two years as part of a major project on PCOR and CER in the elderly conducted at the University of Texas Medical Branch–Galveston (UTMB).<sup>421</sup> These dialogues were completed as part of the AHRQ grant. According to the terms of the grant funding the project, the first rounds of dialogues addressed these PCOR and CER in detail. Once the first round was completed, the group members met over a period of several months to consider the next topic for discussion. These sessions included lively discussions that considered a variety of topics. Ultimately, the

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<sup>421</sup> Brody et al., "Ethical Issues in PCOR and CER," 22.

participants selected Mental Health and Seniors as the focus. Between the PCOR/CER and Mental Health topics, an interim round was held with a smaller group composed of volunteers from the GAIN/GCPAAA group devoted to discussing aging and end-of-life issues to augment the work for this dissertation.

Figure 4 defines the groups that completed the various themes of the Community Bioethics Dialogues, as well as the primary demographic characteristic:

*Figure 4. Groups Participating in Community Bioethics Dialogues*

<b><i>Dates</i></b>	<b><i>Group</i></b>	<b><i>Demographic</i></b>
<i>PCOR and CER</i>		
January and February 2014	St. Vincent's House	African American, predominantly lower income
January and February 2014	Galveston Alliance of Island Neighborhoods and Galveston Citizen's Police Academy Alumni Association–GAIN/GCPAAA	White, predominantly higher income
August and September 2015	Galveston Island Community Research Advisory Community–GICRAC	African American, middle income
September and October 2015	League of United Latin American Citizens–LULAC	Latin American, middle income
<i>Aging and End of Life</i>		
November 2015 (Three-week session)	GAIN/GCPAAA	
<i>Mental Health and Seniors</i>		
January and February 2016	Combination of members from St. Vincent's and GICRAC	
January and February 2016	GAIN/GCPAAA	

All members were recruited from the sponsoring organizations, not the organizers from UTMB.<sup>422</sup>

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<sup>422</sup> Ibid., 23.

For the sessions on PCOR and CER with the first two groups, a list of readings was developed. In order to assist the participants with some of the more academic materials, one-page summaries of the readings were offered, as well as audio materials made from interviews between two of the researchers.<sup>423</sup> Based on feedback received from the St. Vincent's and GCPAAA/GAIN participants in the first round, some of the readings and one of the case studies were amended to integrate materials that were more accessible to lay people. When they elected to continue with the dialogues to consider the Mental Health and Seniors theme, the participants also requested that these sessions include experts on the topics (General Mental Health Issues; Brain Decline; Caregiver Issues; Medication Issues; and Downstream Issues) to provide additional insights. In order to allow the additional information to be disseminated, participants elected to extend the dialogues by an hour for each of those sessions so that the total meeting time was three hours per week for the dialogues. The extension worked well, although we concluded that a three-hour session required a break, so refreshments were prepared for the group.

At the end of each of the sessions, participants were presented with lists of values developed from the content of the sessions, and asked to rank them.<sup>424</sup> The groups used the discussions of the values to prepare reports summarizing these results as well as their individual responses to the sessions, with the complete reports posted on UTMB's PCOR website.<sup>425</sup>

In all cases, the research team provided guidance to the facilitators on the materials, helping them to integrate the information effectively. In some cases, we had intensive training, and in others, we met for a period of time each week to discuss the upcoming week's materials.

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<sup>423</sup> Ibid.

<sup>424</sup> Ibid., 23.

<sup>425</sup> See <http://www.utmb.edu/pcor/proj3.asp> for all reports.

We found that all of these methods were equally effective, and honored the time for the individuals who are serving as the facilitators for the groups. It is important to note that in these dialogues, there was a specific research protocol being employed. As a result, UTMB's Institutional Review Board (IRB) approved the overall research process. Groups that are meeting independently and are not as part of a formal research protocol would not need to have this step.

The meeting locations varied for each group. Two different groups (GAIN/GCPAAA) met in church meeting rooms; the St. Vincent's House group met in the conference room at their location; and the LULAC group met in a local Mexican restaurant. The latter was the least favorable meeting environment: the group met after the restaurant closed to the public, and the venue was noisy due to after-hours cleanup in the kitchen and an outdated air conditioning unit that made it difficult for some of the participants to hear the comments from everyone.

From these experiences, these elements are deemed as critical to the success of the dialogues: materials, facilitation, group size, and location, each of which will be discussed in greater detail.

### **Materials**

The initial PCOR/CER themed sessions only used academic journal articles. In some cases, these were too complex for the participants, and the materials for the subsequent PCOR/CER discussions were amended to include readings targeted for a third- to eighth-grade reading level. In addition, one of the case studies was revised to apply a condition common with seniors (meniscus tear of the knee) rather than kyphoplasty. The materials for the mental health round integrated a few journal articles each week with materials published by various specialty groups such as the National Alliance on Mental Illness and the National Alliance for Caregiving. For the three week session on aging and end-of-life issues, Dr. Atul Gawande's best-selling

book, *Being Mortal: Medicine and What Matters in the End*, was supplemented with additional articles.

In establishing dialogues, there is always a balance to be observed in providing accurate materials with those that are readily available and readable. Consequently, the researchers suggest one way to screen the materials is to invite representatives from the group to review the materials prior to starting the dialogues.<sup>426</sup> Every group will need to accept responsibility for disseminating the materials—a binder with tabs to separate the weekly topics has worked well. Each of the participants can also be invited to bring examples from the news in each of the discussions. This is one place where the digital divide appears; while many participants will have access to news sources and the internet, some may not, so the planners need to be cognizant of possible issues. In our sessions, some participants were uncomfortable with technology, so written materials were mailed, and meeting reminders were accomplished via telephone instead of email.

### **Facilitation**

The facilitator should be comfortable with leading a group to allow the conversations to develop in a manner that allows all voices to be heard without imposing his or her own viewpoints. As noted previously, with these dialogues, the groups selected their own facilitators. If the group is culturally homogeneous (e.g., all African-American), ideally, the facilitator will be a member of that group. If the community bioethics dialogues are expanded and made available through a community education group and consists of a variety of ethnicities and socioeconomic backgrounds, this will not be possible, so the facilitator will need to be versed in

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<sup>426</sup> Brody et al., "Ethical Issues in PCOR and CER," 28.

bringing together different viewpoints in the setting. While it is natural that an individual interested in facilitating community bioethics dialogues would have opinions on the different topics, it is important that these be held in abeyance so that all of the group's members can be heard. The facilitator blends skills—they are not an instructor for the group, but they need to be comfortable in explaining definitions while leading the conversation.

### **Group Size**

The optimum group size is twelve to fifteen people, allowing for diverse perspectives to be presented while providing everyone an opportunity to speak. A group larger than fifteen would require a space where the individuals could not necessarily connect with each other, and result in fewer individuals to be able to be heard. A smaller group might present an impediment to having sufficient discussion, although the group on aging and end-of-life only had seven members, and was successful because of the active engagement of each of the individuals.

### **Location**

It is important that the meeting venue accommodate comfortable seating around a table so that all of the participants can see each other when they are speaking. In addition, if possible, the meeting space should have minimal outside noises and distractions, while having a comfortable temperature. Finally, reasonable accommodations should be available for differently-abled individuals. An ancillary consideration is parking convenience and safety, particularly in large urban areas, and access to refreshments for meetings lasting longer than two hours.

## **Compensation**

An advantage of conducting Community Bioethics Dialogues is the minimal resource requirements. As indicated previously in this chapter, Nagel proposes that participants in deliberative democracy groups, of which Community Bioethics Dialogues represent one model, be compensated for their time.<sup>427</sup> In Galveston, as the result of Agency for Healthcare Research and Quality (AHRQ) sponsorship for the primary topics, participants received a modest remuneration for their time (\$20 for each meeting and a bonus for completing all sessions). The participants in the African American and Latino groups accepted the funds personally, and as noted previously, one of these groups was particularly concerned about their compensation. The participants in the white group donated their proceeds to the sponsoring organizations, and considered participation to be part of benefit to the overall community, in addition to learning new material. For the movement to expand, it may not always be feasible to offer remuneration for time. It is more important that the opportunity be provided for groups of individuals to discuss important issues rather than be compensated for their time. The smaller group that addressed aging and end-of-life issues offered no compensation, and everyone who participated did so because the topic was important to them. Overall, I conclude that the ability to compensate participants is a nice feature, but depends on the funding source.

## **Dialogue Outcomes**

A primary advantage of forming Community Bioethics Dialogues is the opportunity to discuss various issues and values in an environment promoted by thoughtful, knowledgeable consideration. As noted in the Introduction to this dissertation, the intent is to have discussion

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<sup>427</sup> Nagel, "Combining Deliberation and Fair Representation," 1981.

among participants instead of having (*sermo*) instead of *oratory*, in which an individual attempts to convince others of their views. In the specific case of the Community Bioethics Dialogues, different themes were discussed over a period of time. Having an understanding of health-care issues provides a better foundation for making decisions from the myriad of options that are available, especially when facing critical decision points such as those occurring at the end-of-life.

### **Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER)**

For the first round of dialogues discussing PCOR and CER, the groups addressed three ethical questions:

- What ought to be the role of PCOR and CER in guiding health policy in the United States?
- How should PCOR and CER function in connection with the physician-patient relationship?
- What role, if any, should commercial interests play in determining PCOR and CER policy?<sup>428</sup>

#### ***Role of PCOR and CER***

All groups agreed that PCOR and CER needed to be implemented in an environment of patient-centered care focusing on the improvement of patient health.<sup>429</sup> The St. Vincent's group

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<sup>428</sup> The key questions were the same for all groups and are documented in the reports, including St. Vincent's House, *Community Bioethics Dialogue: Patient-Centered Outcomes Research* (Galveston: Partnership between St. Vincent's House and the Institute for the Medical Humanities, University of Texas Medical Branch, 2014), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016).

noted that it is especially important for these concepts to be applied fairly to all constituencies. CER should “inform physicians and patients about what treatments work best, so that they can then discuss and mutually agree on the best treatment for the patient’s individual circumstances.”<sup>430</sup>

### ***Function of PCOR and CER***

For PCOR and CER function, all groups agreed that physicians have a responsibility to spend sufficient time with patients, provide full and truthful information about health conditions, and have trusting relationships with patients. At the same time, patients should become informed, be actively involved in treatment choices, and follow care team recommendations, although blind obedience is not considered to be appropriate.<sup>431</sup> In order to ensure that options are understood and considered, the participants identified bringing a trusted friend or family member to key visits as an important tool. Moreover, the sessions helped participants to understand the importance of discussing all aspects of their care with physicians, including end-of-life choices.

An element discussed by all groups was costs, both for general health care and for specifics like medications. The St. Vincent’s group expressed concern that the current system

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<sup>429</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Community Bioethics Dialogue: Patient-Centered Outcomes Research* (Galveston: Partnership between Galveston Association of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association and the Institute for the Medical Humanities, University of Texas Medical Branch, 2014), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016), 4; Galveston Island Community Research Advisory Committee, *PCOR/CER*, 3; League of United Latin-American Citizens, *Community Bioethics Dialogue: Patient-Centered Outcomes Research* (Galveston: Partnership between League of United Latin American Citizens and the Institute for the Medical Humanities, University of Texas Medical Branch, 2015), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016), 3-4; St. Vincent's House, *PCOR/CER*, 4.

<sup>430</sup> St. Vincent's House, *PCOR/CER*, 4.

<sup>431</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 4; Galveston Island Community Research Advisory Committee, *PCOR/CER*, 4; League of United Latin-American Citizens, *PCOR/CER*, 4; St. Vincent's House, *PCOR/CER*, 4.

appears to be more money than patient-centered. As part of this concern, insurers and third-party payers appear to use comparative effectiveness research as a means of policy-making for covered services.<sup>432</sup> The GAIN/GCPAAA group noted that a tiered system is justified for non-urgent health matters, with insurers requiring less costly interventions to be attempted before more costly ones.<sup>433</sup> Other groups considered the cost of medications to be tantamount, believing that costs should not drive the selected medications. As an example, if an individual requires brand-name medicines, they should be offered regardless of cost, with a subsidy provided if the patient is unable to pay the full amount.<sup>434</sup> Several of the groups were also concerned that the government meet its obligations to protect individuals in approving new drugs, noting that approval should not be granted unless those medications can be shown to improve patient-centered outcomes.<sup>435</sup>

None of the groups was able to achieve consensus regarding the issue of balancing free choice and cost containment. The St. Vincent's group struggled with the difference between "reasonable scientific evidence showing a lack of likely benefit" and "reasonable scientific evidence showing a possibility of at least some benefit," concluding that treatments with a lack of benefit should not be accessible to patients, while those with some benefit should be considered under the existing circumstances.<sup>436</sup> The GAIN/GICRAC group disagreed regarding the extent that rationing should be considered, with some believing that rationing is already

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<sup>432</sup> St. Vincent's House, *PCOR/CER*, 5.

<sup>433</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 6.

<sup>434</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 4; League of United Latin-American Citizens, *PCOR/CER*, 4.

<sup>435</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 4; League of United Latin-American Citizens, *PCOR/CER*, 4.

<sup>436</sup> St. Vincent's House and Galveston Island Community Research Advisory Committee, *Community Bioethics Dialogue: Mental Health and Seniors* (Galveston: Partnership between St. Vincent's House and the Galveston Community Research Advisory Committee and the Institute for the Medical Humanities, University of Texas Medical Branch, 2016), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016), 6-7.

present, and others noting that the term should not be used at all.<sup>437</sup> This group also noted the importance of applying policies fairly to all groups, although individual patients should be allowed to pay for treatments that are not covered by insurers.<sup>438</sup> GICRAC group participants recognize the issue of cost in the health-care system, with some believing that a lower cost treatment option should always be used first, although generally agreeing that Medicare should pay for more expensive name-brand drugs when generic equivalents were less effective. Some of the LULAC group participants consider patients with a terminal illness to have specific needs for expensive treatments, even if they are unlikely to provide benefit.

The GICRAC and LULAC participants did not agree on the role of patient testimonies. Some believe that scientific evidence should override individual patient experiences, while noting the importance of the source of the testimony.<sup>439</sup> Both groups' participants noted the importance of physicians and patients choosing treatment options, even with the absence of strong scientific evidence.<sup>440</sup> Members of both of these groups also considered the use of medical tourism, believing that Medicare should pay for patients to travel abroad if it is more cost effective.<sup>441</sup> This issue was not raised in response to the readings, but rather by individuals who had seen newscasts on the topic, verifying the notion that dialogue participants become more aware of current health issues.

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<sup>437</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 7.

<sup>438</sup> *Ibid.*, 8.

<sup>439</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 6. and League of United Latin-American Citizens, *PCOR/CER*, 6.

<sup>440</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 6. and League of United Latin-American Citizens, *PCOR/CER*, 7.

<sup>441</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 6. and League of United Latin-American Citizens, *PCOR/CER*, 6.

### ***Role of Commercial Interests***

All of the groups noted a concern with the role of commercial interests, but each considered a different aspect. The St. Vincent's group noted that insurers' roles create ethical problems because the payers are more likely to be more concerned with their bottom line than the patient's health.<sup>442</sup> GICRAC's concern was related, expressing a concern that CER not be used by insurers to select treatments for reimbursement.<sup>443</sup> The GAIN/GCPAAA group believes that transparency is important, with commercial ties being disclosed and information provided by a clearing house that is free of commercial interests.<sup>444</sup> This group was unable to agree on commercial interests' ideal role in affecting PCOR/CER issues, with some participants believing that a vote was necessary, while others believed that presence was sufficient without being able to directly choose policies.<sup>445</sup> The LULAC group considers commercial interests to be an ethical issue, but only two-thirds of the group gave it the highest priority.<sup>446</sup>

### **PCOR and CER Summary**

The concepts of PCOR and CER are complex, and the groups continually referred back to the definitions in considering the issues. Overall, all groups were able to identify core issues in health care, noting the importance of good physician/patient communications and learning the importance of understanding and self-advocacy. Numerous participants have cared for aging parents or other family members, and identified the importance of accompanying them to

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<sup>442</sup> St. Vincent's House, *PCOR/CER*, 6.

<sup>443</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 5.

<sup>444</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 7.

<sup>445</sup> *Ibid.*, 8.

<sup>446</sup> League of United Latin-American Citizens, *PCOR/CER*, 5-6.

physician visits. Policy issues were also considered, with the African American groups being particularly concerned about even application of policies and expressing concern about the role and influence of commercial interests.

The individual testimonies by the GICRAC and LULAC participants especially noted the importance of educating one's self about health-care issues and options. One GICRAC participant identified the importance of understanding the changes that occur when one turns 65, and expressed an interest in preparing an information booklet for her church members.<sup>447</sup> They expressed frustration at the different physicians that are present when hospitalized, especially when wanting to change medication regimes.<sup>448</sup> The participants also acknowledged the need to learn more, and to learn to advocate as a group.

The PCOR/CER sessions illustrate the need that community members have for general education about the health-care system and the importance of understanding various treatment options. The recognition that it is acceptable to ask questions and seek second opinions from physicians is a particularly critical element. Some of the participants found this to be particularly enlightening, acknowledging that the information gleaned from the dialogues has given them "permission" to be more proactive when considering health care treatments for themselves and for others.

## **Mental Health and Seniors**

The second theme for the dialogues was selected by the first two groups (St. Vincent's and GCPAAA) to participate in the sessions on PCOR and CER. These meetings were not mandated by the AHRQ grant, nor were the participants compensated for these sessions. The

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<sup>447</sup> Galveston Island Community Research Advisory Committee, *PCOR/CER*, 7.

<sup>448</sup> *Ibid.*, 8.

participants met multiple times over a course of six months to brainstorm possible topics. In the first meeting, general ideas were considered, with all of the participants providing suggestions. During the next meeting, various issues for each of the identified topics were considered. With the selection of Mental Health and Seniors, another meeting was held to narrow the potential list of topics to be discussed, identifying five topics: general mental health issues for seniors; brain decline; caregiver issues; medications; and downstream issues. The joint sessions to select a topic presaged the potential challenges of using a democratic process in topic selection, with disagreements on ways to consider the topics and narrow them. Thus, when using a general forum to consider various topics, the same safe space is needed to consider the options.

The ethical questions addressed by the group included the following:

- What are the critical issues in mental health for seniors?
- What is the role of health-care system in supporting mental health for seniors?
- What is the role for various constituencies (patients, families, caregivers, and government) in managing mental health?<sup>449</sup>

### **Critical Issues in Mental Health**

Both groups attending the sessions on Mental Health and Seniors agreed regarding several core issues: mental health issues are just as important as physical health; the infrastructure needs to support the aging population; drug price increases are of concern to the populace; and the need for individuals to plan for their aging. However, there was a lack of

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<sup>449</sup> The core questions were the same for both groups. See Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Community Bioethics Dialogue: Mental Health and Seniors* (Galveston: Partnership between Galveston Association of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association and the Institute for the Medical Humanities, University of Texas Medical Branch, 2016), <http://www.utmb.edu/pcor/proj3.asp> (accessed June 5, 2016).

consensus regarding other issues, particularly pertaining to government's role in supporting infrastructure for the aging population, including governance and rules associated with extended care facilities.

### **Role of the Health-Care System**

One of the areas of greatest concern to both groups is the infrastructure to support the aging population. To support this, participants believe that all health-care providers should receive core curriculum training in geriatrics, with some members of both groups believing that policies should include incentives for physicians to train as geriatricians.<sup>450</sup> Groups also expressed concern with the quality of care facilities for geriatrics, believing that individuals working in this area should be trained, licensed, and compensated fairly for their work.<sup>451</sup> Some members of the St. Vincent's/GICRAC recall programs where high school students volunteered in hospitals, and believe that this should be expanded in all areas to acquaint young people with aging issues, in addition to offering a class on aging.<sup>452</sup> Both groups expressed concern regarding drug price increases, noting that Medicare should place competitive bids for common drugs to help manage prices.<sup>453</sup> Downstream issues are also of concern, with participants from GAIN/GCPAAA believing that correctional facilities are not appropriate repositories for people

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<sup>450</sup> Ibid., 6-7; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*, 5-6.

<sup>451</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*, 5; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*, 5.

<sup>452</sup> St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*, 7.

<sup>453</sup> Ibid., 6. and Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 5.

with mental health issues, and the police should not be front-line mental health providers for underserved and low-income populations.<sup>454</sup>

While not an explicit topic for planned discussion, a significant outcome from the discussions identified the need for individuals to make plans for themselves as they age, including end-of-life issues, and to put those plans in writing.<sup>455</sup> This is a major outcome when discussing the health-care system and the need for individuals to make plans in view of their personal considerations and personhood. Several of the participants in the GAIN/GCPAAA group indicated that they were giving greater attention to their written plans, and one participant, who had prepared directives, made a point of meeting with his wife and children regarding their wishes. He noted that it was important that his children understand their respective choices, even though they were different, with one wanting heroic treatments, and the other forgoing them.<sup>456</sup> The St. Vincent's/GICRAC response was even more profound. In addition to individuals promoting directives with their friends and family, one member serves as the assistant manager for senior apartment complex, and she met with all of the residents and at least one family member to discuss the needs for Advance Care Planning. All residents completed directives, which were placed on file at the complex.<sup>457</sup> The participant noted the importance of the activity, and believes that it will assist in understanding family contacts if critical decisions are needed. Even though these dialogues did not focus on end-of-life planning, the topics presented provided sufficient impetus for individuals to understand the importance of preparing for one's

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<sup>454</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 5.

<sup>455</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*, 5; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*, 6.

<sup>456</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*, 10.

<sup>457</sup> St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*, 10.

medical treatment wishes. Placed in the context of the health-care system, participants realized the importance of having their voices heard, especially when they were no longer able to speak for themselves. When considering many of the different treatment considerations, the participants realized that patient-centered outcomes are meant to address their personhood, and realized the importance of asking questions and understanding treatment options. Examples from the groups demonstrate the value in encouraging people to examine health-care issues in detail to understand various issues.

### **Constituency Role in Managing Mental Health and Aging**

St. Vincent's/GICRAC participants believed strongly that most people prefer to remain at home as they age, and the health-care system (including government policies) should support that goal.<sup>458</sup> Moreover, family members are responsible for providing care, including assuring the availability of health-care services.<sup>459</sup> However, the group indicated a need for Medicare/Medicaid expansion to care for those whose care needs to be supported.<sup>460</sup> Some members believe that the federal government should encourage construction of senior centers to serve the aging population, while others believe that Medicaid-supported facilities should be expanded so that individuals do not have to be living below the poverty line in order to qualify for assistance.<sup>461</sup> St. Vincent's/GICRAC members expressed chagrin at the Texas legislators' decision in refusing to expand Medicaid, and believe this position should be reversed.<sup>462</sup> This value rose as the result of an article contributed by one of the participants, demonstrating the

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<sup>458</sup> Ibid., 4.

<sup>459</sup> Ibid., 5.

<sup>460</sup> Ibid., 5-6.

<sup>461</sup> Ibid., 7.

<sup>462</sup> Ibid., 8.

value of raising awareness regarding health issues. Another area of concern, particularly for the St. Vincent's/GICRAC group, is the need for reasonable requirements to resolve care issues and survivorship rules for those whose family members have received Medicaid-sponsored nursing facility care.<sup>463</sup> Several participants had experienced unexpected financial claims following a family member's death.

The St. Vincent's/GICRAC group also believed strongly that pharmaceutical and insurance company lobbyists should be disallowed, as they have no place in health care, and that news agencies have a responsibility to provide balanced information regarding mental health issues.<sup>464</sup> Some members of the GAIN/GCPAAA group expressed a similar concern, but others propose a policy refinement to "disallow those benefiting from health care policies from making contributions to political campaigns."<sup>465</sup>

## **Aging and End of Life**

The need for planning for one's advancing years and end-of-life prospects was reinforced by the shorter session held with some of the members of the GAIN/GCPAAA group on aging and end of life. In my three-week session with the smaller group, no formal report was prepared, but the value of personhood in the context of health care was considered tantamount. During the first week, the group identified multiple characteristics for personhood, including all of those considered in chapter 3. A key concern for members is the importance of treating all people with dignity, regardless of their physical condition, with the group concluding that all treatment options should be considered. The other high-priority item identified by the participants was the

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<sup>463</sup> Ibid., 7.

<sup>464</sup> Ibid.

<sup>465</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *PCOR/CER*, 6.

need for families to discuss their health care priorities with each other. Several of the participants had dealt with aging and ailing parents, and understood the import of avoiding family conflicts as the end of a person's life approaches. These participants were particularly adamant about the need to make plans and discuss them with family members. One issue that was raised both in this session and the longer dialogues on Mental Health and Seniors is the importance of good housing as we age.<sup>466</sup> This group noted that a person deserves decent housing as they age, while both of the larger groups noted the importance of an individual being to remain in their own home during their declining years.<sup>467</sup> If this is not possible, the two groups differed on how this should be managed. The St. Vincent's/GICRAC group engaged in the Mental Health and Seniors discussions believed that the federal government should take a stronger role in providing incentives for the construction of public senior living and recreational facilities, while the GAIN/GCPAAA group would generally leave this task to the business community.<sup>468</sup> Thus, both groups agreed on the general goal, but disagreed on implementation. Both groups agreed on the need for those providing health care to be trained in geriatrics, and for those providing direct care in senior facilities to be licensed.<sup>469</sup>

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<sup>466</sup> It is important to note that "good housing" is a qualitative value that was not further described.

<sup>467</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*.

<sup>468</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*.

<sup>469</sup> Galveston Alliance of Island Neighborhoods and Galveston Citizens Police Academy Alumni Association, *Mental Health and Seniors*; St. Vincent's House and Galveston Island Community Research Advisory Committee, *Mental Health and Seniors*.

## Community Bioethics Dialogue Summary

The different values identified by the various groups reflect the emphasis placed by the participants on their understanding of individual rights and responsibilities, and the need to prioritize one's own wishes when availing one's self of the health-care system. When asked to identify the lessons learned during the Community Bioethics Dialogues, multiple participants commented that having the confidence to ask questions and question options that are presented by physicians and health-care team members is an important tool for being well-informed. Others noted the need for understanding available services and making good health-care choices as one ages. Another participant identified the critical juncture of turning 65, when "everything changes," including eligibility for Medicare. Finally, participants recognized the need for knowing about available community resources in meeting individual and familial needs for different types of care.

In the comments solicited at the end of the Galveston dialogues, participants expressed appreciation for acquiring knowledge about various health-care issues as well as being able to solidify their own thinking. The participants took the information gleaned from the sessions and discussed them with friends and family members. Moreover, the seeds were planted for identifying issues that the participants felt that lawmakers needed to consider in setting health-care policy. Participants began to understand the *conduct of conduct* of the health-care system, identify areas where the system affects the well-being of their own persons and families, as well as consider system improvements, asking Kaufman's question, "What values do we want to govern that enterprise?" By taking time to understand and discuss issues in a safe environment, participants are better able to exercise their own personhood in the overarching medical complex.

Individuals begin to take responsibility for their own care, and are empowered to ask questions about the constitution of that care in an aging society.

These dialogues bear witness to the importance of engaging community members in conversation regarding important health care topics. The opportunity to read, discuss, debate, and even disagree is fundamental to one's personhood. Everyone learned new information during the dialogues, and is implementing the knowledge in a variety of ways. The experience of these dialogues demonstrates that it is possible for a variety of viewpoints and values to be expressed without resorting to hyperbole and ugly words. In short, the participants maintained respect for each other throughout the process, demonstrating that reasoned conversation (*sermo*) is still possible when discussing complex issues such as health-care policy and values.

### **Proposed Curriculum**

The sessions held in Galveston, Texas, demonstrate that the format of Community Bioethics Dialogues is an effective way of educating the public on various elements of the health-care system, aging, and considering an individual's wishes at the time when medical treatments may no longer be efficacious. Based on the experiences with these dialogue groups, I have developed a curriculum on "Health Care, Aging, and End-of-Life" that can be offered to community, church, or educational groups using the criteria identified previously. In conversations with potential sponsors of Community Bioethics Dialogue Groups outside of Galveston, some potential groups expressed a preference for a four-week dialogue session. As a result, I have developed two different curricula to consider with future groups: one for four weeks (Appendix A), and one for six weeks (Appendix B), for groups that might be interested in going into more detail on the various topics.

The four-week curriculum would have four key topics:

- Introduction to the health-care system, to provide a brief overview of the system's development, as well as the cost structure.
- PCOR and CER, to introduce some of the critical considerations for health care treatment options.
- Aging, to consider the ways in which health care and living needs change as the population increases in longevity.
- End-of-life, to recognize the importance of making plans, discussing them with family members, and putting them in writing.

I recognize that each group that is formed will have differing priorities and educational needs. However, in order to provide a starting point for groups that might want to sponsor dialogues, a list of resources for each of the topics is included in Appendix I.

The six-week curriculum would offer the same basic topics, but would extend the discussion of the health-care system to two weeks, and separate the discussion on PCOR and CER to two weeks in order to provide more time to discuss these complex issues, providing an opportunity to have additional discussions on facts and on the case studies. A potential list of resources and topics is included in Appendix II.

## **Conclusion: Where Do We Go from Here?**

The ability to discuss and debate issues of public policy is a right and responsibility provided to every inhabitant of the United States, and is especially important to health care, which affects every person at some point in their lives. Along with discussion and debate is the need to ask questions to understand treatment options when seeking care from health professionals. In my experiences with family, friends, and as a critical-care hospital chaplain, I have seen many instances where this has not occurred. As noted previously, physicians ask families gathered in meetings under critical-care circumstances, “what do you want us to do?” The obvious answer is they do not want their family member to be ill or to suffer—restoration to health is the goal. When this is not possible, the care team is asking for direction, sometimes without knowing facts associated with the individual’s personhood—stopping to ask the question “tell me about your loved one” will sometimes provide additional insights. At the same time, since most people do not discuss treatment preferences and goals with each other until a critical moment is reached, discussions do not occur, and families are left to guess what the individual would want. A platform where the health-care system can be discussed in a safe environment provides participants with an opportunity to consider their own personhood in the context of care. While specifics cannot be developed until an illness strikes, at the very least, participants are able to consider general questions of value and provide guidance to their family members regarding potential treatment choices.

The need for enhanced communications is more widely recognized. As an example, the IOM has recognized the need for expanded communication in the health-care system and notes in the report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* that improvements are needed at all levels:

- Societal, “to build support for constructive public policy related to the organization and financing of care near the end of life and for institutional and provider practices that ensure that this care is high-quality and sustainable.”
- “Community and family levels, to raise public awareness of care options in the final phase of life, the needs of caregivers, and the hallmarks of high-quality care.”
- “Individual level, to motivate and facilitate advance care planning and meaningful conversations with family, caregivers, and clinicians about values, goals, and informed preferences for care.”<sup>470</sup>

Community Bioethics Dialogues function at all of these levels to improve knowledge and understanding of various health-care issues for the participants. As noted previously in this chapter, a number of initiatives in various places attempt to expand public education on the importance of preparing Advance Directives, putting end-of-life wishes in writing, and talking with family members about their wishes. These efforts are good, and more work is needed to expand the public understanding of health-care issues and initiatives. The advantage of the dialogues is that the need for ACP is placed in the context of one’s total health plan. Each person is encouraged to advocate for his or her own best treatment, including the acknowledgement that this may change as one ages.

The experiences with different groups in Galveston, Texas, have demonstrated that Community Bioethics Dialogues provide a good platform for engaging a variety of community members regarding the health-care system. Applying a targeted curriculum that can be adjusted to serve different groups provides the educational medium for encouraging and empowering them to discuss the ways in which the health-care system is meant to serve, and also to discuss

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<sup>470</sup> Institute of Medicine, *Dying in America*, S-14.

policy issues that need to be considered and promoted with lawmakers. Respectful discussions can occur, avoiding some of the “death panel” language that proliferated during the effort to pass the Affordable Care Act. Creating an environment of trust and discussion serves to ensure that the public is best informed on this key matter. Further work is needed to evaluate the types of groups that can be formed, including a system to train the facilitators that will be working with those groups. As a start, I would expect to establish a web site where the methodology for forming Community Bioethics Dialogues could be shared. Such a website would include the resources that could be used, emphasizing those that are readily available to the public, some of which are included in the topic lists provided in the appendices. Continuing to make presentations at various meetings will help to promote the dialogues.

Engaging the public in a meaningful discourse provides an application of the humanistic ideal of *sermo*. Open conversations can occur in a civil manner that promotes education and expression of values. With expansion, Community Bioethics Dialogues offer one tool in the arsenal to educate the public on personhood, health-care needs, and end-of-life considerations. My fervent hope is to educate other groups on this tool, expanding the technique to a broader spectrum. An educated public is health care’s best hope for good users.

## **Appendix A. Topic List: Community Bioethics Dialogue on Health Care, Patient-Centered Outcomes, Aging, and End of Life (Four-Week Curriculum)**

### **Week 1**

#### **Case Study: US Health Policy**

Topic: Introduction to the US Health-care system—How much are we spending? How does this compare to the rest of the world?

Brill, Stephen. "Bitter Pill: Why Medical Bills Are Killing Us." *Time*, March 4, 2013.

Gawande, Atul. "Overkill." *New Yorker* (May 11, 2015).  
<http://www.newyorker.com/magazine/2015/05/11/overkill-atul-gawande> (accessed June 5, 2016).

Hajar, Rachel. "History of Medicine Timeline." *Heart Views* 16, no. 1 (Jan-Mar 2015).  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4379645/> (accessed June 5, 2016).

Kane, Jason. "Health Costs: How the U.S. Compares with Other Countries." *PBS Newshour*, October 22, 2012. <http://www.pbs.org/newshour/rundown/health-costs-how-the-us-compares-with-other-countries/> (accessed June 5, 2016).

Young, Pierre L., and LeighAnne Olsen. *The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary*. The National Academies Press, 2010.  
<https://iom.nationalacademies.org/Reports/2011/The-Healthcare-Imperative-Lowering-Costs-and-Improving-Outcomes.aspx> (accessed June 5, 2016).

### **Week 2**

#### **Case Study: Meniscus Tear**

Topic: Patient-Centered Outcomes Research, ethics and cost containment: Is there an ethical mandate to contain health-care costs? How do treatment options contribute to costs?

Brody, H. "Is There an Ethical Mandate to Contain Health Costs in the U.S.?"

Topic: What is PCOR/CER?

Bensing, J. "Bridging the Gap. The Separate Worlds of Evidence-based Medicine and Patient-centered Medicine." *Patient Education and Counseling* 39, no. 1 (January 2000): 17–25.

Katz, Jeffrey N., et al. "Surgery Versus Physical Therapy for a Meniscal Tear and Osteoarthritis." *New England Journal of Medicine* 368, no. 18 (August 15 2013): 1675–84.

Parker, Lisa S., and Howard Brody, "Comparative Effectiveness Research: A Threat to Patient Autonomy?" *Health Progress* 92 (5): 64-71, 2011.

Sihvonen, Raine, et al. "Arthroscopic Partial Meniscectomy Versus Sham Surgery for a Degenerative Meniscal Tear." *New England Journal of Medicine* 369, no. 26 (2013): 2515-24.

Spindler, Kurt P., et al. "Prognosis and Predictors of ACL Reconstructions Using the Moon Cohort: A Model for Comparative Effectiveness Studies." *Journal of Orthopaedic Research* 31, no. 1 (2013): 2-9. <http://www.ncbi.nlm.nih.gov/pubmed/22912340> (accessed June 5, 2016).

"Left Knee Medial Meniscectomy." In *Medical Evaluators of Texas: Independent Review*, September 17 2014. [http://www.tdi.texas.gov/medcases/iro/2014/september/preauthorization\\_and\\_concurrent/wp172975973814.pdf](http://www.tdi.texas.gov/medcases/iro/2014/september/preauthorization_and_concurrent/wp172975973814.pdf) (accessed June 5, 2016).

### **Week 3**

#### **Case Study: Personhood and Aging**

Topic: Personhood and Aging—What is Personhood? How does it relate to our health care? How do we care for ourselves and others during the aging process?

Cassell, Eric J. "The Nature of Suffering and the Goals of Medicine." *New England Journal of Medicine* 306, no. 11 (1982): 639-645.

McFadden, Robert D. "Karen Ann Quinlan, 31, Dies; Focus of '76 Right to Die Case." *New York Times*, June 12, 1985. <http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html?pagewanted=all> (accessed June 5, 2016).

### **Week 4**

#### **Case Study: Facing the End**

Topic: End-of-Life Considerations—How do we choose treatment options? How do we talk to our families?

Gawande, Atul. "No Risky Chances: The Conversation That Matters Most." *Medical Examiner*, October 6, 2014. [http://www.slate.com/articles/health\\_and\\_science/medical\\_examiner/2014/10/end\\_of\\_life\\_medical\\_decisions\\_atul\\_gawande\\_book\\_excerpt\\_on\\_no\\_risky\\_chances.html](http://www.slate.com/articles/health_and_science/medical_examiner/2014/10/end_of_life_medical_decisions_atul_gawande_book_excerpt_on_no_risky_chances.html). Accessed June 5, 2016).

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- Jennings, Tom. "Being Mortal." In *PBS Frontline*. USA: Public Broadcasting System, 2015. <http://www.pbs.org/wgbh/frontline/film/being-mortal/credits/> (accessed June 5, 2016).
- Rauch, Jonathan. "How Not to Die: Angelo Volandes's Low-Tech, High-Empathy Plan to Revolutionize End-of-Life Care." *Atlantic* (May 2013). <http://www.theatlantic.com/magazine/archive/2013/05/hownottodie/309277/> (accessed June 5, 2016).

## **Appendix B. Topic List: Community Bioethics Dialogue on Health Care, Patient-Centered Outcomes, Aging, and End of Life (Six-Week Curriculum)**

### **Week 1**

#### **Case Study: US Health Policy**

Topic: Introduction to the US Health-care system—How much are we spending? How does this compare to the rest of the world?

Brill, Stephen. "Bitter Pill: Why Medical Bills Are Killing Us." *Time*, March 4, 2013.

Gawande, Atul. "Overkill." *New Yorker* (May 11, 2015).  
<http://www.newyorker.com/magazine/2015/05/11/overkill-atul-gawande> (accessed June 5, 2016).

Hajar, Rachel. "History of Medicine Timeline." *Heart Views* 16, no. 1 (Jan-Mar 2015).  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4379645/> (accessed June 5, 2016).

Kane, Jason. "Health Costs: How the U.S. Compares with Other Countries." *PBS Newshour*, October 22, 2012. <http://www.pbs.org/newshour/rundown/health-costs-how-the-us-compares-with-other-countries/> (accessed June 5, 2016).

### **Week 2**

#### **Case Study: Health Care Spending**

Topic: What causes some of the disparities in US health care spending? What can we do to control cost increases?

Gawande, Atul. "States of Health." *New Yorker*, October 7, 2013.  
<http://www.newyorker.com/magazine/2013/10/07/states-of-health>. Accessed June 5, 2016).

Young, Pierre L., and LeighAnne Olsen. *The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary*. The National Academies Press, 2010.  
<https://iom.nationalacademies.org/Reports/2011/The-Healthcare-Imperative-Lowering-Costs-and-Improving-Outcomes.aspx> (accessed June 5, 2016).

## Week 3

### Case Study: Generic Drugs

Topic: Patient-Centered Outcomes Research, ethics and cost containment: Is there an ethical mandate to contain health-care costs?

Brody, H. "Is There an Ethical Mandate to Contain Health Costs in the U.S.?"

Topic: What Are Patient-Centered Outcomes?

Coelho, Tony. "A Patient Advocate's Perspective on Patient-Centered Comparative Effectiveness Research." *Health Affairs* 29:1885-1890, 2010.  
<http://content.healthaffairs.org/content/29/10/1885.full> (accessed June 5, 2016).

Wu, Albert W, Claire Snyder, Carolyn M Clancy, and Donald M Steinwachs. "Adding the Patient Perspective to Comparative Effectiveness Research." *Health Affairs (Project Hope)* 29, no. 10 (October 2010): 1863–1871. doi:10.1377/hlthaff.2010.0660.  
<http://www.ncbi.nlm.nih.gov/pubmed/20921487> (accessed June 5, 2016).

## Week 4

### Case Study: Meniscus Tear

Topic: The potential impact of Patient-Centered Outcomes on patient autonomy and the doctor-patient relationship (How can doctors continue to be patient-centered while applying population-based research? How can we make the research and its application more patient-centered? How would participants prefer to see PCOR results implemented in individual care/ doctor-patient decision making? Should doctors and patients be tied down to what evidence shows works best?)

Bensing, J. "Bridging the Gap. The Separate Worlds of Evidence-based Medicine and Patient-centered Medicine." *Patient Education and Counseling* 39, no. 1 (January 2000): 17–25.

Katz, Jeffrey N., et al. "Surgery Versus Physical Therapy for a Meniscal Tear and Osteoarthritis." *New England Journal of Medicine* 368, no. 18 (August 15 2013): 1675-84.

Parker, Lisa S., and Howard Brody, "Comparative Effectiveness Research: A Threat to Patient Autonomy?" *Health Progress* 92 (5): 64-71, 2011.

Sihvonen, Raine, et al. "Arthroscopic Partial Meniscectomy Versus Sham Surgery for a Degenerative Meniscal Tear." *New England Journal of Medicine* 369, no. 26 (2013): 2515-24.

Spindler, Kurt P., et al. "Prognosis and Predictors of ACL Reconstructions Using the Moon Cohort: A Model for Comparative Effectiveness Studies." *Journal of Orthopaedic*

*Research* 31, no. 1 (2013): 2-9. <http://www.ncbi.nlm.nih.gov/pubmed/22912340> (accessed June 5, 2016).

"Left Knee Medial Meniscectomy." In *Medical Evaluators of Texas: Independent Review*, September 17 2014.  
[http://www.tdi.texas.gov/medcases/iro/2014/september/preauthorization\\_and\\_concurrent/wp172975973814.pdf](http://www.tdi.texas.gov/medcases/iro/2014/september/preauthorization_and_concurrent/wp172975973814.pdf) (accessed June 5, 2016).

## Week 5

### Case Study: Personhood and Aging

Topic: Personhood and Aging—What is Personhood? How does it relate to our health care? How do we care for ourselves and others during the aging process?

Cassell, Eric J. "The Nature of Suffering and the Goals of Medicine." *New England Journal of Medicine* 306, no. 11 (1982): 639-645.

McFadden, Robert D. "Karen Ann Quinlan, 31, Dies; Focus of '76 Right to Die Case." *New York Times*, June 12, 1985 June 12, 1985.  
<http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html?pagewanted=all> (accessed June 5, 2016).

## Week 6

### Case Study: Facing the End

Topic: End-of-Life Considerations—How do we choose treatment options? How do we talk to our families?

Gawande, Atul. "No Risky Chances: The Conversation That Matters Most." *Medical Examiner*, October 6, 2014.  
[http://www.slate.com/articles/health\\_and\\_science/medical\\_examiner/2014/10/end\\_of\\_life\\_medical\\_decisions\\_atul\\_gawande\\_book\\_excerpt\\_on\\_no\\_risky\\_chances.html](http://www.slate.com/articles/health_and_science/medical_examiner/2014/10/end_of_life_medical_decisions_atul_gawande_book_excerpt_on_no_risky_chances.html). Accessed June 5, 2016).

Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington DC: National Academy of Sciences, September 17, 2014. <http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx> (accessed June 5, 2016).

Jennings, Tom. "Being Mortal." In *PBS Frontline*. USA: Public Broadcasting System, 2015.  
<http://www.pbs.org/wgbh/frontline/film/being-mortal/credits/> (accessed June 5, 2016).

Rauch, Jonathan. "How Not to Die: Angelo Volandes's Low-Tech, High-Empathy Plan to Revolutionize End-of-Life Care." *Atlantic* (May 2013).  
<http://www.theatlantic.com/magazine/archive/2013/05/hownottodie/309277/> (accessed June 5, 2016).

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## Vita

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This dissertation was typed by Peggy L. Determeyer